INTRODUCTION

Different grants have different requirements for engaging with the community, consumers, end-users of research or ‘the public’. Increasingly, some grants include a section assessed by representatives of groups affected by the research topics or issues the grants are seeking to address. For example, the Cancer Council NSW has a Consumer Review Panel that decides 50% of the overall score during assessment of their Project Grant scheme. Likewise, the NHMRC is starting to appoint “consumers and community representatives, with relevant lived experience” to peer-review panels for Targeted Calls for Research, and is tasking them with helping to determine how effectively such groups are involved in the different stages of research.

This guide is divided into two parts – designing your consumer engagement, and then writing about it in grant applications. It is intended as a general guide of topics or issues to consider. Please refer to the grant rules for specific information, and consider these suggestions in light of what is appropriate to your discipline and project. For further discussion or advice, please contact FMHHS Research Support team: fmhhs.researchsupport@mq.edu.au

SUMMARY OF KEY POINTS

• Use best practice guidelines and toolkits relevant for your area when developing your consumer engagement (see below).
• Consider what organisations and partners are available to help you develop/build consumer engagement.
• Be specific and precise when writing about consumer engagement: explain what you’ll do, how you’ll do it and why it will matter.

WHY ENGAGE CONSUMERS IN RESEARCH?

The NHMRC seeks to encourage and involve consumers and community involvement in health and medical research because:

“... consumers and community members add value to health and medical research and have a right and responsibility to do so.”

Expectations and Value – Framework for Effective Consumer and Community Engagement in Research, p1

If it is to be done well, consumer and community engagement should be part of your research project – not just part of the grant application. This means you must have considered it and be able to justify and explain it the way you would, say, your chosen research methodology. Consider what makes most sense in terms of your research project’s lifecycle, your research objectives, and the aims and expectations of the funding scheme.

“Consumers and community members can be actively involved throughout the research journey ... However, it is important that involvement of consumers and community is not ... tokenistic but rather is an active partnership that benefits all.”

Expectations and Value – Framework for Effective Consumer and Community Engagement in Research, p1
DESIGNING YOUR CONSUMER AND COMMUNITY ENGAGEMENT

Writing about your consumer and community engagement is always harder if you haven’t done the groundwork, thinking and designing what it should look like. This next section draws together some of the useful resources available to help you design this part of your research.

Most importantly, don’t be intimidated by – or put off doing – this part of the research design. Even if it’s new to you, or less common for your field of research, there are a lot of resources to help you do a good job designing this part of your research project; plus, it takes time.

BEST PRACTICE GUIDELINES FOR ENGAGING CONSUMERS IN RESEARCH

There’s a wide array of best practice guidelines for engaging consumers in research: some are available for specific research schemes, but others have been developed by peak-bodies, advocacy groups or community organisations.

In addition to seeing whether the funding scheme you are applying to has their own guidelines or toolkit, an excellent place to start is the NHMRC. The NHMRC has developed a Toolkit for Consumer and Community Involvement in Health and Medical Research (2020), which is available online. The NHMRC toolkit includes a Framework for Effective Consumer and Community Engagement in Research document.

Several peak-bodies, community organisations and advocacy groups have developed guidelines and toolkits for collaborative research, or for researchers to consider when designing their research or engagement practices. For example, Health Consumers NSW have resources for involving health consumers in research. There are also particular patient- or experience-centric groups or networks like Cancer Voices Australia, or the National Mental Health Commission guide for Consumer and Carer Engagement. Some fields of research activity have additional resources, like the Australian Clinical Trials Alliance.

See if there are any that are particularly relevant to your field of research or grant application. Also look at what services the organisations provide: while some focus on best practice principles, others have a broader remit, and have services to help connect consumers and community to specific research opportunities, or are happy to help publicise research and findings through newsletters, meetings, etc.

THINK ABOUT ENGAGEMENT EARLY

Engagement should be appropriate to the proposed research project, for the groups you’re seeking to engage with, and for the grant scheme.

That can mean thinking about your engagement in relation to the purpose and scale of the project. For example, an evaluation of a service will likely have a different strategy for engaging with consumers or end-users of research than a project centred on animal models; a funding duration of one year might have fewer opportunities for engagement than a multi-year project.

Where in your research project lifecycle does engagement fit in? It isn’t just at the end for dissemination of findings if you’re following best practice engagement approaches. Rather, it would also involve people who could be affected by the research as part of designing the research at the start of the process. It might be in multiple times and/or places. Be clear and specific about how consumers are involved, and what they’re contributing – the same way you would for an academic partner or contributor.

Show meaningful engagement: for example, if you’re asking people for feedback on the project in the development phases, make sure you explain where and how that feedback will be incorporated.

WRITING ABOUT YOUR CONSUMER ENGAGEMENT

Once you’re confident in the design of your consumer engagement, then writing about it becomes much easier. The following are tips and suggestions for how to approach answering the relevant sections on grant applications.

STRIKING THE RIGHT BALANCE IN YOUR ANSWER

Include an appropriate level of detail for your application – be guided by word count.

It’s easy to be too general in these answers, so try to be specific, and explicit, when writing these answers. Don’t just say “will consult” or “will share results”. Who will be consulted? How will they be consulted or involved? What would you like them to contribute? What do you hope will change as a result?
Your answer is more tangible and credible when you include specific information, for example listing specific networks you’d like to disseminate your findings through, or showing evidence you have done similar things before, or naming specific consumers you have been engaging with during the project design, what they have already contributed, and how they will continue to engage with during the project.

**WHO IS READING YOUR APPLICATION?**

Some grant applications have sections assessed by members of the community or stakeholders. Read the guidelines to find out whether there are sections of your grant that will be reviewed by people other than academic peers.

Follow the guidelines or directions for the application – if it says “plain language”, take time to re-read your summary, and consider asking people outside your discipline or research area to review it. This is also something consumers can, and do, help with! Can the project, and why it matters, be easily understood by someone who isn’t involved in your research field? Avoid using jargon.

Think about the terminology the grant instructions, guidelines or funding rules use. Do they talk about consumers? End-users of research? Stakeholders? Choose your terminology to be appropriate to the grant you are applying for.

Try to differentiate between groups involved in or affected by your research. Not all stakeholders have the same interests in your research, and may need different kinds of engagement.

**THINK CREATIVELY AND INCLUSIVELY**

Accessibility and inclusiveness matter, especially for consumer and community engagement. Keep in mind the two key questions about the outcomes from your project:

- Who needs to be able to access the information your research project will generate?
- What is the best way of making sure that they can access it?

For example, if you’re distributing a plain-language summary of your research, is a written summary in English the most appropriate way of reaching your audience? Is it helpful to provide resources in languages other than English? Or a short video that could be captioned? Or creating a guideline or policy document with the key consumer advocacy group in the area?

Think too about the accessibility of your data. Macquarie University has a new [Research Data Management Policy](#), which includes following the FAIR Principles for Research Data when possible (note necessary privacy exceptions). The FAIR Principles suggest research data should be Findable, Accessible, Interoperable and Reusable. For more information, see the [Australian Research Data Commons](#).

**USEFUL RESOURCES**

Other documents that you might find helpful in designing and preparing this part of your grant are:

- [Impact Canvas](#) designed by the Macquarie University Office of Commercialisation and Innovation
- [Stakeholder Mapping Template](#) (see Consumer Engagement section of our page).

Guidelines and/or Toolkits for Consumer and Community Engagement:

- NHMRC Consumer and community engagement resources are available online [here](#).
- [Health Consumers NSW](#) has a variety of resources available online, ranging from training opportunities, to requesting a health consumer representative. They also host other documents helpful for preparing grant applications, or documents intended for consumers, for example a list of [words or phrases that should be avoided](#) in plain language sections, because consumers consider them unclear or ‘jargon’.
- The Australian Clinical Trials Alliance has a [toolkit](#) for consumer engagement and involvement in research. It includes a [timeline](#) with information and opportunities for involvement or inclusion at each stage of the research process.

Samples and Exemplars of Consumer Responses about Engagement:

- Cancer Council NSW has [resources for researchers](#), including [Consumer Review guidelines for research grant applications](#). While specific to the Cancer NSW grants schemes, the Consumer Review guidelines have questions to guide answers and thinking about consumer engagement, and examples of effective or highly rated consumer engagement responses. The examples cover a range of research topics including those that are discovery or fundamental biological sciences, as well as psychosocial examples, and involving clinical trials.

Writing for a Lay Audience:

- The Academy of Medical Sciences in the UK has [tips for writing for a lay audience](#), and [examples of lay summaries](#).