

Consumer and Community Participation in Health and Medical Research

**A practical guide for health
and medical research organisations**



THE UNIVERSITY OF
WESTERN AUSTRALIA



Anne McKenzie and Bec Hanley

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We would like to sincerely thank all the people who contributed to this publication.

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INTRODUCTION

This section gives some information about this book and sets in context our experience of implementing consumer and community participation at The University of Western Australia School of Population Health (the School) and the Telethon Institute for Child Health Research (the Institute).

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Definitions and explanations

A variety of terms may be used to refer to consumers and community members in health and medical research - such as patient, lay person, volunteer, member of the public.

Definitions

In this book we use the definitions from the Australian National Health and Medical Research Council and the Consumers' Health Forum of Australia's *Statement on Consumer and Community Participation in Health and Medical Research*:

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.

Community

A group of people sharing a common interest (for example 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.

Participation

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

Explanations

Because this book is aimed at consumers as well as researchers, we have tried to avoid jargon and abbreviations. But for brevity, we use the term 'the School' to mean the School of Population Health at The University of Western Australia, and 'the Institute' to mean the Telethon Institute of Child Health Research. Following are some brief explanations of organisations commonly referred to throughout the book.

The School of Population Health at the University of Western Australia

The School of Population Health is situated within the Faculty of Medicine and Dentistry. Over 100 staff are involved in a diverse range of teaching, research and consultancy activities. The School of Population Health, formerly known as the Department of Public Health is part of a large international network of academic and service organisations serving the interests of improved public health around the world.

The Telethon Institute for Child Health Research

The Telethon Institute for Child Health Research is Western Australia's only research facility dedicated to child health. The Institute is a non-Government, not-for-profit organisation with strong affiliations with the State children's hospital and all the major Western Australian universities.



Close to 500 staff and students work in the purpose-built research facility to improve and to promote the health and well-being of all children through multidisciplinary research.

Health Consumers' Council of Western Australia

The Health Consumers' Council is an independent community based organisation, representing the consumers' voice in health policy, planning, research and service delivery. The Health Consumers' Council advocates on behalf of Western Australian health consumers to government, doctors, other health professionals, hospitals and the wider health system. Again for brevity we refer to this organisation as the Health Consumers' Council.

Consumer Liaison Officer

The role of the Consumer Liaison Officer was established in 1998 to facilitate greater consumer and community participation in health and medical research at the School and the Institute. We talk more about this role in Section Two.

National Health and Medical Research Council

The National Health and Medical Research Council is Australia's peak body for supporting health and medical research; for developing health advice for the Australian community, health professionals and governments. It also provides advice on ethical behaviour in health care and in the conduct of health and medical research.

Consumers' Health Forum of Australia

The Consumers' Health Forum of Australia is an independent member-based non-government organisation for health consumers. Consumers' Health Forum helps to shape Australia's health system by representing and involving consumers in health policy and program development.

Health Information Linkage Branch

The Health Information Linkage Branch (formerly known as the Data Linkage Unit) is situated within the Information Collection and Management Directorate at the Western Australian Department of Health. It was established in 1995 as a result of collaboration between the School, the Institute and the Western Australian Department of Health. It is unique in Australia and one of only five similar systems worldwide.

The Health Information Linkage Branch is responsible for creating and maintaining the links within and between the state's population health data collections. These collections include state-wide records on births, hospital inpatient stays, mental health inpatient stays, emergency department attendances, reported instances of cancer and deaths. The linked information from these records is used for health planning, policy analysis and research.

Australia's Indigenous People

Aboriginal and Torres Strait Islander people are mainly referred to as Aboriginal people in this book. This is used as an inclusive term and not meant to exclude Torres Strait Islander people in any way. The Nyoongar people are the largest Indigenous group in Western Australia.

Use of Abbreviations

We have tried really hard to make this an acronym free publication to make it easier to read.

For readers outside Australia, WA is Western Australia.

Find out more about the role of the Consumer Liaison Officer on page 30



Foreword

The impetus to resource and promote consumer and community participation within the School of Population Health at The University of Western Australia came from a concern voiced by two people. D’Arcy Holman (a professor at the School) and Michele Kosky (Executive Director of the Health Consumers’ Council) shared concerns about the quality of communication about a data linkage project that had been set up at the School. The Health Consumers’ Council also had concerns about the establishment of the Health Information Linkage Branch and the implications for health consumers’ privacy.

The data linkage project really brought into sharp relief the fact that if we as researchers are here in isolation and community interests are over there in isolation, we don’t even get to first base on being able to talk about research and weighing up things like ethical questions. Because we’re not actually talking about the same thing, we don’t have a common understanding.

(D’Arcy Holman - researcher)

In 1998 D’Arcy Holman and Michele Kosky met to discuss the data linkage project. D’Arcy offered to fund a part-time Consumer Liaison Officer – this would be the first position of its kind in a research organisation in Australia. This person would be appointed by the Health Consumers’ Council, but based in the School, and would act as the link between the two organisations. At this point, D’Arcy’s vision was purely about dissemination – making research findings more accessible to the community. Rebecca Coghlan was appointed to the role in 1999.

D’Arcy was very keen on the idea of having a person to promote and explain but not participate in doing the research. I thought it would be a good opportunity for the community to be told about the strengths and weaknesses of the current approaches to research. Having a consumer liaison position seemed like too good an opportunity to pass up. I didn’t spend too much time reflecting if it was the best way to go. I thought he’s keen, and I am going to capture that keenness now and not let it dissipate over time – it was win-win and it has worked pretty effectively.

(Michele Kosky – consumer)

In the early period of the appointment, a lot of my colleagues thought I was mad. We all felt that there was someone looking for fault, looking over everyone’s shoulder. It was quite a tense time. People were wondering if I’d done the right thing.

(D’Arcy Holman - researcher)



A major shift in attitudes and in thinking about what the role of the Consumer Liaison Officer could achieve was brought about as a result of one research project in particular, called *Duty to Care*. This project looked at the physical illness of mental health consumers and is described in more detail in Section Four. As well as building trust between researchers and community advocates and influencing policy, this project led D’Arcy to think about the benefits that could be achieved by engaging consumers and community members from the beginning of a research project, right across a research institution.

The Duty to Care project gave us a shared interest. Also I think there was a desensitisation process. So people came to understand better what the interest of the other group was. As well the Consumer Liaison Officer began to see we don’t really have two heads, and that public health researchers aren’t aggressive, narrow-minded people who only care about their curriculum vitae and not about ordinary people in the community.

(D’Arcy Holman - researcher)

At the same time that D’Arcy was considering the impact of the *Duty to Care* project, the National Health and Medical Research Council in Australia was beginning to promote consumer and community participation in research. It also invited applications for a new type of grant, a population health research capacity-building grant.

Together, the School and the Institute made a successful application for the grant, which included consumer and community participation as one stream of activity. This meant they were able to employ the Consumer Liaison Officer on a full time basis, to work across both research institutions. The aim of the role was to build on the existing work done at both organisations and to develop new partnerships and collaborations to improve participation. The Health Consumers’ Council provided a community mentoring and support role to the Consumer Liaison Officer.

At the Institute we were involving Aboriginal people in our research. But we weren’t involving non-Aboriginal people in the same way. We had a few projects where we had parent advisory groups, but it was limited. The Aboriginal people said why don’t you do this for everyone? I thought, “Why not? We should do it for everybody”. So we decided to work with D’Arcy to put together the capacity building grant.

(Fiona Stanley - researcher)

Rebecca Coghlan, the first Consumer Liaison Officer, left in 2003. Anne McKenzie, a co-author of this book, who was to work full-time across the School and the Institute, started in 2004. Both Rebecca and Anne have had an enormous impact on the work of these research organisations.

It is difficult to assess and quantify the effectiveness of such a position. But we know from experience that consumer and community participation can lead to:

- Better quality research
- Recognition for our organisations
- Changes in practice

All these things lead to an improvement in the quality of people’s lives.

Our experience of having this position has been very positive and successful and we recommend every health research organisation consider this option.

Find out more about the Duty to Care Project on page 52



About this book and why we wrote it

The idea for this book came from thinking about how much easier it would be if there was a simple plan - or recipe - about how to involve consumers and community members in health and medical research.

At the School and the Institute, we had all the ingredients for success:

- Endorsement and support from senior management for consumer and community participation.
- Senior researchers who were committed to the philosophy of consumer and community participation
- Community organisations that had a long history of involvement in research and an interest in being more involved.
- A dedicated position of a Consumer Liaison Officer.

But there was no easy-to-follow guide or recipe on how to actually do consumer and community participation in a way that would make it a meaningful part of the normal work of all researchers at the School and the Institute.

In 2004, the National Health and Medical Research Council and Consumers' Health Forum of Australia developed a Model Framework on Consumer and Community Participation in Health and Medical Research (the Framework). At the same time the current Consumer Liaison Officer started working at the School and the Institute. Although there was a lot of information available about how to involve consumers in health services and hospitals, it did not always seem relevant when applied to research.

The work being done in the United Kingdom by the INVOLVE Support Unit (formerly known as Consumers in National Health Service Research) was very helpful. It was more able to be adapted and applied into an Australian context. Two publications that were particularly useful were the *Briefing Notes for Researchers* and *Getting Involved in Research – A guide for consumers*. Both documents are available from the INVOLVE website www.involve.org.uk. One of the authors of this book, Bec Hanley, was a lead author on these documents.

We, (Bec and Anne) met in England at the 2004 and 2006 INVOLVE Conferences and had brief talks about how good it would be if we could get down on paper some of what has happened at the School and the Institute, and what we have learned.

Like all good ideas discussed over a cup of tea, we thought there might be value in sharing with other Australian research organisations our recipe for getting started and our experiences. This book is a record of how the School and the Institute are implementing the National Health and Medical Research Council and the Consumers' Health Forum of Australia's Framework.

Our wild idea of meeting together on the other side of the world to write a book has been generously supported by many people, in particular D'Arcy Holman and Fiona Stanley, who funded Bec's travel to Australia, and then by each and every person who has willingly shared their experiences.

We think that this recipe is not one that could or should be copied ingredient by ingredient, but rather one that can be adapted, depending on the finished product you want for your research project or organisation.



Who is this book for?

This book has been written for researchers and research managers who want to take forward consumer and community participation within a particular piece of research, or across their institution.

We have written this book in plain English, so that it will be easy to read and digest. We hope that this will mean that the book can also be read by consumers and community members who want to get involved in research.

Although this book has been written within an Australian context, we think the lessons will be relevant to people in other countries.

How we wrote the book

We wrote this book by developing a set of questions, which we then asked of people who had experience of consumer and community participation in research. This included consumers, community members, researchers and research managers. After the interviews we wrote a draft of this book. In an attempt to share some of the fantastic things people told us during the interviews, we have included direct quotes wherever possible.

For each of the good practice stories, we sent a draft to the people we had interviewed for checking and comment. We then made changes to our draft based on their feedback.

Drafts of the whole book were edited by Jillian Mercer and Janet Wale. Whilst we are very grateful to everyone for their contribution, we take full responsibility for any mistakes or omissions.

Vision Australia provided advice about the appropriate use of fonts, colour and styles.

Using the material in this book

You are welcome to use any of the ideas or resources in this book – all we ask is that you acknowledge this book as the source. You may not use the resources without permission if you intend to make a financial profit from their use.

This book is also available in a PDF format on the websites of the School of Population Health www.sph.uwa.edu.au and the Telethon Institute for Child Health Research www.ichr.uwa.edu.au.

We share some good practice stories in Section Four



About the authors

Anne McKenzie

Since 2004, **Anne McKenzie** has worked as the Consumer Liaison Officer at The University of Western Australia's School of Population Health and the Telethon Institute for Child Health Research. The key task of this position is to increase consumer and community participation in health and medical research.

Anne established the role of Parent Advocate at Princess Margaret Hospital, Perth's only tertiary children's hospital and has a long history of health consumer advocacy.

Anne is involved in the following community areas as:

- The Deputy Chair, current Board Member and consumer representative for the Health Consumers' Council.
- A consumer representative for the Consumers' Health Forum of Australia on national e-health and quality use of medicine committees.
- A member of the Cochrane Consumer Network, the consumer arm of the Cochrane Collaboration.
- The female lay member on the Silver Chain Nursing Association Human Research Ethics Committee, a Western Australian in-the-home aged health care and nursing support service.

Bec Hanley

Bec Hanley has spent the past ten years working to promote the involvement of people who use services in health care and health research in the United Kingdom. She was the director of the INVOLVE Support Unit for five years – which is a unit funded by the Department of Health in England to promote and support public involvement in health, public health and social care research (www.invo.org.uk). During this time she worked in partnership with people who use services, and professionals, to develop policy and practice on involvement in research. She is the lead author of INVOLVE's acclaimed *Involving the Public in NHS, Public Health and Social Care Research*, now in its second edition.

Bec now works with a variety of organisations in the United Kingdom to promote and support consumer and community participation in health services and health research. These include the Department of Health, the Medical Research Council and a range of voluntary organisations. She is co-director of a company called TwoCan Associates (www.twocanassociates.co.uk).

Context

The work done at the School and the Institute to increase consumer and community participation has taken place within a context of a growing national and international interest in consumer and community participation in health and medical research. In Australia, the National Health and Medical Research Council and the Consumers' Health Forum of Australia worked together to develop:

1. Recommendations on consumer and community participation to the *1998 Health and Medical Research Strategic Review*, known as the Wills Review.
2. A *Statement on Consumer and Community Participation in Health and Medical Research* in 2001. The Statement says, "Consumers and researchers working in partnerships based on understanding, respect and shared commitment to research that will improve the health of humankind".
3. A *Resource Pack and Model Framework for Consumer and Community Participation in Health and Medical Research* in 2004, in collaboration with the National Ageing Research Institute and the Queensland Institute of Medical Research.



Since 2005, the National Health and Medical Research Council have required applicants for research grants to give details of their plans to involve consumers and community. These questions have had an impact on the way researchers, throughout Australia, are now thinking about involving consumers and the community.

At the School and the Institute, there has been a significant increase in research applications that have a planned, budgeted approach for consumer and community participation.

Both in Australia and around the world, there are many examples of good practice for consumer and community participation in health and medical research. For example:

- Indigenous Health Research has many excellent examples of how communities are involved in influencing what research is undertaken and how this is carried out.
- HIV AIDS research provides many examples of how the community can have a direct impact on the outcomes of research and the translation of results into policy and practice.
- Survivors of breast cancer have been influential in raising awareness of the importance of consumers and researchers working together to plan, carry out and implement the results of research.
- The Cochrane Consumer Network is an international group of consumers providing consumer perspectives on systematic reviews undertaken within the Cochrane Collaboration.
- INVOLVE, a National Health Service support unit in the United Kingdom provides a unique service in promoting and supporting active involvement in health and social care research.
- The Cancer Council of New South Wales and Cancer Voices New South Wales have developed guidelines for the assessment of consumer participation in grant applications and training modules for consumer representatives involved in assessing these applications.

We recognise that all of the initiatives happening on a local, national and international level are the beginning of a long journey to fully involve consumers and the community in health and medical research. As with all journeys, it involves a series of stops and starts, and to date our experiences at the School and the Institute have been no different. We have experienced some areas of great participation while in others areas the uptake has been slower and less tangible.

The purpose of this book is to give an overview of what we did and what we have achieved so far.

Find out more about the National Health and Medical Research Council requirements on page 18

We talk about the challenges, and opportunities for the future on page 77



CONSUMER AND COMMUNITY PARTICIPATION IN RESEARCH - SOME BASIC INGREDIENTS FOR SUCCESS

In this section, we discuss some of the basic ingredients we have adapted, developed and used to promote consumer and community participation in research over the past four years.

We have found these ingredients to be vital whether you are working to promote participation at an organisational level or at an individual project level. These ingredients are not listed in order of priority - they are all equally important in helping develop and implement a strategic plan to increase participation.

We cover the following topics:

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Ingredient 1:

Over-arching principles for consumer and community participation

Underpinning these ingredients and all of our work at the School and the Institute are some key principles. We think it is helpful to keep these in mind as you promote consumer and community participation:

- a) Start involvement as early as you can – but don't be put off if you didn't start involvement at the beginning – it's never too late.
- b) One size doesn't fit all – it's important to work with consumers and community members to find what will work best for your project.
- c) Consumer and community participation should add value to the research – work with consumers and community members to decide the best way to achieve this.
- d) Treat everyone – consumers, community members, researchers and other stakeholders - with courtesy and respect.
- e) Keep everyone informed and involved by sharing information willingly and in language that everyone understands.

Ingredient 2:

Ladder of consumer and community participation in research

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

We adapted a ladder that had been used to look at consumer involvement in health service delivery, to help us to think about levels of participation in research. For each of the levels of participation, we give a brief description and then refer you to a project we describe later in this book. These project stories illustrate the different levels of consumer and community participation.

To help decide how you want consumers and community members to participate in your research ask these two key questions:

- a) Do you want consumers and community members to help decide the research questions and how the research will be carried out? or
- b) Do you want to ask their opinions but reserve the right to ignore these if you disagree?



Level of participation

Role of consumers & community members

Explanation & examples

HIGH

Initiates the research

The community identifies the research needed and sets the appropriate research agenda. See the Goldfields Renal Study on page 55

Has full control

The researcher asks a community to identify a problem and to make all key decisions on goals and means. The researcher is willing to help the community at each step to accomplish goals. See the Kulunga Research Network on page 54

Has defined level of control

Researchers identify the research needed and present the problem to the community, define the limits and ask the community to make decisions. See the Seniors Research Project on page 61

Plan jointly

Researchers present a tentative plan to the consumers and the community. The plan is open to change (slight or substantial) by those affected. See the Alcohol and Pregnancy Study on page 47

Are consulted

Researchers try to promote a plan. They seek to develop support or facilitate acceptance of the plan. See the Developmental Pathways Project on page 50

Receive information

Researchers make a plan and announce it. The community is convened for information purposes. If relevant to the research, participation is invited under conditions specified by Ethics Committee (no example given).

None

Community not involved (no example given).

LOW

Adapted from Brager & Specht (1973) In Consumer Focus Collaboration (2000) Improving Health Services through Consumer Participation: A Resource Guide for Organisations



Ingredient 3:

Knowledge of current funding and policy requirements relating to consumer and community participation

When you are considering how to influence others to involve consumers and community members in their research, it is helpful to think about what exactly might persuade them to do this. Some people are influenced by moral or political arguments. Others are influenced by leaders, their peers or through contact with consumers. But we have found that a significant number of researchers are influenced by the fact that in Australia they are required to involve consumers and the community in order to secure research funding from some institutions. Alternatively, a powerful lever is that there are policy or ethics committee requirements which require them to involve consumers and community members in their research.

Below, we summarise key information about each of these funding and policy levers – you may want to draw on them if you need to persuade colleagues of the importance of consumer and community participation.

a) Funding requirements

The National Health and Medical Research Council currently asks the following question about consumer and community participation in its research grant application forms:

“Does this research involve consumer and/or community participation?”

If yes, describe how you will ensure that:

- (1) Research participants will have access to their own results, and how you will be accountable to participants for the overall results of the research.
- (2) Consumers will be involved in this research, and how you will communicate the results of the research to participants and the community”

b) Policy requirements

The *Model Framework for Consumer and Community Participation in Health and Medical Research* provides information and assistance to researchers and research organisations wanting to involve consumers and the community in their research.

We have not re-printed this framework here, but you can order a paper copy by telephoning the National Health and Medical Research Council in Canberra or you can read it on their website:

www.nhmrc.gov.au.

It is a requirement of the National Health and Medical Research Council Accreditation for Independent Research Institutes that there are written policies to ensure adherence to the *Statement on Consumer and Community Participation in Health and Medical Research*.

c) Ethics requirements

Researchers will also be influenced by what ethics committees require of them. Research that involves Aboriginal and Torres Strait Islander communities in Australia has special ethics requirements for involving their communities in all aspects of the research processes. Researchers must also take into account the cultural principles and values of the Aboriginal and Torres Strait Islander people. For more information see: www.nhmrc.gov.au/publications/synopses/e52syn.htm.

Good practice stories on pages 47-69 highlight the significant changes in practice that have occurred in research being conducted with Aboriginal communities.



CONSUMER AND COMMUNITY PARTICIPATION IN RESEARCH AT AN ORGANISATIONAL LEVEL

This section tells you how you can develop and implement consumer and community participation at an organisational level, based on our experience of doing this at the School and the Institute. We cover the following topics:

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Getting started

We think that having an organisational approach to consumer and community participation is the key to success. Without an organisational approach, participation is almost guaranteed to be ad hoc, and it will be particularly difficult for consumers and community members to access information for themselves about research and researchers. Involving consumers and the community at an organisational level provides accountability and transparency to the community about research activities.

At the School and the Institute, we have a dedicated position to help take this work forward. For us this position has been significant in contributing to our success.

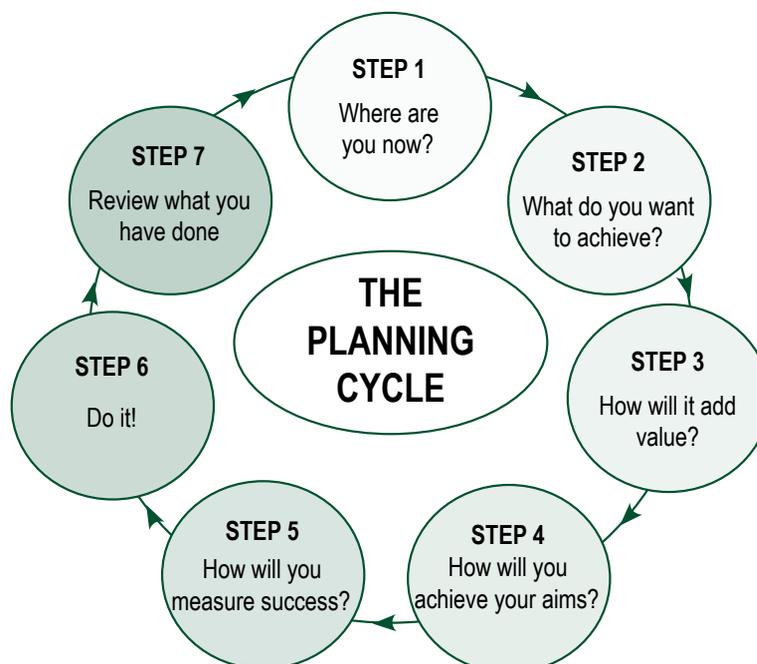
But you do not need a dedicated position to ensure consumer and community participation happens at an organisational level. We suggest that by using the basic ingredients described in the previous section and by following the continuous improvement planning cycle described below, consumer and community participation in your organisation will be increased and enhanced.

Developing participation at an organisational level

We found it helpful to adapt a planning cycle and use it to take forward participation at an organisational level within the School and the Institute. Based on our experience, these are the steps we consider a planning cycle should cover.

Within each of the steps of the planning cycle there are additional smaller steps

All of these steps should be taken in partnership with researchers, consumers and community members. In this section we take you through each of these steps to help you to develop consumer and community participation at an organisational level.



Step 1 - Where are you now?

There are three parts to this step:

1a) Gain senior level commitment

Developing consumer and community participation is very similar to introducing any kind of change within an organisation – it is much harder to achieve if senior staff are not behind it. Check whether you have senior level commitment to taking consumer and community participation forward. If you do not have it, you will need to work to secure it.

You could use the funding and policy requirements described in Ingredient 3 on page 18 to help you argue your case.

Once you have this commitment, we suggest that this is communicated to all staff (this could be through notes of a senior staff meeting), to show that the organisation has made a clear decision to take consumer and community participation forward.

Senior level support means that staff, consumers and community members will know that your actions have backing from the top, and that it is not a waste of time talking with you about this issue.

1b) Find out what is already happening

An audit of consumer and community participation is an effective way to look at where you are now. Establishing what is currently happening will help to:

- Build your knowledge base
- Identify champions and potential allies
- Ensure you recognise good practice
- Highlight where there are any gaps

We suggest asking all senior staff to respond to the audit themselves, or to nominate someone in their team to do this. You will gain more information (and can begin to build effective relationships with any potential champions) if you do the audit face-to-face. If you have senior level commitment to doing this audit, you will stand more chance of getting responses. An audit will also raise awareness with colleagues that the organisation is taking an interest, has a commitment to, and can measure consumer and community participation.

1c) Following the audit

You may also find it helpful to bring together researchers, consumers and community members to talk about where they are now, and the results of the audit. You might wish to meet with researchers and community members separately, or to have one meeting or workshop where you bring everyone together.

For the audit it is helpful to ask:

- Are consumers or community members involved in any of your research projects?
- If so, in which projects?
- How are they involved? (Deciding what to research, deciding how to do it, doing it, letting the community know the results, and/or deciding what to research next)
- At what level are they involved? (see the ladder of participation on page 17)
- Are there opportunities for more consumer and community participation in your research area?
- If so, where, and what are they?
- What are the barriers to taking forward consumer and community participation?
- Is there anything else you'd like to add?

Check out a copy of the audit tool on page 80



At the School and the Institute, we held separate workshops. We held a workshop for senior researchers at each institution and two separate workshops for consumers and community members. The workshops were facilitated by a senior member of staff who was a skilled facilitator and committed to consumer and community participation.

The workshops helped us to clarify what the barriers to consumer and community participation were, and what we might do about it.

The workshops were about trying to consult with consumers, community members and researchers and finding out what they thought about consumer and community participation. The workshops helped us to progress the agenda. They were a good way to get started.

(Ray James - researcher)

Workshops can also be used to agree where you want to go – this is the next step in the process.

Step 2 - What do you want to achieve?

It is important to have a vision about what you want to achieve by involving consumers and the community in your research. This vision can then be shared and owned by researchers, consumers and community members alike. With a vision, any participation you build is more likely to be sustainable. Also it is important to acknowledge that these steps are about organisational change. Success is more likely if you bring people on board along the way. Information gathered in the audit will provide the basis of your plan and goals.

At the School and the Institute our goals and aims were underpinned by the National Health and Medical Research Council and Consumers' Health Forum of Australia's *Statement on Consumer and Community Participation in Health and Medical Research*. We used the workshops (see Step 1c) as the basis for formulating this vision.

It was very interesting to note both researcher and consumer and community workshops raised common themes and issues such as:

- A need for an education strategy that raises awareness inside the organisation as well as in the community.
- A need for training for both researchers and the community on how to involve consumers and the community in research.
- Funding

Check out agenda and questions we used for the consumer and community workshop on page 82

Step 3 - How will consumer and community participation add value?

This can also be drawn from the information you gathered during the audit. Consumer and community participation can improve the quality of research and makes it more relevant and transparent to the community.

At our workshops consumers and researchers talked about the importance of developing effective partnerships. It was considered to be very important that any consumer and community involvement initiatives had a purpose and would be of benefit and add value to both the research and the community. These became the underpinning principles for the development of the plan and policy outlined in the next step.



Step 4 - How will you achieve your aims?

There are three parts to this step:

4a) Develop a strategic plan and get senior level sign off

A plan or strategy helps everyone be clear about what will happen and why. At the School and the Institute we developed strategic plans for how we would involve consumers and the community. These plans have really helped us take consumer and community participation forward in a strategic way.

It is important to be prepared to be flexible, regularly review where you are at, and revisit your plans if something is not working.

My advice to any research organisation that wants to start looking at consumer and community participation is - have a plan. Find out what consumer groups there are with an interest in the research that you're doing. So for example, if the research is mainly about respiratory diseases, I'd say focus on links with those consumer groups. And the first thing you'd ask these interested consumers are what they think might be possible.

(Michele Kosky - consumer)

When you are developing your organisational plan you should also consider including the following:

- **Resources to support consumer and community participation.** We committed to paying an honorarium to consumers and community members to help cover their out-of-pocket expenses and to recognise their contributions. Our payments range from AUD\$25 for attending meetings associated with individual projects through to AUD\$100 per meeting for the consumer and community members of the Consumer and Community Advisory Councils.

We also committed to developing training for consumers, community members and researchers about consumer and community participation in research.

- **A time line.** When you aim to do each step of the plan? You need to tell people so that they know what to expect and how long it is going to take.
- **Recommendations.** If your plan is to be approved by senior staff, you may want to make some specific recommendations – for example a commitment to ensuring funding is made available to pay consumers and community members, or to endorse the establishment of a consumer and community advisory council.

It is important to get the explicit support of senior staff within the organisation to your plan, to help you make sure that it has the best chance of being put into practice.

Unless the person at the top is absolutely supportive of consumer and community participation, and the Board (or the Senate) is very comfortable about the direction of travel, it's not going to happen very quickly. They have to be absolutely clear that this is a priority for the organisation. Without this senior level support for consumer and community participation at the Institute, we would probably be 4-5 years behind where we are now.

(John Finlay-Jones - researcher)

4b) Develop a policy and obtain senior level sign off

An organisational policy for consumer and community participation can act as both a carrot and a stick. By clearly demonstrating the organisation's support for consumer and community participation, a policy encourages staff to put this into practice in their research.



A policy can also be a tool for community members who want to get involved in research but who are finding it hard to find a way in to the research institution or individual research projects.

A policy on consumer and community participation should include:

- The aim of the policy.
- The scope.
- Definitions of consumer and community participation.
- The underpinning principles, governance and ethics.
- The benefits of consumer and community participation.

This policy is best approved by the organisation at the highest appropriate level. At the School, the policy was considered and approved by the Head of School and the Executive Committee. At the Institute it was approved by the Director, the Executive, the Scientific Advisory Committee and the Board of Directors.

The policy is on the website for both the School and the Institute.

4c) Set up a steering committee to help you move forward

A steering committee can help you to think about how to put the plan and the policy into practice.

At the School and the Institute, our vision was to set up a Consumer and Community Advisory Council (the Council) for each organisation. We set up a joint steering committee between the School and Institute to undertake the necessary planning and development associated with establishing the Councils.

The steering committee had a short life and was phased out with the establishment of the Councils. The steering committee had eleven members – senior researchers from each organisation, seven consumer and community representatives and the Consumer Liaison Officer.

The consumer and community representatives came from a range of backgrounds and were generally associated with the research at either organisation.

The steering committee met monthly for six months. Consumer and community members were paid an honorarium of AUD\$50 per meeting, and there was a budget for catering, printing and copying.

The steering committee helped us to think about and develop:

- A business case to fund the establishment of the Council.
- The terms of reference for the Council.
- The structure and membership of the Council.
- The governance of the Council.
- Selection criteria and application forms.
- A glossary of research terms.
- Payment structure for consumer and community members of the Council.

See a copy of the plan developed for the Institute on page 84

An example of a policy for the School is included in the Resources on page 86



Some comments from consumers and community representatives on the steering committee:

As a consumer, I agreed to join the Steering Committee on the proviso that it would be of value. I only wanted to be involved if it was going to make a difference. I felt it worked really well - there was a good balance of researchers and consumers, and there was a commitment from everyone to make it work. There was a clear vision of what was to be done, information was transparent and our input was welcomed. My involvement was for a finite period and you could see an end to it.

(Jackie Softly - consumer)

The good thing about the Steering Committee was that there was a planned approach. It was good to have a framework and to work through it. I now have a different idea about consumer and community participation in research, and have a view about how consumers and community members can be involved. The Steering Committee brought researchers and consumers together as equals.

(Kathie McLure - consumer)

I was very pleased to be invited on to the Steering Committee and then to chair the Consumer and Community Advisory Council at the Institute. I think the steering committee has developed a model that is useful, sustainable and practical. The Steering Committee enabled researchers and consumers to get behind a concept that was realistic and, to work through our disagreements. It worked because we had a planning framework.

(Ben Horgan - consumer)

Step 5 - How will you measure success?

We know that successful consumer and community participation in research can take a long time to develop. We also know that it can be hard to evaluate. But we think it is important to decide with consumers, community members and researchers what success would look like from the beginning of the project, and how you will measure it.

A steering committee can also help you to think about how you will measure success. The steering committee at the School and the Institute discussed this in detail and concluded:

- It is important to measure how successful we are in what we are doing. Consumer and community participation should add value to the research, and we need to know that we are doing that.
- It takes a long time for consumer and community participation to show real benefits. So it is important that we do not rush into expensive and time-consuming evaluations at the end of a relatively short period such as the end of the first year.
- We need ways to measure success that are simple and cheap.
- We do not want to measure the performance of consumers and community members unless we also measure the performance of researchers.
- If we are clear about the aims of consumer and community participation and the aims and purpose of a consumer and community advisory council it will be easier to measure success.

The steering committee agreed that the Councils at the School and the Institute would review progress against their aims, purpose and terms of reference at the end of each year. We also agreed that we will ask anyone who comes into contact with the Council to give us feedback through a simple form.

The Councils will then analyse and review the feedback from these forms.

Check out the terms of reference for this steering committee on page 88

Check our simple evaluation forms on page 89



Step 6 - Do it!

There are five parts to this step.

a) Ensure resources are available

A consumer and community advisory council will need to have the resources to do its job. In the first year, we suggest you budget for:

- An honorarium for consumer and community members (see Step 4 above for more information about payments).
- Catering for the meetings.
- Secretariat support – who will take notes, send out agendas and meeting papers and take action between meetings?

The Consumer Liaison Officer has this role, but if you do not have such a position, you will need to think who will take on this role and how it will be funded.

- Photocopying and postage.
- Training for consumers and community members and researchers who are members of the council (or involved in individual research projects).
- Funds to enable the council to carry out work it has identified as a priority. This might include holding a forum to find out the community's view on priorities for research.

b) Agree on the membership

We suggest that membership of the council includes senior staff, researchers and community members. At the School and the Institute the Councils have the following membership:

- Eight or nine consumers and community members, at least one of whom must be Aboriginal or a Torres Strait Islander.
- Three or four researchers.
- The Consumer Liaison Officer.
- The Head (or Deputy) of the organisation.

Our aim is to have the Councils chaired by a consumer or community member.

c) Recruit members

Members of our steering committee were offered membership on either of the Councils. For other consumers and community members, we advertised in community organisations newsletters and the main Western Australian newspaper. We also contacted all consumers and community members who were already involved in research projects at each institution.

The steering committee felt it was really important to have researchers on the Councils, to put into practice our ideal of consumers, community members and researchers working together. Positions for researcher members were advertised throughout the School and the Institute.

We developed a role statement to help us to decide who we should appoint to the Council. This helped us to think about what kind of skills and experience we were looking for. It also enabled people who were interested in applying to make an informed decision about whether they were interested in working with us.

We also developed a simple information sheet and application form to make it easy for consumers and community members to apply.



The Consumer Liaison Officer and the Health Consumers' Council representative on the steering committee interviewed the community applicants and made appointment recommendations to the Head of the School and the Director of the Institute. We were really surprised and pleased that we had so many quality applicants. Selecting the right people for these new and developing roles was very important. We wanted people who would look at issues from an organisational perspective as well as work in collaboration with researchers. It was really important to have consumer and community members who knew when to speak up and push the point and when to be flexible in how issues or problems could be addressed. Having the role statement and selection criteria in place prior to advertising made the selection easier.

The researcher members were appointed by the head of each organisation. We tried to select people from different areas within the School and the Institute so that the Council membership reflected the diversity of the research conducted at both organisations.

d) Meet and begin work

Both the School and the Institute now have a Consumer and Community Advisory Council. The primary role of each Council is to provide a link between consumers, the community and the research institution. If you are thinking about setting up an advisory council, we suggest you ask your advisory council to address the following three questions:

i. What will the aim of a council be?

The **aim** of the Councils at the School and the Institute is to enable the development of partnerships between consumers, community members and researchers. These groups will work together to make decisions about research priorities, goals, methodologies, questions arising from the research and the dissemination of results to the community.

ii. What will the purpose of a council be?

The purpose of the Councils at the School and the Institute is to enable the process of enhancing the quality and relevance of its research.

iii. What will the terms of reference for the council cover?

The **terms of reference** for the Councils at the School and the Institute are to:

- Provide advice and expertise on consumer and community participation.
- Facilitate access to consumer and community networks.
- Advocate on behalf of consumers and the community.
- Provide support to consumer and community representatives involved in research within the organisation.
- Obtain feedback on research priorities from consumers and the community.
- Evaluate and report to the organisational executive committees and the community on consumer and community participation within the organisation.
- Provide feedback to the executive committees on consumer and community issues.
- Provide feedback on strategic planning and governance relating to consumer and community participation in research within the organisation.

See our advertisement for the consumer and community positions, the role statement and selection criteria and the application form on pages 90, 91, & 92

Check out a sample terms of reference on page 94



At the time of writing this book, both of our Councils have had two meetings, each lasting no longer than two hours. At the first meeting, each Council covered the following issues:

- Welcome and introductions
- The role of the Council
- The terms of reference
- Election of chair
- Agreed meeting times and dates for the year
- Tasks for the Council

The first meeting generated items for discussion and action at subsequent meetings. Following are examples of tasks our Councils will undertake:

- Establishing an advisory panel for researchers who are writing grant applications.
- Considering ways to increase involvement of consumers and community members.
- Reviewing policies that will be relevant to consumers and the community.
- Identifying community priorities for research.
- Involvement in strategic planning and organisational reviews.
- Identifying barriers to the dissemination of research findings.

Researchers and consumers made the following comments about the establishment of the Councils:

To make consumer and community participation sustainable you have to have more than one person determining the destiny of this participation – that's why the Councils are so important.

(Michele Kosky - consumer)

I see the role of the Council as planning, implementation and dissemination of results. So, first of all, there is the question of what sort of research gets done. Then doing the research - are there ways that we can do it more respectfully and sensitively? Is there room for quality improvement in our research processes from that point of view? And finally I hope the Council will add another voice to why the results of research studies in which they have participated are important.

(D'Arcy Holman - researcher)

I think that the Councils will be an avenue for consumers to have a say. It will be a challenge for members to stay in touch with local people.

(Kathie McLure – consumer)

The Council gives us the opportunity to break down the misconceptions some researchers may have about the fact that consumer and community participation is difficult, and that consumer advocates are difficult.

(David Preen - researcher)

Aboriginal people have been researched to the max – we want to see some results. I got involved because I'm passionate about this issue. So it's great we have Councils with Aboriginal people on them.

(Dot Henry - consumer)

We have done a survey of public health academics around Australia, asking about their experience of government suppression of research information. We're going to present those results to the Council to ask them what they think we can do about it, because I feel that this is where research interests and consumer advocacy interests might be aligned.

(D'Arcy Holman - researcher)



Step 7 - Review what you have done

This is an opportunity to reflect on the progress you have made and to implement what you have learnt from the previous six steps. We produce a report on achievements against the milestones of the National Health and Medical Research Council Capacity Building Grant each year, so this has been an ideal opportunity to take stock of what has been achieved and what the next steps for consumer and community involvement will be.

We have also started to be able to evaluate the impact of having an organisational strategy. We have looked at the number of grant applications that have a budgeted and planned component for consumer and community participation. For the past two years, during the major grant application period, the Consumer Liaison Officer has provided a consultancy service to researchers to discuss and plan appropriate ways to include consumers and community members in research projects. This service has become very popular and use has increased each year.

We have not undertaken an evaluation or formal review with our Councils as yet, because it is too early in their existence. However, we have already learned some important lessons:

- Senior level support is very important. Involve them as early as possible in the process.
- Similarly, involve other researchers and staff at all levels, as well as consumers and community members.
- Have a series of steps that keep people on board and working with you. Do not try to do too much too quickly - the changes takes time and patience.
- Be flexible in your planning and in your responses to people's suggestions and concerns.
- Consumer and community participation should add value to research. This value might be to the community, to the research organisation or to individual researchers and research projects.

The Council gives us a unique opportunity to champion consumer and community participation in research. But you have to go gently so that it doesn't alienate people. It will take us a few years to really see results. But eventually I'd like all new research to have had some link with the Council. And I think we'll see the value of the Council through the fact that research that has involved consumers will be more relevant to consumers.

(Ben Horgan - consumer)



The role of the Consumer Liaison Officer

This last part of the organisational section discusses the need for a dedicated role of a Consumer Liaison Officer. As already stated, you do not need a dedicated role to achieve the goals of increasing participation, but we think it helps. Here we talk more about the role, how it has developed, what are the duties, and what difference it makes. We also talk about what skills are needed for the role.

Why was the role set up?

The role of the Consumer Liaison Officer was set up in 1998 after discussion between the then head at the School and the Executive Director of the Health Consumers' Council. Both were concerned about the lack of communication between researchers, health consumers and the community.

The role was to be situated at the School but it also had accountability to the Health Consumers' Council, to become their eyes and ears in the School, working amongst researchers. There was no expectation for the Consumer Liaison Officer to do research. The main objective for the role was to provide a bridge or conduit between the community and the research organisation.

In the beginning

The very early work done by the first Consumer Liaison Officer was about opening the doors and taking each and every opportunity to make inroads into changing the culture. Although there were some tense times, the most significant changes in shifting the thinking of researchers came from the work done on the *Duty to Care* project. This project, funded by the National Health and Medical Research Council, was about the physical health issues of mental health consumers. Some of the outcomes of this significant research were:

- The development of a consumer summary of the research report that was used by mental health consumer representatives and organisations to advocate for change.
- Proactive promotion of the findings of the research amongst health consumers and consumer organisations.
- That the findings of the research project were directly translated into the drafted changes to the Western Australian *Mental Health Act*.
- Researchers saw positive results from the work of the Consumer Liaison Officer and this was a catalyst for the future of consumer and community involvement at the School.

The *Duty to Care* project is described in more detail in Section Four.

A successful application for a National Health and Medical Research Council Capacity Building Grant in 2002 allowed the role to be expanded. The current Consumer Liaison Officer started work in 2004. She works full-time across the School and the Institute.

Some activities the Consumer Liaison Officer has been involved with:

- Working with researchers on individual research projects.
- Developing organisational strategies and capacity to make consumer and community participation a part of the way we do business.
- Lecturing in the university teaching programs about consumer and community participation.
- Expanding networks and creating links with people involved in research projects and consumer and community organisations.



Accountability

The Consumer Liaison Officer reports to the chief investigators of the Capacity Building Grant as well as having relationships with the Head of the School and the Assistant Director of the Institute. The School and the Institute have strong, long-standing links with the Health Consumers' Council, which also provides a mentoring and advisory role for both the Consumer Liaison Officer and the newly-established Consumer and Community Advisory Councils. They have a representative on each Council.

Impact of the role at the School and the Institute

The Duty to Care work provided some insights into what is possible as a beneficial impact of this type of relationship with consumer interests and what happens to results. Having someone doing this role effectively has given the School more credibility and kudos. As consumer and community participation has spread through the School there have been impacts at a process level. The way we do research now is different. Most of our research grant applications that go to the National Health and Medical Research Council now tend to have consumer and community participation as part of the application. And researchers now approach the Consumer Liaison Officer for help. No one's forced to do this. I think what's driving the ones who were originally more skeptical is observing that this actually makes you a better bidder. Because the National Health and Medical Research Council has put out their policy guidelines, we're now in a strong position, so the reality is it's good for business. The other impact is that it has changed some of the research we do.

(D'Arcy Holman - researcher)

The Consumer Liaison Officer has taken the learning's and experiences and brought in a rigour and documentation to what we are doing and put it into a framework. That has legitimised and made more effective what we had already started to do. So from a piecemeal gunshot approach, consumer and community participation is now on a firm footing. For some people in the Institute, consumer and community participation is almost second nature now. When you go out of the Institute you are surprised at how far we have come. We need to think about where we came from, because almost every single public health intervention that I can think of (except fluoridation) fails the disadvantaged, young mothers, Aboriginals, poor mothers - every single disadvantaged group. So the very people at the highest risk are not served by research and services. That is a huge wake-up-call for research and policy. That is what is driving a lot of what is happening here. The answer is: involve the people who are living this and understand the context in which these projects are failing.

(Fiona Stanley - researcher)

The Consumer Liaison Officer is having an impact beyond what she realises. D'Arcy has always been supportive. In this city [Perth] there has been a major change.

(Michele Kosky - consumer)

It's good to have a position like this – it may be the catalyst for greater involvement.

(Heather D'Antoine - researcher)

Having someone to coordinate consumer and community participation - participation probably wouldn't happen without it.

(Dot Henry - consumer)

Consumer and community participation wouldn't have happened without this role because people do not know how to do it – it's a cheap but effective intervention.

(Ray James - researcher)



The skills and experience required for a Consumer Liaison Officer

You have to have someone that gets on with people, you have to get the confidence of the scientists, understand the culture and put the context of where the consumers and their needs fit into this culture. We do not have to feel as though we are not true to our disciplines, not true to our science and be less rigorous because we are involving consumers.

(Fiona Stanley - researcher)

The Consumer Liaison Officer needs skills in leadership, because they need to take the tasks through to success and bring people on board along the way. They also need to be a visionary person.

(Garth Kendall - researcher)

It needs to be someone who has lived the consumer life - you wouldn't employ a researcher unless they had research experience so why would you employ a consumer advocate without experience of consumer issues.

(Ben Horgan - consumer)

You need the right approach. The Consumer Liaison Officer listens, she constantly reminds people, she's a pleasant nagger, her ability to be a bit on people's back, but must have that gift to be able to do it in a way that doesn't create an adverse reaction. That's the skills of the job. It's being an advocate, but being an effective advocate, not a hostile advocate. It has to be someone who stays faithful to the values of a consumer advocate in a very consistent manner. You need a consumer advocate who's going to become part of the organisation but whose mind and heart are never really captured by the organization. Their mind and heart has to be out there with the consumers and the community. Success for this post isn't agreeing on everything. The point of the exercise is to understand how, with our different perspectives, we can actually work together and create some synergies that wouldn't otherwise be there. The aim is not to agree but to acknowledge and respond to the different perspectives.

(D'Arcy Holman - researcher)

You need someone who knows about the health system and is passionate about consumer rights but not precious about them. You need someone who's intelligent and perceptive – who can be a bridge between researchers and the community, someone who researchers can take seriously, but who will not be appropriated by researchers. We need someone from our camp that is able to gain the respect of the research community. Enhancing consumer participation in research doesn't mean that consumers are always right and researchers are always wrong.

(Michele Kosky - consumer)

One of the worst things a head of school could do to a consumer advocate is to expect them to publish in academic journals. It misses the entire point. A consumer advocate is of little value to us if she or he is just the same as us.

(D'Arcy Holman - researcher)

Plans for the future of the role

In organisations that are funded from a variety of sources such as research grants and commissions, government operating grants, consultancies, student fees, investments and private donations, it can be difficult to obtain ongoing funding for the Consumer Liaison Officer role. The School will continue funding the role through ongoing involvement with large research projects and the Institute is aiming to cover funding from their research infrastructure funds. We hope that eventually the role of Consumer Liaison Officer will become redundant, as consumer and community participation becomes part of the everyday good practice in all health and medical research.



STORIES FROM CONSUMERS ON BEING INVOLVED IN RESEARCH

This section is about the thoughts and experiences of two people, Jackie Softly and Ben Horgan. Both Jackie and Ben have been involved in research as consumers or community representatives.

The first story is from Jackie Softly, who is the Deputy Chair of the Western Australian Ministerial Advisory Council on Disability. Jackie is also a consultant advocate for the Down Syndrome Association of Western Australia and has had a long involvement with the Institute.

The second story is from Ben Horgan, who is the Australian National Consumer Coordinator and Ambassador of the World Health Organisation's Bone and Joint Decade. Ben also works as a consumer advocate for the Arthritis Association of Western Australia. He is the inaugural Chairperson of the Consumer and Community Advisory Council at the Institute.

We felt privileged to talk with Jackie and Ben and we were inspired by their positive attitude towards the work being undertaken by the School and the Institute.

We hope you find their thoughts as interesting and as challenging as we did.

Jackie Softly	34
Ben Horgan	36



Jackie Softly

We met with Jackie to talk about her experience of being involved in research. This is what she told us:

I was involved in the *Down Syndrome Needs Opinions Wishes Study* being undertaken at the Institute primarily as an advocate. This population based study looked at the health, functioning, and medical, educational, social and support needs of children and young people with Down syndrome. This is an extension of a similar study which was undertaken at the Institute in 1997.

Getting involved in research

I had a personal interest, as my son Tom has Down syndrome. I am also a member of the Down Syndrome Association, and we thought the information that would be gained from the study would be useful to us. But my main reason for getting involved was because I saw the research as an opportunity to bring about change. Both Commonwealth and State governments are failing to meet the needs of people with Down syndrome and their families.

About my involvement

The researchers approached the Down Syndrome Association and asked us to get involved. We already had links with some of the researchers, so that helped our decision. The researchers showed us the draft survey they had developed.

Although most of us felt it was long, we still felt that it was worth doing, because it could be so useful.

We asked for a number of other questions to be included. These were about:

- Depression and how common it is among people with Down syndrome.
- The prevalence of autism.
- People's behaviour.
- Accommodation.
- Employment.
- How support provided by the Down Syndrome Association was working.
- What other support people would like from the Down Syndrome Association.

The research team made a number of changes to the draft survey in response to our suggestions. We then identified twelve families to pilot the survey. We were involved in reviewing this pilot stage and in agreeing changes to the survey as a result of the pilot.

Once the survey had been sent out, we helped a lot with recruitment. I was employed by the research team at the Institute to contact families to see how they were getting on with the survey. I encouraged people to complete it, and in some cases I helped them to do this. Sometimes this involved home visits. This was a huge job and it took many months.

We have had focus groups for parents of people with Down syndrome and service providers to decide what should be included in the report of the survey, as so much data has been collected. We'll also be involved in disseminating the results of the study, and in pushing for changes to happen in response to these results.



The impact of being involved

The involvement of the Down Syndrome Association has had a huge impact on the levels of recruitment and on the quality of people's responses. We know the issues that families are facing, so parents feel able to respond to us honestly. They provided information to another parent that they might not have given to a professional.

I feel our involvement also had an impact on the researchers. We were able to challenge some of their attitudes and assumptions.

The Down Syndrome Association has gained some status from being involved in this project, so it has benefited us, too.

And on a personal level, I learned a lot from my involvement in the whole process. I had been involved in research projects several years ago where I felt I was the token consumer – I felt I was not valued or listened to. I felt invisible and used, and I felt disempowered because I wasn't a researcher. On this project I felt much more valued.

It is too early to know whether the research will lead to improvements in services and policy, as the report is still being written. But I'm hopeful.

What I would do differently next time

I would value my own opinions and knowledge more and I wouldn't be as quiet as I was at the beginning of this project.

My tips for researchers thinking about consumer and community participation

- Be honest with consumers – do not hide information.
- Value consumer input. Some researchers do not seem to realise the importance of saying thank you. Feeling valued is really important.
- Provide support and training.
- Offer equal pay for work of equal value – this was the most disempowering aspect for me.
- Create a partnership with consumers at the beginning, so that consumers can see the door is open before the research questions have been decided.
- If you already have a relationship with consumers, it's important to maintain it. Don't just dump consumers – you may need them again in future.
- As well as keeping consumers informed of progress with the research they were involved in; ask for their thoughts as results are identified. They may be able to help you decide how the findings could most usefully be put into practice.
- Ongoing consumer and community participation is good for everyone.



Ben Horgan

We also met with Ben, who talked with us about his thoughts on consumers being involved in research.

Getting involved in research

When I was first diagnosed with juvenile arthritis at two, my mother researched the disease and what having a child with arthritis would mean for our family. At that time it was very hard to find adequate answers to the questions my parents had regarding everyday life issues. Within a few years my mother had surveyed about 150 families across Australia about the impact of the disease on the family unit. This led to the development of a follow-up questionnaire, which went to 500 families across Australia and New Zealand. The results were published in 1982, in a book called *Arthritis in Children – A Practical Guide*. To achieve this, my mother worked closely with health professionals, Arthritis Australia and the Association for the Wellbeing of Children in Healthcare. This was an amazing feat considering she was not medically trained and was a woman battling an area that was clinically very male dominated.

For me growing up in this environment, research was part of everyday life. As a child I saw my role in research as that of a guinea pig. As I grew older I realised that I had a far more important role to play. I could use my experience to give researchers a better understanding of the day-to-day issues of living with a chronic illness.

About my involvement

My first experience with research on a global scale came from attending an international conference on the Outcome Measures in Rheumatoid Arthritis Clinical Trials. I attended as a patient participant. I was amazed at the gap between what the researchers thought to be true and what the patients knew to be true through their personal experiences.

One example of this is fatigue, which is a huge issue when living with arthritis. It was not even considered by the researchers to be relevant to their work. Through the determined efforts of the twelve patient participants at this conference, fatigue was better understood by the researchers as being an integral part of the disease process.

Now that fatigue is defined adequately, it is included in mainstream research questions. This inclusion came about as a direct result of consumers having a voice. I think I always knew that giving consumers a voice would make research more efficient, effective and relevant to patients and the community.

Being involved in research as an adult has made me think that some researchers live in a bubble, where they look at numbers and data – not real life. I couldn't understand how researchers could do research that would impact on people's lives without talking to them about what it's like to live with a condition before they start their research. Most researchers don't know what it is like to live with arthritis or the specific illness they are researching.

The more I thought about this, the more I realised it wasn't just about telling people about the results of research – it's about getting involved before the research starts, and thinking about what should be researched. I am always amazed that people keep giving money to research when they often do not get any feedback on results.

I believe that having consumers involved in research can help give researchers a real passion and sense of relevance to their work.



The impact of being involved

After having such a tremendous first-hand experience of seeing the value of consumer involvement in international research, I wanted to be as involved at a local level. I don't think there is much point in consumers sitting back and whinging about not being included.

As fate would have it, the work at the School and the Institute was growing legs, I felt it was the perfect opportunity to share my experience as well as being involved in something that would make a real difference to both consumers and researchers in the future.

With the Councils at the School and the Institute, we are building something new that is effective and sustainable. I want us to embrace research and pull it into the real world, out of the bubble. I think this is just the beginning and although the process has achieved our short term goals of setting up the Councils, our long term goals are going to take a lot longer to achieve.

It is paramount for researchers to embrace the opportunities being offered from willing consumers and get the involvement happening at the beginning of the research. Every research project has opportunities for consumer participation, the 'how' and 'what' needs to be decided together at the earliest possible time.

My tips for researchers thinking about consumer and community participation

- Offer training to consumers - this will help people to be able to understand and contribute fully to the research.
- Use plain English and stay away from acronyms - use consumer input for writing summaries particularly when disseminating the findings of the research to the people who will get the most benefit.
- Budget for participation – reimburse out of pocket expenses.
- Have more than one consumer on your project - ideally people with a range of backgrounds and experiences.



CONSUMER AND COMMUNITY PARTICIPATION IN INDIVIDUAL RESEARCH PROJECTS

This first part of this section offers you some advice about how to involve consumers and the community in individual research projects, rather than across a whole research organisation. Ideally you will be doing both.

The second part of this section has good practice stories about involving consumers and the community in research. Most of these stories are drawn from projects which are based at the School and the Institute, although we have included a few others which are less directly connected to the School or the Institute.

Because the good practice stories are mainly from epidemiological and other applied research projects, we thought it was important to discuss what is also happening in laboratory-based research. The last part of this section is about consumer and community participation in this area.

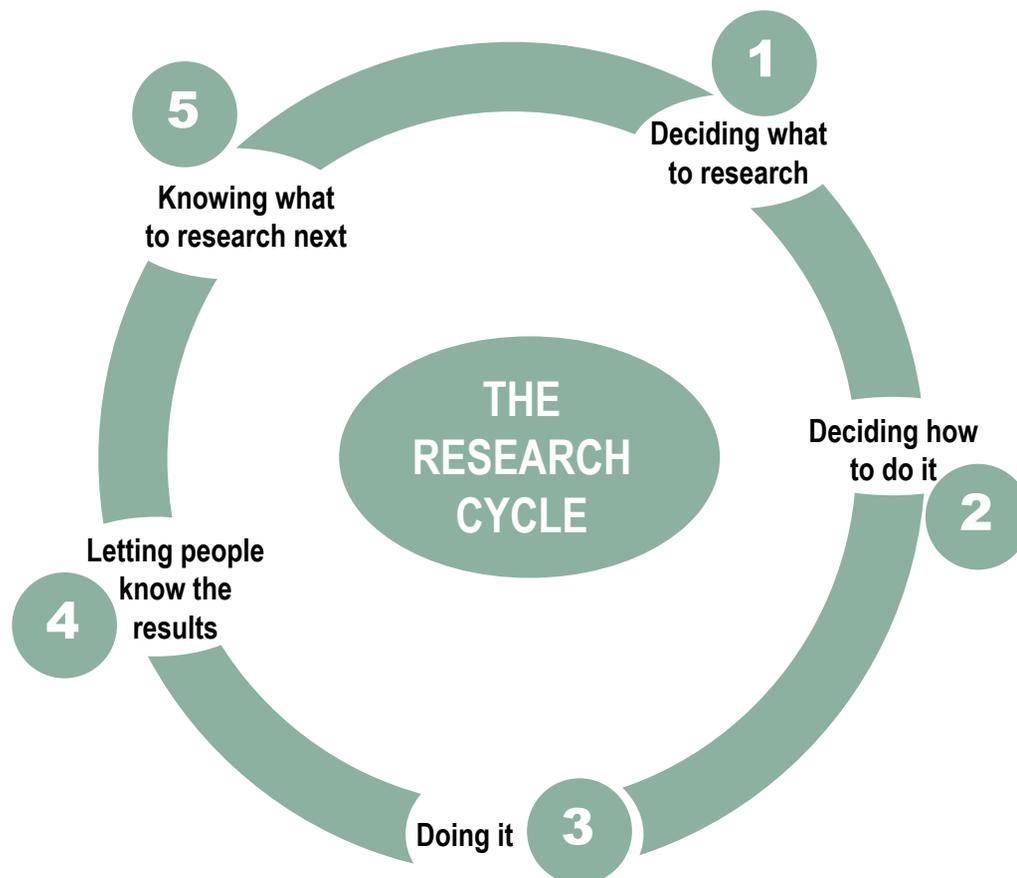
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The research cycle

The research cycle described in *The Framework on Consumer and Community Participation in Health and Medical Research* has five stages (see the diagram below). Within each of these five stages there is a series of smaller steps for involving consumers and community members. We have written about these stages and the smaller steps within them below.

It is important to remember that although the steps are numbered you can start involvement anywhere in the cycle.



Stage 1 - Deciding what to research

Think about what involvement consumer and community members will have

It is important to take time at the beginning of the project to consider their role and how that will happen. The best time is before you have even agreed the research question. However, if you are already past that stage then decide as soon as possible how you will involve consumers and the community. You will find it useful to write down your expectations of consumer and community members so that you can share them with people who may want to be involved. This will become a role description for consumer and community members and can cover the following questions:

- What the project is about.
- What stage in the project you are at – for example:
 - Are you still thinking about the questions the research will ask?
 - Have you started gathering data?
- What stages in your research do you want to involve consumers and community members?
- How much you want to involve consumers and community members?



Think about the ladder of participation (page 17) and the level of involvement you are aiming for in your project.

- What you want consumers and community members to do – for example:
 - Will they help you design the research question?
 - Will they assist with recruitment?
 - Will they help you write a lay summary of the project and the results?

You can review and renegotiate this role description when you talk with consumers and community members who are deciding whether to get involved in your project. Remember it is important to be clear on your ideas right from the beginning, so that consumers and community members can make an informed decision about whether to be involved.

Stage 2 - Deciding how to do it

2a) Think about who to involve

Once you know what you want consumers and community members to do, you will be clearer about what kind of people you want to recruit. For example, if you are doing a project looking at the experiences of consumers with diabetes, and you want people to help you with recruitment and to sit on your project steering committee, you may want to approach a diabetes consumer group. Explain you are looking for someone with diabetes who has experience in sitting on committees, and who might be interested in giving talks or writing articles about your research for people with diabetes.

We think it is good practice to involve at least two consumer and community members. One person can feel very much like they are outnumbered and can easily be silenced by a large group of researchers and other professional people.

Think about the range of different skills, knowledge and experience that consumers and community members can bring to a project. They may be:

- Living with the condition that you are researching.
- Working for a consumer organisation that focuses on a condition you are researching.
- Caring for someone who lives with the condition you are researching.
- A member of a relevant support group.
- A member of a generic consumer organisation (for example we work closely with staff and members of the Health Consumers' Council).
- A member of a community or social group.

My main reason for getting involved in research was because I saw the research as an opportunity to bring about change.

(Jackie Softly - consumer)

I'm doing research looking at health data about prisoners. We want to ask families and prisoners what health issues are important. I do not know anything about that from personal experience. So a consumer perspective is really important. We have involved a consumer advocate who has good networks, and who can help us to reach the relevant consumer groups. We also want to make sure that this research isn't just an academic exercise – we want to get the results out there. So that's another reason for involving consumers, they can help us do that.

(David Preen - researcher)



2b) Get the basics right

Before you go any further, make sure you have got the basics right. These include:

- **Resources and payment**

We think you should offer to pay consumers and community members an honorarium for their input. You should also cover their travel costs, any costs for phone calls, photocopying, etc. At the School and the Institute, we currently pay consumer and community representatives an honorarium for attending a meeting. We try to pay at the time of the meeting or as quickly as possible after a meeting, so that people are not out-of-pocket. This can be especially important if the consumer and community representative has limited income.

- **Flexibility**

Do not always expect consumers and community members to fit in around your schedule. You may need to change the time and the venue for meetings to fit in with when consumers and community representatives are available. For example, the Raine Study Youth Reference Group we describe later in this section meets in the evening, because the young people are at school during the day.

- **Accessible and appropriate.**

Make sure you give information in a way that is suitable for consumers and community members. At the School and the Institute, we try to put together a pack of information for consumers and community members who get involved in a research project.

This might include:

- Information about the organisation such as an annual report.
- The National Health and Medical Research Council and Consumers' Health Forum of Australia's *Statement on Consumer and Community Participation in Health and Medical Research*.
- The policy on Consumer and Community Participation.
- General information about the research project prepared by the researcher.

2c) Decide how you will involve consumers and community members

At the School and the Institute we have three basic models of involvement. Whichever structure or model you choose, you will need to think about how consumer and community participation relates to the overall rules or governance of your project or organisation. The models of involvement are:

- **Involving consumers and community members in an existing structure**

You could invite consumers and community members to join an existing steering group or project team. If you use this model, you should try to involve at least two consumers and community members to support each other. You should also ensure that you involve people who feel confident enough to speak out when meeting with a group of professionals and experts.

- **Reference group or panel**

Involving consumers and community members in a reference group or panel means that you have a group you can refer to throughout your research. The Alcohol and Pregnancy project discussed later in this section uses reference groups.

In some projects, the reference group nominates two people to sit on the main research team (which might also involve other researchers, policymakers and health professionals). The consumer and community representatives on the research team are then able to seek the views of a wider range of interested people from the reference group. The Seniors Research projects described later in this section uses this model of involvement.

Find out more about getting the basics right and reference groups in practice from pages 46 - 77



- **Steering group**

A steering group will help to steer your research, so this model is only appropriate if you involve consumers and community members from a very early stage in your project. On the ladder of participation described on page 17, this type of involvement is described as high participation.

At the Institute we are just beginning to plan a state-wide child development survey, similar to the survey conducted in 1992. We have invited community members to form a steering group to work with the researchers and other stakeholders to develop the pilot study. The researchers have found the input from the steering group on the survey questions very useful. This is a really exciting opportunity to have consumer and community input from the beginning, and throughout the entire research.

Steering groups generally require terms of reference or purpose statements. If you use the steering group model it would be good to have the steering group develop their own terms of reference in consultation with the researchers.

2d) Meet consumers and community members before they become formally involved

Successful involvement requires effective working relationships between researchers and consumers and community members. You need to take time to build this from the start, so people feel welcome and comfortable about joining a research team. It is important to meet consumers and community members before they come to their first meeting or event. Remember to do this at a time and place that suits them.

The interviews for membership on the Consumer and Community Advisory Councils at the School and the Institute were conducted at a place close to the applicant's home or work. We met in coffee shops, the applicants place of work and at the Health Consumers' Council offices. People told us it made them comfortable and they really appreciated our efforts.

2e) Ask consumers what support they need

One of the important things to discuss when you meet is what support the consumer or community member might need. This could include:

- Training about research or about the particular research method that is being used.
- How they would like to receive information – do they prefer email or paper?
Do you need to use large print?
- Is any jargon likely to be used? This is a research project so the answer is almost always yes. If so, can you explain this jargon in advance?

2f) Think about what support you and other researchers might need

If you and any researcher colleagues have not worked with consumers before, you will need to think about any support needs you have, too. For example, you may want to get some training on consumer and community participation, or get advice from an established consumer representative about support groups working in a particular area.



Stage 3 - Doing it

3a) Support consumers and community members at meetings

Do not leave people by themselves at a meeting, especially if it is the first one they have been to. Ensure consumer and community members are introduced to the other members and are properly welcomed.

Make sure that whoever is chairing the meeting does not marginalise consumers and community members or allow excessive use of jargon in the meeting. If your role at the meeting means that you can't offer this support, find someone who is present and can.

3b) Once consumers and community members are involved, make sure you give information in a timely fashion

Make sure people have information in plenty of time for meetings, and that notes go out promptly after meetings. Remember, not all consumers and community members have printers or photocopiers in their homes. Make sure you send people any relevant information on paper and by post if that's what they would prefer. Do not assume everyone has email.

If you make decisions or have important discussions outside of the meetings, it is important to keep consumers and community members informed.

3c) Follow up with consumers and community members after meetings

After meetings, get in touch with consumers and community members. Thank them for coming. Discuss where their input added value to the meeting. Ask them for their feedback on the meeting, and what you (or others) could do to make their involvement more effective. If there are minutes or actions statements from the meeting make sure they are sent out as soon as possible after the meeting.

Stage 4 - Letting people know the results

Keep consumers and community members informed and involved throughout the project

Make sure you keep all people in the research team up-to-date as the project progresses, even if consumers and community members are not involved at all stages of the research. Make sure consumers and community members do not hear the results of the research through the media before you have let them know about the results. One effective way to involve consumers and community members at the dissemination stage is to ask them to help you to develop the lay summary of the findings, and perhaps to give talks to relevant community groups about the research and what you found.

Consumers can help with reporting the results of research. They can give research results relevance and can communicate them in a way that's meaningful.

(Ben Horgan - consumer)



Step 5 - Knowing what to research next

Involve consumers and community members in deciding what to do next

As you come to the end of your research project you will often be reflecting on what has happened and what to research next. Consumers and community members and researchers who have had a positive experience of working together will often want to continue their involvement with a follow-on project. We believe that consumers and the community have a real role to play in advocating for research findings to be translated into policy and practice and they may well be powerful advocates in helping to secure funding for your future research.

The next project will have consumer involvement at the beginning. There has been evolutionary process in the research projects that we have done. In the first project we had no consumer and community involvement, in the next project we had consumers after it started and now we have consumers helping to develop the next project.

(Jan Payne - researcher)

Every research project is different, so you will want to consider how to adapt and add to our suggestions. Whatever you do, it is really important to ensure that any involvement is not just paying lip service to participation. We think many of these steps are basic common sense and good manners. They could apply to the involvement of any stakeholder such as researchers, policy makers, health-care staff, as well as to consumer and community members. Remember the basic ingredients discussed in Section One.



Good practice stories of consumer and community participation in individual research projects

This part of the section contains some good practice examples of research projects where consumers and community members have been actively involved. We conducted interviews with the project managers, research staff and consumers and have included these perspectives in the stories.

Each person we spoke to was very honest about what has worked well, what did not work so well and what could be done differently. Again we felt very privileged to meet with people who willingly shared their experiences.

We acknowledge that this is a very small sample of good practice stories where researchers, consumers and the community are working together to increase participation and ultimately translate research finding into changes in policy and practice.

These good practice stories are listed alphabetically. We hope these stories give you some ideas of what is possible as well as showing you a range of ways that consumer and community participation can be applied.



The Alcohol and Pregnancy Project

We met with the Project Manager Jan Payne to discuss her experiences of consumer and community participation. This is her story.

Fetal alcohol spectrum disorder is a general term that describes the range of effects that can occur in a person who was exposed to alcohol in the womb. The consequences for the baby exposed to alcohol during pregnancy are life-long. They include brain damage, poor growth, developmental delay, birth defects, social and behavioural problems and low intelligence quotient. Fetal alcohol syndrome is one of the diagnoses that come under the general term of fetal alcohol spectrum disorder.

The Alcohol and Pregnancy project builds on previous research which identified that many health professionals do not routinely ask women about their alcohol use. Many also do not feel prepared to advise women about the consequences of alcohol use in pregnancy and lack knowledge about how to diagnose fetal alcohol syndrome.

Health professionals have major strengths that contribute to their ability to make a difference with women around the issue of alcohol use before and during pregnancy. Women expect health professionals to give advice that is personalised.

The current research project will develop and send out evidence-based resources to Western Australian health professionals. The resources have been developed with information gained from interviews and focus groups with Western Australian health professionals and Aboriginal and non-Aboriginal women. It is intended that these resources will support health professionals' knowledge and advice to women. The resources will be evaluated. Overall, the aim is to increase the number of health professionals who routinely ask women about their alcohol use, and routinely provide them with accurate information about the consequences of drinking alcohol during pregnancy.

The Alcohol and Pregnancy project is a three year project funded by Healthway, a Western Australian statutory body that funds activities that promote health, health promotion activities and research.

Involving consumers and the community

Jan had worked on a range of projects that involved consumers and community members. Her training as a nurse and experience as a midwife and community nurse built an understanding and awareness that consumers owned their own health information. This philosophy has translated into the research Jan has been involved with since the 1970s.

I am privileged to be in a position where I can do this. I want to listen to people, and to give something back, not just to take from people. That can be really hard for a researcher.

(Jan Payne - researcher)

Jan worked in research projects involving the health of Aboriginal people in the 1990's. It was then she came to an even greater understanding that research was not about telling people what to do but, rather, about finding the right way to talk with the people who were involved in the research. During this time a research project was set up involving community members using art.

Women involved in research decorated a bus that collected people to come to meetings. Although it wasn't a conventional structure for research, it was very successful, with people in the community really getting involved.



How consumers and the community were involved in this project

Involving consumers and the community in the current project in a meaningful way was a natural progression from the earlier insights gained from working with Aboriginal communities. The inclusion of consumer and community reference groups was first considered early in the project when the governance of the Alcohol and Pregnancy project was being decided.

The Consumer Liaison Officer helped to decide where the community reference groups would fit within the governance structure. It was decided that the reference groups would feed information directly into the project steering group. There was also a lot of discussion about whether to have one reference group or two. In the end it was decided to have two groups; an Aboriginal reference group and a non-Aboriginal group.

People from the Aboriginal Community Reference Group were recruited through existing contacts. People from the Consumer and Community (non-Aboriginal) Reference Group were recruited through the Health Consumers' Council. There are three people on each group. Each group has terms of reference and meets at least four times a year. Both groups are chaired by Heather D'Antoine, who is a senior research officer at the Institute and a member of the Steering Committee. The Aboriginal Community Reference Group wanted to include a man, as they didn't want this issue to be considered as only women's business. The Consumer and Community Reference Group have women members only.

The two groups have meetings as closely together as possible and have similar agendas.

Each group shares the meeting notes of the other group, so that ideas and opinions are transferred. They have now decided to meet together as one group on a one-off basis.

At the end of the project, summaries of the results will be produced for the community, as well as writing journal articles. The aim is for the findings of the research to inform government policy and professional practice.

The impact of consumer and community participation

The groups have helped with consent forms and the information sheets. They have had an impact on the questions discussed in the focus groups and interviews with key informants. The challenge was to develop health promotion material that would be relevant to all women – the reference groups really helped with that.

The involvement of the reference groups has also made a difference to me as a researcher – I feel really secure about our research process because of their involvement.

(Jan Payne - researcher)

In addition to this project, advice was also sought from both reference groups on another closely associated project. They had an input into a survey for women in the community, any changes to it and an additional question was asked based on the reference group's feedback. The consumer and community reference groups will be involved in future projects on this topic when the grant applications are being written. It will be important to include proper funding for consumer and community participation within the funding application.

We also met with the chairperson of the reference groups Heather D'Antoine. Heather considered it is very important to have voices from outside the Institute involved in research, to have input into the project and to make comment on materials and products.

Check out a sample terms of reference for this project on page 96



It's nice to know that they can be involved in other projects as well that come out of this project. The Groups have also helped keep us in check – researchers can sometimes have no fear about what they look for, and we need to be sensitive in our methods and what we look at.

(Heather D'Antione - researcher)

Heather also felt it was important to have separate reference groups for Aboriginal and non-Aboriginal women. Alcohol is a big issue for Aboriginal people and it was important to make sure the voice of Aboriginal women wasn't going to be lost.

A consumer representative from one of the reference groups made the following comments about her experience

There was such a warmth and gratitude from the researchers that we had agreed to be involved and were willing to offer input into the project. It differed from some other consumer committees I have been involved in, in that much of the work was done by project staff between meetings and we were required to comment on very well developed drafts. Other committees require members to carry out all the work!

This was a very practical research project, as it was about applying the results of previous research into information products health care professionals could use in the field. As consumers, we felt we were part of a very constructive process of turning research into useful resources. Finally, there was quite a bit of discussion about future projects, and how consumers could be involved in the process of deciding which research projects would best be focused on in the future. It has been a great initiative to be involved in as a consumer and augurs very well for the future.

(Pip Brennan - consumer)

Tips for other researchers

- Consumer and community involvement in this project was an evolutionary process and it is important to remember that it takes time.
- It is really important to budget for involvement when applying for grants.



Developmental Pathways in Western Australian Children Project

The Project Coordinator Erika Hagemann and the Research Assistant Amber Howard, shared their story about the involvement of consumers and the community in the project.

The Developmental Pathways in Western Australian Children Project aims to bring together data about children and young people. This data is currently held by a range of agencies in Western Australia. These include the Departments of Health, Education and Training, Community Development, Corrective Services, the Disability Services Commission and the Office for Children and Youth. The data used in this project will be in an anonymous form and will be used to:

- Provide an overview of differences in developmental outcomes for different groups of children and young people.
- Describe key factors which seem to help or hinder children's development.
- Identify pathways to health and wellbeing.
- Look at education and juvenile delinquency to identify factors that can lead to an increase or a reduction in persistent juvenile offending.
- Explore what factors increase or reduce the risk of Aboriginal children and young people committing criminal offences.
- Identify the factors that make it more or less likely that children will enter the Child Protection System.
- Look at what happens after children leave the Child Protection System, with a separate component for Aboriginal children.

The project is possible because of collaboration between the Telethon Institute for Child Health Research, The University of Western Australia Crime Research Centre and six government agencies in Western Australia. It is funded by the Australian Research Council. The research is being carried out by a team that included seven postgraduate students, under the supervision of established researchers and agency representatives.

Involving consumers and the community

The lead researchers recognised that it would be important to get community buy-in for research that involved linking data from various government agencies. Discussions about how to do this happened after the research team was established. The early planning was difficult because there was no budgeted funding and no one person had responsibility for ensuring that consumers and the community were involved in the project.

The Consumer Liaison Officer had input into developing the early plans for involvement. In hindsight, plans were based on what might be ideal rather than what was practical. In particular the first plan didn't really take into consideration the varying degrees of acceptance for consumer and community participation from all of the stakeholders. So it was necessary to re-think strategies and plans.

A communication strategy was developed with input from all the stakeholders and included a component on the need to involve and inform the community as the project evolved. Eventually two options for consumer and community participation were suggested to the research team:

1. Establish an overarching consumer reference group with representation from each stakeholder organisation; or
2. Have consumer representatives on each research sub-project (postgraduate project).



The second option was chosen. It was then decided that each research project would have a representative from the Aboriginal community as well as a representative from the consumer and community groups associated with the relevant stakeholder organisation. Having a number of different stakeholders has meant that progress can be slow. However, good practices for communicating between stakeholders have been developed and communication has improved.

The Consumer Liaison Officer and the Management Team went back to basics and held training sessions for the postgraduate students on consumer and community participation. These sessions included information such as: how consumer and community participation has evolved in research; why it is necessary; what the benefits and barriers are, and, how it can be implemented.

There are multiple supervisors for the students, big pressures on them. The students were worried about having to do this as well. But, at the end of the training session they seemed more positive. We now have three consumer reps on advisory panels – and they all have Aboriginal representatives, too.

(Erika Hagemann - researcher)

The impact of consumers and community involvement

It is too early to be able to see the impact of any involvement yet. However the partner organisations are working with students and the project management to find out who are the most relevant consumer and community groups. There have been some small but significant steps forward to involve consumers and the community.

Glenn Pearson, an Aboriginal postgraduate student from Kulunga (page 54), has been helping with this process as well. He organised the students to attend an Aboriginal community health service. For some of the students this has been their first experience of community participation – they were able to engage and communicate and see the value in seeking others' opinions. The service providers at the Aboriginal community service wanted to know what the research will mean to them. The students really responded well to this.

(Erika Hagemann - researcher)

Both Erika and Amber considered that it was important to be able to look back and think about what might have been done differently. It was equally important to work with what was currently happening. They felt that by being flexible and not giving up, consumer and community participation was able to move forward with the project.

This project is a perfect example of the need to work outside the square and of being flexible, so that it's not just a tick-the-box exercise, but rather about getting the benefits from the consumer's involvement.

(Amber Howard - researcher)

Tips for other researchers

- The most important thing is that consumer and community participation needs to be in place at the initial set up of the project with appropriate budgets.
- It is also necessary to think widely and explore different options.
- Talk with researchers and consumers and community members to find out their expectations of how people will be involved.
- It is also useful to identify the stakeholder's current understanding of what consumer representation means and provide evidence of how this can benefit research.
- Be familiar with the stakeholders' competing priorities and shape any proposal to accommodate these needs.



Duty to Care Project

The Senior Researcher David Lawrence and the Consumer Liaison Officer Rebecca Coghlan, worked together at the School to bring this very important research to the attention of those most affected – mental health consumers. David and Rebecca told us their story about the impact of consumer involvement.

The *Duty to Care* project, which was funded by the National Health and Medical Research Council from 1999 to 2000, set out to examine the physical health of people who suffer from mental illness.

Western Australia has a unique resource for research, in that since 1966, the Mental Health Information System has recorded all contacts with mental health services in the state. The project examined the health experience of the 240,000 Western Australians who have used mental health services during the period 1980 to 1998. Using de-identified data, their hospital admission rates, cancer incidence rates and death rates were been examined.

The project found disturbingly high rates of all major physical health problems in people with mental illness, with heart disease and respiratory conditions being major causes of premature deaths. Several issues of concern were identified. One was the effect of smoking, alcohol and drug use, and the lack of suitable programs to help people with mental illness deal with substance use issues. A second issue of concern was the large disparity in level of health care provided to people with mental illness. Despite higher risks for physical health problems, people with mental illness typically had their physical health conditions diagnosed at a later stage, and were less likely to receive treatment than people with no history of mental illness. Many of the people included in the project had only short contact with mental health services and continued to have poor physical health and not receive adequate treatment many years after. This showed the extent to which the stigma of mental illness pervades society in general and affects the health system.

Involving consumers and the community

When the project was first planned it was put forward that lifestyle factors and side effects of treatments may put people with mental illness at higher risk of certain physical health problems. The results of the *Duty to Care* project found much higher risks than first anticipated. It also identified inequities in access to and delivery of health services as a major factor. It was clear that the research team would need to work closely with mental health consumers to achieve positive changes.

Because of the significance of the research findings, the *Duty to Care* project was identified as an early priority for the Consumer Liaison Officer. She played a major role in disseminating the findings, and collaborating with consumers and consumer organisations to lobby for changes in mental health service delivery. The research team met with a range of mental health consumers in a variety of settings:

- Inpatients
- Attendees at day patient and community facilities
- Residents of psychiatric hostels

This was done for three reasons:

- To validate that the statistical findings matched the experiences of individuals with mental illness.
- To develop a greater understanding of the problems faced by people with mental illness.
- To identify the weaknesses in the health system.

The Consumer Liaison Officer collaborated with the research team in the production of a consumer summary and stakeholder report. These were launched together along with the technical report from the project. The Consumer Liaison Officer and the research team worked with the Health Consumers' Council and the Western Australian Association for Mental Health to mobilise and inform consumers



about the research and to develop a strategy to lobby for change. The Consumer Liaison Officer also brought the findings to the attention of relevant government ministers, systems administrators and policy makers.

The impact of consumers and community involvement

Six papers were published from the *Duty to Care* project in scientific journals. The impact of these papers on mental health services policy and practice was limited to academic circles. It became clear that the usual channels for scientific publishing were inadequate for communicating the findings of the project to the health services managers and administrators and the practitioners.

However, the launch of the technical report, and in particular the stakeholder report and consumer summary that accompanied it, have had major impacts in communicating the findings to a wider audience and advocating for change. These activities resulted in the Western Australian Department of Health establishing the HealthRight Committee to develop and implement responses to the reports.

This contributed to changes in mental health service delivery including:

- A requirement for patients with mental illness discharged from inpatient facilities to be seen by a community mental health service within four days of discharge. (Previously, patients were added to waiting lists with delays averaging 12 weeks.)
- Programs to ensure all clients of mental health services have a nominated general practitioner.
- A program of breast screening for female patients with mental illness.
- A pilot program to co-locate general practitioners with mental health services.
- Changes to the *Mental Health Act* that require all persons “admitted to authorised mental health facilities to have documented in their medical record the results of a complete medical assessment within a reasonable period following reception to that service”.

The findings were also picked up in other states. For example, in Victoria, a new guideline issued by the Chief Psychiatrist stipulated minimum levels of physical health care for psychiatric patients in the state. In New South Wales, the *Teams of Two* training program was developed jointly by the Divisions of General Practice and the Department of Health. The program provides specific training for general practitioners to work alongside mental health practitioners. One of three core modules specifically addresses the physical health needs of people with mental illness.

The theme for the 2004 World Mental Health Day was “The relationship between physical and mental health: co-occurring disorders”. Excerpts from the *Duty to Care* project were featured in the 2004 World Mental Health Day report published by the World Federation for Mental Health. This included translating parts of *Duty to Care* reports into French and Spanish. The material was distributed to over 150 countries. This level of impact would not have been achieved without the direct involvement of the Consumer Liaison Officer and the strong participation of mental health consumers. As consumer and community involvement in research was in its infancy at the time the project was first developed in 1996, consumers were not involved in the design of the research. In hindsight this was a lost opportunity. However, it is fair to say it would be done differently today.

Tips for other researchers

- Within the health services sector, the goals of researchers and consumers have strong overlap - both groups want to improve health services for the benefit of patients and the population at large.
- Consumers, community members and researchers can be powerful allies in achieving improvements in health care that are founded in evidence.



Kulunga Research Network

The Kulunga Manager Colleen Hayward talked with us about community participation. Colleen explained that consultation with communities is part of the process of doing research with Aboriginal people.

Whilst the Consumer Liaison Officer does not work directly in Kulunga or its research programs, there is a commonality of goals - working towards greater participation in research. Kulunga is represented on the Institute's Consumer and Community Advisory Council and has a staff member on the Health Consumers' Council Board of Management.

The Kulunga Research Network had its origins in the Bibbulung Gnarneep project which commenced in 1994. That project was one of the first Aboriginal research projects at the Institute and heralded the building of capacity in Aboriginal research. Kulunga was officially formed in 1999 as a partnership between the Institute and the Western Australian Aboriginal community. Kulunga is located at the Institute.

Kulunga is a Noongar word meaning child. The Kulunga Research Network was so named to recognise its focus on improvements in Aboriginal child health. The use of a Noongar word also recognises that the Institute is located on land traditionally owned by the Noongar people.

Kulunga's Vision is:

- To develop a Network which enables Aboriginal people to conduct research and training, which in turn will form a basis for improvement in health and whole of life expectations for Aboriginal children and families in Western Australia.
- Kulunga respects the right of Aboriginal people to control research activities in keeping with the principles of Aboriginal self-determination.

Kulunga has its own research agenda which is overseen by a steering committee comprising of leaders in the Aboriginal community, researchers and representatives of government agencies with which Kulunga partners. Kulunga's work is focused on four core areas of activity which include:

- Research
- Information Dissemination
- Capacity-Building
- Advocacy

Community involvement will differ according to the type of research being done. For epidemiological research it is necessary to involve the community in all aspects of the research. This includes deciding what will be researched right through to how the results of the research will be given back to the community. Even research about Aboriginal people that uses de-identified data or donor samples still requires community input. For example, a researcher might consult with representatives of Aboriginal communities, such as health workers, about the best way of letting people know the results of the research.

Kulunga is trying to be visible at the Institute and in the community and the Consumer Liaison Officer's role is reaffirming that we are doing it the right way.

(Colleen Hayward - researcher)



The Northern Goldfields Renal Study

During the writing of this book, we had the privilege of visiting Dr Christine Jeffries-Stokes and her husband Pastor Geoffrey Stokes at their home in Kalgoorlie. Christine who is the Lead Researcher and Geoffrey, told us about the Northern Goldfields Renal Study and how it began.

This study is a good practice example of a community initiating research. This project also demonstrates how communities can work in partnerships with researchers and clinicians to address the very high incidence of diabetes and kidney disease in the Aboriginal community.

Christine and Geoffrey told us how the community asked for the research to be done because they were attending a funeral nearly every week for an Aboriginal person whose death was related to kidney disease and/or diabetes. The idea for the project came about because people were constantly asking why it was happening, and why nothing was being done to stop people from dying.

The project involves screening every Aboriginal child and adult in the isolated Western Australian towns of Laverton, Leonora and Mt Margaret for symptoms of kidney disease and diabetes. The other aspect, and the most exciting part of the research project according to Christine and Geoffrey, is the health intervention strategy to work with the communities to develop healthier diets. Community and household gardens have been developed in each town to provide a source of fresh fruit and vegetables for the community. This gives people experience in growing things and the bonus of exercise at the same time.

There have been performances and plays, cooking demonstrations, exhibitions and a special festival called the Wanti Sugaba Festival which means *stop the sugar* in the local language.

This research project, although only partly completed, has all the ingredients of true community-driven research that has initiated, collaborated with, and developed partnerships to tackle the problem of diabetes and kidney disease in the Northern Goldfields' communities of Western Australia.

The project is funded by the Rural Clinical School, which is a collaboration between The University of Western Australia and the University of Notre Dame.



Mentally Healthy WA Campaign: Act - Belong - Connect

Ray James, formerly a senior researcher at the Institute and advocate for increased consumer and community participation in research, talked with us about his current work at Curtin University of Technology.

The Mentally Health WA Campaign is about people in six regional communities in Western Australia participating in an innovative campaign to promote positive mental health. The aim is to reduce problems like depression, anxiety and related issues such as social isolation.

The towns of Albany, Esperance, Geraldton, Kalgoorlie, Karratha and Northam/York/Toodyay are participating in a three year community-based campaign implemented by a research team from Curtin University.

The Consumer Liaison Officer joined the research team as an interim community representative at the beginning of the campaign. The Health Consumers' Council then recruited the two permanent community members of the research team.

The project is funded by Healthway and supported by Western Australian Department of Health Country Health Services, Lottery West, the Western Australian Division of Mental Health and Pilbara Iron.

The Mentally Healthy WA Campaign is the first of its kind in the world. It works by influencing attitudes, intentions and behaviour of the whole community, using social marketing and community engagement strategies to promote the simple message of Act – Belong - Commit.

Project officers in the six towns work with community groups to help organise activities that enable community members to be more active, join in and support local clubs, and, make civic communities stronger to help build stronger communities.

The project management committee has actively recruited community representatives on the management team Their contributions have been a valuable to the development of the whole project.

One of the representatives gave a poster presentation of their involvement in the project at a national mental health conference *Kindling the Flame: Promoting Mental Health and Wellbeing*.



The Raine Study

The Raine Study Coordinator Nick Sloan and the Communications Manager Heather Monteiro discussed their experiences of increased involvement of the participants and families.

The Raine Study is one of the most extensive surveys of pregnancy and childhood to be undertaken anywhere in the world. Between 1989 and 1992, almost 3000 women who were 18 weeks pregnant agreed to take part in the study.

Their children have been followed up at birth and at one, two, three, five, eight, ten, thirteen and now sixteen years of age. Raine Study findings have made a significant contribution to global practice regarding the frequency of ultrasound scans in pregnancy and the increase in knowledge for childhood illnesses, such as asthma and allergies.

The latest phase of the Raine Study, the 16-year follow-up, will give researchers a unique opportunity to look at the development of physical characteristics and other factors that can determine life-long health status.

The Raine Study represents collaboration between the Telethon Institute for Child Health Research, the Women and Infants Research Foundation at King Edward Memorial Hospital for Women, and The University of Western Australia Department of Paediatrics at Princess Margaret Hospital for Children

Involving consumers and the community

In 2002, Garth Kendall, a senior researcher for the Raine Study organised a consultant from the United Kingdom to work at the Institute to improve communication with the Raine Study families. As a result in 2003, a communications manager was appointed. In 2005, the management team worked with the Consumer Liaison Officer on a plan to increase opportunities for greater involvement for the families.

All Raine Study families were invited to attend a workshop to talk about how this might happen. Most of the 27 families that came found the concept of consumer and community participation difficult to understand and failed to fully appreciate what was being asked of them. Many of the people suggested that they were happy with the way the Raine Study was going and they felt loyal and supportive of it. Parents talked about fundraising and promotion in shopping centres

I didn't really know much about consumer and community participation, but felt it piggy-backed onto what we were already doing. When we approached people to get involved, initially we didn't get much of a response. We hadn't meaningfully asked the families their opinions about anything and yet we were trying to change their mindset about how they could now be involved. At the time I felt that they didn't want this and we were pushing it at them – it was a bit of a chicken and egg situation.

(Nick Sloan - researcher)

The young people who came to the workshop said:

- They were interested in becoming more involved but also it was important to leave research to the people who knew what they were doing, that is the researchers.
- A young people's management committee could provide feedback to the Raine Study.
- A management committee needed to be representative and democratic.
- They were concerned about managing possible conflict - an adult or a researcher would help keep order.



Parents and carers said:

- They were very happy with the way the Raine Study was being run.
- They were interested in more involvement depending on the level of commitment and obligation.
- A management group should have wide representation from the Raine Study participants.
- Involvement is an opportunity to have input on research topics and priorities and to help present information in lay terms
- They were concerned about children's involvement - in particular time constraints due to study.

Following the workshop it was decided that a young people's reference group would be established. Members were recruited from the workshop, through promotion in the Raine Study newsletter and website, and through personal approaches by research staff.

In the first place it was pushed onto me as part of my role and it was hard work to get going. I saw it as a huge effort for little return.

(Heather Monteiro - researcher)

The Raine Study Youth Reference Group (the Reference Group) was finally established in 2006. It consists of seven young people, who are fairly representative of the whole cohort. They meet every six weeks with the Communications Manager and the Consumer Liaison Officer. The Reference Group took a while to get started, because it was not really clear what they might do or where they would have input.

It was also important for everyone to get to know each other and feel comfortable. As the Reference Group has developed, their involvement is increasingly seen as being very important to the future development and overall success of the study.

It's like a light has gone on and we are really finding they are embracing the opportunity to ask questions and give us their opinions.

(Nick Sloan - researcher)

I'm not sure how they feel about this but I think we have developed a real relationship. We have all really changed and I am proud that in a small way I might be contributing to some of their development.

(Heather Monteiro - researcher)

The impact of consumer and community participation

Right from the beginning, the Reference Group was very forthcoming about the need to make changes to the communication with the families and the teenage participants. So far the Reference Group has had direct involvement in:

- Making massive changes to the newsletter - the major source of communication with the families.
- Having input into the language of the information sheets.
- Helping with the letter that was sent to all Raine Study participants inviting them to take part in the 16 year follow-up.

They have helped with things I took for granted – I wasn't being effective in communicating with the kids – I am not 16 – they were pretty brutal but really helpful.

(Heather Monteiro - researcher)



It is hoped that the Reference Group will ultimately become part of the Raine Study's core management committee. There is a significant opportunity for Raine Study participants to become involved in the development of a new system of management and governance. Their voice will be a major part of the decision-making process.

Already there has been a significant change in attitudes towards the benefit of having a reference group. For example, the Reference Group was invited to take part in a think tank meeting to plan for the 19 year follow-up.

It's easy to forget it is their Study – it is good for all participants in the Study to know they have representatives within the management team.

(Nick Sloan - researcher)

At 18 they will be independent and it's imperative for the Study that we get them involved and we also need to see what they want studied. It is really important to keep them involved, especially in terms of retention.

(Heather Monteiro - researcher)

In February 2007, the Reference Group met with the Director of the Institute, Fiona Stanley. These are some of the comments they made during this meeting:

• **On communication:**

Some of the things that they [researchers] write, that we are supposed to read – they think that we are geniuses and that we can read words that have 27 letters.

• **Putting a face to the data:**

I am research participant no 43 - Just making sure that they know that they are actually testing us and that we are not just lab rats ... the numbers just don't come from anywhere.

• **Providing participants with results:**

Sometimes I feel like it's actually not going anywhere. We know it is going somewhere, but we don't really hear about it that much.

Not being told about something is actually worse, because we might think of something – like make up something ourselves.

• **Retention of participants:**

I think the reason most people probably drop out is that they don't actually know what they are doing it for ... And it's like, what's the point? It feels like we are not actually going anywhere with it.

It was following the meeting with Fiona Stanley that Nick began to see the future potential of having this Reference Group at the institute:

I have really changed my opinion about this Reference Group. When I heard the questions they asked Fiona Stanley about the Study, I thought, these are the questions we hoped the Reference Group might come up with. This participation is really important.

(Nick Sloan - researcher)



In March 2007, the Reference Group was invited to present to approximately 100 researchers at a two day annual forum for the Division of Population Sciences at the Institute. It was really surprising and pleasing that all members of the Reference Group put their hands up to take part in making a presentation at the forum. It gave researchers a chance to talk to the participants and hear what they have to say. The response from the researchers was extremely positive.

The Raine Study is considered to be a flagship study of the Institute. Furthermore, the Reference Group could provide a positive role model for other researchers who are considering involving consumers and the community. Nick thought it would be good to see consumer and community participation become established as part of all new studies, not a 'shall we?' but a 'we shall' approach.

This is quite cutting edge what we are doing. Not a lot of people who are researching children's diseases and conditions ever ask children or young people what they think about it.

(Fiona Stanley - researcher)

Tips for other researchers

Early consideration of the following points might make it easier to get started:

- Have clear objectives on what can be achieved so it is not meaningless.
- Have lots of perseverance, patience and time to develop relationships - it does not happen overnight.
- Budget for consumer and community participation – consider it as an investment.
- Develop terms of reference so everyone knows where they stand.



Seniors Research on Long-Term Illness and Seniors Research on Medication Safety

We talked with the Chief Investigators D'Arcy Holman and Jon Emery and Research Officer Jennifer Dodd, about the involvement of consumers and the community in these two major research projects.

In 2006, the School and The University of Western Australia's Unit of General Practice (General Practice) embarked on two separate studies using linked data to look at the management of long-term illness and medication safety in people over 65 years of age.

One study is looking at the best ways to improve the health of people over 65 who have diabetes, heart disease, high blood pressure, asthma, emphysema, seizures or stomach disorders. It will examine the best way that visits to a general practitioner can promote healthier ageing, and review the benefits of a major change to Medicare that occurred in 1999. The change was about general practitioners being paid to be paid to perform health assessments and prepare health plans for people with a long-term illness.

The second study is looking at ways to tackle the increase in side effects from some prescribed medications given to Australians aged 65 and over. Two groups of medications are being studied. The first is prescribed medications which most often cause a hospital stay because of a harmful reaction. The second is medications which seniors should avoid according to an international expert panel of doctors.

Both projects will be looking at health data, including Medicare use, hospital stays and deaths. The projects are funded by the National Health and Medical Research Council. Researchers from both the School and General Practice will work on the projects.

Involving consumers and the community

The two projects were developed to have budgeted, formalised consumer participation in the whole research process. Consumers are being involved in some planning aspects of the research, carrying it out, and reporting the results. This involvement is part of the grant application and money and resources were allocated. It was seen as an opportunity to develop a model of consumer participation where the community became part of the research team, giving their perspective and offering advice based on their experiences.

It had to be a proper part of the research, part of our accountability as researchers. Both of the projects were funded to include the costs of participation strategies, so it has given me an opportunity to apply community participation principles directly into the research that I'm doing.

(D'Arcy Holman - researcher)

The Consumer Liaison and the General Practice Research Officer worked in collaboration with the Health Consumers' Council to hold three community forums. The aim of these forums was to tell older people about the research planned, and to ask them what they wanted the research to cover.

The forums were publicised through the local press, seniors' newsletters, hospital patients' groups, the Health Consumers' Council newsletter and the annual Seniors Have-A-Go Day. Two forums were held in the city and one in the outer metropolitan area. Everyone who attended received a payment of AUD\$25 to cover their travel costs, and morning tea was provided. One hundred and four people attended the forums.

See the advertisement used to promote the forums on page 98



The forums were about getting some input into the research questions. We were surprised at the amount of interest, as we were told this subject might be boring for people. We had developed the research questions before we began to involve consumers, but we have gone back to the ethics committee and added new parts to our research, based on involvement at the early stages of the research.

(Jon Emery - researcher)

At each forum there was a presentation explaining the two research projects and how people could get more involved. People then worked in small groups to discuss seven questions. These included:

- What do you think are the most important questions about the management of chronic medical conditions that the researchers should be looking at?
- What are the most important questions about prescribed medicines that you think the researchers should be looking at?

At the end of the forums people were offered three choices about how they could be more involved in the project, if they wished. These included taking part in:

- A consumer panel (the Panel).
- Focus groups
- Surveys and questionnaires.

In our planning since the forums we have decided the following roles for each of the above options.

The Panel will:

- Provide advice and guidance to the researchers about issues that are important to health consumers on long-term illnesses and medication safety.
- Ensure that health consumer views and issues are considered by the research team.
- Give consumer input to the management of the research through being part of the research team.

This will be further refined once the panel is convened.

The focus groups will:

- Spend time exploring in more detail the issues raised at the forums.

We also plan to use **surveys and questionnaires** to gather further information. Some seniors who were unable to attend the forums contacted the Consumer Liaison Officer to give their views. They raised issues that were very important for the development of the project.

Look at a sample information sheet and the application form on page 99

Using surveys and questionnaires will ensure that seniors who can not get to meetings will still have a say in the development of the project. Over one half of the seniors who came to the forums wanted to join the Panel.

An application process, which included selection criteria, had to be developed to ensure the best people were recruited.



The impact of consumer and community participation

This project is still in its early stages. Already it is obvious from the amount and quality of the information received from the forums, that consumer and community involvement will add a new dimension to the research projects.

They [consumers] want their voice to be heard and respected and given the opportunity to have their opinions taken into account.

(Jennifer Dodd - researcher)

Before and during the forums, seniors raised issues that had not been considered, but which are very important when looking at long-term illness and safe medication. For example:

- Very few seniors who attended the forums had heard of, or knew about, Home Medication Reviews. Yet it had been assumed by the researchers that there was a high level of awareness about these reviews.
- The researchers had not considered the role of carers in ensuring medication safety.

The issues that were most important to seniors included:

- Investigating ways that general practitioners could communicate more effectively about side effects of and interactions between medications.
- Concerns about the ways to self manage their conditions; and to be informed by their general practitioners and other health professionals about how to do this.
- The need for more information about the long-term side effects of medication and how long they would need to be on them.
- Effectiveness of different medications - particularly generic medicines.

This provided the researchers with important information about what is important to consumers:

We learned some good things and we have been well informed. Also we have learned how to describe things differently - what is a chronic disease – the seniors didn't understand the term chronic disease.

(Jennifer Dodd - researcher)

Consumer participation is challenging, but it has given us a broader range of research questions and helped us to understand some of the issues we're addressing in more depth.

(Jon Emery - researcher)

As a result of the information received from the forums, the research team is now considering the question of the role of pharmacists in the management of long term illness and medication safety.

Seniors who attended the forums have been very positive about the opportunity to be involved in this research. Following is some feedback from the evaluations:

The best thing about the forum was being listened to. *(Consumer)*

The best thing about the forum was people coming together to share their ideas and respect one another. *(Consumer)*

I appreciated knowing this research is being done, as this area could stand a lot of improvement. *(Consumer)*

The next step will be to establish the Panel. It is planned that the Panel will work closely with the Consumer Liaison Officer as part of the research team. Their role will help mould the direction of the research projects.



Panel members will be offered training to help them understand the research. They will also be involved in developing the best way for them to have input on an ongoing basis. It will be important to identify and resolve new challenges to ensure that the Panel has true representation in this research process.

Our hope for the Panel is that it will become a genuine mechanism for the research team to power-share with consumer representatives in decisions affecting the leadership of these research projects. It's going to take commitment on the part of the researchers to put forward issues for the Panel's guidance. In a research career now spanning almost thirty five years, I've not done this before and I'm not sure how it will work out. I have this notion that it's the attitude and willingness of the researchers to listen and respond that will be a key to the success of the initiative.

I suspect also that the ability of Panel members to approach their role with an open mind and a desire for constructive outcomes will also be important.

(D'Arcy Holman - researcher)

Tips for other researchers

- We have found that the processes of consumer and community participation produce indirect benefits beyond the obvious advantages of gaining information.
- We gain insights that assist in better design, implementation of the research and dissemination of research results.
- The heightened awareness of accountability to the community improves researcher motivation and encourages research team members to work together in a highly cooperative manner.
- Most researchers in population health and primary care already have a sense of social mission. When given opportunities to engage with people affected by the very issues under investigation, it puts the lighthouse firmly in front and in view.

(D'Arcy Holman - researcher)



Western Australian Audit of Surgical Mortality

James Semmens, who is now based at the Curtin University of Technology, was the co-initiator and former Project Manager of the Western Australian Audit of Surgical Mortality (the Audit). We talked with James about the involvement of consumers and the community in the project.

The Audit is a process used to review patients who died in hospital while under the care of a surgeon. The Audit is modeled on the Scottish Surgical Mortality Audit model and aims to identify areas where problems have occurred. Feedback is given to surgeons, hospitals and consumers so the care of all patients can be improved.

The Audit was established in Western Australia at The University of Western Australia School of Population Health, as part of the Western Australian Department of Health Safety and Quality Surgical Care Program in 1998. The Audit was managed by the School until 2005, when it was transferred to the Royal Australasian College of Surgeons. Initial funding and support for the project was provided by the National Health and Medical Research Council through the School, and then by the Western Australian Department of Health from June 2001. The Audit system has since been implemented in Tasmania and South Australia. It is currently being established in New South Wales under the direction of the Clinical Excellence Commission and with collaboration from the School of Public Health at Curtin University of Technology, Western Australia.

Participation in the Audit is voluntary and today over 98% of surgeons participate in the process. 73% of those surgeons who participated in the Audit have reported a change in their practice as a result of this.

How consumers and the community were involved in this project

The Audit project was initially set up with a wider scope than other health audit systems as it included a program of research and translation of results to support the mortality audit. The research focus of the project provided an ideal avenue for consumer and community input and acknowledged that consumers provide an important voice in patient care that is recognised internationally. Input from consumers was included in the Audit model from the beginning of the project.

In 2004, the Consumer Liaison Officer worked with the Health Consumers' Council to hold a roundtable consumer consultation to evaluate the Audit project and its first annual report. The consumers were positive and enthusiastic about being given an opportunity to provide feedback on the project. They made the following comments:

Provides assurance to the community that there are state-wide initiatives to address safety of care. (Consumer)

This is a worthwhile project and not before time, I hope it will be taken up throughout Australia as soon as possible. (Consumer)

We need this information in order to find out if surgically-related deaths are due to system errors. (Consumer)

The roundtable consumer consultation concluded with the following recommendations being made to the Audit management committee:

1. Make available to the community a consumer version of the Audit report.
2. Invite consumer representation onto the management committee.
3. Develop and report on key performance indicators.
4. Develop strategies to improve communication with community and clinical groups.



There were several other issues identified as being important for improving quality and safety for health consumers which did not fall within the scope of the Audit project. These were taken on by the Health Consumers' Council Board of Management for action with Western Australian Department of Health's Safety and Quality Committee and relevant agencies. These other issues included calls for:

1. a) A commitment for continued funding for the Audit project.
b) Full participation of surgeons in the Audit process.
c) Processes to be developed in all health services for monitoring and evaluating the implementation of the recommendations from the Audit.
d) Participation in the Audit to be linked to accreditation, credentialing and clinical governance processes.
e) Bi-partisan political support for the Audit project.
2. Hold a community forum to explore issues surrounding declining numbers of post-mortems.
3. Approach the Royal Australasian College of Surgeons, Divisions of General Practice and to the Dean of the Faculty of Medicine and Dentistry at the University of Western Australia regarding the development of a communication module for surgeons, doctors and medical students.
4. Improve information available for patients and families regarding risks of surgery, particularly for elderly patients.

The impact of consumer and community participation

The consumer and community input was important, because it reviewed results of the first two years of the project, and it also identified key areas for quality improvement. An example is the concern regarding the use and trauma of potentially unnecessary surgery (referred to as futile surgery) in elderly patients due to the increased risks of multiple disease complications in this age group.

Following the roundtable consumer consultation the Audit management team focused on this issue through an intensive education campaign on the increased risks associated with futile surgery. This resulted in a significant drop over the next two years in surgery that was considered potentially unnecessary. The decline in futile surgery was due to recommendations made by both patients and surgeons and reflected an improved level of surgeon and patient communication.

The contribution of consumers helped drive the move for overall audit of all deaths in Western Australian hospitals, of which the Audit plays its part. A consumer version of the Audit report has been developed and is now available for the community and health consumer organisations at:

www.surgeons.org/Content/NavigationMenu/WhoWeAre/Regions/WA/WAASM

Tips for other researchers

- It is important to include the consumer voice and input right from the beginning of a project.
- This model of participation was so effective because it made a real difference to policy and practice - consider doing this on an annual basis.
- Take the opportunity to include consumer's comment in scientific publications and presentations at national and international conferences.

The Audit management team now has a consumer member. This is considered to be an important step in including consumer input into the evaluation and dissemination processes of the project.



Western Australian Birth Defects Registry

We talked with the Head and Medical Specialist Carol Bower, about the consultative process between consumer and community groups and the staff of the Western Australian Birth Defects Registry (the Registry).

The Registry commenced in 1980 through funding from the Federal Government. It started because of the lack of data on birth defects being highlighted by researchers investigating the prevalence of birth defects in Vietnam Veterans.

The Registry has been operating for the past 25 years through a voluntary notification process. In 2004, the process of seeking statutory notification to the Registry through legislation was commenced. This was because of the changes in attitudes towards privacy and consent, as well as an increased awareness amongst health professionals of these issues.

This process included both formal and informal talks with members of parent support groups and consumer organisations. Although there was recognition of the research work done due the existence of the Registry, there was a distinct difference of opinion between groups regarding the appropriate notification process.

The application for mandatory reporting was not successful, with the Minister for Health responding, 'until a consensus emerges there are other matters of a more pressing nature that should be progressed'.

Carol then commenced working with the Consumer Liaison Officer to hold consultations with parent groups and consumer organisations to seek a consensus on the preferred model for notification.

Involving consumers and the community

A workshop was held in May 2006. People attending were told about the three models for notification:

- Voluntary notification (current model)
- Statutory notification
- Notification with consent

Although the meeting closed without reaching a consensus, the consumers identified the following key issues:

- It was better to continue with current model for the time being.
- It was important to have wider consultation and seek opinions from other groups.
- Whatever model was decided, people must be told about the existence of the Registry.
- It was important to discuss legal issues and the risks of insurance companies accessing data.

I knew, based on studies elsewhere, that notification with consent would bring a drop in notifications and I knew that from a scientific point of view that wasn't the best model.

(Carol Bower - researcher)

Following the first meeting, consumer participants were invited to give feedback on the development of questions for a survey about the Registry. The survey was undertaken by the Western Australian Department of Health's Office of Population Health Genomics.

The survey was conducted with 600 randomly-selected community members to ask their views about the statutory collection of identifiable data by the Registry and the extent to which the use of the data was perceived to be an invasion of privacy.



Only 5% of the people surveyed had heard of the Registry and 96% felt the data collected was useful information for Western Australia. 79% of people supported a new law for mandatory notification.

A second workshop was held in October 2006 using an external facilitator. The aim of the meeting was to further explore the issues and reach a possible consensus. The consensus would be based on what people could live with, if either mandatory notification or notification with consent was the model for the future.

At the beginning of the workshop, Carol Bower gave a presentation on the various notification models. Michele Kosky from the Health Consumers' Council then talked about the Council's views on privacy and consent. Michele also commented that the consultation process being undertaken was an example of good practice, and, that this was the first time the community had been invited to give input into the reporting process for a registry in Western Australia.

The final decision of the meeting was unanimous. The group concluded that they could live with a mandatory notification model for the Registry, given the following conditions:

1. Comprehensive and open information to be provided to consumer groups and community on all aspects and stages of development, implementation and operation of the new model.
2. Consumer input throughout development stages of the model.
3. An opt-out clause is included.

It was a scary process holding the workshops but then it's a bit scary to have a registry that people don't know about. I feel like the whole process has been incredibly transparent and we haven't been trying to second-guess the consumers.

(Carol Bower - researcher)

In December 2006 the Health Consumers' Council awarded Carol Bower a Consumer Excellence Award, in recognition of her ongoing commitment to consulting with the community regarding the Birth Defect Registry.

It is planned that later in 2007 a consumer reference group will be established to work with the staff and advisory committee of the Registry. They will develop appropriate information for parents and health service providers regarding the issues raised during the consultations.

The issues to be looked at by the reference group will be:

- The appropriate timing of how and when to inform people about the Registry.
- How to raise community awareness of the Registry.
- Issues about access and security of data held on the Registry.
- Ethical standards relating to research using data from the Registry.

Footnote: Although this story does not entirely fit the criteria for an individual research project, it does show the collaboration between consumers and community and researchers. We also thought it should be included because many researchers at the Institute and the School have accessed data from the Registry.



Consumer and community participation in laboratory-based sciences

We believe that it is important for consumers and community members to participate in all types of health research, from 'blue skies' research through to applied studies. But we are aware that both here in Australia and around the world, consumer and community participation in laboratory-based science research has been slower to establish. We consider this to be an area where there are great opportunities for improvements.

At the School and the Institute the up-take has been limited. We discussed this with the Institute's Assistant Director John Finlay-Jones. These are his thoughts about this issue.

At the Institute, we undertake a range of research projects and programs, from basic biomedical studies to clinical and population studies. Those at the basic end of the spectrum may use only test tubes and plastic dishes; others perhaps studying health and disease in experimental (animal) models. Consumer participation in our laboratory-based research, which can include some clinical research, is still at the early stages. However, we found that researchers working in our laboratories and clinical areas were very keen to get involved in the Institute's Consumer and Community Advisory Council. They are starting to think and talk about how they might take forward consumer and community participation in their research.

Researchers can find it difficult to know what to do to incorporate consumers and community in their research, especially as they see themselves as one or two steps removed from patient, participant or specimen donor required for their research work.

The importance is not to underestimate people. Don't underestimate the capacity of people to get involved with these complex issues and do them well.

(Fiona Stanley - researcher)

We are exploring a number of models of consumer and community participation in laboratory-based research within the Institute. Our priority has been to set up procedures that recognise the need to support researchers in reaping the benefits of consumer and community participation. This includes the need for flexibility in the way the Institute's policy on consumer and community participation is implemented. The greatest opportunities for participation may be seen initially at later stages in the research cycle (page 40). Successes achieved in those areas may lead to building involvement at all stages, which is the intent of the policy.

The ultimate aim is to have consumers and community members helping us to:

- Decide what to research, by seeking the views of the Consumer and Community Advisory Council.
- Decide how to do the research, by involving consumers and community members in an ethical review of our research plans.
- Oversee the research as it progresses.
- Tell people about the results of the research in plain language.

The ongoing commitment to consumer and community participation needs to make sense at the institutional level as a minimum. This priority may mean that the pathways of participation extend further down the line in some areas than others. Researchers addressing specific diseases may be able to see more immediate benefit in engaging consumers than those working on normal body function, such as how cells divide or how we think. But we will pursue how best to engage consumers in this type of research, learning from the experience of others.



Good practice story in laboratory-based research - learning from other experiences

Researchers working in laboratories elsewhere have involved consumers and community members in a number of ways. For example, in the United Kingdom, the Multiple Sclerosis Society has trained people affected by multiple sclerosis to act as buddies to researchers who receive funding for multiple sclerosis research. This has included laboratory-based research and tests using animals.

The buddies undertake training about research, how it is funded and what types of research the Multiple Sclerosis Society funds. They also learn about reviewing research proposals and reports. Two buddies are allocated to each research project. It is a condition of the grant researchers receive that they meet with the buddies twice a year to talk about the research and how it is progressing. There are a number of benefits to this approach:

- Researchers are able to meet and spend time with people affected by the condition that they are researching. This can help to give meaning to their research. For some researchers, this is the first time they have had meaningful interaction with people living with the condition they are studying.
- People affected by multiple sclerosis gain more of an understanding about the research, and research becomes more meaningful to them
- This means that they are able to tell other people affected by multiple sclerosis about the research as it progresses. They also give feedback to the Multiple Sclerosis Society.
- The Multiple Sclerosis Society therefore has another way of ensuring research stays on track, on budget and on time

We believe that consumer and community participation will enable us to be more accountable to the people who fund much of our research – taxpayers and donors. We also believe that it will benefit consumers and community members, and add value to researchers and the research institution.



TEACHING CONSUMER AND COMMUNITY PARTICIPATION IN RESEARCH

This section covers our experience of raising awareness of consumer and community participation amongst health services and health research students at the School. We have made a consistent effort to build knowledge about participation, with an aim of having students enter the workforce considering participation as normal practice.

Around the world there have been initiatives to involve consumers and community members in the process of teaching health professionals. In thinking about writing this section, and in teaching students about consumer and community participation in research we have been influenced by the report of some of this work which was written by Christine Farrell, Angela Towle and William Godolphin entitled *Where's the Patient's Voice in Health Professional Education?*

www.health-disciplines.ubc.ca/DHCC/PtsVoiceReportBook.pdf

We also asked a senior lecturer and a student from the School to give some feedback on the lectures given by the Consumer Liaison Officer.

The section covers the following topics:

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The lectures

At the School, students studying for the Bachelor of Health Sciences degree have sessions in their second, third and fourth years on consumer and community participation. Post-graduate medical students, those studying for a Masters in Public Health and those attending the summer school on clinical epidemiology also attend at least one lecture on consumer and community participation in health and medical research. The Consumer Liaison Officer and on occasions, staff of the Health Consumers' Council have conducted these lectures and tutorials.

We have described these sessions as lectures, but we try to ensure that there are participatory elements so that the behaviour we are encouraging – participation – is modelled in the session. We think it's best that lectures about consumer and community participation are led by a consumer. Similar topics are discussed in lectures about the role of the consumer as a voice in both the health system and research.

These are the topics we generally cover in lectures.

a) A participatory exercise

This exercise is designed to get people thinking about their experience of participating in research. We often start a lecture by asking people to take part in a quick statistically valid, randomised controlled, very reliable research study called the Hands up Research. People are asked to:

- Put up your hand if you have even been a participant in a research project – for example telemarketing.
- Put up your other hand if you were unhappy about any aspect of the research – for example, the questions that you were asked, when you were asked them, or how you were asked them.
- Keep your hands up if you had any ideas about how the research could be improved.
- Keep your hands up if you were invited to give feedback about the research.

By the end of this 3 minute fun exercise usually most people have put their hands down. If there is time we ask people to talk in pairs about the improvement they could have made to the research project. Then we talk about the fact that this is how many consumers and community members feel when they are asked to take part in a health research project.

Find out more about the definitions of consumers, community representative and community, and what participation in research means on page 6

b) Definitions of consumer and community participation in research

Here we talk about the definitions of consumers, community representative and community.

c) An overview of the development of consumer and community participation in research

We go back to the World Health Organisation declarations of 1978, 1986 and 1997, where consumer participation became a right, moving the view of patients as passive recipients of health care to one in which they have a key role to play in health services, health policy and health research.



We talk about the development of consumer and community participation in health research drawing on examples from breast cancer research, HIV/AIDS research and the INVOLVE organisation in the United Kingdom. We then talk about the Australian context, and about the various levels of involvement described on the ladder of participation.

d) A local perspective

In this topic we talk about the work that the School, the Institute and the Health Consumers' Council are doing to promote consumer and community participation in research. We draw on examples such as those we describe in Section Four.

e) An outline of the benefits of consumer and community participation in research.

Having given some examples of how consumer and community participation is working, we summarise the benefits. We think these are:

- Research is relevant to community needs.
- Research is accountable and transparent.
- The quality of the research can improve.
- Recruitment of participants may be easier or quicker.
- Community issues are identified and prioritised.
- The value of the research to the community means that there is more likelihood of changes in policy and practice.

f) The barriers to consumer and community participation in research

We then talk about some of the barriers to consumer and community participation in research. These include:

- Researchers fear that consumers will bring a biased view.
- Researchers are reluctant to share power and knowledge.
- Language is not shared.
- There can be a lack of respect for different points of view.
- There can be stereotypes and stigmas on both sides.
- Consumers and researchers may have different agendas.
- There may not be funding available for research in areas prioritised by consumers and the community.
- Consumers may be reluctant to participate because they do not value their expertise and feel that researchers have all the expertise, or because they do not trust researchers.

See the Ladder of Participation on page 17

Read about examples of consumer and community participation in research from pages 46-69



g) Why consumer and community participation is important

Next, we talk about why consumer and community participation in research is important.

We cover the following:

- It works!
- It is a moral right in a democracy.
- It improves engagement with communities.
- It is increasingly a requirement by funding bodies.
- It enables researchers to build their understanding of and experience on working with consumers.
- It gives research greater relevance to consumers and community members.
- Consumers can lobby for changes.

h) What researchers and organisations can do to improve participation?

We encourage students to think about what they can do to ensure consumer and community participation in their research. This includes:

- Ensuring that resources and funding to enable consumers and community to participate is allocated appropriately.
- Developing and implementing policies about consumer and community participation in research.
- Involving consumers and the community in all stages of the research process - deciding what research to do, deciding how to do it, doing it, letting people know the results and deciding what research to do next.

i) Further information

Finally, we tell people where they can go for further information. We give the contact details for the Consumer Liaison Officer, publications and websites like those listed at the end of the resources section of this book. We always allow time for questions and discussion at the end of the session.

Feedback on the lectures

Jane Heyworth, the Sub Dean of Health Sciences at the School and Jen Girschik, a former Health Science student shared their thoughts and perspectives on consumer and community participation in research.

Look out for
useful websites
on page 101



From the lecturer - Jane Heyworth

“Consumer and community participation is now a requirement for a lot of publicly-funded health research. So we need to ensure that students understand what ‘consumer’ and ‘participation’ are and why it’s important.

We try to give students a consistent message that this is an important issue.

Having a consumer teach the students means that the students are learning from someone with the experience of using health services and getting involved in research.

If I taught this stuff, I’d be a talking head, just focussing on the theory”.

From the student - Jen Girschik

“My initial impression was that I thought it was important to have a non-academic conduct the lectures on consumer participation. It showed a genuine commitment on the part of the lecturer and university to involve lay people in the research process.

The relevance and importance of consumer participation was a message that was intuitively easy to understand and made sense. There is no point doing research that doesn’t help anyone and the best way to find out what would help is to ask the people (i.e. the consumers) that know, right?

I came away from the lecture thinking consumer participation was a no-brainer, it is an essential and easy part of research. Why wouldn’t you do it?

What I am now finding out in the working world is that consumer participation is not quite the easy, mutually beneficial exchange of ideas I thought it was going to be. This also highlights the importance of consumer representatives or the Consumer Liaison Officer giving the lectures rather than academics. I think they are in a strong position to be able to tell stories and bring a perspective about the reality of consumer participation.

There are the entrenched power structures that don’t see or support consumers’ rights and participation – I was shocked by the title of an article that I came across recently, “the biggest barrier to successful chemotherapy: the patient”. I have also discovered consumer representatives are people too. They can sometimes have an agenda to push just as much as the research community. I guess the reason they became representatives was because they were passionate about something, but having been cornered and brow-beaten by an angry consumer representative, I am guilty of having thought, “I hope I never have to deal with that person again”.

While I was still a student though, through interactive tutorials with other students, I got the impression that for some of them (being fit and healthy twenty year olds), consumer participation was something that happened to other people, the elderly, cancer patients, other identifiable groups. They didn’t feel that consumer representation or participation might apply to them directly as members of a wider general community. It makes me wonder how many of my peers have stayed committed to the practice of involving the community now that we are in the real world and realise community collaboration isn’t as easy as we thought it would be.

Although I don’t think genuine appreciation and respect for collaboration with consumers can be taught, anything that can be done by universities and schools to get students more aware and involved in community participation in general would be beneficial. I know the first year psychology students at The University of Western Australia are required to participate in a certain number of psych experiments for course credit. Perhaps it would be useful for public health students to be required to participate in a public forum or write a submission to gain a better understanding of what it is to be an active member of a community and how the process of community consultation can and does work”.



The future

We have had good feedback from students about these lectures. In the future, we would like to involve students in planning these lectures, to ensure they are as relevant as they can be.

Also we feel there is an opportunity to teach students how to involve consumers and the community in research meaningfully. We plan to invite some of our Council members or consumer and community representatives to talk to the students about their experience of involvement and if and how it added value to the research.

We would also like to look at making these sessions more participatory. We want to give consumer and community participation a higher profile across all of the courses at the School. We aim to make it more integral to our mainstream teaching as well as giving one-off lectures.

I came in to do research at the Institute and there was an expectation that I would engage consumers and community members in the research. I wish I'd been taught about that when I was training to be a researcher, as a student.

(Amber Howard - researcher)



CONCLUDING THOUGHTS

Where are we now?

Writing this book provided us with an opportunity to reflect on what has been achieved at both the School and the Institute. The many examples of researchers working together with consumers and the community to improve participation show that the strategies we have implemented are having some success. There has also been a ripple or flow-on effect. We are continually hearing of examples where change is taking place and many research areas are now setting up reference groups or seeking consumer representatives.

The School and the Institute now have supporting structures for researchers to increase participation. These include the Consumer and Community Advisory Councils, a consumer and community participation policy and a range of models for implementing consumer and community participation.

But it would also be remiss not to look carefully at the areas where there has been only limited or no success and ask what we could do differently. There are still research groups at both the School and the Institute where there is no involvement of consumers or the community other than as 'the participants'.

Therefore it is necessary to ask the following questions:

- How can we reach the researchers that have no involvement of consumers and the community in their research projects?
- What are the barriers to greater participation?
- What needs to be done to break down those barriers?
- Are there health and medical research projects where consumer and community participation is not relevant or appropriate?
- What needs to be done to continue moving forward?

Perhaps the next challenge for the School and the Institute is to facilitate debate between researchers, consumers and the community to honestly seek answers to these questions.

This debate might also need to take into consideration what is required from a national perspective to support researchers, consumers and the community in these endeavours.

As mentioned earlier, the National Health and Medical Research Council now asks researchers to state in grant applications how they will involve consumers and the community in their research. There is work to be done at a national level on how the responses to this question are assessed and what involvement consumers and the community have in the assessment process.

One other area that has been highlighted in the writing of this book is in the tips for other researchers at the end of the good practice stories. The tips had a constant message of the need to properly budget and allocate enough time to fully develop consumer and community participation. These are strong messages that we need to share with researchers starting new projects that will involve consumers and the community.



Where to next?

The School and the Institute has been successful in obtaining funding to hold a symposium on consumer and community participation in health research in 2008. Major sponsors of the symposium will be the National Health and Medical Research Council, The University of Western Australia, the Western Australian Department of Health and the Health Consumers' Council.

This inaugural national meeting '*Involving People in Research*' will bring together researchers, students consumers, and community members to showcase success stories, share experiences and to further explore the barriers to participation, and to give more thought to how researchers and the community can work together to add value to research.

At the School and the Institute we will invest time in the further development of simple tools to measure the effectiveness of our strategies. We will report back to both the organisation and the community about the effectiveness of our efforts to increase consumer and community participation.

It will be important for the Consumer and Community Advisory Councils to seek information from the community about priorities for health and medical research. Consultations with the community may also be an ideal opportunity for taking information back to the community about the many and varied research projects within each organisation.

There is an also obvious need to further develop training on consumer and community participation in health research for researchers and consumer and community members. In June we held a training session for early career researchers, consumers and community members involved at the School and the Institute. The feedback from the session was extremely positive and people found it very useful as it increased their understanding of the complex processes involved to fund and conduct research. Over 90% of the people who attended said they would like more training.

It was evident that consumers and community members were not aware of funding or ethics processes, track records, data collections or data linkage. Likewise the early career researchers who attended were interested in the consumer and community perspective offered during the session.

We acknowledge the journey is only just starting.

In conclusion

Writing this book has been a larger task than first discussed over a cup of tea in September 2006.

In February and March of this year, we envisaged being able to conduct the interviews, write the book, and have it at the printers at the end of two weeks we had allocated for the task. As with all journeys it's the unexpected turns and twists along the way that are not planned for that have the greatest learning experience.

But now that it is nearly finished, it again seems a worthwhile venture. Our hope in writing this book is that our experiences might be helpful or adaptable for use in your research project or organisation.

Anne McKenzie and Bec Hanley

October 2007



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RESOURCES

This section has all the documents that we referenced throughout the book. The documents are in the order that they appear in the book.

You are welcome to use any of the resources in this section – all we ask is that you acknowledge this book as the source. You may not use the resources without permission if you intend to make a financial profit from their use.

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The Telethon Institute for Child Health Research

Consumer and Community Participation Audit

August 2004

Please provide as much information as you have to the following questions. Your responses will be collated to provide an overall view of the current situation of consumer and community participation at the Institute. As this audit is in a developmental phase, your comments on the process will be greatly appreciated and used for improvement.

1. Are consumers and/or the community involved in your project in the areas of:	Yes, please describe how:	No, can you identify some ways this could be improved?
a) Developing the goals of the project		
b) Designing the survey instrument or questions?		
c) Developing the methodologies?		
d) Dissemination of information and results?		
2. How are consumers in your project informed of their roles and options to support or be involved, raise a concern or receive information as:	Yes, please describe how:	No, can you identify some ways this could be improved?
a) Participants in research		
b) Non participants in research		



Questions	Opportunities/goals	Actions needed to achieve goals	Resources required to achieve goals
3. Please identify opportunities for enhancing consumer participation in your project in the areas of:			
<ul style="list-style-type: none"> • Developing goals 			
<ul style="list-style-type: none"> • Designing survey instruments or questions 			
<ul style="list-style-type: none"> • Developing methodologies 			
<ul style="list-style-type: none"> • Dissemination of information and/or results 			
4. If question 3 is not relevant please indicate why. (This will provide valuable planning information)			

General comments:

Thank you for participating in this very important first step in the process to increase consumer and community participation at the Institute.

Your feedback on this audit will be invaluable, please make comments or suggestions about anything you would like to see included (or deleted) for improving the process.



Consumer and Community Meeting
Increasing consumer and community participation in research

Telethon Institute of Child Health Research
Roberts Road Subiaco
December 13 2004

AGENDA

1:00pm	Introduction and format
1:10pm	Welcome
1:15pm	Indigenous Research – ‘best practice’
1:20pm	Current happenings
1.30pm	Group discussion
2:15pm	Group reports - (5 mins per group)
2.30pm	General discussion and questions
2:50pm	Where to now
2:55pm	Closing comments
3:00	Afternoon tea



Consumer and Community Meeting

GROUP DISCUSSIONS - PARTICIPANTS BREAK INTO 3 GROUPS

Questions – Please answer all questions

- 1) What are some of the ways consumers and the community can become more involved or contribute to research projects at the School or the Institute?
- 2) What can we do to make it easier for consumers and the community to be more involved in research at the School or the Institute?
- 3) Do we need to raise the level of trust and confidence in research projects at the School or the Institute - if so what needs to be done?
- 4) When consumers and community members become more involved in research what supports will they need?

General Discussion Questions

- Do we need to run public forums or discussions on:
 - specific issues relating to consumer participation i.e. payments, consent and privacy
 - current research projects
- How will we know when we have started to make a difference?
- Are you interested in participating in a steering committee/consumer advisory council



Consumer and Community Participation Strategic Plan

Background

In 2001 the National Health and Medical Research Council and the Consumers' Health Forum of Australia *Statement on Consumer and Community Participation in Health and Medical Research* (the Statement) describes:

Consumers and researchers working in partnerships based on understanding, respect and shared commitment to research that will improve the health of humankind.

This Statement identified opportunities for the Telethon Institute for Child Health Research (the Institute) to further develop existing relationships with the community of Western Australia. In July 2002 the Institute Executive accepted the following proposal:

1. Appoint a liaison/communication officer
2. Develop a committee to facilitate consumer and community participation
3. Develop a policy on consumer and community participation in research at

Implementation of Point 1

A National Health and Medical Research Council Capacity-Building Grant enabled the shared appointment of a Consumer Liaison Officer between the Institute and the School of Population Health. The current incumbent commenced in Jan 2004.

Proposed Implementation of Point 2 & 3

The Institute was recently re-endorsed as a National Health and Medical Research Council Accredited Independent Research Institute. In future Research Institutes will be required to demonstrate adherence to the Statement by having written consumer policies in place. Also the National Health and Medical Research Council now require final project reports to state evidence of consumer participation.

In order to address the multi-faceted requirements of a consumer participation strategy for the Institute it is proposed to develop and implement a plan that will:

- Support the ethos of the Statement
- Expand and build on current consumer and community participation, in particular widen the established strengths of the Kulunga Research Network to other areas of the Western Australian community
- Manage organisational change through a series of steps that are inclusive of both staff and community ideas and values
- Address accreditation requirements

The Aim

The consumer participation strategy will increase participation by building the capacity of the Institute's staff to: acknowledge the various levels of participation; understand and respect the contributions of each party; and willingly share knowledge and power. By adopting a planned long-term approach that is inclusive and seeks to address issues as they arise, risks will be minimised of implementing a policy that is tokenistic and has little added value to the staff, the community and the quality of research.

The proposed strategy will not only demonstrate adherence to accreditation requirements but will also take maximum advantage of: high community support and exposure, willingness of dedicated staff to try new ideas and the dedicated resource of a Consumer Liaison Officer.

How Consumer Participation Adds Value

The Statement presents the background, vision, and some of the relevant literature concerning consumer participation in research. Part of the aim of establishing a Consumer and community Advisory Council (the Council) at the Institute will be to evaluate the evidence that it adds value to the research programs.

Approach

The consumer participation strategy will follow an ongoing long-term approach with three main phases:

Phase 1: ascertain current organisational capacity and goals concerning consumer participation

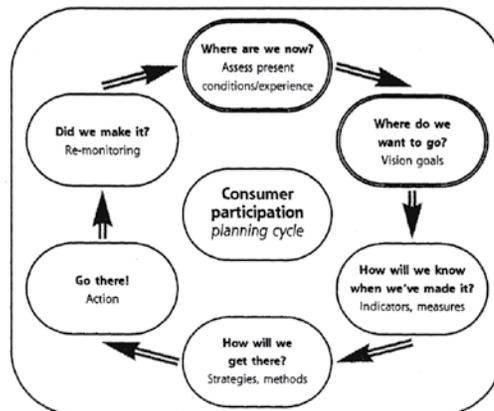
Phase 2: establish a steering committee to develop plans and policies

Phase 3: establish Consumer and Community Advisory Group

Each phase will incorporate planned incremental changes ultimately to enable the School to maximise consumer participation.

Planning Framework

As with any strategic direction, to start the process, it is necessary to adopt a framework to guide the organisation through the various stages of assessment and planning. The framework below describes the various stages of the cycle. (Diagram source: Improving Health Services through consumer participation)



Phase One: Assess the current situation

1. Conduct half-day workshop with senior staff at the Institute to discuss goals and vision for enhanced consumer participation
2. Conduct an audit of current consumer participation



The information gathered from the workshop and audit will provide the basis to develop the goals and vision for enhanced consumer participation and the terms of reference for a steering committee.

Phase Two: Establish a Steering Committee

Community members and staff members ('champions') will be invited to form a steering committee.

Community members may be representatives from organisations such as Friends of the Institute, Western Australian Health Consumers Council, or relevant Support Groups. The steering committee will be sponsored by the Executive and will report to the Executive through the Consumer Liaison Officer on a bi-monthly basis.

The establishment of a steering committee will have a two-fold purpose, firstly it will be a formal point of reference for the Executive and secondly it will provide support and focus during planning and developmental phases of the strategy.

During this phase the Consumer Liaison Officer will conduct a series of consumer participation awareness-raising sessions with staff.

Phase Three: Establish the Council

It is envisaged that the steering committee will have a relatively short life and be phased out with the establishment of a Council which will report directly to the Board.

The Council will have responsibility for developing organisation-wide policies on:

- Consumer participation
- Seeking consumer feedback
- Consumer complaints
- Consumer Rights and Responsibilities

Evaluation

As part of its function, the Council will maintain a summary of the ways in which it has added value to research at the Institute. This will be used in a biennial evaluation of its effectiveness by the Board, and for inclusion in the quinquennial scientific review of the Institute.

Funding

The initial phases of planning and conducting a workshop and audit will not require any additional funding as this will be conducted by the Consumer Liaison Officer. Areas that will eventually require an allocation of funds are:

- Running costs for a steering committee and the Council
- Payment of sitting fees for consumers
- Out of pocket expenses for consumers
- Training for staff and consumers

As phases two and three are implemented, staff may require both financial and mentor support as they increase their capacity to engage with consumers.

The allocation of appropriate funding for a consumer participation strategy sends a clear message of importance, commitment and support to both staff and the community.

Conclusion

Whilst there are numerous articles on the benefits of actively involving consumers in research there is little written evidence about the most successful way of implementing an organisation-wide consumer participation strategy.

By adopting and implementing a planned strategy that is based on continuous improvement principles, accreditation requirements and the ethos of the Statement, the Institute has the opportunity to:

- Take proactive steps to address the National Health and Medical Research Council's thrust to fully involve consumers and the community in research.
- Lead the way in Australia by developing a best practice model for implementing consumer participation.

Time line - 2004

Sept 2004 Workshop with senior staff

July-Aug 2004 Audit conducted by Consumer Liaison Officer

Sept-Oct 2004 Steering committee and terms of reference established

Dec 2004 Steering committee to meet and commence development of goals and vision

Recommendations

The following recommendations are for endorsement by the Executive:

1. Endorse in principle the proposed plan to enhance consumer participation at the Institute
2. Endorse and support to conduct a workshop and audit
3. Endorse an Executive sponsored steering committee to operate during the developmental and implementation phases of the proposal
4. Consider future budget requirements and strategies for enhancing consumer participation at the Institute

References

Statement on Consumer and Community Participation in Health and Medical Research. Joint statement of the National Health and Medical Research Council and the Consumers' Health Forum of Australia.

Improving health services through consumer participation: A resource guide for organizations. A Consumer Focus Collaboration Publication, Commonwealth Department of Health & Aged Care 2000.

May 2004, Telethon Institute of Child Health Research



Consumer and Community Participation Policy

Aim

The University of Western Australia's School of Population Health (the School) recognises the central role of health consumers and community members in its research programs. Our aim is to build partnerships in which consumers, community members and researchers shape decisions about research priorities, goals, methodologies, questions, and dissemination of results.

This aim is aligned with the National Health and Medical Research Council and Consumers' Health Forum of Australia's *Statement on Consumer and Community Participation in Health and Medical Research*.

Scope

This policy covers all research projects undertaken at the School. It is acknowledged that each research project is unique and there will be varying levels of consumer and community participation depending on the research project.

Definitions

The National Health and Medical Research Council and Consumers' Health Forum of Australia define consumers as

- Patients and potential patients.
- Carers.
- Organisations representing consumers' interests.
- Members of the public who are targets of health promotion programs.
- Groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services.

The National Health and Medical Research Council and Consumers' Health Forum of Australia define community as

- A group of people sharing a common interest – for example, cultural, social, political, health, economic interests – but not necessarily a particular geographical association.

Principles

- Consumers and the community will be acknowledged as a key stakeholder in all research projects undertaken at the School.
- Consumers, the community and researchers will work together to add value to research at the School.
- Partnerships between consumers, the community and researchers will be based on mutual respect for one another's different knowledge and experience.
- Partnership roles will be decided by consultation between consumers, community and researchers.
- Consumers and community members will be provided with all information related to fulfilling these roles.
- Consumers and community members will be required to comply with The University's policy on Intellectual Property and the National Privacy Principles.
- Remuneration for consumer and community participation is to be allocated in research project planning and budgets.
- Consumer and community participation will be evaluated in consultation with consumers, community members and researchers, and made available to the public.



Governance and Ethics

- A Consumer and Community Advisory Council will be established and supported by the Consumer Liaison Officer.
- The Consumer Liaison Officer will provide regular reports on the activities of the Council to the Head of School and Executive Committee.
- Consumer and Community Advisory Council membership and terms of reference will be decided by consultation between consumer and community representatives and researchers.
- The Consumer Advisory Council will establish a link to the School Ethics Committee through the Consumer Liaison Officer.

Benefits

The establishment of effective partnerships between consumers, the community and researchers will:

- Add value to evidence based research at the School.
- Facilitate and enhance understanding of consumer and community priorities, perspectives and issues.
- Enhance the planning, conduct and analysis of the School's research programs.
- Enhance the dissemination of research findings and increase translation into policy and practice.
- Provide increased opportunities to obtain funding for research which addresses the needs and priorities of the community.

Endorsed by the School Executive Committee
July 2005



Joint Consumer and Community Participation Steering Committee

Terms of Reference

Background	In accordance with the second phase of the plan to increase consumer and community participation at the School and the Institute a joint steering committee is to be established to undertake the necessary planning and development associated with establishing Consumer and Community Advisory Councils (the Councils). The steering committee will have a short life and be phased out with the establishment of the Councils.													
Purpose	The steering committee will be responsible for developing: <ul style="list-style-type: none"> • Terms of Reference for the Councils • Membership of the Councils • Guidelines for Consumer and Community Participation Policies • Consumer Glossary of Research Terms • Remuneration structures for consumer and community participation 													
Membership	The steering committee will include: <ul style="list-style-type: none"> • Senior staff representatives from the School and the Institute • Consumer Liaison Officer • Six consumer representatives including a representative from Health Consumers Council of WA 													
Accountability	<ul style="list-style-type: none"> • The steering committee will report bi-monthly through the Consumer Liaison Officer to the School Executive Committee and the Executive Committee at the Institute 													
Meetings	<ul style="list-style-type: none"> • The steering committee will meet monthly for 6 months commencing August 2005 • The meeting times will be established to suit the majority of members • The Consumer Liaison Officer will be responsible for all administrative tasks associated with the meetings including records of meetings and tasks undertaken by the steering committee • Quorum and chair to be established at the first meeting • Consumer members will be paid an honorarium for meeting attendance and associated out of pocket expenses 													
Proposed Budget	<table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 60%;">Catering costs @ \$30 per meeting (x 6 meetings)</td> <td style="width: 20%; text-align: right;">\$ 180.00</td> <td style="width: 20%;"></td> </tr> <tr> <td>Honorarium for consumer members @ \$50 per meeting</td> <td style="text-align: right;">\$1800.00</td> <td></td> </tr> <tr> <td>Consumables: printing, photocopying, postage, purchase of reference materials</td> <td style="text-align: right;">\$ 500.00</td> <td></td> </tr> <tr> <td>(costs to be shared by the School and the Institute) Total</td> <td></td> <td style="text-align: right;">\$2480.00</td> </tr> </table>		Catering costs @ \$30 per meeting (x 6 meetings)	\$ 180.00		Honorarium for consumer members @ \$50 per meeting	\$1800.00		Consumables: printing, photocopying, postage, purchase of reference materials	\$ 500.00		(costs to be shared by the School and the Institute) Total		\$2480.00
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(costs to be shared by the School and the Institute) Total		\$2480.00												

Endorsed July 2005



The Telethon Institute of Child Health Research
Consumer and Community Advisory Council
Evaluation Form



VISION

Enhanced quality and relevance of research through consumer and community participation

Thank you for using the services provided by the Council in your research project. We need your feedback to help us improve our services and performance and appreciate you taking the time to fill in the form below. The results of this evaluation will form part of our performance evaluation strategy and will be made available through the Council's annual reporting process.

Project Title: _____

Researcher/s Name: _____

Contact person: _____ Telephone no: _____ Date: _____

Performance	Comments
Please give a brief description of the service the Council provided to your research project.	
Was this service useful to your project? (please tell us how)	
Did the Council's service facilitate you reaching your target consumer or community group? (please tell us who the groups were)	
Did the Council provide you with additional services? (please tell us what the services were)	
Did the Council provide you with information that had not been considered by your team prior to contacting the Council? (please tell us what sort of information was provided)	
Did the services provided by the Council add value to your research project? (please tell us if the service did or did not add value)	
Will you use the services of the Council in future research projects? (If not please tell us why not)	
Do you have any suggestions to improve the service or performance of the Council?	

Any additional comments: _____

Thank you very much for taking the time to fill in this sheet. Please contact the Consumer Liaison Officer if you require any assistance or would like to discuss your evaluation.



Advertisement: Expressions of Interest



THE UNIVERSITY OF
WESTERN AUSTRALIA



The UWA School of Population Health &
Telethon Institute for Child Health Research

Consumer & Community Advisory Councils

The Councils are being established to enhance the quality and relevance of health and medical research through consumer and community participation.

Expressions of interest are invited from health consumers and/or community members who have an interest in research, for appointment to one of the Councils.

Applicants are required to have an interest in health and medical research, have the ability to collaborate with researchers and provide a link between community groups and the organisation. Appointments will be for two years and meetings will be held four times per year.

Closing date for applications is August 31st 2006.

For more information and application form please contact the
Consumer Research Liaison Officer



The University of Western Australia School of Population Health

Role Statement and Selection Criteria

VISION

Enhanced quality and relevance of research through consumer and community participation.

Scope of Role

The purpose of the Consumer and Community Advisory Council (the Council) is to enable and support its Vision for research undertaken at The UWA School of Population Health (the School).

The aim of the Council is to facilitate the development of partnerships in which consumers, community members and researchers will work together to make decisions about research priorities, goals, methodologies, questions, and dissemination of results.

Council members will have an opportunity through their Council membership to provide a consumer and community perspective on research undertaken at the School.

The School is committed to supporting and enabling equal opportunities and participation for aboriginal people, people from cultural and linguistically diverse backgrounds and people with disabilities.

Key Duties

- Attend the Council meetings.
- Participate and be involved in all activities of the Council.
- Provide advice and expertise relating to consumer and community priorities and perspectives on research.
- Provide access to broad community networks which may be used for consultation if necessary.

Other Requirements

- Council Members will be required to comply with The University's policies on Privacy and Intellectual Property. Details of these policies are available on request.
- Council members will be required to participate in a consumer and community participation induction program.
- Declare any potential conflict of interest.

Selection Criteria

- The Council member will have an interest in research conducted at the School.
- The Council Member will have an understanding of consumer and community issues that arise in health and medical research.
- The Council member will have established networks or links to consumer and community organisations which may be consulted if required.
- The Council member will be available to participate fully in the work of the Council as outlined in the terms of reference.
- The Council member will have good communication skills and an ability to work collaboratively with researchers, consumers and community groups.

Statement of Interest

In addition to responding to the selection criteria applicants will be required to write brief statement (up to one page) about what attracted them to apply for Council membership. Assistance to complete the application form is available if required by contacting the Consumer Liaison Officer.



The Telethon Institute of Child Health Research
Consumer and Community Advisory Council



Application Form for Consumer or Community Member

VISION

Enhanced quality and relevance of research through consumer and community participation

Please fill in both sections of the Council Member Application Form and forward to: Consumer Liaison Officer, (address). The closing date for applications is (date).

If you require any assistance with your application please contact the Consumer Liaison Officer.

Part A - please include your personal details and a short statement (up to one page) about what interests you in becoming a member of the Consumer & Community Advisory Council.

Name:

Address:

Telephone:

Home / Work:

Mobile:

Referees (2 required)

1. Name

Contact details

2. Name

Contact details

Relevant experience details

Statement of interest



Part B - please provide a short statement outlining your experience against each of the following selection criteria.

The Council member will have an interest in research conducted at the Institute

The Council member will have an understanding of consumer and community issues that arise in health and medical research

The Council member will have established networks or links to consumer and community organisations which may be consulted if required

The Council member will be available to participate fully in the work of the Council as outlined in the terms of reference

The Council member will have good communication skills and an ability to work collaboratively with researchers, consumers and community groups



The University of Western Australia School of Population Health

Consumer and Community Advisory Council

Terms of Reference

VISION

Enhanced quality and relevance of research through consumer and community participation

Purpose

The Consumer and Community Advisory Council (the Council) has been established to enable the process of enhancing the quality and relevance of research undertaken at The University of Western Australia School of Population Health (the School).

Aim

The aim of the Council is to enable the School to develop partnerships between consumers, community members and researchers. They will work together to make decisions about research priorities, goals, methodologies, questions, and dissemination of results. This aim is aligned with the National Health and Medical Research Council and Consumers' Health Forum of Australia's *Statement on Consumer and Community Participation in Health and Medical Research*.

Governance

The Council will have sponsorship from the Head of School and will report to the School Executive Committee through the Consumer Liaison Officer on a bi-annual basis. The Consumer Liaison Officer will provide support and guidance to the Council. The Council will evaluate and report on its activities annually. The report on the activities of the Council will be made available to the public on the website and in the School's Strategic Plan Report.

Membership

The Council membership will reflect the diversity of people involved in research at the School. The School is committed to supporting and enabling equal opportunities and participation for aboriginal people, people from cultural and linguistically diverse backgrounds and people with disabilities in its membership. Membership of the Council will be:

- 6 – 8 consumer and community members, one of whom will be Aboriginal or Torres Strait Islander.
- 2 – 3 researcher staff.
- Consumer Liaison Officer
- Head of School (or nominee)

The Chair of the Council will be a consumer or community member. The Council will have the authority to co-opt other members as required or establish working parties for specific approved projects.

Method of appointment

The availability of consumer and community positions on the Council will be advertised in relevant and disability appropriate media including the Health Consumers' Council's Newsletter. Consumer and community members currently involved in research and organisations with links to the School will also be notified of vacancies. Researcher positions on the Council will be advertised within the School.

Selection of Council Members

New appointments to the Council will be done by a selection panel of at least three Council members. The Chair of the Council and the Consumer Liaison Officer will have membership on all selection panels. The panel will be responsible for selection processes of all Council Members and will make appointment recommendations to the Head of School. See attached selection criteria.



Term

To enable the Council to have a continuity of membership initial appointment terms will be staggered with 50% of Council members being appointed for 2 years with the remaining members appointed for 3 years. The selection panel will make all decisions and recommendations associated with appointment terms. Members may apply for re-appointment for a second term.

Meetings

The Council will meet four times a year on a quarterly basis. The duration of Council meetings will be no longer than two hours. The Council meeting times will be determined by the sitting members.

Council members will also be required to pre-read meeting documents and if necessary and/or appropriate consult with other groups. Council members may also be consulted on an ad-hoc basis between meetings if required.

Quorum

A quorum shall consist of six members providing there are representatives from consumer / community members and researchers. In the absence of a quorum, any discussion or decisions will require ratification by the Council members either prior to or at the next meeting.

Payment and Support

Consumer and Community Members will be paid an honorarium for each Council meeting attended to acknowledge their contribution of time and any associated out of pocket expenses.

All paperwork relating to the Council meetings will be provided in an appropriate and timely manner at least one week prior to the Council meeting.

Council members will be able to access support and mentoring for their position on the Council from the Chair of the Council or the Consumer Liaison Officer.

Council members will be expected to access training on consumer and community participation in research at the School. There will not be any cost to Council members for participating in training.

Council members will have an opportunity to be involved in research projects if deemed appropriate by the Council.

Terms of Reference

The Council will provide or facilitate:

- Consumer and community perspectives on research undertaken at the School;
- Links between consumers, the community and researchers at the School;
- Advice and expertise on consumer and community issues and priorities for research;
- Advocacy on behalf of consumers and the community;
- The implementation of the Policy & Guidelines for consumer and community representatives involved in research at School;
- Evaluation and reports on consumer and community participation at School; and
- Feedback on strategic planning and governance structures relating to consumer and community participation in research.

The Council Terms of Reference will be reviewed annually.

Dated: April 2006

Endorsed: December 2006

Reviewed:



The Telethon Institute of Child Health Research

**Alcohol and Pregnancy Project
Consumer and Community Reference Group**

Terms of Reference



1. The Role of the Consumer and Community Reference Group

The role of the Consumer and Community Reference Group is to provide a consumer/community perspective on all activities of the *Alcohol and Pregnancy Project*.

Because of the cultural sensitivity of the topic of alcohol consumption in pregnancy and the different issues for Aboriginal and non-Aboriginal women there will be an Aboriginal Community Reference Group for Aboriginal women and a Consumer and Community Reference Group for non-Aboriginal women.

2. Accountability

The Consumer and Community Reference Group will report to the Alcohol and Pregnancy Steering Committee through the Project Manager

3. Membership

- Membership of the Consumer and Community Reference Group will comprise:
- Three members of the general community who are not Project Investigators Research Support for the Consumer and Community Reference Group:
- Chairperson, Telethon Institute for Child Health Research, WA;
- Consumer Liaison Officer
- Project Manager; and
- Administrative Secretary.

3.1 Meetings

The Consumer and Community Reference Group shall meet on dates to be decided on the first Wednesday of the month, or at other agreed times, not less than four times per year.

3.2 Quorum

A minimum of two Consumer and Community Reference Group members and two Research Support members is required for the meeting to be recognised as an authorised meeting.

3.3 Payment

An honorarium will be paid to Members of the Consumer and Community Reference Group (excluding members who provide Research Support) to acknowledge their contribution of time and out of pocket expenses.

3.4 Method of Appointment

The Project Steering Committee shall appoint three community members to the Consumer and Community Reference Group following advice from the Health Consumers' Council in WA.

3.5 Term of Appointment

Members of the Consumer and Community Reference Group will be appointed for a two year term. Members may be re-appointed at the end of the term.



3.6 Chairperson

The Chairperson shall convene the Consumer and Community Reference Group meetings. If she is not available she will nominate a person responsible for convening and conducting that meeting.

3.7 Agenda Items

All agenda items must be forwarded to the Chairperson by close of business on the Friday before the next scheduled meeting.

The agenda with attached meeting papers will be distributed on the Monday before to the next scheduled meeting.

3.8 Notes and Meeting Papers

The notes of each Consumer and Community Reference Group meeting will be prepared by the Administrative Secretary.

Full copies of the notes, including attachments, shall be provided to all members no later than the Friday following each meeting.

By agreement with the Group, out-of-session decisions will be deemed acceptable. Where agreed, all out-of-session decisions shall be recorded in the notes of the next scheduled Consumer and Community Reference Group.

4. Terms of Reference

To provide the Project Steering Committee with comment and advice on:

- The management of data, publications, and the protection of individual and/or community identities;
- The methodology, conduct, dissemination of results and potential outcomes of the Project;
- Alcohol use in pregnancy and how it is dealt with in a culturally sensitive way;
- Project documents such as consent forms and participant information sheets, interview guides, questionnaires and health promotion resources;
- The Alcohol and Pregnancy Final Report and draft manuscripts before they are published in scientific journals, and
- The preparation and development of summaries for the community for dissemination.

5. Values Underpinning the Terms of Reference

The Consumer and Community Reference Group Terms of Reference are underpinned by the National Health and Medical Research Council, Consumers Health Forum's *Model Framework for Consumer and Community Participation in Health and Medical Research* (NHMRC, 2004).



Are you over 65 and interested in health and medical research?

The University of Western Australia will be conducting research during the next three years about long-term illness and medication safety in people over 65. One research project will look at patients with diabetes, heart disease, high blood pressure, asthma, emphysema, seizures and stomach disorders. The other project will look at the side effects of a broad range of medicines and the impact they have on older people's health.

The University of Western Australia and the Health Consumers' Council invite you to attend one of two Community Forums to learn more about the research and give your opinions about these important issues. Please see details below.

Community Forums

October 31st and November 27th 2006

9.30 am – 12.30 pm

**The Banquet Room, The University Club
Hackett Drive Crawley**

**RSVP to the Health Consumers' Council
Telephone 9221 3422 or email info@hconc.org.au**

To attend the October Forum RSVP by 21st October

To attend the November Forum RSVP by 20th November

Morning tea will be provided and you will receive a small payment towards transport costs

Public Transport Information: Buses no 23 & 102 leave from:

- Platform B Stand 11 Wellington St Terminal
- Stand C1 at the Bus Port



Consumer Panel Information Sheet

Background

The University of Western Australia will be conducting research over the next three years about long-term (chronic) illness and medication safety in people over 65 years of age.

One research project will look at the management of people with diabetes, heart disease, high blood pressure, asthma, emphysema, seizures or stomach disorders.

The other project will look at the side effects of a broad range of medicines and the impact they have on older people's health.

To encourage ongoing health consumer involvement throughout the research projects, people are being offered an opportunity to participate in one or more of the following ways

- Attending community forums.
- Becoming a member of the Consumer Panel for the research projects.
- Participating in focus groups, questionnaires and surveys.

Community forums held in 2006 gave an opportunity for health consumers to answer questions and raise important issues relating to the research. The broad themes from the forums will be used to develop future proposed activities.

Purpose

The Consumer Panel is being established to provide an opportunity for

- Health consumers to give ongoing advice and guidance to the researchers about issues that are important to them on long-term illness and medication safety.
- Health consumer perspectives to be considered by the research team.
- Health consumer input into the management of the research project through being part of the research team.

Aim

In order to represent as many health consumers as possible, the membership of the Consumer Panel will aim to reflect the diverse groups the research projects plan to cover. It is important for members of the Consumer Panel to be able to:

- Speak strongly and independently on consumer issues relating to the research projects
- Have insight into consumer issues that affect a wide range of health conditions, that is, not limited to the condition the member has the most direct experience with.

Membership

The Consumer Panel will have 8 to 10 members. Appointments will be made through a selection process (see application form) with the Chief Investigators of the research projects making the final decisions by June 2007.

Time Commitment

The Consumer Panel will meet four times a year for the duration of the research projects. Meetings will be no longer than two hours and will be held at a time that suits the majority of the members of the Consumer Panel.

Payment and Support

The Consumer Panel will be supported in the following ways:

- Members will be paid an honorarium to cover expenses associated with attending meetings
- Members will be offered an opportunity to attend a training and induction course
- Members will be provided with all meeting documents one week prior to the meetings
- The School of Population Health Consumer Liaison Officer will provide support to the Consumer Panel and be the link between the Consumer Panel and the researchers.

If you require any assistance with your application please contact the Consumer Liaison Officer

Applications close June 5th 2007



Consumer Panel Application Form

Please fill in the application form and return in the enclosed pre-paid envelope.
The closing date for applications is **June 5th 2007**

Part A - please provide your personal details

Name:

Address:

Telephone:

Mobile:

Part B - please provide a short statement about your interest or experience against each question.

1. Why you would like to be a member of the Consumer Panel?		
2. What do you think you would contribute to the Consumer Panel?		
3. Have you any relevant experience as a member of an advisory group, panel, consumer group etc?		
4. Do you have other groups/ friends with health issues that you could consult with and represent on the Consumer Panel?		
Will you be available to attend meetings approximately once a quarter?	Yes	No
Would you be available and interested in attending a training session?	Yes	No
What is the most suitable time for you to attend meetings?	morning	afternoon evening

If you require any assistance with your application please contact the Consumer Liaison Officer

Applications close June 5th 2007



Useful websites

The University of Western Australia School of Population Health
www.sph.uwa.edu.au

The Telethon Institute for Child Health Research
www.ichr.uwa.edu.au

The Health Consumers' Council of Western Australia
www.hcc-wa.asn.au

The National Health and Medical Research Council
www.nhmrc.gov.au

The Consumers' Health Forum of Australia
www.chf.org.au

INVOLVE
www.invo.org.uk

Cochrane Consumers Network
www.cochrane.org/consumers/homepage.htm

Cancer Council NSW
www.cancercouncil.com.au

TwoCan Associates
www.twocanassociates.co.uk

The University of British Columbia
www.health-disciplines.ubc.ca

The Alcohol and Pregnancy Study
www.ichr.uwa.edu.au/alcoholandpregnancy

The Kulunga Research Network
www.ichr.uwa.edu.au/kulunga

Mentally Healthy WA
www.actbelongcommit.org.au

The Raine Study
www.rainestudy.org.au

Western Australian Audit of Surgical Mortality
www.surgeons.org/Content/NavigationMenu/WhoWeAre/Regions/WA/WAASM



THE UNIVERSITY OF
WESTERN AUSTRALIA



A Collaboration between
The University of Western Australia School of Population Health and the Telethon Institute for Child Health Research

Designed by Heather Monteiro