

Planning for Consumer and Community Participation in Health and Medical Research

A practical guide for health
and medical researchers



THE UNIVERSITY OF
WESTERN AUSTRALIA



Anne McKenzie and Bec Hanley



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Contents

Acknowledgements	2
SECTION A: INTRODUCTION	3
Foreword	3
About this book	6
Acronyms and abbreviations	7
About the Consumer and Community Participation Program.....	8
Using the material in this book	8
SECTION B: FOUNDATIONS	9
What is consumer and community participation in health research?	9
Why is consumer and community participation important?	10
Principles for consumer and community participation	14
SECTION C: PREPARING TO PLAN.....	15
What will you need to have in place?	15
SECTION D: PLANNING FOR PARTICIPATION	17
Why are you involving consumers and community members?	17
At what stages will you involve consumers and/or community members?.....	20
What level of participation are you aiming for?.....	23
Can you summarise what your research is about in plain language?	25
Which method will you use?	27
Who will you involve?	37
How will you evaluate consumer and community participation	41
How will you plan to prevent possible barriers occurring?.....	45
SECTION E: CASE STUDIES.....	47
Case Study 1:	48
Case Study 2:	51
Case Study 3:	54
Case Study 4:	57
Case Study 5:	60
SECTION F: RESOURCES.....	63
Useful websites	63
Australian consumer organisations	64
Planning form example.....	65
Plain language summary	66
Reviewing documents	67
Role description examples	68
Advert template	70
Advert example.....	71
Application form example	72
Terms of reference example	73
Budgeting template.....	74
Evaluation form example	75



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Section A: Introduction

Foreword

Medical research is a vast and deep vessel into which people facing health challenges pour their hopes and dreams, and billions of dollars in taxpayer funds. For many, now and in the future, medical research is and will be literally a life and death matter.

But it's more than that because medical research can't take place without ordinary people. They provide the data, take the leap into the unknown, swallow the pills and gamble their health on a better tomorrow. So it's no wonder there's a growing expectation amongst health consumers that they should be part of the decision-making process around what and how research is conducted and funded.

For researchers who have deep and often esoteric knowledge, it can be difficult to see a role for consumer representation, but time and again I've seen the value that trained consumers can bring – helping to ensure that the research question is one that will make a difference, and providing insight into the patient journey that can profoundly influence research strategies and outcomes.

The School of Population Health at The University of Western Australia and the Telethon Kids Institute, lead by pioneering consumer advocate Anne McKenzie, have been at the forefront of consumer participation in research. They have developed practical and effective tools, and programs to support researchers to involve consumers and to make consumer participation more effective.

This book brings together some of the leading thinking and experience in the field and will help both consumer advocates and researchers achieve their common goal: discoveries that advance health and wellbeing.

Karen Carey

Consumer advocate and Chair of the National Health and Medical Research Council's Community and Consumer Advisory Committee



The development of the contribution of consumer and community participation in research in Western Australia is largely the result of a dedicated team led by Anne McKenzie and supported by a strong collaboration between the School of Population Health at the University of Western Australia and the Telethon Kids Institute.

The Consumer and Community Participation Program has gained national and international recognition and is now widely acknowledged across health research groups as being a necessary collaborative component in the development of research ideas, the submission of research grants and in the translation and dissemination of findings.

The aspiration of shared decision making across consumer and research groups has gained traction through a great deal of combined effort and has increased awareness throughout the research and lay communities.

Against a backdrop of informed consumers and limited resources, it is important to build the capacity of community members to contribute to decisions around health care and health research in order to ensure that decision-making is fair, transparent and optimal for the community.

We have come a long way, but there is more to do.

Our experience has taught us that planning for consumer and community participation is vital, if this participation is to be effective. Hence the need for this book. I believe the guidance it contains will continue to uphold the Program as the national benchmark for consumer and community participation.

Professor Elizabeth Geelhoed

School of Population Health, The University of Western Australia



Consumers and the community have always been a big part of the Telethon Kids Institute and our research.

The Consumer and Community Participation program we have run jointly with the UWA School of Population Health for many years has been a leader both nationally and internationally.

With the development of our Strategic Plan, Working Together 2013 - 2017, we've created a new blueprint for a research institute, one that embraces its community and judges itself by its ability to make a difference in that community.

Now more than ever, consumers and the community are intrinsic to the way we do research.

Having consumers and community members actively involved in research gives our research an increased transparency and accountability. It also brings about the need for research to include consumer and community participation from the very beginning, when researchers are planning their research projects and programs. Consumers have a great deal to offer our researchers and they are genuinely interested in what we are trying to achieve and have ideas that can help. So it's important for our researchers to plan for this involvement.

We want our community to be proud of our work and to recognise and understand what we do and what we've achieved and will continue to achieve.

The community can be strong advocates for research as well as the translation of research into policy and practice. After all, they are the ones who will benefit from the findings and results of our projects.

Telethon Kids looks forward to continuing and building our relationships with consumers and the community so we can keep putting kids at the heart of everything we do.

Professor Jonathan Carapetis

Director, Telethon Kids Institute



About this book

This book is based on our experience of supporting researchers to plan effective consumer and community participation in research. Many of the stories included are from researchers and consumers based at the School of Population Health at The University of Western Australia (the School) and Telethon Kids Institute, formally the Telethon Institute for Child Health Research (the Institute). There are also other examples from elsewhere in Australia as well as in the United Kingdom (UK).

We wrote a book in 2007 summarising the experience of consumer and community participation across the School and the Institute¹, and subsequently have offered training and further support to hundreds of researchers from across Australia. One of the key things that people seek help with is how to plan for participation – hence this new publication.

This book aims to guide you through the steps to follow if you are planning to actively involve consumers and/or community members in your research. We begin in Section B with an introduction to consumer and community participation – what it is, why it is important and the principles underpinning it. Section C focuses on the foundations that you need to have in place before you start – senior support, a budget, time, training and administrative support. Section D looks at:

- Why you might want to involve consumers and community members
- What stage in the research process you might involve them
- What level of participation you are aiming for
- How to write your research summaries in plain language
- What methods you will use to involve consumers and community members
- Who you will involve
- How you will evaluate the participation activities

In Section E we offer some case studies to illustrate how planning can lead to effective participation and some advice on how to overcome barriers to consumer and community participation. Lastly we have included a series of resources in Section F for you to draw on for further information and support.

Although this book follows a very linear structure, we know that planning for involvement does not follow one simple path. For example, you might think about who you want to involve before you think about the methods you will use – or you might think about them at the same time. For simplicity we have used a linear format.

We hope this book will be useful to researchers who are planning to involve consumers and community members in their research, perhaps for the first time. We also hope that researchers who have experience of involvement might find the range of examples here a helpful refresher for what's possible.

1. McKenzie A, Hanley B, *Consumer and Community Participation in Health and Medical Research, A practical guide for health and medical research organisations* Perth; The University of Western Australia and the Telethon Institute for Child Health Research. 2007.



We are grateful to the Chief Investigators of the Institute's National Health and Medical Research Council Program Grant: *Early Developmental Pathways Linking Health, Disability, Education, Welfare and Justice* for providing the support and funding to enable us to write this publication.

Acronyms and abbreviations

We have attempted to limit the use of acronyms in this manual but for brevity we have used the following acronyms:

Institute - Telethon Kids Institute

NHMRC - National Health and Medical Research Council

NHS - National Health Service

NSW - New South Wales

School - School of Population Health

UWA - The University of Western Australia

UK - United Kingdom

WA - Western Australia

About the authors

Anne McKenzie has worked as the Consumer Advocate at the School and the Institute since 2004. Anne now leads and manages the joint Consumer and Community Participation Program at both organisations. Her role is to support and facilitate active consumer and community participation in the research and teaching programs at the School and the Institute.

Anne is a senior consumer representative for Consumers Health Forum of Australia and former Chair of the Health Consumers' Council of WA. She serves on key state and national committees for the NHMRC, The Department of Health, the Therapeutic Goods Administration and the Western Australian Health Department.

Bec Hanley has spent the past twenty years working to promote the involvement of people who use services in health care and health research in the UK. For five years she was the director of the INVOLVE Coordinating Centre, an organisation 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 Bec worked in partnership with health professionals and the people who use health services, to develop policy and practice on involvement in research.

Bec is the lead author of INVOLVE's acclaimed *Involving the Public in National Health Service (NHS), Public Health and Social Care Research*, now in its third edition. Bec is now co-director of TwoCan Associates (www.twocanassociates.co.uk) and works with a range of research and consumer organisations.



About the Consumer and Community Participation Program

The School and the Institute have actively and successfully pursued greater consumer and community participation in their research since 1998. The Consumer and Community Participation Program (Participation Program) has been supported by the Health Consumers' Council of WA and is underpinned by the principles in the NHMRC and Consumers Health Forum of Australia's joint Statement; *Consumer and Community Participation in Health and Medical Research*² and *A Model Framework for Consumer and Community Participation in Health and Medical Research*³.

The Participation Program has implemented a multi-faceted strategy that is driven by community values. Please see our website for more information (www.involvingpeopleinresearch.org.au).

Using the material in this book

You are welcome to use any of the ideas or resources in this book with permission, 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 free downloadable format on the Participation Program's website www.involvingpeopleinresearch.org.au

2. National Health and Medical Research Council and Consumers Health Forum of Australia: *Statement on Consumer and Community Participation in Health and Medical Research* 2002.

3. National Health and Medical Research Council and Consumers Health Forum of Australia: *A Model Framework for Consumer and Community Participation in Health and Medical Research*. 2004.



Section B: Foundations

This section covers:

1. **What** is consumer and community participation?
2. **Why** is it important?
3. Some **principles** underlying consumer and community participation

1. What is consumer and community participation in health research?

Consumer and community participation in health research is about consumers and/or community members and researchers working in partnership to shape decisions about research priorities, policies and practices. It is about consumers and community members being part of a process, rather than just observing or commenting on research processes. Consumer and community participation is sometimes referred to as community engagement.

A variety of terms may be used to refer to consumers, carers and/or community members in health service delivery, health research and organisational development. The definitions below are taken from the *Statement on Consumer and Community Participation in Health and Medical Research 2002*² and the Participation Program at the School and the Institute.

Consumer

Refers to people who directly or indirectly make use of a health service e.g. patients

Consumer representative

A member of a committee, steering group or similar who voices the consumer perspective

Carers

Families and/or friends providing unpaid care

Community

A group of people sharing a common interest but not necessarily a common geographic location

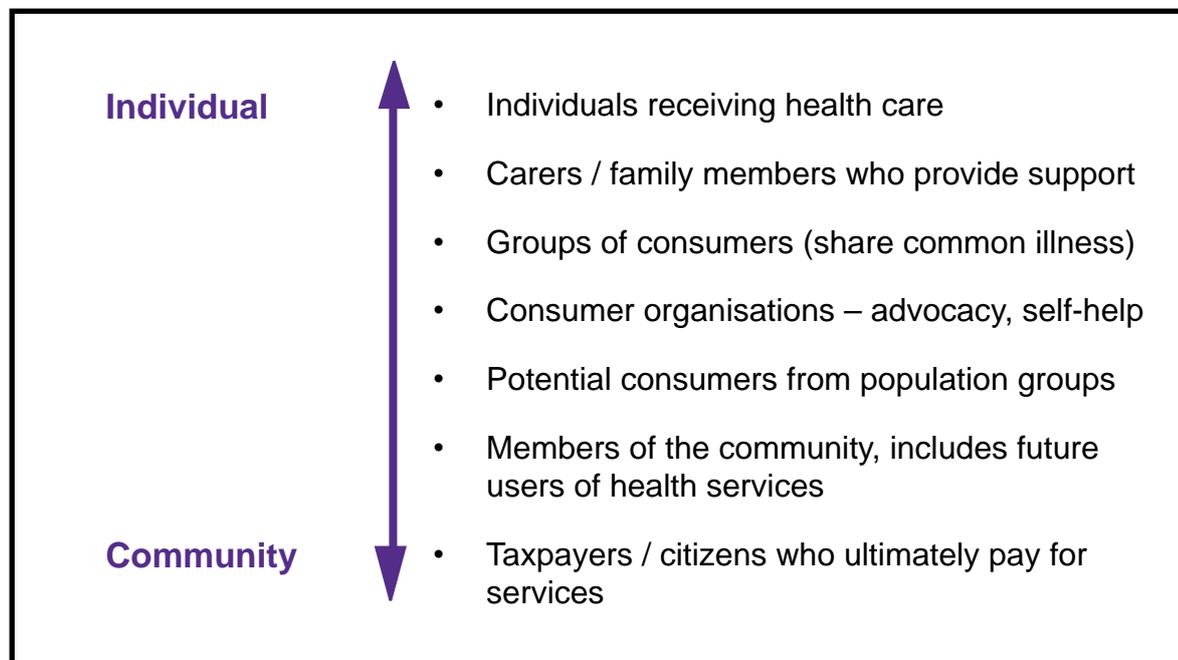
Stakeholders

An individual or group from within or outside the organisation who has a key interest in the research



The range of consumer and community voices

There are a range of voices that can contribute in consumer and community participation, from the individual through to the taxpayer and citizen. Each has an important role to play.



2. Why is consumer and community participation important?

Consumer and community participation is increasingly being recognised as an integral component of the Australian healthcare system. In health and medical research there are many reasons why consumer and participation is important. For example:

1. Consumer and community participation can help to enhance or improve the quality of research
2. Current funding and policies often require some form of participation
3. Accreditation requirements may include consumer and community participation
4. Human Research Ethics Committees may require evidence of participation
5. Participation can help empower consumers and/or community members
6. The involvement of consumers and/or community members can increase the level of openness and transparency in the use of public funds

Some of these points are now considered:



2.1. Consumer and community participation can help to enhance or improve the quality of research⁴

Consumers and/or community members can offer different perspectives

You may be an expert in your field, but that does not necessarily mean that you are able to see all the perspectives on what occurs in the area of your research interest. Even organisations that specialise in research in a particular health area have a view from the 'inside looking out' and do not necessarily understand how their activities are experienced by those on the 'outside looking in'.

When prioritising topics for future research, lymphoma researchers identified the measures of treatment that they thought were important such as white/red cell count and reduction in tumour size, whereas consumers wanted to include everyday issues such as constipation, tiredness, and the quality of the life lived when undergoing treatment for cancer.

Consumers and/or community members can help ensure the issues identified and prioritised are important to them

Researchers at the University of Sydney organised a workshop for researchers, clinicians, patients, carers, non-government consumer organisations and policy makers to seek input into research priorities for chronic kidney disease. A framework for the workshop was developed in collaboration with a UK consultant. Over 80 research questions were generated with priority questions focusing on prevention, lifestyle, quality of life and long-term impact. The prioritised questions will inform a shared agenda for future research.

Consumer and community participation can help to ensure that money and resources aren't wasted on research that has little or no relevance

The Cancer Council NSW held a consumer research forum in 2009 to identify research priorities across the cancer control spectrum, i.e. from prevention through to survivorship and bereavement. The feedback from the forum provided valuable information for future planning and funding.

Consumer and/or community members can help to ensure that research doesn't just measure outcomes that are identified as important by researchers

Sometimes, researchers on their own cannot identify outcome measures that are important for consumers and community members. Health consumers are ultimately the end users of most health and medical research, and are in the best position to identify issues that arise from their own experience.

An international conference of Outcome Measures in Rheumatoid Arthritis Clinical Trials (OMERACT) highlighted a gap between what the researchers thought was important, and what the patients knew to be important from their

4. This section is adapted from a publication produced by INVOLVE using Australian examples. *Involving the public in NHS, public health and social care research: Briefing notes for researchers.* INVOLVE 2004.



personal experiences, i.e. living with fatigue. Although fatigue is a huge issue for people living with arthritis, it had not previously been considered relevant by the OMERACT researchers.

Consumers and/or community members can help to disseminate the results of research

The Down Syndrome Needs Opinions Wishes Study looked at the health, medical, educational, social, functional and support needs of children and young people with Down Syndrome. At the end of the data collection phase, a series of focus groups were held with parents from the Down Syndrome Association and other stakeholders to ensure that the final report included relevant information for everyone and that it would be made widely available to all groups.

2.2. Current funding and policy requirements

a) Funding requirements

The NHMRC currently require successful grant applicants to outline their plans for accountability and the dissemination of research results to participants and the community. Research that is conducted with Aboriginal communities has specific requirements about participation.

Other funding bodies, such as Cancer Australia, require researchers to provide information in their grant applications about how they will involve consumers in their projects.

b) Policy requirements

The NHMRC's *Model Framework for Consumer and Community Participation in Health and Medical Research*³ provides information and assistance to researchers and research organisations wanting to involve consumers and the community in their research.

c) Government commitment

Many Australian government agencies acknowledge the contribution the community can make to organisational development i.e. planning, governance, operations and research. These requirements are generally articulated in policy and/or funding requirements and are often the impetus for organisation-wide community engagement strategies being developed and implemented. For example, the *National Health and Hospitals Reform Commission Report 2009*⁵ stated:

5. *A Healthier Future For All Australians* – Final Report of the National Health and Hospitals Reform Commission – June 2009



'We believe that the National Health and Medical Research Council should consult widely with consumers, clinicians and health professionals to set priorities for collaborative research centres and supportive grants which:

- integrate multidisciplinary research across care settings in a 'hub and spoke' model*
- have designated resources to regularly disseminate research outcomes to health services.'*

2.3. Accreditation requirements

It is a requirement of the NHMRC's 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*².

2.4. Human Research Ethics Committees

Researchers will also be influenced by what ethics committees require of them.

Research that involves Aboriginal communities in Australia may have special ethics requirements for involving their communities in all aspects of research processes. Researchers must also take into account the cultural principles and values of the Aboriginal people.

2.5. Participation in research, done well, can help empower consumers and/or community members

Consumer and/or community members can acquire new skills and knowledge through their active involvement in research. They can become strong advocates for all aspects of research.

Consumer and community members involved in the Participation Program at the School and the Institute provided strong support for the national Discovery Needs Dollars campaign in 2011, which was established to lobby the federal government about potential cuts to research funding.



3. Principles for consumer and community participation

There are certain key principles that underpin all consumer and community participation activities. Regardless of the level or method of participation being used, these principles provide support and guidance for consumer and community participation activities:

- Start participation as early as you can
- Participation must add value to the research, researchers and/or consumers and community members
- Be inclusive and reach out to diverse groups
- Treat everyone with respect and integrity
- Work in partnership
- Keep everyone informed and involved
- Use language that everyone understands
- One size doesn't fit all – it's important to work with consumers and/or community members to find what will work best for your research

There are specific principles to guide research conducted with Aboriginal people that are outlined in the *NHMRC Roadmap II*⁶, which aim to be of practical value to Aboriginal communities.

While these principles were developed to ensure that the community 'voice' is integral to research conducted with Aboriginal and Torres Strait Islander people, they are applicable to research affecting all Australians.

6. National Health and Medical Research Council. *Road Map II: a Strategic Framework for Improving the Health of Aboriginal and Torres Strait Islander People through Research* Canberra: Australian Government 2010



Section C: Preparing to Plan

This section covers:

- The **support and resources** that need to be in place to ensure that your participation activities are as effective as possible

What will you need to have in place?

Try to ensure you have the following in place before you start your participation activities. Each is considered further below:

- Senior level support and sign-off
- Budget
- Time
- Training
- A coordinator for the participation activities
- Administration support

Senior Level support and sign-off

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. Ensure you have senior level commitment to take consumer and community participation forward. Funding and policy requirements described on page 12 could be useful in helping you put your case forward.

Budget

It is necessary to secure funding for the participation activities. The amount of funding required will depend on the method of involvement you choose. Most methods will require payment or honorariums for out-of-pocket expenses such as parking, child minding or petrol. Consideration will also be needed for items such as refreshments, venue hire, postage and printing. There is a budgeting template in Section F on page 74.

Time

You need time to plan for consumer and community participation, but you will also need to allow time throughout the project to ensure that the participation is meaningful. This might mean you need to allow more time for specific aspects of the project. It will also mean that you will need to allow time to organise any participation activities and to support colleagues and consumers and/or community members. For example, a community conversation requires approximately six weeks to organise, advertise and recruit the appropriate people to attend.



Training

You will need to talk with colleagues and the consumers and/or community members you involve in your research about any training and support that might be helpful. For consumers, this might include:

- Induction training
- Training about research
- Mentoring or support to enable them to participate effectively in the project

For researchers, this might include:

- Training on consumer and community participation
- Support to ensure they can facilitate meaningful participation throughout the research

A coordinator for the participation activities

It is important to clarify who will be responsible for the participation activities in each research project. Will it be the project's Chief Investigator, the Research Assistant or the Administration Officer? Knowing who to contact can make it easier for consumers and/or community members to raise any queries or support needs they may have.

Administration support

You will also need to ensure that you are able to provide administration support for consumer and community participation. For example, if there are meetings, someone will need to book a venue, devise and circulate an agenda, take notes and circulate them.



Section D: Planning for Participation

This section covers:

1. The **importance of being clear** about why you are planning to involve consumers and community members in your research
2. The **different stages** of the Research Cycle and how you might involve consumers and community members at each stage
3. The **levels** of consumer and community participation that are possible in a research project
4. **Plain language summaries** and some advice on how to write them
5. **Methods** you can use to involve consumer and community members in your research and how to choose which method is right for your project
6. The **different groups** of consumers and community members you might choose to involve and how to find them
7. Why you should consider **evaluating** consumer and community participation when you are at the planning stage and how you might go about this
8. **Barriers** to consumer and community participation in research and how you might overcome them

1. Why are you involving consumers and community members?

Being clear about why you're planning to involve consumers and/or community members is the first important step to planning for effective consumer and community participation in research. If you are clear about your aims, this will help you to decide **who** to involve, **how** to involve consumers and/or community members and **at what stages** to involve them. It will also help you when you invite people to get actively involved in your research and enable consumers and/or community members to make a more informed decision about whether they want to work with you.

Possible reasons for involving consumers and/or community members in your research include:

I want to ensure my research is relevant and important to the needs of the people my research is about.

If this is your key motivation for involving consumers and/or community members, you are likely to involve people with direct experience of the condition or issue you are studying e.g. a patient, a carer, family or community members.



Researchers at the Institute planned to undertake a project to develop a diagnostic instrument for Fetal Alcohol Spectrum Disorders in Australia. They wanted to ensure that women's experiences of talking with health professionals about alcohol consumption in pregnancy were considered in the development of the tool. Two community conversations were held in Perth and Cairns to seek input from women in the community. Community members and representatives from community support groups were involved with researchers and clinicians in the project steering group.

I want to ensure that there is some accountability back to the people who have funded my research – directly or indirectly.

If your research is publicly funded and the possible beneficiaries are very general such as health promotion research, you might wish to involve nominees from a generic consumer organisation e.g. the Health Consumers' Council of Western Australia or a similar organisation in another state (see page 64 for a list).

A research project to look at the impact of increasing patient costs for medicines provided through the Pharmaceutical Benefit Scheme (a system of subsidising the cost of most prescription medicines in Australia) was conducted at the School. Requests to the researchers for policy recommendations to address the findings led to researchers and the Health Consumers' Council of Western Australia holding a large consumer forum to seek input into the recommendations. A report outlining the forum's discussions was distributed across Western Australia via the Health Consumers' Council newsletter and the Participation Program's Network.

I want to ensure my research is done respectfully and sensitively with a particular group of people.

We can all learn from the approach developed by Aboriginal and Torres Strait Islander people to health research. Researchers who wish to conduct research with Aboriginal and/or Torres Strait Islander peoples are required to actively involve them in all areas of their research from an early stage⁷. Researchers working in other areas have adopted a similar approach to ensure their research is undertaken respectfully and sensitively.

The Domestic Violence In Communities of African Refugee Backgrounds Project undertaken at the School, aimed to explore the nature and understanding of family and domestic violence within the Sudanese, Somalian, Ethiopian, Liberian and Sierra Leonean communities and its impact on individuals, family relations, the community and settlement. In order to ensure that the research reached members of these communities and was sensitive to the issues being researched, fourteen members of the five communities involved were recruited and trained as community researchers.

7. National Health and Medical Research Council. *Keeping research on track: a guide for Aboriginal and Torres Strait Islander peoples about health research ethics*; 2006. This document is available at <http://www.nhmrc.gov.au/publications/synopses/e65syn.htm>



I want to ensure I understand the perspectives of a range of people and I need to make sure I recruit from a diverse range of people.

If it is important that your research includes the perspectives (or other types of contribution) from a diverse range of people, you may consider involving a larger group of consumers and/or community members in your research, as part of a reference group (see page 32). They will be able to help you to make links with groups or communities that may seem ‘hard to reach’.

The Developmental Pathways Project at the Institute investigates the pathways to health and wellbeing, education, disability, child abuse and neglect, and juvenile offending outcomes among Western Australian children and youth. Researchers wanted to ensure that their research included the perspectives of a wide range of consumers and community members, because of the far-reaching nature of their research. Following extensive community consultation they set up a community reference group to provide a community perspective on the research. The reference group includes fourteen community members with an interest in, and/or connection to, one of the government partner agencies involved with the project.

‘The value of having community perspectives on our work is immeasurable, and will only be truly seen once our work has been completed and disseminated.’

Dr Rebecca Glauert,
Developmental Pathways Project
Manager

I want to ensure the results of my research are put into practice.

This does not mean that you should wait until the dissemination stage to involve consumers and/or community members. People who feel ownership of the research are much more likely to want to make sure it is put into practice, so this means you will want to involve consumers and/or community members at an early stage.

A study analysing health records from over 2,000 women who use hormone therapies as part of their treatment for breast cancer involved consumers from the early stages of project planning. Now that the project is funded and running, a consumer advocate sits on the Project Advisory Committee. As well as commenting on priorities for upcoming work and helping to interpret findings, this committee will also suggest avenues for dissemination and implementation of findings.



2. At what stages will you involve consumers and/or community members?

The Research Cycle described in the NHMRC's *Model Framework on Consumer and Community Participation in Health and Medical Research* has five stages (see diagram below). It is important to remember that although the stages are numbered you can start participation activities at any stage – but earlier is better.



Stage 1 – deciding what to research

Consumers and/or community members can play a key role in identifying and prioritising topics for research. You could do this by:

- Running a consumer or community consultation to ask people for their ideas (see page 29)
- Involving consumers and/or community members in a steering group (see page 33)
- Talking to the Consumer and Community Advisory Council, if you have one (see page 35)

Stage 2 – deciding how to do it

Consumers and/or community members could help you to make sure the plans for your research are practical and achievable. They could do this by:

- Helping to write or to comment on funding applications, protocols and patient information sheets (see page 28)
- Being involved in a steering group (see page 33)

Stage 3 – doing it

Consumers and/or community members can be involved in doing the research in a number of ways, including:

- Acting as consumer or community researchers (see page 34)
- Taking part in community consultations about specific issues (see page 29)
- Being involved in a steering group or advisory group (see page 33)
- Acting as a research buddy (see page 31)

Stage 4 – letting people know the results

Consumers and/or community members can help researchers to disseminate the results of their research through:

- Writing or helping to write plain language summaries of the research and the results (see page 25)
- Giving talks to consumers and/or community members about the research
- Writing articles about the research in plain language for consumer or community group's newsletters or websites
- Using their networks to tell people about the research

Stage 5 - deciding what to research next

If you have involved consumers and/or community members at earlier stages, they will be keen to help you to think about future topics for research. You could also:

- Talk with the Consumer and Community Advisory Council, if you have one (see page 35)
- Run a consumer or community consultation to ask people for their ideas (see page 29)



The Miracle Babies Foundation: planning for involvement at every stage of the Research Cycle

Miracle Babies Foundation (an organisation that supports premature and sick newborns, their families and the hospitals that care for them) has been involved in all stages of the Research Cycle with the Westmead International Network for Neonatal Education and Research Centre.

Deciding what to research

Through our social media channels Miracle Babies has been able to conduct surveys on what is important to parents to assist researchers to focus on topics of interest. Consumers participate in research steering committees to share what is important as parents of premature and sick newborns.

Deciding how to do it

Miracle Babies has parent representatives attend research conferences to provide a parent's perspective and to advise on how best to communicate with parents. We have found that consumer involvement in research committees provides insight into the challenges of what might block a parent's involvement in research. Consumers have assisted in making the research information easy to understand and easy to participate in. Their help has ensured recruitment will be a success.

Doing it

Miracle Babies Foundation has been able to assist researchers through our family support programs via education and providing support to families participating in research. Our consumers give a vital viewpoint of obstacles, challenges and rewards from a similar perspective as a research participant.

Letting people know the results

Working with consumer groups gives the researchers another avenue to access the community and inform them on results and any future changes in care or treatment. For Miracle Babies this happens regularly when we also inform parents of upcoming research opportunities.

Knowing what to research next

Social media and our Nurture Program provide a large community platform for Miracle Babies Foundation to continue the conversation with our families and supporters on future research projects.

Consumer participation will provide new and fresh ideas for future projects and assist with topics that are important to them and valued by the wider community.

Kylie Pussell

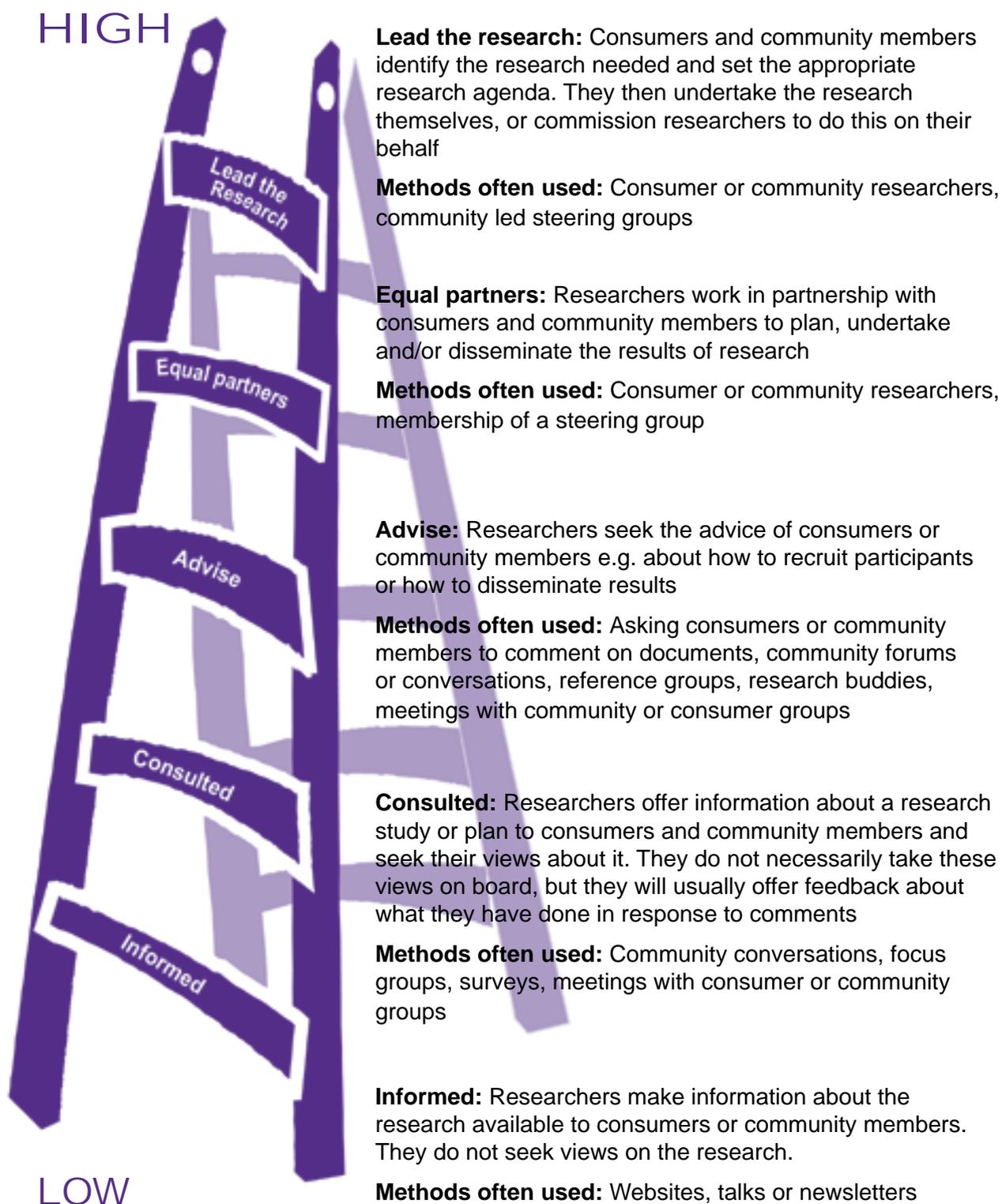
**Cofounder, National Program & Media Manager
Miracle Babies Foundation**



3. What level of participation are you aiming for?

Using the Ladder of Participation as shown below can help to illustrate the levels of consumer and community participation.

The Ladder of Participation



© McKenzie & Hanley 2014 Revised and adapted from McKenzie and Hanley, (2007) Consumer and community participation in health and medical research: A practical guide for health and medical research organisations



Below are some examples of projects at the School and Institute and the different levels they have used:

Informed

The Community Reference Group for the Infectious Disease Research Group at the Institute have developed plain language descriptions of all research projects being undertaken (<http://telethonkids.org.au/wesfamers-centre-of-vaccines-infectious-diseases/infectious-diseases-community-reference-group/>).

Consulted

Two NHMRC funded research projects conducted at the School used linked state and commonwealth health information to look into enhanced primary health care outcomes in chronic illness and medication safety in seniors (aged 65+). Three community forums were held in collaboration with the Health Consumers' Council of WA to seek community feedback about the projects. The feedback from the forums was comprehensive and raised issues that were not previously considered by the researchers.

Advise

The Bethanie project (see Section E page 57) at the School aimed to engage consumers of aged care communities in health professional education. Researchers established a reference group to provide input and advice to the project management group.

Equal partners

Researchers in the Down Syndrome Needs Opinions Wishes Study worked in partnership with Down Syndrome WA to plan and undertake the research and disseminate the results of this project.

Lead

The Northern Goldfields Renal Study was initiated and undertaken by the Aboriginal community in and around Kalgoorlie. It aimed to screen every Aboriginal child and adult in the area for symptoms of kidney disease and diabetes and to work with the communities to develop healthier lifestyles.

Some points to note about this ladder:

It's not a hierarchy, where 'informed' is the worst type of involvement and 'lead' is the best. Different levels of involvement will be appropriate in different types of research and in different contexts. For example in laboratory based research projects it's just not appropriate for consumers to lead the research.

The ladder can help you be clear in your own mind about the level of consumer and community participation your research project is aiming for. If you're clear how much involvement you want, you can then be clear about this with the people you are seeking to involve.



Being clear about the level of participation you are seeking is very important.

This is not to say it should be fixed for the whole project – you might start out wanting to consult, but after discussion with the consumers and community members you are seeking to involve, you may agree together that they will advise you. But it's important to tell people how much say they will be able to have in a project, so that they don't feel you have involved them on false pretences.

This clarity will also mean that ***consumers and/or community members can make an informed decision about whether or not to get involved in your project.***

You can move up and down the ladder within the same project.

4. Can you summarise what your research is about in plain language?

What is a plain language summary?

A plain language summary is a brief outline of a research project or research proposal that has been written for members of the public rather than researchers or professionals. Plain language summaries (sometimes referred to as lay or plain English summaries) are not an attempt to 'dumb down' scientific information. It is important to be able to speak or write about research in a way that potential funders, supporters, policy makers, consumers and the community can understand. A plain language summary can be helpful in making information about research more open, transparent and accessible, and therefore helpful in recruiting consumers and community members to get involved in your research.

Researchers suggest plain language summaries are also useful for:

- Developing grant and ethics applications
- Scholarship/bursary applications
- Seeking consumer and/or community support and/or input
- Recruiting participants
- Media releases and informing the wider community
- Presenting to a non-scientific audience
- Submissions to ethics committees

What should be covered in a plain language summary?

We have included advice on what to cover in a plain language summary in Section F page 66.



Developing a plain language summary⁸

When you write your plain language summary of your research, you might find it helpful to think about:

Your writing style

Write as if you are explaining your work to a friend or family member who has no scientific background. This will help you keep it simple. You will be writing for a mixed audience with a range of reading ages and levels of education. Some may have little medical or scientific knowledge. Those with a better understanding will not be offended by simple and direct language. Try to:

Talk directly to your reader

As you are writing, imagine you are talking to your reader and write the way you would speak to them. Refer to the researchers as 'we'. For example, 'we will look for...'

Use simple words and avoid scientific jargon

Your vocabulary should be as simple as possible. Try to use everyday alternatives to jargon. For example, use 'give' instead of 'administer'. If technical terms must be used, then provide a simple definition.

Be direct

Try to write in a direct style. Make sentences short and without too much punctuation. If more than one comma or connecting word seems necessary, then consider more than one sentence or a list of dot points. Make sure your main point is in the first part of a sentence and/or paragraph.

Use active verbs rather than passive

Clear writing describes people doing things, not people having things done to them. Use active verbs not passive ones. For example, use 'we will look for the effects on quality of life' rather than 'the effects on quality of life will be observed'. It's usually clearest to keep subject, verb and object in that order.

Avoid turning verbs into nouns

This is often done in formal documents. It doesn't help people's understanding. For example, 'When your blood has been tested, a decision will be taken with respect to your continued participation' could read 'We will test your blood and decide if you should stay in the trial.'

Test your writing with consumers and community members

This is the only foolproof way to find out if your writing can be read and understood. Online tools for scoring readability can also be helpful but do not replace asking consumers and/or community members if they understand what you have written.

8. This section is taken from TwoCan Associates UK. *Getting it right for service users and carers, getting it right for researchers: How to decide whether to help researchers find people to take part in research.* 2008



Layout and presentation

Guide your reader

In a long document, a short introduction can be used to highlight important points and guide the reader through detailed text. Make an effort to select and use clear sub-headings. Group related points together under a clear heading.

Format and style

This is always a matter of personal preference. Some people may have problems with their sight, so it is often best to:

- Use Arial font, minimum point size 12 or 14
- Use line spacing of 1.5
- Align text to the left (justified text is harder to read)
- Use italic, bold and underlined styles sparingly
- Highlight headings by additional space rather than underlining
- Leave plenty of clear space in your document – particularly around bullet points and lists
- Vision Australia, a not-for-profit provider of blindness and low vision services, have a range of tools to guide the use of colours and format.
<http://www.visionaustralia.org/business-and-professionals/digital-access/resources/tools-to-download>

5. Which method will you use?

There are many ways that consumers and/or community members can be meaningfully involved in research. The method that you use will influence the number of consumers and/or community members you involve. Ideally there will always be at least two consumers and/or community members involved. Having one consumer or community member can be very daunting, particularly if the research group is large. Having two people will provide a wider perspective as well as ensuring there is consumer or community input if one person is unavailable to attend a meeting. You might wish to talk with other researchers, consumers and/or community members to decide the right number of people for your project. Following are some suggested methods that can be adapted to suit most types of research.

Writing or commenting on documents

What documents are we referring to?

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

- Grant applications
- Information sheets and consent forms
- Pamphlets and brochures
- Plain language summaries
- Reports and documents about the dissemination of research results
- Presentations to community groups



Why ask consumers and/or community members to write or comment on research documents?

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

Who can write or comment on research documents?

- Consumers or members of the community group the research is focused on
- Organisations that represent the consumers or community groups
- Parents or carers of children in the relevant consumer or community group

If you're planning to ask consumers and/or community members to comment on documents, think about...

- What type of document is being reviewed?
- Are consumers and/or community members involved enough in the project to be able to write any of the documents?
- Will the consumers and/or community members require any training e.g. do the consent forms need to contain legal information?
- Provide clear instructions of what is expected of consumers and/or community members
- Will consumers and/or community members be paid? Discuss this with them
- Do consumers and/or community members know about any privacy/confidentiality requirements?
- Consider meeting with the consumers and/or community members to discuss your requirements

Writing or commenting on documents

The Western Australian Register of Developmental Anomalies collects information about where and when developmental anomalies are occurring in Western Australia. The Register has a community reference group, which provides comments on applications from researchers to access Register data and new grant applications. They were also involved in the development of the Register website and printed materials.



Consumer and community forums

What are they?

Consumer and community forums or conversations are one-off or occasional meetings between consumers and/or community members and researchers. They provide an opportunity for community input into research priority setting and planning at an organisational level as well as individual projects.

Alternatively these can also be used to inform or seek specific information from the community. This is low level participation. Forums can be a good way of accessing input from large groups of people in a short period of time.

Who could attend a community forum?

- Consumers and/or community members
- Members of consumer, advocacy or community organisations
- Carers
- Community members with a common interest or health issue

When should forums be used?

- To seek input on priorities for future research projects
- At any time in the research project
- A number of times throughout the same project
- To discuss the design of the project
- To recruit people to get involved at any stage of the project
- To advise the community of the potential impact or benefits of the project
- To tell consumers and/or community members about the results of the project

What to think about if you're planning a forum

- Be very clear about what you want to achieve from the forum
- Invite the most appropriate people
- Budget for expenses/honorariums, refreshments and venue hire
- Provide attendees with information about any payments they will receive
- The place where the forum is held needs to be convenient, accessible and big enough to hold a large group of people
- Provide any written information and presentations about the topic or project in language that is easy to understand

Consumer and community forums

A community forum was held to seek consumer input into findings of a research project conducted at the School about consumer co-payments for prescription medicines. It was important to have input from a diverse group of health consumers who took multiple medicines that were funded by the Pharmaceutical Benefits Scheme. The researcher worked with the Health Consumers' Council of WA to access consumers and took part in a radio interview to explain about the purpose of the forum. The forum was well attended by over 60 people aged between 18 and 92.



- Avoid using jargon and acronyms and provide explanations if technical terms have to be used
- Tell people at the forum how you will give them information from the forum and if there will be any further follow-up
- Do you need any advice or support to help you to run a forum successfully?

Consumers and community members in research teams

What are they?

Consumer and/or community members who are part of research teams are commonly referred to as consumer or community representatives. If you use this model, you should ensure that you involve people who feel confident and supported enough to speak out when meeting with a group of professionals and experts. Involving people who are connected to, or have membership of, a consumer or community organisation can bring the wider perspective of the organisation to the research team.

Where do you find them?

- Health consumer, community or non-government organisations have members that might be interested in joining your team
- Contact a group that has an interest in your research topic or area, such as a support group or non-government organisation

What to think about if you are planning on having consumers and/or community members on your research team

- Discuss any support and training the consumers and/or community members will need to ensure their contribution to the team is as effective as possible
- Discuss your expectations of the role with the consumers and/or community members

Consumers and community members in research teams

The School's Breast Cancer Environment and Employment Study had a consumer representative on their project advisory group. Researchers felt the consumer representative had a very valuable role in the study, as her advice was considered and sensible as well as bringing a different perspective. The Chief Investigator gave the following example to highlight her contribution:

'We had a computer glitch and lost eleven interviews. We were just going to mark them as missing rather than bother the participants. But our consumer rep thought that we should phone them and explain the problem, and let them decide if it was worth their time to re-do the interviews (making it really clear that we realised it was a big ask and we would understand if they didn't want to). And so we did, and all the participants agreed to do the interview again.'



Research buddies

What are they?

Research buddies are consumers and/or community members who provide links between the researcher, other consumers and community members, organisations and/or the research funder.

They may be particularly helpful when the researcher is using linked data or working in a laboratory and does not have any direct contact with consumers or community members.

Research buddies may provide insight into unexpected or unexplained research findings, and can also help with the dissemination of the research.

How do they work?

- The researcher will either meet with or send the research buddy a report once or twice a year on the research progress
- Research buddies will feedback the report to their consumer and/or community organisations

What to think about if you're planning to involve research buddies

- Develop draft Terms of Reference (see page 73) for the research buddies
- Be clear about the role and expectations of the buddies, as contact may be limited
- Write reports in plain language – avoid using jargon and give explanations of any technical terms
- It is essential that the research buddies understand any issues so they can accurately report back to consumers and/or community members or organisations
- Consider how the research buddies will be supported to engage with other consumers and community members
- Discuss honorarium and payment of expenses

Research Buddies

A laboratory researcher at the Institute doing melanoma research worked with two research buddies to develop grant applications and plain language summaries of his research. One buddy had experience as a consumer representative on a breast cancer project at the School. The other buddy is the founder of a community support group for melanoma patients. The researcher will meet with the buddies at least three times a year to discuss and provide reports on his research.



Reference groups

What is a reference group?

A reference group (sometimes referred to as a reference panel) is a group of consumers and/or community members that can be referred to by researchers throughout a research project. Reference groups can provide advice throughout a project, or at a particular stage of a project. Representatives of the reference group may be on the main research team and report back to the reference group. Reference groups can be particularly helpful in getting information out to a large number of people who may have an interest in the research or its findings.

Who would be in a reference group?

- Consumers and/or community members
- Members of consumer advocacy organisations and/or non-government organisations
- Other stakeholders of the research

What to think about if you're planning to set up a reference group

- What support and/or training will be needed or offered?
- A member of the research team will need to set aside time to organise and support meetings
- Is there a budget for payment of expenses and/or honorariums? Has it been discussed with the members?
- You will need to provide updated information about the research project to the reference group prior to any meetings
- Be clear in advance about which aspects of the project cannot be changed
- Work with consumers and/or community members to decide the right number of people for your reference group. This will often depend on the size and topic of the research project, so it is important to make sure you have enough members to generate a wide range of ideas and perspectives.

Reference groups

The Institute's Developmental Pathways Project established a community reference group in 2011 that has up to fourteen community members. The members have an interest in, or association with, the research being undertaken within the project.

Establishing the reference group was a gradual process that included community conversations, training workshops, seminars and presentations to researchers and government agencies. The reference group:

- *Provides a community perspective on project activities*
- *Builds understanding that linked data may be about private and sensitive issues*
- *Provides advice on research findings and results*
- *Provides input into dissemination strategies to inform the community about the research*
- *Receives information regarding the impact of the research projects and their translation*
- *Provides input into the development of priorities for future research projects*



Steering groups

What is a steering group?

A group of stakeholders who steer and influence the research project. This is high-level participation (see page 23). A steering group may be referred to as a steering panel.

Who would be in a steering group?

Groups can consist of any or all of these stakeholders:

- Researchers
- Clinicians, policy makers, health administrators
- Consumers and/or community members
- Members of consumer advocacy organisations and/or non government organisations

What to think about if you're planning to involve consumers and/or community members in a steering group

- If mixing a range of stakeholders, always ensure that there are at least two consumers and/or community members in the steering group
- Consumers and/or community members must be involved at an early stage of the project for their participation to be meaningful
- Avoid the use of acronyms and technical language in meetings - consider creating a glossary if you expect technical language will be used
- A member of the research team will need to set aside time to organise and support meetings
- Consider what support and/or training consumers and community members will need or be offered
- Payment of expenses and/or an honorarium should be budgeted for, especially if all other members of the meeting are being paid for their time
- Be clear in advance about which aspects of the project cannot be changed

Steering groups

The WA Insurance Commission funded a research project to look into costs associated with catastrophic injury. The Chief Investigators established a project steering committee that included health consumers, disability advocates, a parent carer, non-government agency representatives, an injury lawyer and government agency representatives. The steering committee had input into the methodology, recruitment, the project report and dissemination strategy.



Consumer and community researchers

What are they?

Consumers and/or community members who have been trained to work with researchers to conduct research. On the Ladder of Participation (see page 23) this usually represents high-level involvement.

What role will they have?

Consumer and/or community researchers can:

- Have input into the development of methodologies
- Carry out interviews with other consumers and community members
- Co-facilitate focus groups
- Analyse results of interviews
- Evaluate the consenting procedure

Why involve consumers and/or community members as researchers?

- Research participants may feel more comfortable with members of their own community
- Consumer and/or community researchers can provide insight into the experience and implications of living with a condition or disability
- Consumer and/or community researchers can help researchers understand a community's response to research findings

What to think about if you're planning to involve consumers and/or community members as researchers

- Training and support that will be required if they haven't done this before
- Training may require extra funding and/or support
- Be prepared to accept changes from consumer and/or community researchers and be upfront about items that are not open to negotiation
- Consider any legal or ethical considerations; for example, will police clearances or working with children checks need to be completed?
- Budget for expenses/honorarium/payments
- It is important to be clear about payments for the consumer and community researcher at the beginning of the project
- A budget for the consumer and/or community participation activities

Consumer and community researchers

The Domestic Violence in Communities of African Refugee Backgrounds Project had fourteen members of the five communities involved who were recruited and trained as community researchers. Their tasks included:

- *Reviewing the interview guide and providing feedback on appropriate changes*
- *Identifying members of the public to be interviewed*
- *Conducting and translating interviews (52 in 7 languages)*
- *Cultural interpretation at the analysis stage*
- *Input into the final report*
- *Organising a launch of the report which was attended by the participants*



Consumer and Community Advisory Councils

What are they?

Consumer and Community Advisory Councils (Councils) have been established at the School and the Institute to support partnerships between researchers, consumer and community members.

Their aim is to enhance research through consumer and community participation.

The Councils provide advice at a strategic level across the organisation.

It is important to remember that the Council is generic for the whole organisation so members may not have experience in the area you are researching.

The School and Institute's Council membership includes:

- Consumers and community members
- Researchers and students
- Senior management staff
- Consumer support staff such as an advocate or project officer

Tasks undertaken by both Councils have included: input into strategic plans; advice on participation activities for large programs of research; and audits of participation activities.

Consumer and Community Advisory Councils

The Chief Investigators of a NHMRC funded Program Grant: 'Early Developmental Pathways Linking Health, Disability, Education, Welfare and Justice' at the Institute (the Program Grant) consulted with the Council during all aspects of the grant which included:

- *Seeking input on the research areas and opportunities for consumer and community involvement in the development phase of the application*
- *Providing progress reports during the interview preparation and process*
- *Meeting with the Council following the success of the application to request the development of minimum standards for consumer and community participation for all research projects conducted within the Program Grant*
- *Inviting the Consumer Advocate to join the governance committee to provide advice on integrating these minimum standards*
- *Providing an update on activities at every Council meeting*

The consumer and community participation activities for the Program Grant have provided a benchmark for good practice consumer and community participation at the Institute. It will also provide a model that is easily transferable to other large programs of research.



Deciding which method to use

It can be hard to decide which method to use to involve consumers and/or community members. There is no one right or wrong method for any project and you may use more than one method. The following questions may help you to identify which method/s to use in your project:

What skills and level of confidence do you have?

If you have never involved consumers before, think about using a method that you feel confident about. For example, many researchers who are new to participation begin by asking consumers to comment on patient information sheets or other written materials.

What level of participation are you seeking?

Some methods are more suited to particular levels of participation (see pages 23 and 24). For example, if you are only planning to consult, don't invite consumers or community members to join a steering group.

What kind of budget do you have available?

If you are running a large research program and you have a budget for consumer and community participation, you might consider setting up a consumer reference group or steering group and running some consultation forums. If you are planning a PhD project and have a very limited budget for participation you might want to access the Consumer and Community Advisory Council (if you are based at the School or the Institute), or find a research buddy.

Is your supervisor supportive of consumer and community participation?

If so, you could be more adventurous in the methods you choose, and you could also think about using methods that require more resources. If not, you might prefer to choose methods that are low cost – for example asking consumers or community members to comment on documents.

Do you already have good working relationships with consumers and community members?

If you have already involved consumers and/or community members in previous research studies and have good relationships with them, you might want to increase the level of participation and choose methods accordingly. For example, if you have previously involved people in a reference group, you might want to involve them in a steering group.

“Being on the Council was a chance to have strategic consumer input into the research community. Meetings were always well organised, refreshments were provided, parking was arranged, and honorarium payments for time/expertise/out-of-pocket expenses were available”.

Julie Ireland, former Chair of the Institute's Consumer and Community Advisory Council



Who are you involving?

It's impossible to generalise about what methods might work best for different groups of people. Almost all consumer and community participation methods can be adapted to ensure they don't exclude people who wish to be involved. But it is worth thinking about who you will be involving when you are thinking about involvement methods. For example, if you are planning to involve children and/or young people, they might not want to join a steering committee of adult professionals. It's important to check if people are happy to be involved in the way you are suggesting.

What type of research are you planning?

Some types of research do not lend themselves to particular types of consumer and community participation. For example, if you are undertaking laboratory based research you are unlikely to invite consumers or community members to act as researchers, but you might ask them to act as research buddies and/or to comment on the plain language summaries of your research findings.

6. Who will you involve?

Once you are clear about the purpose of the consumer and community participation and when and how much you want to involve consumers and community members, you can begin to think about **who** to involve.

Some of the groups of consumers and community members you may wish to consider include:

Patients:

People who are currently using, or have recently used a particular service.

Two consumers who have chronic obstructive pulmonary disease met with researchers at the School who were researching this condition to discuss research results that varied from the current guidelines and clinical practice.

Carers:

Family members and friends who have direct experience of supporting someone who lives with a particular condition.

Parents and carers of children with cerebral palsy attended a community forum at the Institute about the changes to legislation for the mandatory reporting of developmental anomalies in Western Australia.

Potential patients:

People 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.

The Kwinana Community Action Group, a community environmental group, had membership on the Steering Committee for an Institute-led research project looking at the respiratory health of children in the Kwinana region.



Consumer representatives:

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.

The Health Consumers' Council of WA has a consumer representative on the Councils at both the School and the Institute to provide a wider consumer organisation perspective.

Community members:

Someone from a group of people who share a common interest (for example cultural, social, political, health, economic interests) but not necessarily a particular geographic association.

The Developmental Pathways Project at the Institute has community members on its reference group with a wide range of interests such as mental health, local government, education, health, Aboriginal communities, child protection and housing and homelessness.

How to find consumers and/or community members

There are several routes you could use to identify consumers and/or community members.

The Participation Network

The School and the Institute's Participation Network database was established in 2012. This Network has registered members who have an interest in being involved in research. Vacancies for specific research projects and committees are circulated to the Network members who can then apply to be involved if they are interested in the topic.

Other ways to access consumers and community members may include:

Advertising

You could advertise in the local paper, on radio, through social media or via relevant websites or newsletters. A template for an advert is included in Section F page 70.

Peak health consumer organisations

The Health Consumers' Council WA (www.hconc.org.au) is an independent patient group that aims to raise awareness of, and advocate for, health consumers' rights in Western Australia.

The Health Consumers' Council WA provides information, advice and training for people wanting to be involved in consumer activities. They can help you by advertising for consumers or community members to be actively involved in your research. One of the main advantages of recruiting people through health consumer organisations is they may have attended training on being an effective consumer representative and will be able to access other advice and support.



In Section F page 64 we provide contact details for Australia's peak consumer organisations.

Consumer and/or community organisations

If you are doing research about a particular condition or issue, you may find that there is a consumer and/or community organisation that seeks to represent this group. This organisation may be able to assist you by advertising opportunities for involvement through their website, newsletter, Facebook page or other media. Or it may nominate a member of staff, consumer or community member to get involved with your research.

Using your contacts

You may also choose to use your own networks and contacts to find consumers and/or community members, especially if you have involved people in the past and have built a good relationship with them.

Can research participants also get actively involved in a study?

Deciding if consumers and/or community members of steering groups can also be participants in the research can be a dilemma. It is important to consider issues about ethics, confidentiality and bias, and to discuss this with consumers and/or community members. You may find it helpful to speak with other researchers who have had experience of addressing this issue. Following are two examples about this issue:

The Raine Study, a prospective cohort study of pregnancy, childhood, adolescence and now young adulthood has been operating at the Institute since 1989. A reference group of young people in the study was established in 2006. This group of young people, who are also participants in the study, have provided invaluable information to management and researchers.

The steering committee for a project about costs associated with catastrophic injury conducted at the School decided against their members being included as participants in the project. This was because steering committee members had been involved in the development of the online survey and interview questions being used in the research.

Getting the right consumers and community members for the project

Following the steps outlined in this book will help all parties understand what they can contribute and what they want from the participation activities. This may overcome any potential conflicts. It is important to:

Draft a role description

Consumers and/or community members who might become involved in your project need a clear understanding of what you want them to do and what skills or experience they might require. A role description can help you to be clear about this. A template is included in Section F page 69.



Review this role description in partnership with the consumers and/or community members you recruit to ensure that it is clear and to check whether they wish to make any changes to it.

Ensure you are clear about confidentiality

You will need to be clear about what information consumers and/or community members can share with others, and when it is appropriate for them to do this.

Draft terms of reference

If you are setting up a steering group or a reference group (see pages 32 and 33), this group will need clear terms of reference. An example is included in Section F page 73.

Ensure you have a budget for participation

Include funds to pay expenses (promptly) and any honorariums. You will need to provide clear information on what can be paid and how to claim it. Your participation budget may also need to include venue costs if you are running community conversations (see page 29) and refreshment costs – especially if people are travelling a long way to work with you. An example budget is included in Section F page 74.

Consider what support or training may be required

It's impossible to be prescriptive about this, as the training and support both you and the consumers and/or community members will need depends on a variety of things, including:

- What you are asking people to do (e.g. if you are asking them to act as consumer or community researchers they will need different skills than if you are asking them to comment on documents)
- The skills and knowledge people already have (consumers and/or community members may have experience of research, or of sitting on steering groups)
- The type of research project and the topic covered – for example whether this is likely to cause people any distress
- Your experience of involving consumers and/or community members in research

Give people who get involved clear information

In addition to the plain language summary of the research, role description and terms of reference, this might include:

- Information about the research organisation
- The NHMRC Statement on Consumer and Community Participation in Health and Medical Research
- Your organisation's policy on consumer and community participation (if you have one)
- Information about what expenses and/or fees can be claimed and how to claim them
- Future meeting venue, dates and times



7. How will you evaluate consumer and community participation in your research?

Why evaluate consumer and community participation?

It is important to evaluate consumer and community participation in research to make improvements to the **process** of involvement and to understand the **impact** of the participation activities on the research. It is vital to consider how you will evaluate the participation activities as part of your planning process.

Evaluating consumer and community participation activities can:

- Help you to understand the effectiveness of the participation activities
- Give people an opportunity to comment on their experiences
- Lead to improvements to future activities
- Assist with developing an evidence base about the process and impact of consumer and community participation

Who will take part in evaluating consumer and community participation?

All stakeholders need to inform the evaluation of consumer and community participation activities. This includes consumers and/or community members, researchers and all other stakeholders (see example of an evaluation form on page 75 and 76).

It is not appropriate to evaluate the performance of the consumers and/or community members involved in research teams.

Planning to evaluate at an early stage

Considering how you will evaluate consumer and community participation when you are at the planning stage will enable you to ask everyone involved some questions at the beginning of the participation – for example:

- Why do you think it's important to involve consumers and/or community members in this project?
- What do you want this involvement to achieve?
- What challenges might there be?

This will enable you to demonstrate any impact more clearly at the end of the project.

It will be useful to decide as early as possible if the evaluation is about the **process** of involving consumers and/or community members and/or about the **impact** of the participation activities on the research.

Each is considered below.



Evaluating the process

This type of evaluation is about how well the participation activities functioned. For example:

- Were all participation activities adequately budgeted for?
- Were consumers and/or community members able to contribute effectively?
- Were meeting papers sent to allow time for reading?
- Were everyone's expectations of the participation activities met?

There are some basic questions that can be used to evaluate the process of involving consumers and/or community members:

- What worked well?
- What didn't work so well?
- What suggestions do you have to improve the process?

Evaluating Consumer Participation

Two NHMRC funded research projects conducted at the School used linked State and Commonwealth health information to look into enhanced primary health care outcomes in chronic illness and medication safety in seniors (aged 65+).

The research team set up a reference group to provide ongoing input and advice throughout the duration of the projects. At the end of the projects they evaluated the impact of the consumer and community participation. Researchers, health professionals and reference group members completed an anonymous online survey on their expectations of the consumer participation activities at the beginning and then the end of the projects. Twenty people responded with nineteen saying their expectations were either met or exceeded. This survey showed that the impact of the reference group has been significant for both the research projects and in bringing about a definite and measurable change in attitude on the benefits of consumer and community participation.

"I now believe that consumer input can make a difference." (Comment from a researcher)

"Consumers should be involved in projects from the beginning and they add much value to how the planning develops and focus areas of the research - keeps things in perspective and focused on what's important and what makes a difference." (Comment from a researcher)



Evaluating the impact of consumer and community participation

This type of evaluation will help you to think about the difference consumer and community participation made to your project. You might choose to look at any or all of the following:

- The impact of consumer and community participation on the research e.g. whether researchers made changes to documentation or recruitment practices, or how the research was undertaken or findings disseminated in response to the contribution of consumers or community members
- The impact of consumer and community participation on the researchers e.g. did they feel they learnt more about what it is like to live with a particular condition?
- The impact of the participation activities on the consumers and/or community members who were involved i.e. did their confidence increase as a result of their involvement?
- The impact of consumer and community participation on the organisation i.e. what has changed as a result of the participation activities? This information can be used to inform future participation activities or you may wish to share it with your colleagues who are considering how to involve consumers in their research

Challenges related to evaluating impact

A report published by INVOLVE (www.invo.org.uk)⁹, a national advisory group in England that supports greater consumer and community participation in NHS, public health and social care research has considered the impact of consumer and community participation in research. It also raises questions about the quality of the evidence for the impact of such involvement, revealing huge variation in how this is assessed and reported, and highlighting difficulties in judging it or drawing general conclusions. These include:

- There aren't any agreed measures
- There usually isn't a comparison (i.e. the same project without the involvement)
- Different stakeholders may have different views
- Consumers and/or community members are often part of a group and it's hard to identify exactly what impact they had
- There are many different types of impact you could measure

9. Staley K. *Exploring impact: Public involvement in NHS, public health and social care research*. INVOLVE, Eastleigh. 2009



Practical considerations

Many evaluations are conducted using questionnaires or interviews. If you are using a questionnaire, questions that use a numbered scale are generally easier for respondents. On the other hand, questions that allow people to freely express themselves can give you more detailed answers and get more imaginative responses. Using anonymous evaluation surveys can allow people the opportunity to be more open about their experience.

If there are different groups involved at different stages of the research project, it may be best to evaluate the participation at these different stages, rather than waiting until the end of the project.

There is an example of an evaluation form used at a community forum in Section F page 75 and 76.

Jan Payne and colleagues at the Institute have published a paper describing how they evaluated consumer and community participation in a research project looking at the consumption of alcohol in pregnancy¹⁰.

10. Jones HM, McKenzie A, Miers S, Russell E, Watkins RE, Payne JM, Hayes L, Carter M, D'Antoine HA, Latimer J, Wilkins A, Mutch R, Burns L, Fitzpatrick J, Halliday J, O'Leary CM, Peadon E, Elliott EJ, Bower C. Involving consumers and the community in the development of a diagnostic instrument for Fetal Alcohol Spectrum Disorders in Australia. *BMC Health Research Policy and Systems* 2013, 11:26



8. How will you plan to prevent possible barriers occurring?

Taking time to identify the reasons why you might not involve consumers and/or community members can be helpful in seeking solutions to any barriers, real or perceived. Involving consumers and/or community members early in the planning process can help to work out solutions for any barriers. All members of the research team can then 'sign off' early in the project that the issues have been identified and where possible addressed.

Following are examples of key barriers identified by researchers who have attended training workshops facilitated by the Participation Program. Some suggested solutions are also included.

Barrier: lack of time and money

Suggested solution: when you are planning the project, ensure you include time for participation activities. Always apply for funding for consumer and community participation activities in grant applications. Seek advice from people who have been doing it about the real costs and budget items. Allocate funding for out-of-pocket expenses or honorariums and be up-front about the availability of funding for consumers and/or community members.

Barrier: researchers' lack of training and confidence

Suggested solution: discuss the research team's training needs and provide information about, and access to, training. Researchers who have attended training on consumer and community participation say it has helped to build their confidence and skills. Talk to other researchers about their experiences.

Barrier: lack of evidence for the benefits

Suggested solution: there are many publications from other countries (particularly from the UK) about the benefits of consumer and community participation. Increasingly, researchers from Australia are starting to publish accounts of their experiences. Always include a description of the participation activities in any publications about your project to help build the evidence base.

Barrier: concerns about ability and knowledge of consumers

Suggested solution: apply flexibility and think broadly about the people you want to involve. Communicate widely the opportunities to be involved through consumer, community and non-government organisations. Discuss training needs and provide access to training or support needs identified. Be honest about your expectations of the role consumer and community members will have.

Barrier: language and terminology

Suggested solution: provide information in plain language without using jargon and acronyms. Ask consumers and community members to help to prepare plain language summaries.



NOTES



Section E: Case Studies

This section includes:

- Five **case studies** about consumer and community participation in research.

We have found that stories and case studies can bring a subject and the learning about it to life. Here are five case studies from the School and the Institute about planning for consumer and community participation in research.

Case Study 1. The Developmental Pathways Project: Trends in Pre-Existing Mental Health Disorders Among Parents of Infants Born in Western Australia from 1990 to 200548
Case Study 2. Alcohol in Pregnancy Study51
Case Study 3. Consumer Co-payments: Impact on Health Service Utilisation and Outcomes54
Case Study 4. Beyond the Teaching Nursing Home: Community Partnership of Learning and Care57
Case Study 5. Long Term Use and Cost–Effectiveness of Secondary Prevention Medications for Heart Disease in Western Australian Seniors60



Case Study 1:

The Developmental Pathways Project: Trends in Pre-existing Mental Health Disorders Among Parents of Infants Born in Western Australia from 1990 to 2005

Researcher: Melissa O'Donnell, NHMRC Early Career Research Fellow

Consumer: Margaret Cook, independent mental health consumer

Background

The Parental Mental Health Trends Project, which is part of the Developmental Pathways Project, aims to determine the prevalence of prior and current mental health disorders in parents, including trends over time.

From the Researcher - Melissa O'Donnell

Why did you want to involve consumers/community members in this project?

My research is in a very sensitive area of parental mental health and risk for child abuse and neglect. I felt it was important in my research to ensure that I included the concerns and voices of community members who had personal experiences and knowledge, which could enrich the quantitative research that I was doing.

Did you put anything in place before you started?

My research is part of a larger research project which has a community reference group that has senior level support and a budget for participation activities.

At what stages did you decide to involve consumers and/or community members and why?

In our broader research project we have involved community members from the beginning in developing our research plan, presentation of preliminary analyses and gaining feedback on papers and reports. I think that having this involvement is important in improving the research that we do by having a consumer and/or community voice within all levels of our research process.

What method/s did you use to involve them?

The community reference group, which meets regularly, provided me with an opportunity to present my research and seek feedback on specific issues. I also have consulted a sub-group of the reference group who have more specific experiences in the area of parental mental health.

Who did you involve?

This sub-group is made up of carers and consumer representatives who have accessed the government agency services that we utilise data from, as well as community members who have an interest.



How did you find people to involve?

We have a Consumer Advocate and Program Manager within our organisation who has contacts within many of the consumer and/or community groups in our area. My specific research has utilised consumer and/or community members from mental health community support groups and those who support families at risk.

How did you support people to be involved?

Our larger reference group provides an honorarium for representatives and I tried to ensure that I provided flexibility in the ways that consumers chose to be involved in providing me input and feedback.

Did you evaluate the participation activities?

No.

What made the involvement work well?

The passion and interest of the consumer and/or community group members about the research I was doing made it work well. I also supported them to be involved as much as they wanted to in terms of meeting in person or as a group, emailing out information and my interpretation of research findings for their response.

What difference did it make to involve consumers and/or community members in this project?

The involvement of consumers and community members has been invaluable. The group I consulted with gave me valuable insight into the difficulties that parents with mental health problems face and things that I should include in my research and analysis. It also helped me to contextualise my research and be aware of the sensitivities of families when interpreting my research findings.

What would you advise other researchers about planning consumer and community participation in research?

It is really important to consult with consumer and/or community reference groups that are related to your research area. It helps to have them involved from the beginning to develop the research plan to ensure that the research is relevant to the community you are trying to improve outcomes for and that you have considered and addressed the issues and concerns regarding your research.

From the Consumer - Margaret Cook

How did you get involved in the project?

I was invited by Anne McKenzie, the Participation Program Manager, to be a member of the committee following attendance at a training course.

What was your role?

My role on the reference group was representing a group of intergenerational children and parents affected by mental illness. I have over 60 years of experience involved in these issues and worked for 20 years as a consumer advocate.



What made the involvement work well for you?

Gaining a wider knowledge and insight of the work that is being developed by the Participation Program.

How did your involvement make a difference?

My colleagues and I added our knowledge to the research team in a way that will influence the findings and outcomes of the research. We had two meetings with one of the research team members, and discussions were presented back to the reference group. The researchers acknowledged that this information had been beneficial for the research findings.

Has it made a difference to you personally or to the other consumers and/or community members who were involved?

The difference this has made to me has been the experience of being involved at the coalface of research and not tacked on at the end when it is done and dusted. I met others who I learnt from, and this has added to my experience and knowledge. I also learnt how research and data linkage works.

What would you advise other researchers when they are planning to involve consumer and/or community members in research?

The ideal set up is like the one we have with the Consumer and Community Participation Program at the Institute, or something similar where you have a proper structure and a governance approach.



Case Study 2:

Alcohol in Pregnancy Study

Researcher: Jan Payne, Research Program Manager

Consumer: Julie Whitlock, consumer representative

Background

The Alcohol and Pregnancy Project provided educational resources for Western Australian health professionals to inform them about the prevention of prenatal alcohol exposure and Fetal Alcohol Spectrum Disorder (FASD).

From the Researcher - Jan Payne

Why did you want to involve consumers and/or community members in this project?

We involved community members in this research to comply with the NHMRC Statement on Consumer and Community Participation in Health and Medical Research, to add value to the research, to conduct good research practice that made a difference to the lives of children and families, and not as a condition of achieving funding.

Did you put anything in place before you started?

Before we commenced the research we put in place:

- Commitment at an organisational level through the Community and Consumer Advisory Council, and support from the Consumer Advocate
- Plans for additional use of research resources and personnel including time for researchers to plan, coordinate and manage processes involving communication, meeting procedures and provision of documentation
- A sufficient budget for sitting fees and refreshments, note taking, venue and parking for community members

At what stages did you decide to involve consumers and/or community members and why?

At this time, we had no practical knowledge and experience with consumer and community participation in research and involved community members at the earliest opportunity following the submission of the grant proposal for funding; we learnt from this experience to involve community members as early as possible when ideas for research are being discussed.

What method/s did you use to involve them?

We established two consumer and community reference groups - one for Aboriginal and one for non-Aboriginal community members because of the sensitivity of the topic and different issues faced by Aboriginal and non-Aboriginal people.



Who did you involve?

We involved community members who were women of childbearing age, as some of the main outputs of the research involved health promotion for women of childbearing age.

How did you find people to involve?

We found people to involve with help and nominations from the Consumer Advocate and researchers.

How did you support people to be involved?

At that time, there was no training available for consumer and community members or researchers so we established a culture of 'learning together'. We paid sitting fees to acknowledge community members' contribution of time and out-of-pocket expenses.

Did you evaluate the participation activities?

We developed an evaluation framework and asked community members and researchers to complete a self-administered questionnaire at the end of the research to assess the process, context, and impact of consumer and community participation¹⁰.

What made the involvement work well?

The involvement worked well because of the high value placed on community and consumer participation, the respect for community members' opinions and expertise, and getting advice from community members who were not looking at the study through a research lens.

What difference did it make to involve community members in this project?

Community members offered their perspectives on all aspects of the research, including attitudes of women of childbearing age; they contributed their perspectives on the development of documents (such as consent forms, information sheets, topic guides), health promotion materials; research dissemination activities (such as abstracts, presentations, recommendations, articles for peer reviewed journals) and proposals for future research.

What advice would you give to other researchers about planning consumer and community participation in research?

- Secure institutional and leadership support
- Involve consumers and community members as early as possible to contribute to research design and planning
- Agree terms of reference for the level of involvement
- Provide informational material and training for consumers and community members
- Recognise the importance of different levels of participation, each research project will be different



- Develop sustainable processes for involving consumers in all research and evaluate this so there is a continuous cycle of quality improvement and sharing of lessons learnt with other researchers.

From the Consumer - Julie Whitlock

How did you get involved in the project?

I saw an advert. I had just had my first baby and was looking for a little more intellectual stimulation. I was already involved in some local consumer work and was looking for a little more.

What was your role?

My role was as consumer representative for the *Alcohol in Pregnancy: health promotion for health professionals* project.

What made the involvement work well for you?

I had been exposed to a range of different consumer groups and the way they operated. I really valued the professionalism, organisation and appreciation the Telethon Institute had for me as a consumer, individual and a mum. The organisation and clear research objectives made it very clear what my role was and how I was able to contribute. I felt my opinion was highly valued and wasn't constrained by organisational practices or how things had previously been done. Also, the researchers on the project were thoroughly nice, passionate, egoless people who had the best interests of the project and belief in the work they were doing.

How did your involvement make a difference?

I believe my involvement has positively influenced the outcomes of this project. I was able to make a difference in the way we surveyed consumers and in the general approach of the project. But at the end of the day I believe it is up to the researchers to determine if we as consumers have added value.

Has it made a difference to you personally or to the other consumers or community members who were involved?

I'm very proud of my involvement. It has also led to being invited to participate in other related projects. I believe my association with the Institute has given me professional rounding and helped me with my related consumer and professional work.

What would you advise other researchers when they are planning to involve consumer and/or community members in research?

Sometimes we do have opinions different to your own and as long as you hear us and acknowledge us, ultimately we need to accept this is your project and you need to lead it. Please appreciate us and value the time we contribute, as the stipend often doesn't cover the time or effort we put in as effectively. We're volunteers so a simple thank you is all we need.

'Please involve us, we're not scary and we don't want to hold up your projects. We are really interested in what you're trying to achieve and have ideas to help you.'



Case Study 3:

Consumer Co-payments: Impact on Health service Utilisation and Outcomes

Researcher: Anna Kemp, Research Assistant Professor at the UWA Centre for Health Services Research

Consumer: Michele Kosky, consumer consultant and former Executive Director of Health Consumers' Council WA

Background

Co-payments are the government-set amount that patients pay toward the cost of each prescription medication, with the remainder being paid under the Pharmaceutical Benefits Scheme (PBS). A large co-payment rise was implemented in January 2005, increasing the cost of prescriptions by approximately 21%. This project explored the impact of this increase on consumers.

From the Researcher - Anna Kemp

Why did you want to involve consumers/community members in this project?

This research involved analysing existing datasets (e.g. hospital records, prescription claims etc.) with all the identifying information about the individuals removed before I receive the records. This meant that I had no contact with the 'participants' of my research and so I missed the 'human face' of the issues I studied. I wanted to involve consumers and community members so I could understand my research better.

Did you put anything in place before you started?

Senior staff on this project were very committed to involving consumers and community members. When they designed the project and applied for funding, they built in time and money for consumer and community participation.

At what stages did you decide to involve consumers/community members and why?

Consumers and community members were involved in the interpretation of findings, dissemination of findings, and in suggesting the direction for future research.

What method/s did you use to involve them?

We had consumer and community representation on the Project Advisory Committee. We also held a community conversation to share the project findings, develop policy solutions, and seek ideas for future research priorities.



Who did you involve?

A consumer representative from the Health Consumers' Council of WA sat on our Project Advisory Committee, and we publicly advertised for any interested consumers, carers or community members to attend our community forum.

How did you find people to involve?

We recruited our consumer representative from the Health Consumers' Council, and advertised on radio and in the community newspaper for people to attend our community forum.

How did you support people to be involved?

We provided the consumer representative and forum attendees with an honorarium to cover their time and travel expenses. We also provided refreshments and parking whenever we asked a consumer or community member to come to us.

Did you evaluate the participation activities?

No.

What made the involvement work well?

I think the main things were organisation, lots of opportunities for people to provide feedback, and respect. In terms of organisation, we planned our agenda and discussion questions ahead of time, and provided these to consumers and community members to keep the conversation targeted. We also gave handouts of all the slides we presented so people attending could have their own copy to write notes and take away with them. We wanted to make sure everyone could have their say and was treated with respect. As well as giving people their chance to speak, we had 'bright ideas' slips of paper on all tables so they could leave us with any thoughts they didn't get to discuss. We also had an experienced facilitator coordinating the discussion so that we (the researchers) could focus on writing down everything we needed.

What difference did it make to involve consumers/community members in this project?

Involving consumers and community members made a huge difference to my research. When I was initially trying to get my work published reviewers and editors wanted me to include policy suggestions to help consumers. I realised I didn't have the experience to make any such suggestions. I have expertise in analysing large data sets – but I'm not an expert in what it's like to use multiple medicines, or cope with a chronic illness, or in deciding whether to buy medicines or pay the gas bill. Hearing about the lived experience of consumers and community members, and asking them what policies would help them, was enormously helpful and humbling. They came up with feasible policy solutions that would never have occurred to me and that I would never have read in the scientific literature.

What would you advise other researchers about planning consumer and community participation in research?

Do it! Do it as early as possible in the research process! Listen and learn.



From the Consumer - Michele Kosky

How did you get involved in the project?

I was invited to become involved in my role as Executive Director at Health Consumers' Council.

What was your role?

I was part of a reference group.

What made the involvement work well for you?

It was time limited, and the scope, purpose and the role of the reference group was explained with care and clarity. And the people were kind and helpful and expectations were managed.

How did your involvement make a difference?

I think we all contributed by reflecting on our experience - either our own or family members – and the challenges of the complexities of medicines, including confusion about co-payments and what the expected contribution would be, what could be afforded and the lack of information for consumers about co-payments.

Has it made a difference to you personally or to the other consumers or community members who were involved?

The difference it made to me (you can never underestimate what you will learn from other consumers) was to be aware of and advocate for a better method of explaining costs to consumers and the reason for the costs and the concessions people might have and not be aware of. Co-payments for people on low or fixed incomes can make access to medicines problematic if other priorities are seen as more important for survival.

What would you advise other researchers when they are planning to involve consumer and/or community members in research?

For researchers, involving consumers in research requires clarity about the scope of the project, what will be required in terms of time and preparation, and listening to the consumers - not just tokenism. And of course some education about research (e.g. what we think, what we know and what we can prove), data, analysis and conclusions.



Case Study 4:

Beyond the Teaching Nursing Home - Community Partnership of Learning and Care

Researcher: Rosemary Saunders, Associate Professor and Course Coordinator (Master of Nursing Science) at the UWA School of Population Health

Consumers: Reference Group members and older adults who participated in the project

Background

The Nursing discipline in the School collaborated with the Bethanie Group, one of Western Australia's largest not-for-profit aged care and retirement village providers to implement the Beyond the Teaching Nursing Home: Community Partnership of Learning and Care Project (www.uwa.edu.au/bttnh).

This project developed a clinical training environment within a residential aged care campus to engage older adult consumers in the teaching and learning of nursing, medicine, social work and podiatric medicine students. The project was undertaken with funding from Health Workforce Australia. The research aspect of the project is being undertaken as part of a PhD.

From the Researcher - Rosemary Saunders

Why did you want to involve consumers/community members in this project?

The decision to engage consumers was part of the vision of the project concept and was fundamental to the planned teaching and learning activities. The engagement of consumers was critical to students understanding older adults' needs and providing opportunities for students to engage with older adults.

Did you put anything in place before you started?

Involving the older adult consumers in the learning activities required considerable planning. The project was developed in partnership with academic staff, the Participation Program, Legal Services, Safety & Health Advisers at UWA, Bethanie staff and residents and other partners. The project commenced with establishing the project governance groups (<http://www.meddent.uwa.edu.au/community/bethanie/about/governance>)

At what stages did you decide to involve consumers/community members and why?

Consumer and community engagement was a key part of the initial concept of the project and then the development, implementation and ongoing evaluation of the project.



What method/s did you use to involve them?

Older adult consumers were involved in the project in several ways, including gaining consumers' views and suggestions for the development, implementation and evaluation of the project; contributing to producing learning resources; consumer involvement in the classes; and consumers as teaching aids. At the development stage, consumers participated in an initial community conversation, a consumer-led reference group and as members of the project advisory group.

The reference group has membership from the residents, staff, students and project leaders and has been supported by the Project's staff and staff from the Participation Program.

Who did you involve?

Older adult consumers, staff of the residential aged care facility, university staff.

How did you find people to involve?

Older adult consumers for the community conversation and reference group were recruited from the residents in the hostels and independent living units at Bethanie Joondanna. This was achieved by informing older adults at the community conversation, resident meeting, invitation letters and flyers.

How did you support people to be involved?

Resources for the project were developed to support all stakeholders in consultation with the project reference group. The resident members of the reference group were invited to attend a one-day training workshop facilitated by the Participation Program on basic research information. Other participants were provided with training prior to participating.

Did you evaluate the participation activities?

All evaluation approaches and outcomes for the project were discussed as part of the advisory committee and the reference group. Participation activities have been evaluated throughout the project using a variety of evaluation approaches including individual interviews, focus groups and surveys. Student participants have also participated in evaluation activities.

What made the involvement work well?

This project has worked well due to the engagement of consumers from the beginning of the project and the well established processes that provided ongoing engagement and evaluation of both the consumers and students.

What difference did it make to involve consumers/community members in this project?

It has resulted in a project where teaching and learning experiences are grounded with real people and students have the opportunity to learn from the perspective of people they may be caring for in the future. Consumer involvement in the reference group meetings enabled the development of a feedback sheet for nursing students from the perspective of consumers who had previously received nursing care. The



reference group also developed a Participant Charter to describe the standards of behaviour that participants, staff and students are expected to adhere to.

From the consumer

Older adult consumers describe their experience of being involved in this project in this video:

<http://www.youtube.com/watch?v=3fLxRMIazxQ&feature=c4-overview-vl&list=PLD31E0E48AB1E4CA3>



Case Study 5:

Long term Use and Cost–Effectiveness of Secondary Prevention Medications for Heart Disease in Western Australian Seniors

Researcher: Frank Sanfilippo, Associate Professor at the UWA School of Population Health

Consumer: Anne Cordingley, research buddy for the Cardiovascular Group at the UWA School of Population Health

Background

Clinical trials show that long-term treatment with selected medicines greatly reduces the risk of further heart attacks or stroke in persons with known heart disease. Levels of such prescribing are high when patients are discharged from hospital, but the extent to which patients continue with long-term treatment is unknown. This project will investigate adherence to treatment, and the costs and effectiveness of these medicines in a population study of patients aged 65 years or more in Western Australia.

From the Researcher - Frank Sanfilippo

Why did you want to involve consumers and/or community members in this project?

To provide the research team with a set of questions that are important to consumers and the public. This may provide a different perspective to the research objectives than what the researchers and clinicians could provide.

Did you put anything in place before you started?

Yes. I included consumer representatives at the design stage when the research grant application was being prepared. I consulted with the Consumer Advocate at the School, who provided advice on what to include in the grant and reviewed the consumer participation component of the grant. The grant included a budget and plan for the consumer participation activities.

At what stages did you decide to involve consumers and/or community members and why?

At the design stage of the research project (i.e. grant application stage). It is important to plan early for consumer participation, just like you would when planning a study. This also allows you to include an adequate budget for consumer and community participation in the rest of the study.

What method/s did you use to involve them?

Consumers and the community will be asked to participate in several community conversations to provide feedback to inform the researchers. These will be held in the first and second years of the study. A community seminar will be held in the



final year of the study to provide feedback to the participants on the findings of the research questions they provided in the forums.

Who did you involve?

Two consumer representatives were included as part of the research team (they are listed as associate investigators). The community conversations will involve consumers (i.e. people with heart disease and taking medications) and other people from the community (e.g. no heart disease). I also obtained advice from the Participation Program in our School and its two consumer representatives about running the community conversations.

How did you find people to involve?

The consumer representatives and the Participation Program at the School will find participants through their existing networks. In addition, the UWA media manager was able to secure a radio interview for me with ABC 720 a week before the first community forum.

How did you support people to be involved?

The budget included payment for the consumer representatives who were part of the research team, as well as a small monetary contribution to people attending the community conversations to help with out-of-pocket expenses. These were included as budget items in the research grant application.

Did you evaluate the participation activities? If so, how?

The project is just commencing but it is planned that each participation activity will be evaluated as it is completed.

What made the involvement work well?

All the researchers were in favour of consumer involvement, and the consumer representatives were enthusiastic about being involved in the research planning and carrying out the consumer components of the research.

What difference did it make to involve consumers and/or community members in this project?

The consumer forums will run in the middle of 2014, but I expect that the consumers/community participants will contribute a different perspective to the research questions than what researchers and clinicians will provide. This will provide a more rounded set of research questions that will benefit researchers, clinicians and the community.

What would you advise other researchers about planning consumer and community participation in research?

Engage one or two consumer representatives during the design stage of your research and build it up as you go rather than tacking it on at the end. Include an appropriate budget for the consumer component. Involve consumer representatives who are enthusiastic about research and want to help you.



From the Consumer - Anne Cordingley

How did you get involved in the project?

Through being a member of the School's Community and Consumer Research Advisory Council. An aim of the Council was to involve Council members as a consumer mentor (research buddy) to a research group within the School.

What was your role?

My role at first was as a consumer mentor to the cardiovascular research group, mainly to demonstrate how consumer participation could be an advantage in research. This led to my invitation to be included as an associate investigator consumer representative on a research project applying for National Health and Medical Research Council grant funding.

What made the involvement work well for you?

The other researchers in the project accepted my opinions and comments. I was included in all the meetings and kept informed via e-mail. I always felt that I could ask questions or for explanations if I did not understand a particular point. I am very much part of the research team.

How did your involvement make a difference?

National Health and Medical Research Council funding is very difficult to obtain and I would like to believe that having a consumer representative included on the grant application as an associate investigator may have helped in the successful outcome. The researchers willingly accepted that community feedback be included over the course of the project.

Has it made a difference to you personally or to the other consumers or community members who were involved?

Being involved in this project from the grant application has given me some ownership and the wish to see it through to its completion. The fact of being so well accepted by the other researchers means the consumer voice will be heard and hopefully, the research findings made more relevant for the community.

What would you advise other researchers when they are planning to involve consumer and/or community members in research?

- Accept that consumer participation in research can make the project more credible and legitimate
- Never underestimate the consumer, listen to their viewpoint and comments.
- Include the consumer from the beginning of the project if possible
- Know in advance what level of consumer participation you want or expect during the project
- Fully understand what consumer participation means to you and the consumer



Section F: Resources

This section contains:

- **Useful websites**, including websites for Australian consumer organisations
- **Templates and examples** of documents that have been used at the School, the Institute, the National Institute for Health Research, England and INVOLVE

Useful websites

Involving People in Research www.involvingpeopleinresearch.org.au

This is the website for the Participation Program, a joint initiative of the School and the Institute. The website includes links to:

- Factsheets - short simple 'tools' to support the implementation of consumer and community participation in health research
- The 'Green Book' - guidance on involving consumers and community members in research

Information about training is also available.

The Cooperative Research Centre for Aboriginal and Torres Strait Islander Health <http://www.crcah.org.au>

A virtual organisation that brings together stakeholders to ensure that research conducted is controlled by and benefits Aboriginal people.

INVOLVE www.invo.org.uk

A national advisory group with the role to support and promote active public involvement in NHS, public health and social care research in England. This website includes lots of useful guidance, as well as a database of publications about consumer and community participation in research. There is also a section on writing in plain English - <http://www.invo.org.uk/makeitclear/>

TwoCan Associates www.twocanassociates.co.uk

This website includes links to guidance for people who chair research committees which involve consumers and community members and a route map for consumer and community participation in research management.



Australian consumer organisations

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

The national voice for health consumers, helping to shape Australia's health system by representing and involving consumers in health policy and program development.

The Health Consumers' Council of WA www.hconc.org.au

An independent community based organisation, representing the consumers' voice in health policy, planning, research and service delivery.

Health Care Consumers' Association of the ACT <http://www.hcca.org.au/>

The principal health consumer advocacy organisation in the ACT.

Health Issues Centre www.healthissuescentre.org.au

Health Issues Centre is an independent, not-for-profit organisation that promotes equity and consumer perspectives in the Australian health system.

Health Consumers Alliance Inc of South Australia <http://www.hcasa.asn.au/>

South Australia's peak body for health consumers.

Health Consumers NSW <http://www.hcnsw.org.au/>

Providing the voice of health consumers in shaping policy and service in NSW.



Planning form example

A form used to support and assist researchers in planning for consumer and community participation in a research project



THE UNIVERSITY OF
WESTERN AUSTRALIA

Participation Planning Form



TELETHON
KIDS
INSTITUTE
Disorder Prevention, Care

This form is to support and assist you in planning for consumer and community participation. Please complete and forward to the Consumer Participation team by clicking the submit button below.
If you require assistance to complete this form please see the more [Participation Planning Form Information Sheet](#) or contact the Project Officer at ipir@icmr.uwa.edu.au

Project Name

Researcher Name **Tel**

Chief Investigator **Date**

1. Why are you involving consumers and community members in your research? Limit 500 Characters

2. In which stages of the project are you going to involve consumers and community members?
You may select more than one option

Deciding what to do Deciding how to do it Doing It
 Letting people know the results Deciding what to do next

3. What level of participation are you aiming for?
You may select more than one option

Informed Consulted Advise
 Equal partners Leads the research

4. Who will you involve? Limit 500 Characters

5. How will you find consumers and community members? Limit 500 Characters

6. What methods will you use to involve consumers and community members?
You may select more than one option

Writing or commenting on documents Community conversations/forums Community members on research team
 Research Buddies Reference groups Steering groups
 Consumer and Community Researchers Consumer and community advisory council

Other

7. Plain language summary
Please include your plain language summary below Limit 500 Characters

8. What resources will you need to support consumer and community participation?
Limit 500 Characters

9. How do you plan to evaluate the participation activities? Limit 500 Characters

10. Would you like any support? Yes No

10a. If yes what support would you like? Limit 500 Characters



Plain language summary

Provides guidance on what to include in a plain language summary in funding applications to the National Institute for Health Research, England

What to include in a plain English summary

When writing the plain English summary consider including the following information where appropriate:

Aim(s) of the research

- What are you aiming to find out?
- How will patients / carers / members of the public and services benefit from your research – either directly or in the longer term?

Background to the research

- Why does this research need to be done now?
- What is the scale of the issue? For example:
 - How many patients / members of the public are affected?
 - What are the costs to services?

Design and methods used

- What design and methods have you chosen and why?
- Who are your participants? (if appropriate)

Patient and public involvement

- How have patients / the public been involved in developing this research to date?
- How will patients / the public be involved in the conduct / management of the research?

Dissemination

- Who will the findings be communicated to and how?

Taken from: Guidance for researchers on producing a plain English summary in a NIHR funding application, available online at NIHR Make it clear <http://www.invo.org.uk/makeitclear/>



Reviewing documents

Examples of questions that consumers can ask while reviewing documents

- What is the purpose of this document?
- Who is the audience of the project?
- Does it provide all the information required by participants about this research project?
- Is the information in plain language?
- Is there anything that is not easy to understand such as:
 - jargon
 - acronyms
 - technical words
- Does the format suit the audience e.g. do pamphlets for children contain illustrations?
- Are there any other documents such as posters or brochures, if so are they easy to understand?
- Are there alternate formats or languages available?
- Would this information encourage me to take part in the research, or put me off?
- Are any potential benefits of the research discussed?
- Is there any information about how the research could be translated into changing policy and/or practice?
- Have consumers or community members been involved in developing the research?

Adapted from: McKenzie A. Haines H. Consumer and Community Participation Fact Sheet M08: Writing or Commenting on Documents, Revised (2014).



Role description examples

Role description for consumer and community position

The University of Western Australia School of Population Health (the School) CONSUMER AND COMMUNITY ADVISORY COUNCIL (Council)



THE UNIVERSITY OF
WESTERN AUSTRALIA
Advancing tomorrow's frontiers

Applications are being invited for consumers and community members to join our Council. **Closing date: Friday 28th March 2014.** Please see information below relating to these positions.

What is a Council?

Councils are a formalised group of people brought together to support the development of partnerships between consumers, community members, researchers and research organisations. A Council's purpose is to enhance the quality and relevance of research through consumer and community participation. **To find out more about councils please see our Fact Sheet.**

What is the purpose of this council?

The Council was established to enhance the quality and relevance of research undertaken at the School. The aim of the Council is to develop partnerships between consumers, community members and researchers to work together to make decisions about research priorities, goals, methodologies, questions and the dissemination of results.

The Council meets to 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 Participation Policy for consumer and community representatives involved in research at the School
- Evaluation and reports on consumer and community participation at the School
- Feedback on strategic planning and governance structures relating to consumer and community participation in research
- The Consumer and Community Advisory Council will provide oversight and advice on the activities of the Participation Program through the Consumer Advocate or the Head of School

Please find a full copy of the Terms of Reference attached.

What is expected of Council members?

- Good links to the community and demonstrated experience in consumer and community participation at an organisational and /or strategic level.
- Committee experience is desirable

When does the Council meet? Four times a year usually on Monday afternoons (times may be changed to suit members of the Council)

How long am I expected to be involved? Minimum 2 year term

Where will meetings be held? School of Population Health, Clifton Street, Nedlands

What expenses are offered? Out of pocket expenses are covered.

Closing date for applications: Friday March 28th 2014

To apply please return a completed copy of the attached application form to ipir@icmr.uwa.edu.au.



Role description example



Telethon Kids Institute Research Focus Area Steering Committees Consumer / Community Representative Role

Scope of the role

- The purpose of the consumer representative role is to provide a consumer and community perspective to the Research Focus Area Steering committees
- The aim of the consumer representative is to facilitate partnerships with consumers, community members, and researchers to work together to make decision about research priorities, practice and policies.

Key duties

- Attend Research Focus Area Steering Committee meetings
- Participate in activities of the committee
- Provide advice and expertise relating to consumer and community priorities and perspectives on research
- Provide access to relevant community networks
- Provide input into consumer and community participation activities in collaboration with the Consumer and Community Participation Program
- Provide input into reporting of consumer and community participation activities
- Provide regular updates to the Consumer and Community Advisory Council on participation activities

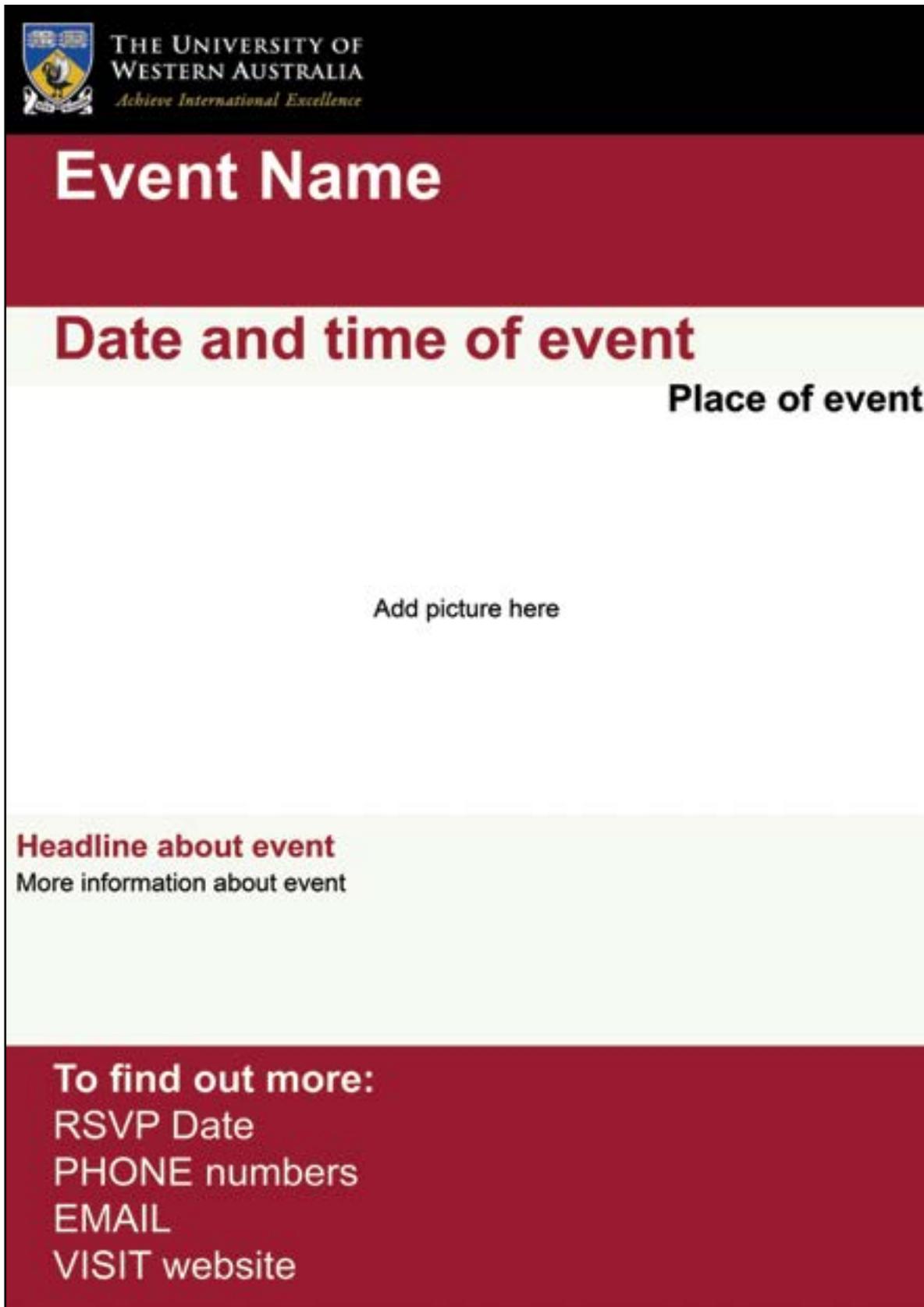
Support

- The Consumer and Community Participation Program will support the consumer representative
- An honorarium to cover out-of-pocket expenses will be paid for each meeting attended
- Training relevant to the consumer representative role will be made available to the consumer representative



Advert template

Template for an advert used to promote consumer and community participation activities at the School



The University of Western Australia logo and name are at the top left. The main content area is divided into several sections: a red header for the event name, a light green section for the date and time, a white section for the place of event and a picture placeholder, a light green section for the event headline and more information, and a red footer for contact information.

THE UNIVERSITY OF WESTERN AUSTRALIA
Achieve International Excellence

Event Name

Date and time of event

Place of event

Add picture here

Headline about event
More information about event

To find out more:
RSVP Date
PHONE numbers
EMAIL
VISIT website



Advert example

Example of an advert that has been used to promote consumer and community participation activities at the Institute

Community Research Expo

10th July 2014, 10am - 12.30
Telethon Kids Institute, Subiaco

Are you interested in research dedicated to improving the health of children?



The Telethon Kids Institute undertakes a wide variety of research into children's health and development. You are invited to come and hear about our research, meet our researchers and express your interest in working together with researchers on current and future projects.

This Expo is proudly sponsored by the Program Grant and the Developmental Pathways Project.

RSVP essential by 6th July 2014
E-mail ipir@telethonkids.org.au
Phone on 9489 7742 or 6488 8176
www.involvingpeopleinresearch.org.au



We reserve the right to make changes to the event and the right to determine the confirmed registration list.



Application form example

A consumer application form for membership on a strategic committee at the Institute

 TELETHON KIDS INSTITUTE <small>Disorders. Prevent. Cure.</small>	Telethon Kids Institute Research Focus Area Steering Committee Application Form	
Vision <i>Enhanced quality and relevance of research through consumer and community participation</i>		
<p>Please fill in the Application Form and forward to Anne McKenzie anne.mckenzie@uwa.edu.au</p> <p>Please include your personal details, indicate which Research Focus Area Steering Committee you wish to join. Please provide a short statement about why you would be suitable for a position on the Steering Committee.</p>		
Name:		
Address:		
Telephone:	Home / Work:	Mobile:
E-mail:		
Relevant experience details:		
Research Focus area:		
Statement of interest:		



Terms of reference example

The Terms of Reference developed for the Centre for Health Service Research Community Reference Group at the School



**University of Western Australia School of Population Health
Centre for Health Services Research Community Reference Group
Terms of Reference**



1. Purpose
The Centre for Health Services Research (the Centre) at the University of Western Australia School of Population Health (the School) acknowledges the importance of community members having the opportunity to give feedback and guidance about issues that are important to them relating to research undertaken at the Centre.
The purpose of the Community Reference Group (the Reference Group) is to provide a community perspective on all current and future research activities and to work in partnership with researchers to inform the community of research findings and outcomes.

2. Membership
The Reference Group will have up to 16 members:

- 8-12 community members,
- Director Centre for Health Services Research
- Researcher from Centre for Health Services Research
- Consumer and Community Participation Program staff member

2.1 Method of appointment
The Director of the Centre for Health Services Research will appoint the community members. If a selection process is necessary the selection panel will include a community member. Reference Group vacancies will be advertised through existing community networks of the Participation Program at the School.

2.2 Term of appointment
Members of the Reference Group will be appointed for a two-year term. Inaugural members will be appointed for either a two or three year term. Members may be re-appointed at the end of the term for one extra two-year term.

2.3 Meetings
The Reference Group will meet four times a year with additional meetings as determined by the Group. Meetings will be held at a time that suits the majority of the members. The Chair will be decided at the first meeting of the Reference Group.

2.4 Quorum
A minimum of 50% of members, a majority of which must be community members will be required to be present for the meeting to be recognised as an authorised meeting.

2.5 Payment and Support
Members of the Reference Group will be supported in the following ways:

- Community members will be reimbursed for out-of-pocket expenses associated with attending the meetings
- It is anticipated all Reference Group members will attend the Participation Unit's training course on basic research information
- Members can seek support from the School's Participation Unit if required

3. Reporting
The community members of the Reference Group will be encouraged to report and promote the activities of the Centre to their wider community groups. The Reference Group will be informed of any conflicts or confidentiality issues.

4. Terms of Reference
The Reference Group will:

- Provide a community perspective on activities associated with the research within the Centre.
- Identify gaps and priorities for research within the Centre to ensure we are responsive to the needs of the community.
- Provide input into the development of information strategies to inform the wider community about research associated with the Centre
- Adopt a collaborative approach when providing advice to researchers on overcoming challenges of involving consumers and community members in their research

Terms of Reference Final October 2013 To be Reviewed October 2014



Budgeting template

Budget items to be considered when undertaking consumer and community participation activities

Item	Cost
<p>Honorarium or fee for those taking part Number of people involved x honorarium/fee to be paid (e.g. 20 people to attend community forum = 20 x \$25 = \$500) If this does not cover travel and related expenses, you will need to budget for these separately</p>	
<p>Catering You should budget for tea/coffee as a minimum at meetings, but you may also want to build in a budget for meals if participation activities are likely to take place during a meal time</p>	
<p>Venue booking Do you need a venue for any activities?</p>	
<p>Training and support Does anyone (consumers, community members or researchers) need to access any training or support? If so, what is this likely to cost?</p>	
<p>Additional expenses Do you need to budget for any additional expenses to ensure effective participation – e.g. printing costs</p>	
<p>Conference fees Will consumers/community members attend conferences or other events to talk about the research? If so you should budget for associated costs e.g. registration, travel, accommodation</p>	
<p>Coordinator time You may wish to include time for someone to coordinate the participation activities</p>	

Resources
 Will you need other resources in order to involve people effectively e.g. time to develop/maintain a website or Facebook page?



Evaluation form example

The evaluation form used to seek consumer and community feedback on a Community Conversation held at the Institute



TELETHON
KIDS
INSTITUTE
DISCOVER. PREVENT. CURE.

The Telethon Institute for Child Health Research
'Let's Get Smart'
Community Conversation
August 27th 2013

Evaluation Form

Please circle the responses which best match your view:

1. The community conversation was:

NEGATIVE	→	OR				→	POSITIVE
1. Very poor	1	2	3	4	5	6	Informative
2. Not useful	1	2	3	4	5	6	Useful
3. Some people talked too much	1	2	3	4	5	6	Participative

2. Did the 'community conversation' meet your expectations?

Not at all
 Slightly
 A fair amount
 Mostly
 Completely

3. Did the 'community conversation' cover areas that were important to you?

Not at all
 Slightly
 A fair amount
 Mostly
 Completely

If "not at all" please specify what additional information could have been included:

4. Did the presentation on the research project provide enough information?

Not at all
 Slightly
 Adequately
 Mostly
 Completely

5. How well were your questions answered?

Not at all
 Slightly
 Adequately
 Mostly
 Completely

6. Did you have an opportunity to put forward your ideas / priorities for research?

Not at all
 Slightly
 Adequately
 Mostly
 Completely

7. Is there anything else you would like to add? _____

PTO →

Consumer and Community Participation in Health and Medical Research

75

8. The **best** thing about the 'community conversation' was: _____

9. The **worst** thing about the 'community conversation' was: _____

10. Do you have any suggestions about how we might improve future 'community conversations'?

- Longer session
- More time on the questions
- More pre- information
- Different process for seeking feedback from the community
- Other (please specify): _____

11. Would you be interested in attending future 'community conversations' on other research areas at the Institute?

- Yes No Maybe

If yes please provide contact details:

Thank you for attending and for your valuable feedback



NOTES



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A Collaboration between
The University of Western Australia
School of Population Health and Telethon Kids Institute



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