

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

Consumer and Community Participation in Health and Medical Research

Fact Sheet Series, Second Edition



THE UNIVERSITY OF
WESTERN AUSTRALIA



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Thank you

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Consumer and Community Participation Fact Sheets 01: Fact Sheet Overview

This series of Fact Sheets have been developed in response to requests from researchers for short, simple resources/tools to support the implementation of consumer and community participation in health research.

The content of the Fact Sheets are based on information and experience gained from the Consumer and Community Participation Program at The University of Western Australia's School of Population Health and Telethon Kids Institute. We acknowledge the significant contribution of Bec Hanley from TwoCan Associates (UK) to our Participation Program.

The Fact Sheet Series covers a range of topics as listed below:

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The Fact Sheets are supported by:

McKenzie and Hanley, (2007) Consumer and Community Participation in Health and Medical Research: A practical guide for health and medical research organisations.



Consumer and Community Participation Fact Sheet P01: Why Involve Consumers and Community Members in Research?

What is consumer and community participation?

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

And what it is not....

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

Requirements for consumer and community participation

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

What are the benefits?

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

Researcher's comments about the importance of participation:

"It's something that should be done, in my view, simply because it is the right thing to do ... my experience in over 10 years now of embracing the ethic of community participation is that it does in fact produce benefits for the researcher ... when you come to actually producing your results... the community becomes your ally and they will assist you disseminating and advocating for those results where it really counts". (Professor D'Arcy Holman)

"If we have the attitude that involving consumers and the community will improve our research ... it means our research may be more relevant...we may go into a new research area because the community thinks its important and we respond to it. ... The way that we then feed our research back to people means that, that will enable them to use the research information in ways that improves their health and their well being". (Professor Fiona Stanley)



Consumer and Community Participation Fact Sheet P02: Principles of Participation

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

Over-arching principles

- **Start participation as early as you can**

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

- **One size doesn't fit all**

It is important to work with consumers and community members to find the best level of participation for your project. Work together to decide what will be most appropriate and will suit the consumers or community members involved in your research team.

- **Consumer and community participation should add value to the research**

Work with consumers and community members to decide the best way to achieve this. Be clear about what you are hoping to achieve.

- **Treat everyone with respect**

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

- **Share information willingly**

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

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

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

The Rural and Regional Health and Aged Care Services Division, Victorian Government Department of Human Services lists the following as principles for consumer, carer and community engagement:

- Trust
- Respect
- Openness
- Equal opportunity
- Advocacy and support
- Responsiveness
- Shared ownership
- Dissemination of information

Tips for researchers

Deciding if consumers and community members of reference and steering groups can also be participants in the research project can be a dilemma. It is important for each project to consider issues of ethics, confidentiality and bias.

Useful reading:

Telford, R., Boote, J., Cooper. C. 2004. 'What does it mean to involve consumers successfully in NHS research? A consensus study'. Health Expectations, 7, pp209-220



Consumer and Community Participation Fact Sheet P03: For Consumers and Community Members

Why do consumers and community members get involved in research?

There are a number of reasons that consumers and community members choose to get involved in research;

- To improve health outcomes and/or the health system.
- To give something back to research and/or health services.
- To contribute to wider community issues such as environmental health.
- To get their story heard and influence how research is done.
- To turn a negative experience into something positive.

What do consumers and community members need to consider before agreeing to be involved in the research?

Here are some questions that consumers and community members may wish to ask themselves before agreeing to get involved in the research project;

- Does the research project interest me?
- Do I feel well enough to get involved in the research project?
- Do I have the time that the research project requires?
- Do I have the confidence to speak up in front of researchers?
- Will I need training or other support to help me?
- How will I get to where the meetings are held? Will my expenses be covered or an honorarium paid?
- How will my involvement affect my other commitments?
- Do I have any conflicts of interest to declare or confidentiality issues to discuss with the researcher?
- Do I have enough information from the researcher to decide if I should get involved in this research project?

See other Fact Sheets P01 Why Involve Consumer and Community Members, T02 The Research Cycle, T03 Ladder of Participation and T04 for Further Sources of Information.



What can consumers and community members expect?

It is really important to be upfront and discuss your queries with the researcher before agreeing to be part of the research team. It is likely your involvement will require a long-term commitment. We have a number of Fact Sheets on consumer and community participation that may help you make a decision. Please read the ones that are most relevant to the project you are considering becoming involved with.

Comments from a community member on participation:

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



Consumer and Community Participation Fact Sheet P04: Identifying Appropriate Consumer and Community Members

Planning and careful consideration of consumer and community participation will ensure that the correct resources and the right people are in place to support consumer and community participation having real impact on the project.

- Involve consumers and community members as early as possible in the research cycle.
- The method of consumer and community participation will influence the number of people who participate in the research project; ideally there will always be at least two consumers and community members involved.
- Work with consumers and community members to decide what is the right number of people for your project.

Deciding if consumers and community members of steering groups can also be participants in the research can be a dilemma. It is important for each research project to consider issues about **ethics, confidentiality and bias.**

Decide who should be involved

- Consumers and community members
- Members (including carers) of the consumer or community group that you are researching.
- Organisations which represent consumer or community groups.
- Members of relevant support groups.

Getting the right consumers and community members for the project

Following the steps below will help all parties understand what they can contribute and what they want from involvement. This may overcome any potential conflicts.

- Draft a plain language summary of the project. This may change once researchers, consumers and community members have met (see Fact Sheet M11).
- Draft a role description and Terms of Reference for the project which, like the plain language summary, should be open to changes.
- Budget for payment of expenses and/or honorarium, discuss this with consumers and community members.
- Advertise expressions of interest for the roles.
- Contact all applicants to discuss their potential involvement in the project; explain that research can be a long and slow process.
- Contact all applicants, even unsuccessful ones; explain why they have not been successful. Contacting all applicants helps to build networks as people may wish to be involved in future projects.



Planning considerations

- Consider what support or training may be required by this consumer and community group
- Who will be responsible for supporting consumers and community members?
- Budget for the cost of venue and refreshments if required.
- Pull together a pack of information for the consumers and community members. This could include;
 - Information about the research organisation.
 - The National Health and Medical Research Council Statement on Consumer and Community Participation in Health and Medical Research.
 - The policy on consumer and community participation.
 - Draft a plain language summary of the research project and any other relevant information.
 - Draft Terms of Reference for the group.

Tips for researchers

People who are not involved in research may not understand that research can be a long drawn-out process. It is important to be upfront about time expectations so people can commit to long-term participation.



Consumer and Community Participation Fact Sheet P05: Meeting with Consumer and Community Members

Organising the first meeting

- The time and place must be practical for consumers and community members as well as other stakeholders e.g. early morning or early evening and places with little or no parking are often not suitable.
- Face-to-face meetings need to be in an accessible and comfortable room/venue.
- Consider using technology if face-to-face meetings are not possible i.e. teleconferences, Facebook, e-mail, video conferencing (resources may have to be provided to do this).
- All information must be accessible to consumers and community members, print large documents and post them out in time for the meeting, consider using websites.

At the meeting

- Introduce all members.
- Work through documents/drafts that you already have, make amendments as necessary.
- Avoid using acronyms and technical language.
- Discuss confidentiality and if appropriate sign agreements.
- Allow time for members to ask questions and ensure that all questions are answered.
- Consider and discuss any training needs that the consumers and community members may have or be offered in order to continue being involved in the research project.
- Ensure all members show respect by not interrupting one another.
- Have a separate note taker.
- Ensure there are adequate breaks and refreshments if it is a long meeting.
- If required, set a time for the next meeting.
- Issue/complete claim forms for payment or issue payment itself if you are able.
- Thank members for coming and advise when further contact will be made.
- If technical terms are constantly being used, you may wish to provide a glossary.

Have members agree to simple ground rules at the start of each meeting.



After the meeting

- Summarise notes of the meeting including action points and post or e-mail them to the members in a timely way. Detail the next steps; date of the next meeting or when you will next be in contact.
- Update consumers and community members on changes that have been made to the project as a result of their input. If any ideas were not followed through explain why. It is important to inform everyone about out of session decisions that may be made.

Throughout the research project

- Keep consumers and community members updated throughout the project even if they were only involved in one part of the research project.
- Always share the results of the project with every applicant who wanted to be involved with the project, even if they were unsuccessful, this will strengthen consumer and community networks.

Comment from a community representative involved in the Alcohol and Pregnancy Project (2006-2008) at Telethon Kids Institute.

“The team ensured that representatives always felt valued and that this wasn’t a token activity to satisfy the project requirement. Representatives were given adequate information to give comment on or influence decisions.”



Consumer and Community Participation Fact Sheet M01: Planning Participation

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

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

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

What level of participation do you want to achieve?

- One size does not fit all.
- The level of participation may change at different times of the study. Using the ladder of participation (Fact Sheet T03) may help to decide which level is appropriate.

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

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

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

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

How will you find them?

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

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

- Decide what method you want use to achieve the level of participation you are aiming for and will add most value to your project (Fact Sheets M02 - M12).
- Allow enough time for participation activities to be carried out.
- You might also consider using more than one method at different stages of the project.

Consider training needs for both consumers and community members and researchers.

What resources will you need?

- Plain language summary of research (Fact Sheet M11), summary of research protocol, draft Terms of Reference, plain language PowerPoint presentation.
- Training opportunities/support for all team members.
- Budget – honorariums for out-of-pocket expenses (parking, child-minding), refreshments.
- Time - plan, manage and coordinate processes involving communication, meeting procedures, provision of documentation.
- Administrative support - note taking and records of meetings, circulation of agendas and documents.





Consumer and Community Participation Fact Sheet M02: Reference Groups

What is a reference group?

A reference group is a group of consumers and community members that can be referred to by researchers throughout the research. Reference groups are sometimes referred to as a Reference Panel.

Who would be in a reference group?

- Consumers and community members.
- Members of consumer advocacy organisations and/or non-government organisations.
- Other stakeholders of the research (Fact Sheet T01).

Planning considerations:

- Reference groups can provide advice for all or part of the research 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.
- What support and/or training will be needed or be offered?
- Time for a member of the research team will have to be set aside to organise and support meetings.
- Is there a budget for payment of expenses and/or honorariums? Has it been discussed with the members?
- Provide updated information about the research project to the reference group prior to any meetings.
- Work with consumers and community members to decide what is the right number of people for your 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.

Deciding if consumers and community members of steering groups can also be participants in the research can be a dilemma. It is important for each research project to consider issues about **ethics, confidentiality and bias**.



The Infectious Diseases Research Group at Telethon Kids Institute established a community reference group in 2008.

A key task for this group has been to work with researchers on plain language summaries of all research projects.

Although this task took many months to complete it had the added benefit of giving all members of the reference group a clearer understanding of the diverse range of topics being researched.

The reference group is confident the project summaries are now in a format and language that will be more readily understood by the wider community. The summaries will be available on the Institute's website.

Practical issues:

Develop draft Terms of Reference and a plain language summary (Fact Sheet M11) of the research for the group – be prepared to accept changes from the reference group and be upfront about items that are not open to negotiation.

See other Consumer and Community Participation Fact Sheets for help in:

- Identifying appropriate consumers and community members (Fact Sheet P4).
- Organising the first meeting (Fact Sheet P5).



Consumer and Community Participation Fact Sheet M03: Steering Groups

What is a steering group?

A group of stakeholders who steer and influence the research project, these members have more involvement with the direction of the research. This is high level participation. 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 community members.
- Members of consumer advocacy organisations and/or non-government organisations.

Deciding if consumers and community members of steering groups can also be participants in the research can be a dilemma. It is important for each research project to consider issues about **ethics, confidentiality and bias.**

Planning considerations:

- If mixing a range of stakeholders, always ensure that there are at least two consumers and community members in the steering group.
- Consumers and 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 throughout the planning and the project, consider creating a glossary if using technical language.
- Time for a member of the research team will have to be set aside 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 recompensed for their time. This should be discussed with members.



Practical issues:

- Develop draft Terms of Reference and a plain language summary (Fact Sheet M11) of the research for the group – be prepared to accept changes from the steering group.
- Be upfront about items that are not open to negotiation.
- See other Consumer and Community Participation Fact Sheets for help in:
 - Identifying appropriate consumers and community members (Fact Sheet P4).
 - Organising the first meeting (Fact Sheet P5).

Consumer and community participation has been an integral part of two large research projects undertaken at The University of Western Australia. The research looked at medication safety and chronic disease in seniors (age 65+).

There was a planned budgeted strategy for the participation activities which included establishing a Seniors Consumer Panel. The Seniors Consumer Panel provided input into many aspects of the research and took part in several workshops with researchers and health professionals.

Unexpected by-products of the participation were issues relating to packaging and labelling of prescription medicines which were highlighted by panel members. These issues have major safety implications for the quality use of medicines in seniors. Extensive lobbying with relevant government agencies has since been undertaken for changes to be made to national policy and practice.



Consumer and Community Participation Fact Sheet M04: Consumer and Community Advisory Councils

What are consumer and community advisory councils?

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. They may be set up for a research organisation or a faculty or school to provide input at a strategic level. They would not be established for individual projects.

Who should be a member?

A council membership should consist of:

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

Ideally the council will have a majority of consumers and community members representing a variety of groups.

What do they do?

A council will provide or facilitate:

- Consumer and community perspectives on research.
- Links between consumers, the community and researchers.
- Advice and expertise on consumers and community issues and priorities for research.
- Advocacy on behalf of consumers and the community.
- The implementation of policies for consumer and community participation.
- Evaluation and reports on consumer and community participation.
- Feedback on strategic planning and governance structures relating to consumer and community participation in research.

The University of Western Australian School of Population Health and Telethon Kids Institute established Advisory Councils in 2006.

The Council membership is aimed at reflecting the research programs and interests of the organisation.

A community member's perspective on being involved:

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

Practical issues:

- Identify appropriate consumers and community members. It is important for the council's consumers and community members to have an interest/links with the organisation's research programs as well as established networks with the community (see Fact Sheet P04).
 - Draft Terms of Reference and role statements for the group, be prepared to accept changes from the council and be upfront about items that are not open to negotiation.
 - Consider what support and/or training will council members need or be offered.
 - Organise meetings at regular intervals (Fact Sheet P05) and provide updates of any decisions that have been made between meetings.
 - Time for a member of the organisation will have to be set aside to organise and support meetings.
 - Consumer and community advisory councils are long term solutions, so members who can commit to long term involvement, and on-going sources of funding should be considered in the first instance.
 - Payment of expenses and /or honorarium should be budgeted for, and discussed with members.

See Fact Sheets P04 and P05 for more information





Consumer and Community Participation Fact Sheet M05: Consumer and Community Consultation Forums

What are they?

Consumer and community consultation forums are one-off or occasional meetings between consumers and 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.

- This method is particularly relevant when conducting research with Aboriginal and Torres Strait Islander people (where it is a good practice example of high level consultation).
- Alternatively it can also be lower level participation when researchers want to inform or seek specific information from the community. This will depend on the amount of input consumers will have into the research project (see Fact Sheet T03). If only one meeting is held between the researchers and consumers there may not be time to build ongoing relationships.
- This can be a good way of accessing input from large groups of people in a short period of time.
- Some projects refer to this style of consultation as 'Community Conversations'.

Who could attend a forum?

- Consumers and 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 the results of the project to consumers and community members.

At Telethon Kids Institute the Consumer and Community Advisory Council developed a process to seek feedback from the community about their priorities for research. These seminars known as 'Community Conversations' have been held on a range of topics and have discussed topics such as disability, infectious diseases and vaccinations, genetics and alcohol in pregnancy. Feedback from the community conversations has been used to make improvements at an organisation-wide level and for planning for individual projects. The Improving Rural Cancer Outcomes Project at The University of Western Australia is using 'community conversations' to seek input from rural and remote cancer consumers on a range of topics associated with the project.

See Fact Sheets P05 and T03 for more information



Considerations when setting up a forum

- It is important to invite the most appropriate people;
- Budget for expenses/honorariums and refreshments, discuss this with attendees.
- The place where the meeting is held needs to be convenient, accessible and big enough to hold a large group of people (see Fact Sheet P05).
- Be very clear about what you want to achieve from the consultation.
- Provide any written information and presentations about the topic or project in plain easy to understand language. 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 I need any advice or support on running this forum?



Consumer and Community Participation Fact Sheet M06: Consumer and Community Researchers

What are they?

Consumers and community members who have been trained to work with researchers to conduct research. This is high level involvement (see Fact Sheet T03).

What role will they have?

Consumer and 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.
- Go through consenting procedure (training is essential for this).

See Fact Sheets
M02 - M12 for help in
deciding which method
you will use.

Why use consumer and community researchers?

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



Practical considerations

- Training and support that will be required if the consumer and community researchers haven't done these activities before. This may require extra funding and/or support.
- Develop draft Terms of Reference and a plain language summary (see Fact Sheet M11) of the research, be prepared to accept changes from the stakeholders and be upfront about items that are not open to negotiation.
- Decide what method you will use to achieve the level of participation you are aiming for (Fact Sheets M02 - M12).
- Consider any legal or ethical considerations; 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.

The Nature, Understanding and Impact of Family and Domestic Violence in Five African Refugee Background Communities in Perth project was a community-initiated participatory action research project. It drew together a researcher from The University of Western Australia, government and non-government agencies and members from five African refugee background communities. A steering committee was formed and included one member from each community as well as members from each of the stakeholder groups. Representatives from the five communities were equal partners across the entire research process including research design, interview guide development, research documentation, and input and feedback on draft research reports. Importantly 14 members of the five communities collected the data for the research from members of their community using in-depth interviews after receiving training in qualitative research. The training and experience the interviewers gained had the added advantage of building research capacity in the communities.



Consumer and Community Participation Fact Sheet M07: Research Buddies

What are they?

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

Having contact with consumers and community members who have an interest in your work, directly or indirectly, can help to gain public support and lobby for current and future research.

How does it work?

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



Practical considerations

- Develop draft Terms of Reference and a plain language summary (see Fact Sheet M11) of the research for the research buddies. Be clear about the role and expectations of the buddies as contact may be limited.
- For help with identifying appropriate consumers and community members see (Fact Sheet P04).
- Consider the ability of the buddies: will the report be technical?
- Write reports in plain language – avoid using jargon and give explanations of any technical terms
- Draft parameters of the report: what will it include and when will be completed?
- It is essential that the buddies understand any issues so they can be accurately reported back to consumers and community members or organisations.
- Consider how the research buddies will be supported to engage with other consumers and community members. Discuss honorarium and payment of expenses.

At The University of Western Australia we successfully used a modified version of the research buddy system in a large project investigating older people with chronic obstructive pulmonary disorder (COPD). Analysis of the study data found unusual patterns in medication use so researchers met with two health consumers who were of similar age to the study sample and who had COPD. They provided valuable insight into how medications were used 'on the ground' which was different to what may be expected from the available literature such as national clinical guidelines. It assisted with the interpretation of results that would have been difficult to explain based on previous research findings alone.

In the UK the Multiple Sclerosis Society trained a number of people affected by Multiple Sclerosis (MS) to act as buddies to researchers who received funding from the MS Society. Benefits of this approach;

- Researchers had meaningful interaction with people living with the condition they were studying.
- The research buddies (consumers) understood the research better.
- The consumers provided feedback to other consumers and the Multiple Sclerosis Society.
- The Multiple Sclerosis Society (the funder) had another way of ensuring the research was on track, on budget and on time.



Consumer and Community Participation Fact Sheet M08: Writing or Commenting on Documents

What documents are we referring to?

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

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

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

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

Who can write or comment on research documents?

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

Planning considerations

- What type of document is being reviewed?
- Are consumers and community members involved enough in the project to be able to write one of the documents which explain it?
- Will the consumers and community members require any training e.g. are the consent forms required to contain legal information?
- Provide clear instructions of what is expected of consumers and community members.
- Will consumers and community members be paid? Discuss this with them.
- Do consumers and community members know the privacy/confidentiality requirements?
- Consider meeting with the consumers and community members to discuss your requirements (Fact Sheet P05).

Examples of questions that could be asked about the document

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

Consumer and Community Reference Group members of the Alcohol and Pregnancy Project (2006-08) at Telethon Kids Institute, offered their comments and perspectives on all documents associated with the project such as: consent forms and information sheets; topic guides for focus groups; educational resources for health professionals; reports and PowerPoint presentations; and grant applications for future research. Researchers considered consumer and community participation gave the project credibility and was vital for the development of educational resources.



Consumer and Community Participation Fact Sheet M09: Grant Application Reviewers

Consumers and community members are increasingly involved in providing a perspective on grant applications. The Western Australian Health Department and the Cancer Council NSW have consumers and community members involved in reviewing their grant applications.

Planning or support considerations

- What training or support will be required and/or offered to the consumers and community members?
- Guidance should be offered to provide the focus of the review, this can be in the form of providing a review document which asks questions such as;
 - Is the project practical for the participants to do?
 - Are there any ethical considerations about this research project?
 - Is this research useful?
 - Has the project any consumer and community participation?
- Reviewers should be aware and understand the funding criteria in good time for the review.
- Payment of expenses and/or honorarium should be discussed.
- How will the review take place? Face-to-face panel style review or sending the applications to reviewers at home?
- All research requires ethics approval, those projects focused on Aboriginal and Torres Strait Islander communities have more stringent requirements regarding community involvement. Plain language summaries may help members to understand the research.

Conditions on the reviewer

- The reviewer has to build confidence which happens over time. This means that they may need support such as providing an explanation of technical terms.
- Sometimes the simplest questions can be the most important.
- Consumers and community members will offer a different perspective to other reviewers.
- It is very important that consumer and community reviewers are made aware of confidentiality requirements before the process starts.
- Check for conflicts of interest, reviewers must declare any conflicts of interest prior to reviewing the application.

The Western Australian Health Department's State Health Research Advisory Council has provided funding for short term research projects since 2007. Since 2008, a member of the Advisory Council at The University of Western Australia School of Population Health has been a consumer representative on the grant review panel.

The consumer representative's input is considered to be an integral aspect of the Panel's deliberations in allocating grants.

Consumer Review Guidelines see cancercouncil.com.au

- Reviewers with a conflict of interest must not review an application or try to sway any other reviewers' view of the application.
- Pre-submission review panels have been established in a bid to pre-empt and solve any problems that may be identified by the reviewer.
- Having high level consumer and community member involvement in the whole of the research project should identify any issues with the project before it is reviewed.



Good practice

- The Cancer Council NSW in collaboration with Cancer Voices NSW has developed comprehensive guidelines for consumers involved in reviewing grant applications.



Consumer and Community Participation Fact Sheet M10: Writing Grant Applications

Why involve consumers and community members in writing grant applications?

- Funding bodies such as the National Health and Medical Research Council and the Cancer Council NSW require researchers to state in the grant application how they intend to involve consumers and community members in their project.
- Consumers and community members can make valuable contributions and add a different perspective to other stakeholders in the development of a grant application.
- It is integral to high level consumer and community participation.
- It demonstrates the openness and transparency of the project.
- Its a good way of ensuring participation from an early stage.

Deciding if consumers and community members of steering groups can also be participants in the research can be a dilemma. It is important for each research project to consider issues **about ethics, confidentiality** and bias.

How can consumers and community members be involved?

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

- Being co-applicants on the grant application.
- Reading through and commenting on the application so that amendments can be made prior to final application.
- Helping to write the plain language summary.
- Planning the proposed consumer and community participation activities.

Practical issues

- Identify consumers and community members to assist in writing the grant application.
- Draft an outline of the participation activities for discussion with the consumers and community members. They can then help with developing a plan for the participation activities.
- Discuss what support will be needed and/or offered, see other Consumer and Community Participation Fact Sheets (M02 - M12) for more information on consumer and community participation.
- Meet or be in contact with the consumers and community members frequently throughout the grant writing process.
- Being clear about roles and expectations from the outset may avoid problems along the way.
- Payment of expenses and/or honorarium should be discussed.



On the grant application remember to include:

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

Community members met with researchers from Telethon Kids Institute to learn about the current research being done in the Developmental Pathways Project. This project involves 12 Western Australian government agencies and industry partners and is looking at health and wellbeing in children. The meeting also discussed community priorities for future research projects. The feedback from this meeting had a two-fold positive outcome i.e. the inclusion of community suggestions such as questions about appropriateness of services and service use into the grant application, and the addition of the WA Department of Housing to the government agencies involved in the project.



Consumer and Community Participation Fact Sheet M11: Plain Language Summaries

What are they?

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. They are helpful in making information about research more open, transparent and accessible.

Plain language 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.

What should be covered in a plain language summary?

- Aims and purpose of the research.
- How the research will be conducted?
- What are the intended benefits of the research?

Researchers suggest plain language summaries are also useful for:

- Developing grant and ethics applications.
- Scholarship / bursary applications.
- Seeking consumer or community support and/or input.
- A recruitment tool.
- Media releases and informing the wider community.
- Presenting to a non-scientific audience.

Useful reading

Getting it right for service users and carers, getting it right for research: How to decide whether to help researchers **find people to take part in research**. P47, TwoCan Associates (2008), Hove.

Practical considerations

- Write as if you were explaining your research to a friend or family member with no scientific knowledge or background.
- Talk directly to the reader.
- Use simple words, avoid jargon and don't use acronyms.
- Be positive and direct, making sentences short and using bullet points.
- Use active verbs rather than passive.
- Don't turn verbs into nouns.
- Test your writing with consumers and community members.
- Consider if you need support or training in writing Plain Language Summaries. How do you access it?



Scientific Explanation

Using 26 years of data from a large population based birth cohort, we will investigate associations between restricted foetal growth, gestational age, apgar score and mode of delivery with incidence of Epilepsy. This will enable us to identify at risk groups within the population with the aim to improve the efficacy of current treatment regimes.

(Matt Cooper, Telethon Kids Institute, 2010)

Plain Language Summary

We are looking at a large, diverse group of people to see if differences at birth (for example birth weight, health at birth and type of birth) can help identify what makes someone more likely than someone else to be affected by Epilepsy.

(Matt Cooper, Telethon Kids Institute, 2010)



Consumer and Community Participation Fact Sheet M12: Evaluation

What is the purpose of the evaluation?

The impact of consumer and community participation can be difficult to measure and quantify however evaluating consumer and community participation activities is fundamental to the principles of continuous quality improvement.

Evaluating participation activities can help to:

- Understand the effectiveness of the participation activities.
- Give people an opportunity to comment on their experiences.
- Make improvements to future activities.

What should be evaluated?

- ✓ Consumer and community participation activities in individual projects.
- ✓ Organisational engagement strategies - conduct an audit on what is currently happening across an organisation to be able to effectively evaluate the strategy.
- ✓ Consultations and forums.
- ✓ Training courses.

What is it not?

- ✗ Evaluating the performance of the consumers and/or community members involved in research teams.

What should be included?

Normally evaluations are conducted in questionnaire format. There are some basic questions which should be asked in any evaluation so that people's individual views are sought. Some questions may be specific to a particular part of the project.

Three basic questions that can be used for any evaluation:

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

Practical Considerations

- 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. How will the evaluation be collected?
- Consider how the evaluation will be given to recipients. Will it be sent to them, handed out at a meeting or available electronically?
- If there are different groups involved at different stages of the research project, it may be best to send the evaluation forms at different stages, or adapt the evaluation forms for each group.
- Consider evaluating expectations of consumer and community participation at the beginning of the project and again at the end of the project.
- How will it be collected?

The Seniors Consumer Panel, researchers and health professionals involved in research on medication safety and chronic illness, at the University of Western Australia, completed an anonymous online survey to find out about their expectations about the participation activities.

"I feel we have made an impact". (Consumer)

"consumer participation... added so much value in a common sense way" (Researcher)



Consumer and Community Participation Fact Sheet T01: Stakeholder Wheel

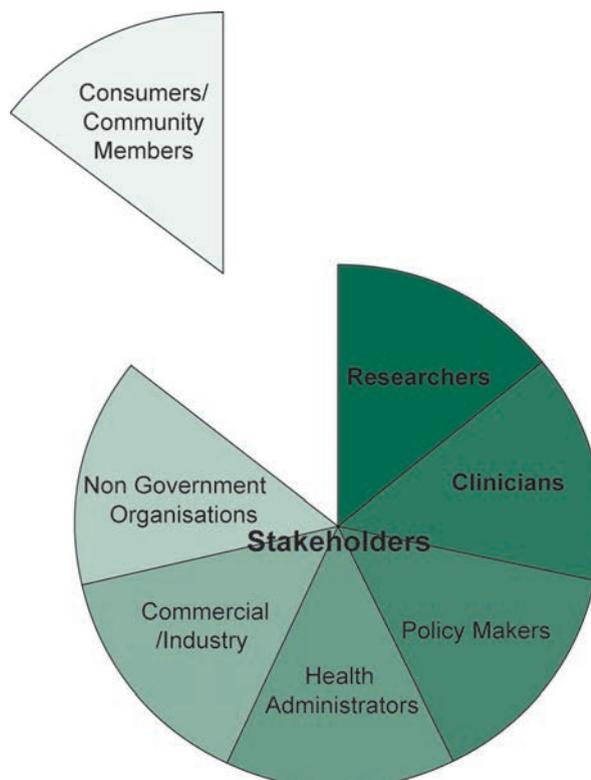
A stakeholder can be described as an individual or organisation with a key interest in a research project and its findings. It is important to remember that:

- Within the health sector the goals of all stakeholders will have a strong overlap: improving health outcomes
- The particular make-up of stakeholders will differ from project to project although generally they can be grouped under the headings below.

Including consumers and community members in the stakeholder group for a research project will ensure that all perspectives are included in the research project. This makes the stakeholder wheel complete.

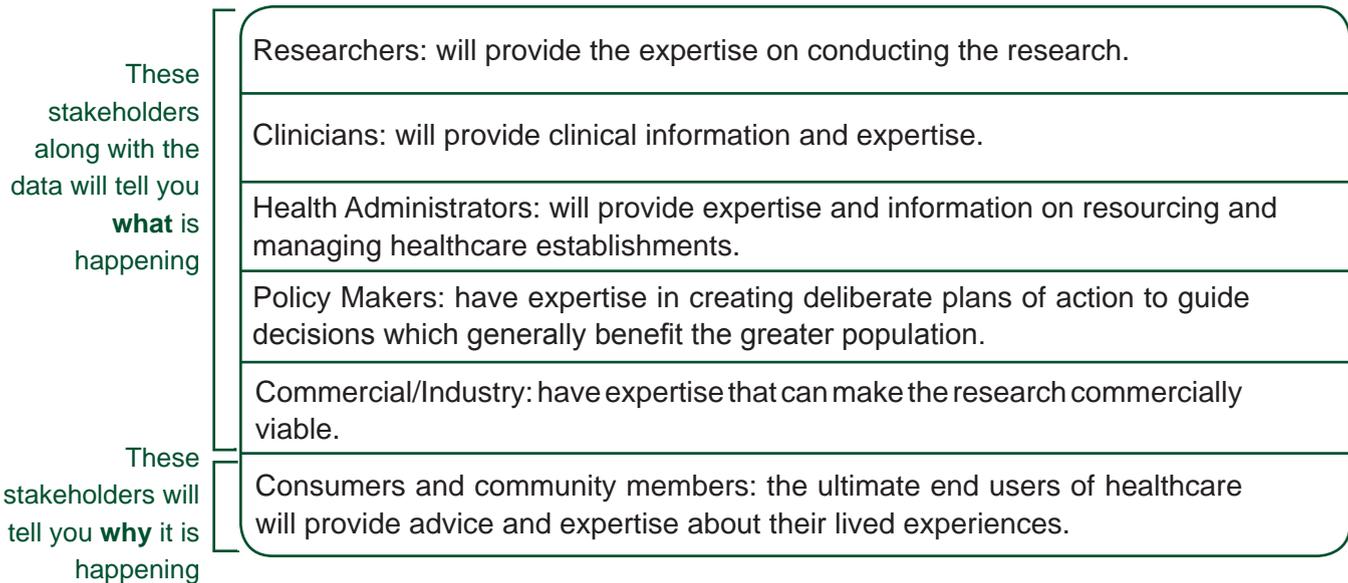


Having other stakeholders speak on behalf of consumers and community members will not always give an accurate picture of people's lived experiences. This makes the stakeholder wheel incomplete.





It is important to canvas input from each stakeholder directly as their roles can differ greatly even if their end goal for the research project is the same.



Considerations for involving all stakeholders

- Develop Terms of Reference for the participation activities which clearly state the limits and boundaries of stakeholder roles. It is important to discuss the areas of expertise that each stakeholder group will contribute to the project.
- Allow time to manage the interests of the different stakeholders as they may have different agendas and/or competing interests.
- Budget appropriately for engaging with all stakeholders – remember the consumer and community stakeholders may not have the backing of an organisation to cover their out-of-pocket-expenses.
- Identify appropriate consumer members (Fact Sheet P04)
- Consider all stakeholders needs when setting up meetings (Fact Sheet P05)
- For more help on how you might canvas the views of consumers/community members please see (Fact Sheets M02 – M12).

Comments from a researcher on working with a diverse stakeholder group

‘Having a clear understanding of the parameters, expectations and roles for those involved are essential to the smooth running of a project. Miscommunication and misunderstanding about the scope, timeframe of the project and availability of part time staff, can lead to difficulties. It is important for the group to acknowledge who is responsible for the ultimate decision making in the project. Discussing these points at the outset of a project will help to avoid problems along the way’

(Caroline Bulsara, The University of Western Australia)



Consumer and Community Participation Fact Sheet T02: The Research Cycle

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

5. Knowing what to research next

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

- Advisory councils and groups (Fact Sheets M02 - M04)
- Consultation Forums (Fact Sheet M05)

4. Letting people know the results

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

- Community Consultations (Fact Sheet M05)
- Research Buddies (Fact Sheet M07)
- Utilising members of advisory councils and groups to spread the word (Fact Sheets M02 - M04)
- Consumer and community networks
- Plain language Summaries (Fact Sheet M11)

1. Deciding what to research

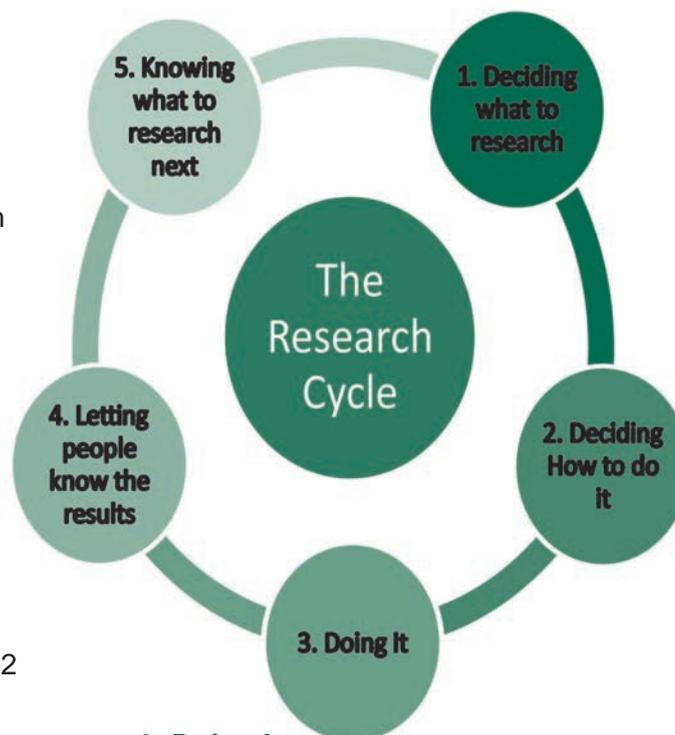
Deciding what to research can be influenced by a number of groups;

- Funding body interests
- Researchers, professionals, staff and students
- Consumers and community members through:
 - Advisory councils and groups (Fact Sheets M02 - M04)
 - Consultation Forums (Fact Sheet M05)

2. Deciding how to do it

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

- Writing/commenting on documents, surveys, questionnaires (Fact Sheet M08)
- Writing grant applications (Fact Sheet M10)
- Reviewing grant applications (Fact Sheet M09)
- Advisory councils and groups (Fact Sheets M02 - M04)
- Research Buddies (Fact Sheet M07)



3. Doing It

Consumers and Community members can be included in doing the research in a number of ways;

- Consumer and community researchers (Fact Sheet M06)
- Advisory councils and groups (Fact Sheets M02 - M04)
- Community consultations and forums (Fact Sheet M05)

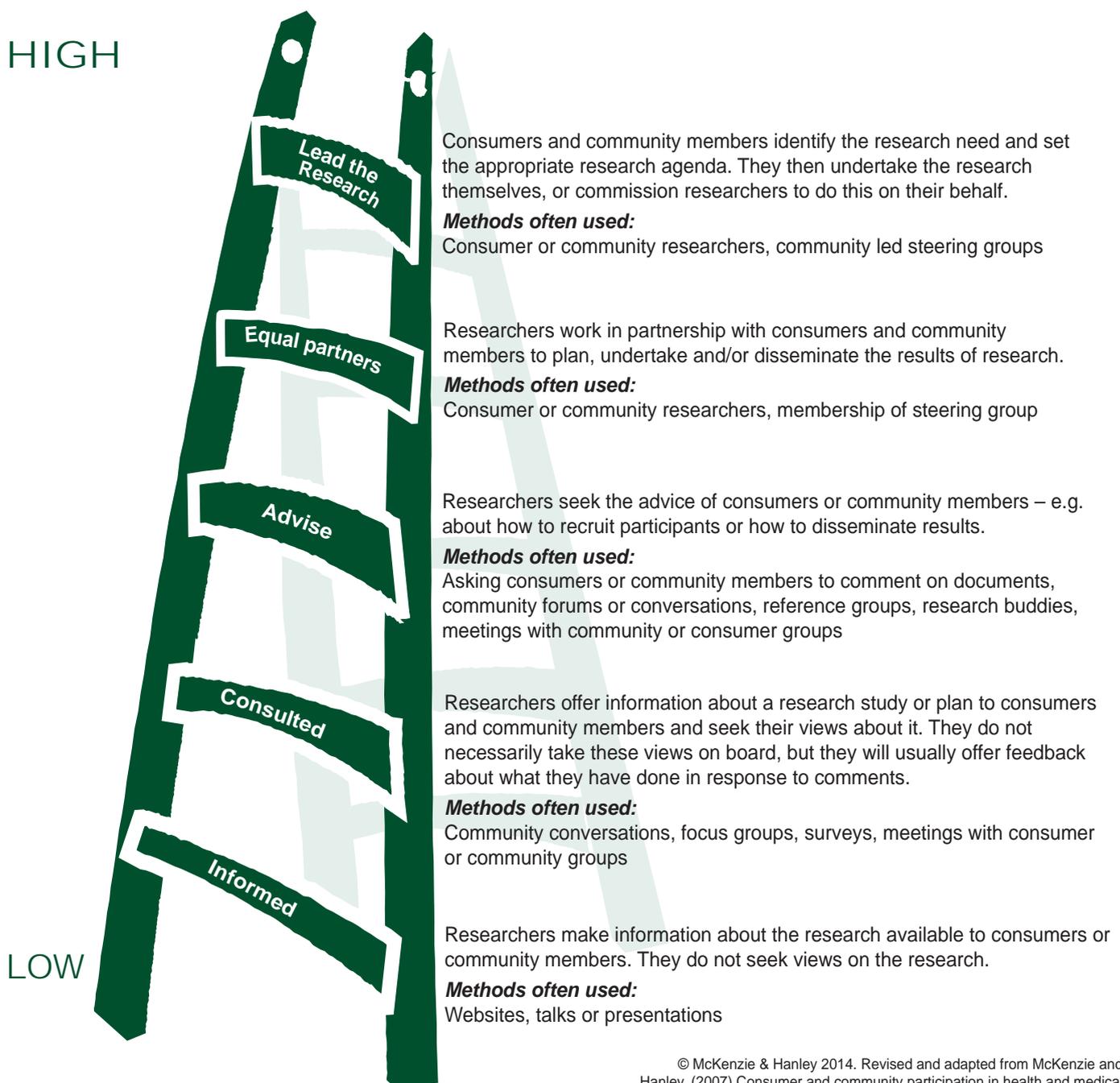


Consumer and community Participation Fact Sheet T03: Ladder of participation

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

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

The Ladder of Participation



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Consumer and Community Participation Fact Sheet T04: Further Sources of Information

The Consumer and Community Participation Fact Sheet Series

These are a series of 22 short informative Fact Sheets designed to give you quick and simple access to information about consumer and community participation.

01. Fact Sheet Overview		
P01. Why Involve Consumer and Community Members in Research	P04. Identifying Appropriate Consumer and Community Members	Principles
P02. Principles of Consumer and Community Participation	P05. Meeting with Consumer and Community Members	
P03. For Consumer and Community Members		
M01. Planning Participations	M06. Consumer and Community Researchers	Methods and Support for Participation
M02. Reference Groups	M07. Research Buddies	
M03. Steering Groups	M08. Writing or Commenting on Documents	
M04. Consumer and Community Advisory Councils	M09. Grant Application Reviewers	
M05. Consumer and Community Consultation Forums	M10. Writing Grant Applications	
	M11. Plain Language Summaries	
	M12. Evaluation	
T01. Stakeholder Wheel	T03. Ladder of Participation	Tools and Resources
T02. The Research Cycle	T04 Further Sources of Information	

Other Sources of Information

- McKenzie and Hanley, (2007) Consumer and Community Participation in Health and Medical Research: A practical guide for health and medical research organisations.
- McKenzie and Hanley, (2010) Consumer and Community Participation: A training workshop for health and medical researchers.
- National Health and Medical Research Council & Consumers Health Forum of Australia, (2002) Statement on Consumer and Community Participation in Health and Medical Research.
- National Health and Medical Research Council & Consumers Health Forum of Australia, (2002) A Model Framework for Consumer and Community Participation in Research.
- National Health and Medical Research Council, (2003) Values and Ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research
- National Health and Medical Research Council, (2005) Keeping research on track: a guide for Aboriginal and Torres Strait Islander peoples about health research ethics

Further Sources of Help and Advice

The University of Western Australia School of Population Health

www.sph.uwa.edu.au/community/consumer-and-community-participation

Telethon Kids Institute

www.telethonkids.org.au/join-us/community-consumers

Consumer and community Participation Program website

www.involvingpeopleinresearch.org.au

National Health and Medical Research Council

www.nhmrc.gov.au/publications/synopses/r22syn.htm

Consumers' Health Forum of Australia

www.chf.org.au

Health Consumers' Council of WA

www.hconc.org.au

INVOLVE UK

www.invo.org.uk

TwoCan Associates

www.twocanassociates.co.uk

Cancer Council New South Wales

www.nswcc.org.au



Notes



Notes



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