Partnering with consumers in research

PURPOSE

This guideline provides an overview of consumers partnering in research and outlines best practice recommendations for Metro South Health (MSH) researchers to consider when planning their consumer engagement journey.

OUTCOME

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** MSH supports consumer partnering activity through policies and resources.

SCOPE

This guideline applies to all MSH employees and collaborators who conduct human research within or in association with MSH, or through access to MSH participants, health records or data.

GUIDELINE

The following MSH principles guide all consumer partnering practices in research:

- **Open**: be approachable, communicate in plain language and welcome questions, constructive feedback, and different ideas.

- **Inclusive**: actively seek contributions from all partners who reflect the diverse beliefs, values, experiences, preferences, and abilities of our communities.

- **Culturally safe**: continuously reflect on and action ways of working that acknowledges, respects, and accommodates all cultural identities and creates culturally safe health care environments.

- **Mutual respect and value**: partner together with mutual respect and value all stakeholders' experiences and contributions.

- **Responsive**: be proactive in doing what we say, when we say it. 'Close the loop' about the influence and contributions of partners on decision making.

- **Reflective**: strive to always be better, and actively seek feedback to understand the lessons learned and improve how we operate.

Refer to all MSH consumer partnering policies, procedures, and resources available via Consumer Partnering (NSQHS Standard 2) when partnering with consumers in research.

ICARE² values

INTEGRITY   COMPASSION   ACCOUNTABILITY   RESPECT   ENGAGEMENT   EXCELLENCE

Queensland Government

1. WHAT IS CONSUMER PARTNERING IN RESEARCH?

Consumer 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 consumers.

2. WHY CONSUMER PARTNERING IN RESEARCH IS IMPORTANT

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

- Improvement in participant recruitment

- Increased participant retention

- Higher quality data and data interpretation

- Wider and more effective dissemination of findings (1).

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

2.1 MSH demographic and consumer partner profile

The Consumer Partnering Clinical Governance – MSH Demographic + Consumer Partner Profile 2022 paper develops a demographic profile of diversity of the MSH community, to ensure consumer and community engagement reach is representative of the MSH community as per the MSH Consumer and Community Engagement Strategy 2020-2022. Researchers may refer to the profile as part of their projects if relevant/required.

2.2 National Clinical Trials Governance Framework

From July 2023 partnering with consumers became a mandatory component of the Australian Health Service Safety and Quality Accreditation Scheme. For more information, refer to the National Clinical Trials Governance Framework | Australian Commission on Safety and Quality in Health Care. See also MSH guideline GL2021-77 Clinical trials for more information.

3. BEFORE STARTING

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

- **Support** - from their team leader, Director and/or research supervisor.

- **Funding** - it is best practice to remunerate/reimburse consumers for their time and out-of-pocket expenses (for example mileage, parking), so be sure to include these costs in any research grant applications.

  - Refer to MSH procedure [PR2021-285 Remuneration and reimbursement of consumer partners](#) for rates of remuneration and access [Consumer Partner Remuneration / Reimbursement Claim form](#).

  - Health Translation Queensland (HTQ) provides micro grants to support costs associated with consumer involvement in the grant application phase if the application is multi-site as part of the [HTQ Consumer and Community Involvement Program](#).

- **Time and type** - partnering with consumers should involve time across all stages of the research cycle and should be factored in when mapping out research timelines. It is also important to identify and define the frequency, type (i.e., onsite, or virtual) and duration of involvement as this will impact upon training, vaccination, and reimbursement requirements.

- **Mandatory training** - to help everyone get the most out of partnering, consider the training needs of both researchers and consumers, and who will be responsible for this. Consumers engaged in a formal ongoing Consumer Partner role **must** complete the MSH Consumer Partner Orientation Program, including mandatory training before attending the first research meeting:

  - See MSH procedure [PR2019-186 Consumer Partner orientation, onboarding and exit](#) for more information.
  - MSH Consumer Partner Orientation Program – delivered 5 times per year to all new MSH consumer partners, hosted on MSHLearn. A new Consumer Partner Orientation Evaluation tool has also been developed for deployment six (6) weeks post completion.

- **Other training** – other recommended training modules are available online and these are an excellent starting point for consumers partnering in research:

  - [MSH Research Induction](#) – available via MSHLearn it is recommended that any consumer partner who may be involved in research complete this online module.

  - [Health Literacy](#) – available via MSHLearn, assists the learner to understand health literacy and why it is important.

  - The Centre for Functioning and Health Research (CFAHR) has comprehensive [Partnering with Consumers in Research](#) training resources available.

- **Vaccinations** – see MSH procedure [PR2019-186 Consumer Partner orientation, onboarding and exit](#) for information relevant to MSH consumer partners.

- **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.

- **Engagement** – consider how researchers will engage with consumers and if they intend to develop or display any consumer information.

  - See MSH work instruction [WI2023-233 Developing and displaying consumer information](#) and

o MSH procedure PR2023-342 Delivering health literate consumer services for more information.

4. ETHICS AND SITE SPECIFIC ASSESSMENT 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 researchers 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 co-investigators on the HREA.

- If interactions with consumers 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 co-investigators on the HREA.

- **Note:** 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.

- See MSH work instruction WI2023-299 Ethical and scientific review of research for more information.

4.1 Authorship

- When completing a HREA, researchers may notice there is a section about peer review. This is where researchers should outline any consumer partnering activities they have undertaken or plan to undertake for their research.

- See the MSH work instruction WI2023-290 Research authorship, peer review and publication for more information.

4.2 Site Specific Assessment (SSA)

- As part of the SSA process the Research Governance office must be advised when consumers are engaged for a specific study. The MSH Consumer engagement and consent form template is required when the consumer is engaged as part of the research team and is likely to be included as a co-author on any resulting publications.

- To illustrate by way of examples, the MSH Consumer engagement and consent form is required if the consumer is a listed co-investigator, given data to analyse, involved in writing the PICF (Participant Information and Consent Form) or protocol, involved in study design and/or their work is being included.

- Include the **research project/study title and ERM (Ethics Review Manager) Reference Number** and ensure the information sheet/consent form is signed by the relevant Principal Investigator/Supervisor.

5. WHERE/ WHEN TO PARTNER WITH CONSUMERS IN THE RESEARCH CYCLE

The NHMRC (National Health and Medical Research Council) breaks the research process down into a five-stage cycle (Figure 1):
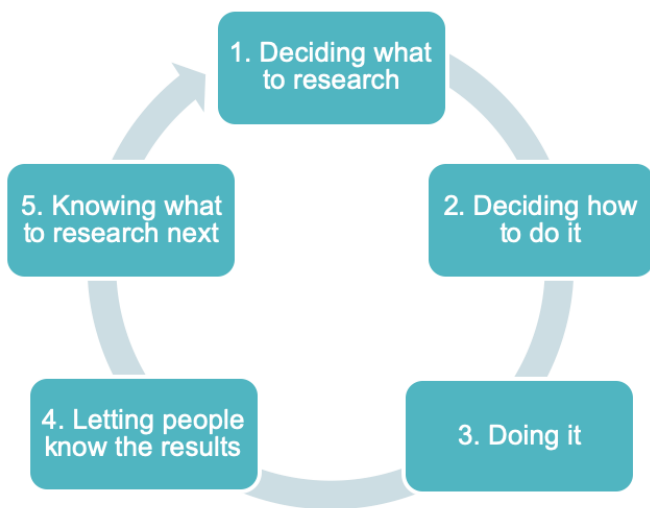
Figure 1: The NHMRC research process.

The earlier researchers can partner with consumers in the research cycle the better, but it is never too late. They can still establish partnerships for the first time later in the research cycle. For example, researchers could discuss the results of their study and check for differences in how they are interpreted, or researchers could seek ideas around innovative ways the results could be shared or taken up in practice.

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

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

6. STAGES OF CONSUMER PARTNERING IN RESEARCH

6.1 Stage 1: Deciding what to research

Consumers can help 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 researchers 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.

6.2 Stage 2: Deciding how to do the research

Consumers 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.

6.3 Stage 3: Doing the research

Consumers 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.

6.4 Stage 4: Letting people know the results

Consumers can assist with sharing research findings in several 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.

6.5 Stage 5: Knowing what to research next

Once the research is completed, consumers could help researchers 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. HOW TO PARTNER WITH CONSUMERS AND COMMUNITY MEMBERS IN RESEARCH

Once researchers have decided where in the research cycle they want to partner with consumers, it is time to plan how they are going to do it. As per the MSH Standard 2 – Partnering with Consumers 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 researchers are familiar with consumer partnering they may have noticed that these steps are set out in the context of consumer 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 the research is completed.

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

Pre-planning

This is where researchers consider their research and opportunities for partnering. Two key questions to ask are:

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

    o For example, have researchers decided:

        ▪ What their research questions are?

        ▪ Who they will be targeting to take part?

        ▪ How they are going to carry out their research, for example the design of research plan?

        ▪ The types of data they want to collect and how they might collect it?

2. **Can consumers contribute to these decisions?**

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

If researchers answered yes to both questions, consumer partnering for their 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 the project or research goals.

This is another good time to pause and consider the breadth of the partnership with consumers. If there are multiple decisions to be made throughout the research cycle that consumers can contribute to, then it is 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 (i.e., NHMRC). When reviewing overall project costs, it is also important to consider a financial incentive for consumers (i.e., a percentage of the project budget) when submitting a grant application.

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

Step 1: Prepare

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

- **Investigate what has already been done**
    - It is worthwhile to first check whether any form of consumer partnering has been undertaken in relation to the research area of interest as it may be applicable to the researcher's work. Researchers could check with:
        - Relevant local or state-wide organisations (e.g., 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 cannot be assumed that research priorities are the same locally.
    - If researchers are hoping to partner with the community to determine research priorities for their 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 researchers think about why they want to partner, consider the following:

- **The purpose and scope of partnering**
    - Think about what they want the partnership to achieve:
        - What aspects of the decisions can consumers give insight into or feedback on?
        - How can researchers work together with consumers and bring them in to become members of the team?
        - Can consumers 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 purpose? (e.g., start with a blank page and see if the consumer's ideas align with the project).
        - Consider the number of consumers needed, remembering that at least two are recommended. Would involving a core group of consumers be the best way to achieve the objectives?
        - How can researchers 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 will consumer members have?**
    - Table 1 below is adapted from the Metro South Consumer and Community Engagement webpage and outlines the five levels of engagement, which span from 'Inform' to

'Empower/Lead'. Researchers may require feedback on parts of their research (consult) or want to partner with consumers throughout the research process (collaborate). Alternatively, researchers may be aiming for consumers to drive the research and make the final decisions (empower).

Table 1: Levels of consumer engagement

	Level of engagement				
	Inform	**Consult**	**Involve**	**Collaborate**	**Empower**
Community engagement goal	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
Promise to the community	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
Level of consumer / community interface	Level of consumer/ community influence is zero	Consumer/ community involvement and influence is low	Consumer/ community have some influence	High consumer/ community involvement and influence	Consumer/ community control

o   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 researchers may

feel more comfortable working with consumers at the 'Consult' or 'Involve' level while they build relationships, develop their skills, and familiarise themselves with the partnering process.

- **Who could researchers recruit as consumer partners?**

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

    o Consider how diversity of consumers may be important to the topic. Are there people from a particular demography, or people who have had experiences that researchers need to approach? Is a wide range of viewpoints important to the outcomes?

- **Where could researchers go to recruit consumers?**

    o Researchers can recruit consumers via several channels:

        ▪ From their existing networks, by asking colleagues for recommendations, or by approaching people they provide clinical care to.

        ▪ From their 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 their research topic (e.g., Cancer Council, the Heart Foundation, the Asthma Foundation).

        ▪ Contact Health Consumers Queensland

    o Before researchers approach individuals or organisations, it is important to develop an information sheet utilising the [Consumer engagement and consent form](#) that outlines the project and what is involved. This will:

        ▪ Prompt researchers to think about what they will be asking of individuals or groups; how many people they might need; how they might interact with individuals/groups; where this will occur; any training that might be needed; what reimbursement and/or payment researchers 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. Researchers 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**

    o Just as researchers need education and guidance when first embarking on the consumer partnering journey, consumers 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 are involved in.

- Any Consumer Partner who will be involved in an **ongoing formal way** with the research team will have to undergo the MSH Consumer Partner Orientation program. Refer to MSH procedure [PR2019-186 Consumer partner orientation, onboarding and exit](#).

- There may be specific content knowledge or research skills that consumers will need to participate as partners in research. The Metro South Research Induction online module introduces how research is conducted in MSH. It is recommended that any consumer who is partnering with a research project complete this module.

- The NHMRC have developed a resource pack which may be useful, or researchers may need to develop specific training on tasks they are wanting consumers to undertake. Researchers should be clear about what they need from consumers; provide written resources if required; give examples so people can see how it has been done; 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, researchers will need to check whether there are any training or administrative requirements (such as organising computer access, visitor badges, provision of information, reimbursement, and remuneration) that are needed prior to starting.

Step 2: Plan

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

- **Think about how researchers might partner with consumers**

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

- **Plan of what researchers will need to do before, during and after an engagement activity**

  - Start to dive into the details. If researchers plan to hold a community forum or small workshops - how might they 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 researchers 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 researchers are thinking of conducting interviews, how many people might they aim for? What kind of methods can they offer – face-to-face, telephone, Zoom or Teams? How much flexibility can they offer regarding when interviews will be conducted? Will they record the interviews so they can summarise the main points afterwards? Again, this is where they will need to consider what education and training is needed - both for themselves and consumers - to ensure everyone gets the most out of the engagement experience.

- **Consider what could go wrong and the steps you will 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 these be managed?

- **Decide how you will know if your engagement activities were effective**

  o What kind of things will researchers 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 were interviewed. Could everyone share ideas? Was the venue suitable for everyone involved? How did the consumers feel about the experience?

Step 3: Engage

Once researchers have implemented an action plan and met with consumers, it is time to:

- **Examine consumer ideas and feedback**

  o 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 to use the feedback**

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

- **Communicate this back to consumers**

  o Be sure to contact consumers soon after the event to thank them for their time and input. This step is vital. Even if researchers have not been able to sort through their own ideas and feedback yet, let people know when this will be done and when they will get to hear how their input has shaped the research. It is 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.

  o Keeping the style of communication consistent may be helpful for consumers. This means consistency of terms used, and use of glossaries where required. A standard visual style/template that identifies the research and sets out information clearly, may improve the consumer experience.

Step 4: Evaluate

Undertake this step once the end of the research project is reached. Researchers will need to:

- **Complete their evaluation**

  o Complete an engagement activity report and think about what went well, what did not go so well and what they might do differently next time. Think about asking consumers to provide feedback via an anonymous survey or feedback form.

- **Share what they did**

- o Discuss their partnership journey in any presentations given about their research and be sure to include it as part of their methods in any manuscripts they submit for publication. There are multiple guidelines available to help researchers, including the Guidance for Reporting Involvement of Patients and the Public (GRIPP) and the British Medical Journal (BMJ).

RESPONSIBILITIES

Position	Responsibility	Audit criteria
MSH Consumer Partnering Team	Ensure policies and procedures are in place which supports the integration of clinical governance of partnering with consumers in MSH. Implement processes pertaining to the reimbursement of consumer partners. Provide consumer partner orientation, onboarding and exit support and advice. Coordinate feedback from consumer partners.	N/A
Metro South Research	To review completed MSH Consumer Partnering Information Sheet/Consent Forms as part of the Site Specific Assessment (SSA) authorisation process.	N/A
Principal Investigator (PI)/ Coordinating Principal Investigator (CPI) - responsible officer	Ensure meaningful and ethical collaboration, including involving the consumer in the research process, respecting their perspective, addressing their needs, and valuing their input to enhance the relevance and impact of the research.	N/A

DEFINITIONS

The definitions below are taken from the MSH agreed definitions for Consumer Partnering and the NHMRC's statement on consumer involvement in health and medical research (2).

Throughout this guideline certain words are used interchangeably to match how they may be used across different organisations around the world, for example:

- 'partnering' may also be referred to as 'involvement', 'engagement', 'driving ideas', 'collaborating' or 'working together'

- 'consumers' may be referred to as 'public'.

Term	Definition
Community	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.
Consumer	People who use, or are potential users/patients, of health services and includes family, carers, care partners and communities.
Consumer Partner	Consumers who partner with Metro South Health for health care decision making or for the planning, design, delivery, measurement, evaluation and/or governance of health care. Consumers may partner with Metro South Health as individuals (patients, family, carers, care partners, Consumer Partners) or groups and communities.
Consumer Partnering	An ethos and practice that seeks to engage with consumer partners as fundamental collaborators for health services improvement in patientcare and for the planning, design, delivery, measurement, evaluation and/or governance of the health care services. Partnering practices use a range of approaches, tools and techniques that are appropriate for consumer partners, the issues at hand and the health service decisions to be made.
Formal Ongoing Consumer Partner Role	A person who has been selected and had agreed to commence in a formal ongoing Consumer Partner role to support a committee/project/working group/research activity within MSH.
Orientation	A process of informing and socialising a consumer to the position of a Consumer Partner on a committee, project, or research, and which aims to welcome the consumer, gain commitment, help the consumer to understand the organisation, and provide the opportunity for establishing shared expectations.
Research cycle	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 [5].
Stakeholder	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. Stakeholders may provide support, expertise and influence decisions about the research and its findings.

RELATED DOCUMENTS

Legislation and other Authority	• *Hospital and Health Boards Act 2011 (Qld)* • Hospital and Health Boards Regulation 2012 (Qld) • ICH Topic E6 (R2) Integrated addendum to ICH E6 (R1): Guideline for Good Clinical Practice (ICH E6 R2) with TGA annotations • National Statement on Ethical Conduct in Human Research (2023) • QH-HSD-047-1:2016 Health Employment Directive No.01/16 Vaccine preventable disease (VPD) requirements • QH-POL-183 (G6 Policy) Queensland Health Human Resource (HR) policies Service Level Agreements

Standards	• National Clinical Trials Governance Framework
	• National Safety and Quality Health Service (NSQHS) Standards 2nd Ed.
	    o Standard 1 – Clinical Governance
	    o Standard 2 – Partnering with Consumers

Supporting resources	**Policies** • PL2019-64 Consumer Partnering **Procedures** • PR2021-285 Remuneration and Reimbursement of Consumer Partners • PR2019-186 Consumer Partner orientation, onboarding and exit • PR2023-411 Research excellence • PR2023-412 Research support and management • PR2023-413 Research administration and compliance **Work instructions** • WI2023-287 Research integrity • WI2023-288 Research quality management systems • WI2023-299 Data and privacy • WI2023-290 Research authorship, peer review and publication • WI2023-291 Research complaints and misconduct • WI2023-292 Assessing and managing risk in research • WI2023-299 Ethical and scientific review of research • WI2023-301 Site specific assessment of research • WI2023-297 Registration of research gift cards

Guidelines

- GL2021-75 Partnering with consumers in research
- GL2023-97 Aboriginal and Torres Strait Islander health research
- GL2023-98 Research translation and impact
- GL2023-99 Planning a research project
- GL2021-77 Clinical trials

Other

- MSH Centre for Functioning and Health Research – Research training resources (Partnering with Consumers in Research)

Other - external

- [Queensland Health TRIP Training and education](#)
- [Australian Clinical Trials Alliance Toolkit for Researchers and Research Organisations](#)
- [Monash Partners | Consumer and Community Involvement](#)
- [NHMRC Consumer and Community engagement resources](#)
- [Patient-Centred Outcomes Research Institute](#)
- [Health Consumers Queensland (HCQ)](#)
- [International Association for Public Participation (IAP2)](#)
- [Community Mental Health Drug and Alcohol Research Network (MHDARN) Co-design kickstarter](#)
- [Health Translation Queensland | Consumer and community involvement resources](#)

REFERENCES

No.	Reference
1	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.
2	Consumers Health Forum of Australia. Statement on consumer and community involvement in health and medical research. National Health and Medical Research Council; 2016.
3	BMJ. Patient and public partnership: BMJ Publishing Group; 2018.
4	Queensland Government. Metro South Health Research Strategy 2019-2024. Brisbane 2019
5	National Health and Medical Research Council. Resource pack for consumer and community participation in health and medical research. 2004.

HUMAN RIGHTS ACT 2019

Metro South Hospital and Health Service is committed to respecting, protecting, and promoting human rights. Under the *Human Rights Act 2019*, MSH has an obligation to act and make decisions in a way that is compatible with human rights and, when making a decision, to give proper consideration to human rights. When making a decision about partnering with consumers in research, decision-makers must comply with that obligation. Further information about the *Human Rights Act 2019* is available at: https://www.forgov.qld.gov.au/humanrights.

GUIDELINE DETAILS

Guideline Name	Partnering with consumers in research
Guideline Number	GL2021-75
Current Version	2.0
Keywords	Research, Consumer Partnering
Primary Document Reference	PR2023-411 Research excellence
Executive Sponsor	Chief People, Engagement and Research Officer
Endorsing Committee / Authority	Metro South Health Research Council
Document Author	Manager, Research Development, Metro South Research
Next Review Date	December 2026

REVIEW HISTORY

Version	Approval date	Effective from	Authority	Comment
1.0	5/01/2021	5/01/2021	Metro South Research Committee	Partnering in Research: Allied Health and Consumer Collaboratory (PRACC), MSH Consumer Partnerships and Metro South Research - update • Change to practice • Removal out of date information
2.0	07/12/2023	14/12/2023	Chief People, Engagement and Research Officer	• Title change, general updates and removal of out-of-date information. • Update to reflect Research Policy Framework requirements