

GUIDE: Describing and Assessing Consumer Involvement in Health Research in Funding Applications

ABOUT THIS GUIDE

Researchers submitting funding applications to Sydney Health Partners (SHP) and many other funding organisations (e.g., the Medical Research Future Fund and National Health and Medical Research Council) are required to demonstrate how they will involve consumers and/or community members in their proposed research projects. Consumer involvement is also part of the National Clinical Trials Governance Framework for all health organisations across Australia and promotes consumers as key partners in clinical trials. Consumers are being included as team members and named investigators, including as Chief Investigators in some cases. Consumers are also being included in application review processes. This challenges researchers to consider consumers as important stakeholders when designing and writing research proposals and funding applications.

This Guide aims to help **researchers** to describe planned consumer involvement in their research funding applications; and **reviewers** to assess proposed consumer involvement in such applications. It has been developed by SHP's Consumer Advisory Panel comprising experienced health consumers from across our partnership. It has also been tested with SHP researchers as part of the development process. The Guide is for use within SHP but may be helpful in other contexts and settings.

SHP has a strong commitment to promoting and supporting greater consumer and community involvement in health research. In this context, 'involvement' refers to a partnership between consumers and researchers, where consumers are actively involved in the research process, and 'consumers' include persons who use, have used, or are potential users of, health services.[1] We advocate that consumer involvement in research rests on four key principles: Respect, Equality, Inclusion, and Evidence.[2]

Evidence shows the design, conduct, benefits, and use of health research are significantly improved by the involvement of consumers and community members throughout the research process. Consumers bring their lived experiences, not only of health services and health conditions but also personal and professional backgrounds that are unique and add a different perspective to the research team.[3] Both consumers and researchers develop new skills and capabilities through such partnerships. Importantly, consumers are part of the wider community of potential beneficiaries of research and can help ensure research is relevant to them.[4]



SHP's Consumer Advisory Panel, a sub-committee of the SHP Board, is working to make it easier for consumers and researchers to find ways to connect and collaborate. SHP also has a strategic partnership with Health Consumers NSW, the state's peak health consumer organisation, which works with us to develop and deliver training and resources that help consumers and researchers work in ways that are mutually rewarding and respectful. Many organisations across Australia and internationally also provide free access to tools and resources[5,6,7] to support consumers and researchers to work together in mutually beneficial ways.

This Guide draws on several existing resources that provide related guidelines and instructions.[8,9,10,11,12]

GUIDANCE FOR RESEARCHERS

Best practice in consumer involvement means investing in relationships. It is important that there are clear, shared expectations of what the role of consumers will be in the research. Each consumer should be given a clear description of their role, which may include where, when, and how you will work together, anticipated contributions and time commitments, approaches to communications and meetings, and reimbursement and/or remuneration details. These factors and several others have been identified as key enablers for meaningful consumer engagement.[13]

Ideally, researchers should engage with consumers early in the development of a research proposal. If the project then continues, consumers should be invited to be part of the research team supporting the conduct of the project and reporting of results.

Researchers should consider whether they wish to involve consumers with "lived experience" relevant to the research project, or other consumers who may have an interest in health research but not necessarily direct experience with the health issue being studied. For example, in an oncology study one might involve a person with cancer or who has previously had cancer, or their carer, or someone skilled who has had no experience with cancer. In all cases, it is important to recognise that consumers bring a range of life experiences and skills that may be relevant and helpful to a research project.

Partnering with consumers also requires researchers to work in different ways. Meaningful consumer involvement requires self-reflection, a willingness to share power, and to recognise that lived experience is a type of knowledge that can be integrated into research without risking its scientific integrity. Ignoring or dismissing consumer perspectives can adversely impact consumers as well as the reputation of researchers and their institutions.

When describing the involvement of consumers in a research project, the following questions may be helpful as a guide to information a researcher might include. Some related preparatory operational considerations are included in the Appendix. It should be noted that SHP and other funding organisations include consumer representatives in the review process so research proposals should be written in ways that are readily understood by a diversity of readers.



1. At what point did consumer(s) become involved and what is their role in the research team?
2. Were consumers involved in selecting and shaping the research question(s)? Why was their input relevant and helpful? How did this involvement influence the research question(s)?
3. Were consumers involved in designing the project proposal? For example, perhaps they commented on the feasibility of the project design, the burden placed on research participants, or the levels of risk or discomfort participants might be exposed to? Did the consumers advise on the recruitment process?
4. Were consumers involved in writing or reviewing other aspects of the funding application? For example, did they review the lay summary to make sure it was easy to understand? Were they involved in decisions about the budget and proposed funding for consumer-related activities?
5. If consumers were NOT involved in developing the funding application, can you explain why? How will they subsequently be involved? What specific actions will be taken to bring consumers into the project if it proceeds?
6. If the project proposal is funded, how will consumers continue to be involved in the project going forward (e.g., start up, data collection, data analysis, interpreting results, communicating findings, etc.)? For example, will they be involved in drafting or reviewing participant information sheets and other documents which might be used with prospective research participants? Will they contribute to plain English summaries about the project? Will consumers conduct aspects of the research?
7. Do you plan to set up a consumer advisory group to support the project? What role and influence will this group have in decisions about the project?
8. What skills and experience does the research team have to engage with consumers?
9. Will training or support be offered to consumers and researchers involved in the project to work together? For example, can access be arranged for consumer involvement training like the options developed by SHP and Health Consumers NSW? [14,15]
10. Has additional time been included in the project timeline to support consumer involvement activities? Remember, consumers are usually not scientists with knowledge of how research works.
11. Will consumers be reimbursed and/or remunerated? Has this been included in the proposal budget? There are guidance documents with suggested payments (for example,[16,17])
12. How will the contributions of consumers be acknowledged? For example, will they be included in publications arising from the project, or co-present the results at meetings?



Each consumer is different. An individual consumer brings unique experiences and perspectives that are not necessarily the same as others from the same community. For this reason, you may consider involving more than one consumer for diversity in backgrounds and experiences. This can also be achieved by engaging with consumer advocacy groups, disease-specific support groups, or other community groups as part of the project. Not every consumer has to be involved in the project in the same way. Different people can have different roles or tasks.

Researchers should also note that the nature and extent of consumer involvement in a project funded by SHP will also be monitored through progress reports requested by SHP from time to time. It is recommended that researchers keep a log of consumer involvement activities throughout the project for such reporting purposes.

GUIDANCE FOR REVIEWERS

Funding opportunities offered by SHP include assessment of applications by a panel of reviewers. Panels may involve volunteers from our partner organisations with requisite research and healthcare experience, and independent reviewers including experienced consumers. Funding applications should include enough detail to allow all reviewers to assess and score the application and should avoid using overly technical language and excessive use of abbreviations.

Consumer reviewers are sometimes asked to score specific sections of a funding application, such as a plain English summary of the proposal, and sections that describe how consumers have been involved in the development of the proposal and how they will be engaged in the project if it is funded. Alternatively, consumer reviewers may be asked to assess the full application.

The following scoring matrix aims to assist all reviewers in assessing consumer involvement in a funding application submitted to SHP. The matrix and the examples of how consumers might be involved in research are intended as a guide only. It is recognised that the nature of consumer involvement will vary across different projects, as will the specific scoring method for each funding opportunity (the guide below uses a score out of 10 for illustrative purposes). What remains consistent is the goal of authentic, meaningful, and respectful consumer involvement.



SCORING GUIDE FOR ASSESSING CONSUMER INVOLVEMENT IN RESEARCH APPLICATIONS

Degree of consumer involvement HIGH	Score (out of 10) 7-10

The application demonstrates broad and meaningful ongoing involvement of consumers in the research and includes detailed and specific information about their involvement throughout the research. For example:

- Specific consumers are named; how they have been involved in the planning of the research is well described as well as what they will contribute if the research proceeds.
- Specific strategies and activities are described to ensure consumers are well integrated and supported by the research team. This includes how consumer perspectives are sought, e.g., in meetings and on draft documents, and how decisions are made about how these perspectives are integrated into research.
- There is a high degree of consumer involvement in decision-making at various stages of the research.
- Budget discussions and decisions include input from consumers, and an appropriate level of funding has been allocated for consumer-related activities and meaningful involvement.

Degree of consumer involvement MODERATE	Score (out of 10) 4-6

The application demonstrates consumer involvement in some specific aspects of the research journey and/or the input from consumers is primarily in the form of consultation and advice rather than being part of the decision-making about the research. For example:

- Consumers are involved only in reviewing participant information sheets, informing recruitment strategies, or designing participant surveys.
- Details about how consumers will be supported by the research team are limited or missing.
- Consumers have advisory rather than decision-making roles.
- Budget discussions and decisions include some input from consumers, e.g., regarding proposed funding for consumer-related activities only.

Consumers may not yet have been involved in the development of the research proposal and funding application. However, a detailed explanation is provided and there are specific plans to remedy the situation.

Degree of consumer involvement LOW	Score (out of 10) 1-3

The application demonstrates minimal or no consumer involvement in the research. For example:

- There has been limited or no involvement of consumers in the development of the application and it has not been explained.
- The proposed research includes general statements of intended activities associated with consumer involvement (e.g., “consumers will be consulted …”, “results will be shared with consumers …”) and there are few or no details about how this will be done, who will be involved, etc.
- Consumers may be given information about the research and invited to ask questions but have little or no opportunity to influence its design.
- There is little or no input from consumers in budget discussions and decisions, and/or little or no funding allocation for consumer-related activities.



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APPENDIX: SOME PREPARATORY OPERATIONAL CONSIDERATIONS

Ethical: The involvement of consumers as partners in research, including as members of an advisory group, does not require ethical approval. At times, researchers who are involved in providing health care may identify patients or family members as potential partners in research. Consideration should be given to any potential, perceived or real conflicts of interest. Asking an independent colleague to discuss partnering opportunities may be one option.

Finding consumers interested in research: As mentioned in the Guide, each consumer is different, and researchers should endeavour to partner with a diversity of people. Some options to help find consumer partners include: tapping into personal or professional networks; approaching disease-specific patient-support or advocacy groups; or asking Health Consumers NSW to promote a research partnership opportunity to its members. Not all health consumers are interested in research. Some may be interested but not have much experience with research and will need to be supported with training and resources. Researchers can use a simple Expression of Interest form that includes information about the proposed study, the partnering role and related responsibilities and seeks limited details from the consumer to help with identifying potential candidates.

Onboarding procedures for consumers: Organisations have different processes and requirements for on-boarding new consumers as partners in research. Researchers should familiarise themselves and allow sufficient time to complete relevant procedures. Researchers may consider appointing a team member as a key contact for their consumer partners who will be responsible for regular communication, assisting with any processes, answering questions, etc.

Continuity of consumer involvement: The time from research proposal development to research completion and reporting of results can frequently extend over many years. The life circumstances of research team members, including consumers, may change over time. For example, a consumer may need to take a break from research involvement activities to manage their own health or that of a loved one. Having strong relationships and good communication pathways will help foster openness and honesty about the need to change involvement arrangements. Involving more than one consumer partner in a research team can also help support continuity of consumer input over the research life cycle as well as providing diversity of views.