

# GUIDELINE

## Research Management - Partnering with Consumers in Research

GL2021/75  
Version No. 1.0

### PURPOSE

---

The Metro South Hospital and Health Service ('Metro South Health') recognises that maximising the benefits of health research requires - a community that guides and supports our research efforts, informed consumers who participate in research, and employees who effectively apply their knowledge and skills. The [Metro South Health Research Strategy 2019-2024](#) acknowledges the importance of consumer and community opportunities to participate and be involved in research, viewing it as an integral part of person-centred care. This guideline provides an overview of consumer partnering in research and outlines best practice recommendations for Metro South Health (MSH) researchers to consider when planning their consumer engagement journey.

### SCOPE

---

This guideline applies to MSH or Queensland Health (QH) employees whose usual reporting line is through a MSH facility or service, who conducts human research within or in association with MSH, or through access to MSH participants.

### RELATED DOCUMENTS

---

#### Attachments

- Attachment 1: Partnering with Consumers: Researcher Resources (map)
- Attachment 2: How to Engage with Consumers (developed by Consumer Rep Jessica Taylor)

#### Supporting resources - internal

- [Metro South Health Research Strategy 2019-2014](#)
- [Metro South Health Consumer and Community Engagement](#) (intranet only)

#### Supporting resources - external

- [National Safety and Quality Health Service Standards \(NSQHS\) – Second Edition](#)
- [Telethon Kids Institute](#)
- [Engage 2020 Action Catalogue](#)
- [National Health and Medical Research Council \(NHMRC\)](#)
- [Patient-Centred Outcomes Research Institute](#)
- [George and Fay Yee Centre for Healthcare Innovation](#)
- [Health Consumers Queensland \(HCQ\)](#)
- [International Association for Public Participation \(IAP2\)](#)
- [Involve](#)

## References

1. INVOLVE. Briefing notes for researchers: involving the public in NHS, public health and social care research. Eastleigh; 2012.
2. Wright M, Springett J, Kongats K. What is participatory health research? In: Wright M, Kongats K, editors. Participatory health research: Voices from around the world: Springer International Publishing; 2018. p. 3-15.
3. Consumers Health Forum of Australia. Statement on consumer and community involvement in health and medical research. National Health and Medical Research Council; 2016.
4. BMJ. Patient and public partnership: BMJ Publishing Group; 2018.
5. Queensland Government. Metro South Health Research Strategy 2019-2024. Brisbane 2019.
6. McKenzie A, Hanley B. Planning for consumer and community engagement in health and medical research: A practical guide for health and medical researchers: The University of Western Australia School of Population Health and the Telethon Kids Institute; 2014.
7. National Health and Medical Research Council. Resource pack for consumer and community participation in health and medical research. 2004.

## DEFINITIONS

---

The definitions below are taken from the NHMRC's statement on consumer and community involvement in health and medical research (3).

<b>Consumer</b>	People (patients/participants) who engage with or who will potentially utilise health care services, including carers and family members.
<b>Community</b>	A group of people who share a common interest, such as cultural, social, political, health or economic interests, but who do not necessarily share a geographical location. Note that different types of communities are likely to have different perspectives and approaches to research involvement.
<b>Consumer representative</b>	A person who acts on behalf of consumers, voicing consumer perspectives and taking part in decision making processes. A consumer representative may be nominated by, and/or be accountable to an organisation of consumers. Keep in mind that the perspective offered by a consumer representative may be reflective of their organisation rather than the broader community. A consumer representative may be trained or may undergo training and be supported to advocate for consumer-centred health care.
<b>Stakeholder</b>	An individual or group from within or outside a research/health care organisation with a key interest in the research. Examples include members of consumer organisations, professional bodies, government agencies, non-government organisations, research funders, or industry partners as well consumers and community members. Stakeholders may provide support, expertise and influence decisions about the research and its findings.

<b>Research cycle</b>	The planning, funding and conduct of research, in addition to the publication, dissemination and implementation of research findings. The research cycle can be broken down into a five-stages: deciding what to research, deciding how to do it, doing it, letting people know the results and knowing what to do next. (7)
-----------------------	--

Throughout this guideline certain words are used interchangeably across different organisations around the world, for example:

- ‘partnering’ may also be referred to as ‘involvement’, ‘engagement’, ‘driving ideas’, ‘collaborating’ or ‘working together’
- ‘consumers’ or ‘community members’ may be referred to as ‘public’.

## **GUIDELINE FOR PARTNERING WITH CONSUMERS IN RESEARCH**

---

### **Contents**

1.0 What is consumer and community partnering in research? .....	4
2.0 Why consumer partnering in research is important .....	4
3.0 Before you start.....	5
4.0 Ethics and consumer partnering.....	5
5.0 Where to partner with consumers and community members in the research cycle.....	6
6.0 Stages of consumer and community partnering in research .....	6
Stage 1: Deciding what to research .....	6
Stage 2: Deciding how to do the research .....	6
Stage 3: Doing the research .....	7
Stage 4: Letting people know the results .....	7
Stage 5: Knowing what to research next .....	7
7.0 How to partner with consumers and community members in research.....	7
Pre-planning.....	8
Step 1: Prepare .....	9
Step 2: Plan.....	12
Step 3: Engage.....	12
Step 4: Evaluate.....	13

This guideline may enhance researcher knowledge and skills surrounding:

1. **What** consumer partnering in research is and **why** it is important.
2. **Where** to partner with consumers across the research cycle.
3. **How** to partner with consumers in research.

The following principles taken from McKenzie and Hanley (2014) should underpin all consumer and community partnering, regardless of how much input consumers will have or where in the research cycle it takes place:

- Establish the partnership as early in the research process as you can (eg engage the consumer at the start as part of the scoping process).
- Ensure partnering adds value to the research and the efforts of all of those involved.
- Be inclusive and reach out to people from diverse backgrounds.
- Maintain integrity and treat everyone with respect.
- Keep people informed and involved throughout.
- Use language that can be understood by everyone.
- One size does not fit all – maintain an open mind and work with people to determine how you can build a partnership.

## 1.0 What is consumer and community partnering in research?

Consumer and community partnering in research involves researchers and healthcare providers working together with members of the community – including patients, carers, family, friends and consumer organisations – to make decisions around:

- **Research priorities:** choosing research topics and asking research questions that are important to people
- **Research practices:** how research is undertaken, what outcomes to measure, what the results might mean and how they are shared
- **Research policy:** how organisations support researchers and healthcare providers to undertake research in partnership with the community.

## 2.0 Why consumer partnering in research is important

The traditional way of doing research is changing. Worldwide, there is a shift towards research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them (1). Involving people affected by the health issue being researched is associated with:

- Improvements in recruitment of participants
- Increased participant retention
- Better quality data and data interpretation
- Wider and more effective dissemination of findings (2).

Consumer partnering can empower the community to drive the direction of research. It can also prevent resources from being wasted on research that has no relevance to the people it is intended to benefit.

### 3.0 Before you start

Before you begin planning your consumer engagement journey, it is important to have the following in place:

- **Support** - from your team leader, director and/or research supervisor.
- **Funding** - it is best practice to reimburse consumers for their time and out-of-pocket expenses (for example mileage, parking), so be sure to include these costs in any research grants you apply for.
- **Time** - partnering with consumers effectively takes time across all stages of the research cycle and this should be factored in when mapping out research timelines.
- **Training** - to help everyone get the most out of partnering, consider the training needs of both researchers and community members, and who will be responsible for this. Training modules are available online and these are an excellent starting point.
- **Assistance** - think about which members of the research team will be responsible for partnering activities and if administration support will be needed to book venues, send invitations, record and distribute meeting minutes (6).

### 4.0 Ethics and consumer partnering

Ethical approval is not required to partner with consumers, but consideration needs to be given to whether consumer researchers are listed as investigators on the Human Research Ethics Application (HREA). Whether you do this or not depends on the level of involvement that consumers will have:

- If consumers are key members of the research team and partners throughout the life of the research project, it is appropriate to list consumers as investigators on the HREA.
- If interactions with consumers and community members are likely to be once-off or occurring at sporadic times throughout the research (such as providing feedback on the research design or reviewing documents) there is no need for consumers to be listed as consumer researchers on the HREA.

When completing a HREA for your research, you may notice there is a section about peer review. This is where you should outline any consumer partnering activities you have undertaken or plan to undertake for your research. Please see the [Authorship, Peer Review and Open Access Publications Procedure \(PR2021/TBA\)](#) for more information.

Note: that any consumers listed on the research team are unable to be participants in the research study itself as this generally constitutes a conflict of interest.

Please see the [Ethical and Scientific Review of Human Research Procedure \(PR2017/113\)](#) for more information.

## 5.0 Where to partner with consumers and community members in the research cycle

The NHMRC breaks the research process down into a five-stage cycle:



The earlier you're able to partner with consumer and community members in the research cycle the better, but also know that it's never too late. You can still establish partnerships for the first time later in the research cycle. For example, you could discuss the results of your study and check for differences in how they are interpreted, or you could seek ideas around innovative ways the results could be shared or taken up in practice.

If you're new to consumer and community partnering it may be more achievable to start with just one step of the research cycle. As your experience and skills grow, you're likely to feel more confident to expand the partnership across multiple stages, or perhaps even the whole research cycle.

The next section will go through each step of the research cycle and suggest different ways in which consumers and community members might be involved. This is to get you thinking about where it might fit into your own research. Note this is not an exhaustive list and you may identify other opportunities.

## 6.0 Stages of consumer and community partnering in research

### Stage 1: Deciding what to research

Consumers and community members can help you decide what to research by sharing their experiences and the issues that are important to them. Bringing a consumer in as part of the project and giving them defined activities and roles enables the consumer to drive ideas and collaborate as part of the team.

It is important to support the consumer so they can partner with their networks. When partnering at this stage of the research cycle, it is advisable to approach consumer groups or organisations where you can connect with a larger number of people, rather than relying on a few individuals. Local consumer groups or state-wide peak bodies may have already undertaken priority setting workshops, or they can provide advice on running a consultation forum with their members.

### Stage 2: Deciding how to do the research

Consumers and community members can assist with multiple activities that can shape how the research is carried out by:

- Providing feedback on aspects of recruitment - eligibility, exclusion criteria, how and when might be best to approach potential participants.
- Commenting on data collection and methods - what type of data are necessary to collect, ways to minimise inconvenience or discomfort and strategies to make it easier for people to take part.
- Reviewing and contributing to documents - grant applications, ethics applications, research protocols, information and consent forms, data collection forms and questionnaires.

### **Stage 3: Doing the research**

Consumers and community members may get involved in the research process itself by:

- Talking to potential participants about the research project, providing information and consent forms.
- Facilitating focus groups or undertaking interviews, provided appropriate training has been given.
- Administering questionnaires and other data collection tools.
- Keeping relevant consumer groups and community organisations up to date regarding research progress.
- Assisting with interpretation of the results and preparation of manuscripts or reports.

### **Stage 4: Letting people know the results**

Consumers and community members can assist with sharing research findings in a number of ways:

- Developing plain language summaries and suggesting other methods of communicating results, such as infographics, audio bites or short videos.
- Suggesting different channels for dissemination, such as consumer group meetings, newsletters, magazines, websites or via social media.
- Presenting or co-presenting findings at academic conferences, research showcases or local meetings.

### **Stage 5: Knowing what to research next**

Once the research is completed, consumers and community members could help you figure out 'where to next' by:

- Sharing ideas for how results could be implemented and who the key stakeholders are
- Suggesting other research questions (related or otherwise) that are yet to be answered
- Taking a more active role in working with community groups to determine research priorities (back to stage 1).

## **7.0 How to partner with consumers and community members in research**

Once you've decided where in the research cycle you want to partner, it's time to plan how you're going to do it. As per the Metro South Consumer and Community Engagement intranet page, the partnering process can be broken down into pre-planning, followed by these four steps:

1. Prepare
2. Plan
3. Engage
4. Evaluate

If you are familiar with consumer partnering you may have noticed that these steps are set out in the context of consumer and community partnering for other purposes in healthcare, such as strategic planning, planning of quality improvement or evaluation of consumer feedback.

These same steps remain relevant for research. The only difference is that some steps are likely to be repeated for each stage of the research cycle, and the evaluation step undertaken once your research is completed. Please see Attachment 1: Consumer and Community Partnering in Metro South Health: Resources for Researchers for more information.

Each step in the partnering process will now be explained, outlining what you need to consider.

### **Pre-planning**

This is where you consider your research and opportunities for partnering. Two key questions to ask yourself are:

#### **1. Are there decisions to be made?**

For example, have you decided:

- What your research questions are?
- Who you'll be targeting to take part?
- How you're going to carry out your research, for example the design of research plan?
- The types of data you want to collect and how you might collect it?

#### **2. Can consumer and community members contribute to these decisions?**

That is, are you able to collaborate and work together with consumers so that their ideas shape and drive your research?

If you answered yes to both questions, consumer and community partnering for your research is appropriate. It is also important to then engage with consumers at the start of the project – their experiences and ideas can positively impact your project or research goals.

This is another good time to pause and consider the breadth of your partnership. If there are multiple decisions to be made throughout the research cycle that consumers can contribute to, then it's shaping up to be a long-term research relationship. Bringing in a consumer and/or a core group of consumers as part of the team demonstrates a serious commitment to consumer engagement and may be a requirement of grant submissions (ie NHMRC). When reviewing overall project costs, it is also important to consider a financial incentive for consumers (ie a percentage of the project budget) when submitting a grant application.



If there's only one or two opportunities for consumer influence in the research cycle (or you want to focus on just one stage of the research cycle to begin with), it's more likely you'll be planning for a once only event.

### **Step 1: Prepare**

This step is where you investigate what partnering activities have already taken place, think about why you want to partner and who you might approach.

#### **Investigate what has already been done**

It is worthwhile to first check whether any form of consumer or community partnering has been undertaken in relation to your research area of interest as it may be applicable to your work. You could check with:

- Relevant local or state-wide organisations (eg the Cancer Council)
- The Health Consumers Queensland website
- Recent literature

There are organisations around the world dedicated to partnering with the community to set research priorities for different health conditions. One example is the James Lind Alliance. While the consultation process undertaken by such organisations is rigorous, it can't be assumed that research priorities are the same locally.

If you're hoping to partner with the community to determine research priorities for your health issue of interest, work undertaken by organisations such as the James Lind Alliance can still serve as a launch pad for local discussions.

When thinking about why you want to partner, consider the following:

#### **The purpose and scope of partnering**

Think about what you want the partnership to achieve:

- What aspects of the decisions can consumers give insight into or feedback on?
- How can you work together with the consumer and bring them in to become a member of the team?
- Can they be assigned activities or roles to aid in driving the project?
- Should the consumer be involved as part of the scoping process in developing the how/purpose? (eg start with a blank page and see if the consumer's ideas align with your project).
- Do you need one consumer, or would a core group of consumers better suit your purpose?
- How can you support the consumer so they can partner with their networks?
- What training might be required so that the consumer feels engaged with the organisation?

## How much influence consumers and community members will have?

The table below is adapted from the Metro South Consumer and Community Engagement webpage outlines the five levels of engagement, which span from 'Inform' to 'Empower'. Perhaps you're after feedback on parts of your research (consult), or maybe you want to partner with consumers throughout the research process (collaborate). Alternatively, you may be aiming for consumers and community members to drive the research and make the final decisions (empower).

	Level of engagement				
	Inform	Consult	Involve	Collaborate	Empower
<b>Community engagement goal</b>	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions	To obtain public feedback on analysis alternatives and/or decisions	To work directly with the public throughout the process to ensure that public concerns and aspirations consistently understood and considered	To partner with the public in each aspect of the decision making, including the development of alternatives and the identification of the preferred solution	To place the final decision making in the hands of the public
<b>Promise to the community</b>	Metro South will keep you informed	Metro South will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input can influence the decision	Metro South Health will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced decisions	Metro South Health will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendation into the decision to the maximum extent possible	Metro South Health will implement what you decide
<b>Level of consumer/community interface</b>	Level of consumer/community influence is nil	Consumer/community involvement and influence is low	Consumer/community have some influence	High consumer/community involvement and influence	Consumer/community control

Different research questions and projects will lend themselves to different levels of consumer involvement. There is no single correct approach, and when first starting off you may feel more comfortable working with consumers at the 'Consult' or 'Involve' level while you build relationships, develop your skills and familiarise yourself with the partnering process.

## Who could you recruit as consumer partners?

This will depend on the topic you are researching and the purpose of your partnership. If you're planning to collaborate throughout your research study, it may be more worthwhile to approach people who have the health condition of interest or who use the specific health service your research will take place in. Alternatively, if you're planning consultation to gain feedback on information sheets and consent forms, that may not be as important.

## Where you could go to recruit consumers and community members

You can recruit consumer and community members via several channels:

- From your existing networks, by asking colleagues for recommendations, or by approaching people you provide clinical care to.
- From your service, by advertising in waiting rooms or asking other members of the multidisciplinary team to spread the word.
- Approach state-wide peak bodies or consumer organisations relevant to your research topic (eg Cancer Council, the Heart Foundation, the Asthma Foundation).
- Contact Health Consumers Queensland

Before you approach individuals or organisations, it is important to develop an information sheet that outlines the project and what is involved. This will:

- Prompt you to think about what you'll be asking of individuals or groups; how many people you might need; how you might interact with them; where this will occur; any training that might be needed; what reimbursement and/or payment you can offer; and estimated dates and timeframes for involvement.
- Help consumers to know exactly what they are signing up for, what is expected of them and what types of support (both training and reimbursement) they will receive. You may also need to develop an Expression of Interest (EOI) and/or application form if the role/s will be advertised or distributed through consumer networks.

## Orientation, training and support

Just as researchers need education and guidance when first embarking on the consumer partnering journey, consumers and community members will also require research training, orientation and support. This is likely to vary with each project and will depend on which aspects of the research consumers and community members are involved in. There may be specific content knowledge or research skills that consumers will need in order to participate as partners in research. The NHMRC have developed a resource pack which may be useful, or you may need to develop specific training on tasks you are wanting them to undertake. Be clear about what you need from consumers; provide written resources if required; give examples so people can see how it's done; and check in regularly to answer questions; and clarify uncertainties and provide encouragement.

For consumers who are partnering throughout the research cycle or who are key members of the research team, you will need to check whether the following requirements are necessary:

- Recruitment and orientation as per MSH Recruitment and Orientation of Consumers on Committees Procedure
- Administration tasks such as organising computer access, visitor badges and submitting paperwork to enable timely reimbursement and remuneration of consumer partners.

## **Step 2: Plan**

It's time to make an action plan, taking into consideration the following:

### **Think about how you might partner with consumers and community members**

There are many different ways you can engage with people to develop strong partnerships. The chosen engagement strategy will likely depend on how much influence consumers will have on decision-making, what stage of the research cycle you are at, and what aspects of the research you're seeking input on. Some examples of different engagement methods include community forums, small workshops or one-on-one interviews. Alternatively, if you're seeking input to develop or gain feedback on written documents, you might schedule meetings either face to face, via phone or videoconference.

### **Make a plan of what you will need to do before, during and after an engagement activity**

Start to dive into the details. If you plan to hold a community forum or small workshops - how might you advertise this? Does a venue need to be booked? How does the room need to be set up? Who will run the event? What kind of questions might you ask and who will take notes? It may be useful to develop checklists for before and after the event, as well as a run sheet or agenda for the event itself. If you're thinking of conducting interviews, how many people might you aim for? What kind of methods can you offer – face-to-face, telephone, Zoom or Teams? How much flexibility can you offer regarding when interviews will be conducted? Will you record the interviews so you can summarise the main points afterwards? Again, this is where you'll need to consider what education and training is needed - both for you and consumers - to ensure everyone gets the most out of the engagement experience.

### **Consider what could go wrong and the steps you'll take to reduce the risk**

Think carefully about some of the risks – people not showing up, running out of time, unrelated ideas or agendas taking up time. How might you manage these?

### **Decide how you'll know if your engagement activities were effective**

What kind of things will you evaluate to figure this out? This might include a process evaluation that looks at the number of people who showed up to a forum or focus group, or how many people you interviewed. Could everyone share ideas? Was the venue suitable? You may also ask yourself what worked well, what didn't work so well and what you might change for next time. Think about asking consumers themselves to provide feedback via an anonymous survey or feedback form.

Now it's time to implement your action plan!

## **Step 3: Engage**

Once you've implemented an action plan and met with consumers and community members, it's time to:

### **Examine consumer ideas and feedback**

Summarise the main points or themes that came up and check back in with your consumer partners to ensure your understanding is correct.

### **Decide how you can use the feedback**

This will depend on the purpose of the engagement activity and the partnership overall. Have you now determined your research question? Or perhaps your research question has changed? Has the engagement activity provided some clarity around your eligibility criteria or how you might approach potential participants? What about the type of data you want to collect or the questionnaires you use?

### **Communicate this back to consumers and community members**

Be sure to get in touch with consumers and community members soon after the event to thank them for their time and input. This step is vital. Even if you haven't been able to sort through their ideas and feedback yet, let people know when you'll be doing this and when they'll get to hear how their input has shaped the research. It's also a good opportunity to keep people informed of where the research is going, if there will be another opportunity to engage in the project and when this will be.

### **Step 4: Evaluate**

Undertake this step once you've reached the end of your research project. You'll need to:

#### **Complete your evaluation**

Complete an engagement activity report and think about what went well, what didn't go so well and what you might do differently next time.

#### **Share what you did**

Discuss your engagement journey and community partnering experience in any presentations you give about your research and be sure to include it as part of your methods in any manuscripts you submit for publication. There are multiple guidelines available to help you, including the Guidance for Reporting Involvement of Patients and the Public (GRIPP) and the British Medical Journal (BMJ).

## GUIDELINE DETAILS

---

**Guideline Number**

GL2021/75

**Guideline Name**

Research Management - Partnering with Consumers in Research

**Policy Reference**

PL2017/55 Research Management Policy  
PR2017/113 Ethical and Scientific Review of Human Research Procedure

**Supersedes**

Nil

**Procedure Author**

Amy Nevin, Spinal Injuries and Food Allergy/Intolerance Dietitian, Department of Nutrition and Dietetics, Clinical Support Services, Princess Alexandra Hospital, Metro South Health

**Portfolio Executive Director and Approving Officer**

Professor John Upham, Chair, Metro South Research, Metro South Health

**Approving Date**

05 January 2021

**Effective From**

05 January 2021

**Date of Last Review**

05 January 2021

**Date of Next Review**

January 2024