

Heart Foundation Research Program

Consumer Guide for Researchers



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1. Consumer Engagement Guide

The purposeful involvement of consumers in health research can pay remarkable dividends both to the research project at hand and to the general population. This guide discusses the practical considerations that encourage researchers to incorporate consumer participation into every major research study they undertake and discusses the principles and best practices that inform such participation.

In the broadest view, the public benefits from greater awareness of science and research. Awareness is a somewhat intangible benefit, but a greater public understanding of medical research can make all the difference when that research is translated into policies and programs that seek to measurably improve health outcomes on a large scale.

Greater community involvement in science and research can even help guide researchers toward the most profitable avenues of inquiry. When communities are engaged in scientific research, they tend to support it more fully; with greater community support comes greater encouragement for researchers to conduct studies that are immediately relevant to the community's needs.

This dynamic also benefits researchers. Medical research is a practical field whose successes are measured in improved public health; greater public engagement means more relevant research and more real-world success. It also provides researchers with more opportunities to refine and improve the quality of their studies.

Researchers benefit in an even more fundamental way from consumer involvement. Because so much health research relies in whole or in part on public funding, increased public understanding of and engagement with medical research renders the entire research process more open and transparent. This, in turn, supports greater levels of public confidence in researchers' use of public funds. Demonstrations of accountability can be just as important—indeed, even more so—when appealing for support from private sources.

The following guide is based on material provided by the National Health and Medical Research Council: *Statement on Consumer and Community involvement in Health and Medical Research, National Health and Medical Research Council (2016), Consumers Health Forum of Australia.*



2. Involving consumers in your research

Elements of consumer involvement

Health and medical research comprise a wide range of work, from statistical analyses to studies of the frontier between biology and nanotechnology. Each study's character and scale determine, to some extent the opportunities researchers have to engage and inform the public. Most health research, though, can be supported by these three key elements.

- **Direct involvement.** Research is a multi-layered process encompassing planning, fundraising, facilities management, and many other functions aside from those performed by credentialled scientists. Some studies even benefit greatly from the employment of community members in the gathering of raw data. Each of these elements presents researchers with an opportunity to engage the public. Health research that focuses explicitly on health-related behaviours often benefits from the direct input of community members.
- **Skills development.** When community members are directly involved in conducting research and communicating results, they typically require information, training, and other forms of support to fulfill their roles. This is a perfect time to introduce consumers to the inner workings of health and medical research.
- **Representation.** Without some explicit effort to solicit the participation of all community members, research institutions may find themselves employing—in both volunteer and paid roles—persons who collectively represent a relatively narrow demographic. The best person should be selected for each role, with respect to age, gender, physical ability, cultural background, experience, and availability. When the applicant pool for a given position fails to represent the greater community, research institutions should consider the reasons why, and take affirmative steps toward encouraging the broadest possible spectrum of applicants.

Why is consumer involvement so crucial?

The health consumer movement has become a cornerstone of both public and private health practice. Over the last quarter-century, Australian health care providers have come to embrace the notion that greater consumer involvement allows health-services professionals to plan more confidently, develop more robust policies, and deliver health care services more effectively.

The Heart Foundation embraces this view. Our research efforts find their fullest expression in the advancement of health care for all Australians, and only with the participation of consumers can we ensure that both the questions we ask and the answers we pursue are rooted in the most beneficial context possible. For us, involving consumers throughout the research process is a critical component of the research process itself.

Levels of consumer involvement

Consumer involvement for any research activity will depend on the purpose of the involvement, the resources available, and the type and subject of the research.

When looking at consumers in research, the Heart Foundation appreciate that consumers could look different depending on the research category. A piece of research could be aimed at the patient, doctors, nurses; all projects will vary.

Consumers can be, and are, involved at various levels of research, at various stages of the research cycle and in the institutions in which research is conducted, including but not limited to:

- as a member of the institution's governing board
- as a member of a strategic research advisory group advising on research priorities
- as a chief investigator on a research project or grant application
- providing their perspective on specific research programs or projects over the course of the research cycle
- providing their perspective on the translation of research into patient care
- clinical trials
- being provided public information on the research being conducted

Considerations for researchers

Institutions

Consumer involvement with health research touches on how research projects are proposed, selected, funded, and undertaken. It bears especially heavily on how the results of the research are communicated and how research is translated into health care practice.

Because of this, consumer involvement is primarily an institutional concern, however motivated individual researchers may include the community in their work. Institutions who wish to involve the public more fully must commit to a few guiding principles toward this goal, including the following.

- Incorporate community involvement at all stages of the research cycle
- Identify and minimise barriers to consumer participation in research studies
- Support community-involvement initiatives through training, capacity building, and support for both researchers and consumers
- Explicitly define the level of consumer involvement at each stage of the research cycle, with respect to the project's objectives
- Respect the time and effort invested by consumers and acknowledge it through meaningful remuneration or by other means
- Develop a formal policy on consumer involvement in the institution's research reflecting the considerations listed above

Practical expressions of these principles are most effectively guided by the last item on that list. A formal policy of consumer involvement provides a framework for developing effective engagement strategies.

Among the most important forms of commitment to greater community participation in health research is a deepened resolve to communicate research findings. A robust communications strategy does more than simply educate the public on the value of scientific research. It also makes the entire research cycle better understood and more accessible to a more representative spectrum of community members.

Institutions can go even further by working with community stakeholders to actively increase their ability to participate in the research cycle. Workshops and other formal initiatives help ensure accurately representative participation by a better-prepared and educated public.

A better-prepared community deserves better-prepared researchers. By building the capacity of researchers to incorporate consumer and community involvement in their projects, research institutions can greatly encourage future public participation while helping researchers reap all possible benefits from greater consumer and community involvement.

These strategies require some investment of both time and money. Institutions should be prepared to give researchers extra time to plan consumer-involvement initiatives, and to budget resources for training and other forms of support, along with any administrative overhead that may be required. Workshops and other events may require one-time expenditures, and consumers and community members whose participation is especially valuable may best be recognized with honoraria. Finally, resources should be allocated to support the evaluation of consumer-involvement initiatives and to report on their success.

Researchers

While much of an institution's consumer-involvement programs are best administered centrally, individual researchers are the best arbiters of how and to what extent consumers are best invited to participate in a project.

This is best achieved by including consumer involvement in each project's early planning stages. When the project's goal and scope are first identified, researchers can greatly increase their chances of meaningful and beneficial community involvement by seeking collaboration with all stakeholders, including consumers and the public at large.

Best practices for consumer involvement

While each research project is unique, successful efforts to include consumers' health research tend to follow a core group of best practices.

Above all, researchers should begin planning for consumer involvement as early as possible. Outreach to consumers and the general public can take time, and early inclusion of community involvement helps ensure that its greatest possible benefits serve the project's overall goals.

Extra effort may be needed to secure the participation of a representatively diverse group of consumers and community members. If initial efforts to solicit consumer involvement result in too homogeneous a range of participants, researchers should be prepared to reach out to underrepresented groups.

While a new research project is being developed, and while it is underway, researchers should communicate regularly and respectfully with all participating stakeholders, using accessible, plain language when addressing members of the public.

Researchers and research facilities should also be aware of some common impediments to mutually beneficial consumer and community involvement.

Research investigators should bear constantly in mind that, while the research study at hand may constitute *their* full-time jobs, participating consumers may well have commitments outside the study that occasionally threaten their availability. This challenge extends to the costs borne by some participants in the form of transportation and missed opportunities for more remunerative employment.

A research project can be an intimidating environment even for highly motivated participants from the general citizenry. Pains should be taken to welcome such participants into what, can be a rigid organisational structure, and to combat any real or perceived power imbalances with respect and recognition of each person's uniquely valuable contributions to the whole.

Consumers can also feel left out in the cold by more passive factors. Poorly defined roles, or a lack of training and support, can inhibit community members from contributing as meaningfully as they are able. Even a failure to involve consumer participants early enough can cause them to feel, quite rightly, that their involvement is somewhat tacked-on to the research study proper and neither integral nor especially important to it.

Research Cycle

Over time, professionals tend to develop their interpretations of standard practice. This is as true of health and medical researchers as for any other group.

When working with consumers, though, it may be helpful to revisit the traditional research cycle. Doing so can help researchers appreciate what consumers understand of the research process and can help place-specific observations or requests invaluable context.

The traditional model of the research cycle is as follows¹.



We will now look at each of these five stages to encourage, support, and make profitable use of greater community involvement.

Deciding what to research:

The first stage of a research project is the best time to plan for any consumer involvement. It may be tempting to consider this step a precondition of consumer involvement—that to solicit the participation of consumers, researchers need to give them some reasonably

¹ Based on the Resource Pack for Consumer and Community Participation in Health and Medical Research (2004), NHMRC. p.13.

detailed idea of what the research project will entail. But this common mistake can prevent consumers from having their deepest and most beneficial impact on a research study.

Instead, this is the perfect stage at which to discuss issues surrounding the research topic and the possible benefits of the project to public stakeholders. Researchers are often surprised to find that consumers have valuable contributions to make even before a project has been completely defined. If the research question is settled before researchers get a chance to discuss it with consumers, it is wise to admit as much before discussing opportunities for public participation.

Health-consumer organisations can be valuable sources of community representation. When a project's subject aligns with an established consumer organisation, a quick inquiry may provide a valuable and representative slate of consumer participants.

Once the project is sufficiently well defined, researchers should prepare a plain-language summary of its subject, scope, and methodology. Consumers themselves can help identify any jargon that remains in a researcher's draft of this summary.

Consumer-involvement activities can be planned at this stage as well. The character and scope of consumer involvement, along with any required training, support, and remuneration, should be noted in an outline that will be fleshed out in the following stages.

Deciding how to do it:

Consumers can provide valuable commentary on elements of a research project's methodology, particularly its documentation. This includes materials such as consent forms and information sheets intended for use with other members of the public but can also encompass operational documents like grant applications that benefit from the perspective of the very consumers the project is ultimately intended to benefit.

All phases of the study's methodology should be considered in this stage, including questions surrounding representation among consumer participants. Researchers whose previous recruitment efforts resulted in unrepresentative public involvement should consider enlisting the help of community institutions that can help recruit participants from underrepresented groups.

On a related note, it is not too early at this stage to consider how to disseminate research findings as widely as possible, especially to groups who may not have been adequately served by previous communications. In some cases, members of the public may even have the talents and wherewithal to serve as investigators or co-authors.

Doing it:

Before the research project begins, all training requirements for consumer representatives should be identified, and a complete training regimen developed for each role fulfilled by a participant from the greater community.

Training should begin as soon as possible, but not before consumer participants are made fully aware of the project's timelines and confidentiality requirements.

As the project proceeds, regular discussions of the research's progress can help consumers remain engaged and can generate valuable insights for researchers themselves. Seemingly anomalous results can sometimes be explained remarkably well by consumers whose knowledge and expertise lie outside of health science.

When the project's findings start to round into view, researchers should solicit the participation of consumers in drafting reports and policy recommendations. Plans for communicating the project's findings and for translating research findings into health care practice benefit especially from the input of consumers.

Letting people know the results:

All public-facing documentation of the project's findings should be vetted and edited by consumers and community members representing the documentation's target audiences. When results have the potential to cause public controversy, the plain-language text that results can be especially important.

How such documentation is disseminated may be nearly as important as its contents. Consumers can help research teams get their message to the greatest number of people. Researchers may be invited to speak at community events and should themselves consider inviting members of the public to speak at academic conferences and media briefings.

Knowing what to research next:

The best research raises many more questions than it answers. Consumers can play vital roles in assessing the outcomes of a recently concluded research project and identifying profitable avenues of further inquiry. Researchers should encourage members of the wider community to identify questions the project touched upon but did not answer.

Consumers can provide especially helpful critiques of the implementation phase when research findings are translated into general practice. These critiques themselves can point the way toward profitable and widely beneficial future research.



3. Completing a Heart Foundation Application

Assessment

As noted in the Heart Foundation Research Funding Guidelines (available online: <https://www.heartfoundation.org.au/research/research-funding-available>), applications are now assessed by both peer and consumer reviewers. Guidelines detail the assessment criteria for each of the funding programs and the questions that reviewers, both peer and consumer, will be assessing.

Applications

Due to the changes in our review process, application questions have been updated to ensure that our consumer reviewers can assess applications. The changes are also addressing equity and consumer priorities that the Heart Foundation will be addressing going forward.

Questions Requiring Lay Answers

Some questions within the applications require applicants to answer using lay terminology, this may be due to the requirement for consumer assessment or because the Heart Foundation are using the response to promote your project externally if successful in funding. These questions are:

- Simplified title
- Project Synopsis
- Leadership Summary (only required in Fellowship programs)
- Project Plan
- Consumer Engagement
- Improvements in related Health Practices, Policy and Knowledge
- Promoting Health Equity

Consumer Engagement Question

Provide details of your plans for consumer and community engagement within the proposed research. What policies and processes are in place or do you plan to put in place regarding consumer and community participation?

Applicants will not be assessed on the types of engagement being used in the project; they will be assessed on the level of engagement. Reviewers want to see that the applicant has considered where consumers fit in the project and what their requirements may be.

Be mindful that the stage of the project funding is being requested for, may not include consumers however your answer to this question can include that. For example, explain that should this piece of research be successful, then the next stage will include trials featuring consumers.

Improvements in related Health Practices, Policy and Knowledge Question

How and what potential does this research have to lead to widespread improvements in related health practices, policy, and knowledge relevant to the grant you are applying for? How will the potential improvements be utilised?

This is another question that could link into the consumer engagement question. Translating research into health practices, policy or knowledge can have a direct or indirect impact on consumers.

Promoting Health Equity Question

The Heart Foundation is dedicated to improving health inequalities. Your research project should address, at a minimum, one of the populations below:

- **People who are socioeconomically disadvantaged?**
- **Residents of regional, rural, and remote areas?**
- **Australians from culturally and linguistically diverse backgrounds?**
- **Aboriginal and Torres Strait Islander people?**
- **Gender Inequalities?**

Equity in research is a priority for the Heart Foundation, from who is funded and how applications are assessed, but also how the research projects are addressing inequities in health. Again, these segments can relate back to the consumer engagement question. An applicant may struggle to see how their research may impact these inequalities, but they should think outside the square. Will it be including these populations in project, in translation of results, resulting after this initial piece of research?



4. Consumer Review FAQ's

Why is the Heart Foundation including consumers in the review process?

The Heart Foundation is introducing consumer review panels that will run concurrently with the peer review process. As a charity relying on donations from the public, we have an obligation to ensure research that is being funded is consistent with our values and has translatable outcomes.

What is the Heart Foundation's consumer review process?

The Heart Foundation's consumer review process is very similar to the current peer review process. Both consumer and peer reviews will run concurrently. Consumers will score applications against a predetermined criterion, which will differ depending on the award or grant. Consumer ranking contributions will be combined with peer review rankings for a final score.

Please refer to your awards eligibility document for further information on consumer criteria and final percentage contributions.

What is expected of researchers?

It is expected that researchers take the time to address the consumer criteria in their application. When applying through the portal, applicants will need to take note of sections that ask them to reference this guide.

Will I risk my chance of being funded by the Heart Foundation if I do not sufficiently address the consumer review criteria?

Yes. Consumer rankings currently contribute 30% of your final score. If you do not address the consumer criteria in the same manner as the rest of the application, you will greatly reduce your chances of being successful.

Will the Heart Foundation be facilitating connecting trained consumers to researchers?

The Heart Foundation has identified a need to include consumers in more aspects of our organisation and have recruited our own consumer community. This community will assist us with membership on committees, consumer reviews in research, feedback on internal Heart Health programs and input into campaigns.

The Heart Foundation has now other specifically trained consumer groups and therefore is unable to be a conduit for researchers in this space. We do recommend that researchers reach out to their institutes, as many now have consumer strategies which may be able to assist researchers.

Would the Heart Foundation promote calls for consumers to engage in particular projects from current/Previously funded researchers?

Current and previously funded researchers who are members of our [Alumni Program](#), will be assisted where we can, to promote their research. This can include promoting calls for consumers via our social media networks.

Are there disease specific consumer committees?

At the Heart Foundation we do not have specific committees for specific diseases. However, if we are working on a priority area then there may be a committee, for example Rheumatic Heart Disease (RHD) is a priority currently and there are committees relating to RHD. If you are interested in knowing more about Heart Foundation priorities, please visit our website.

How do you identify consumers?

The first step is to review your research, what are you doing, who is your intended end user, what is the expected impact your research is hoped to have on the Heart Health of Australians. Once you answer those questions, identifying consumers will become easier.

How can we identify consumers interested in research?

This will depend on who your consumer group is:

- Is it the person delivering the end use of a medicine? *Try connecting with GPs, practice nurses,*

- Is it patients required for a clinical trial? *Try hospitals, support groups, calls out via social media*
- Is it relating to policy change? *Try contacting your local Member, advocacy groups such as Australian Cardiovascular Alliance (ACvA)*
- Is it relating to commercialisation? *Try reaching out to industry members*

Will consumer engagement look the same in all funding programs?

Different funding opportunities will mean that consumer engagement will differ across our portfolio. The larger the grant and/or longer the funding period you have, will affect the level of engagement.

A Vanguard Grant has the purpose to test a theory or idea. When we talk about consumers it might be gathering their input in the planning or providing detail on where consumers will be involved if this stage of research is successful.

A Future Leader Fellowship on the other hand, might have clinical trial or specific translational goals, where you could detail quite in-depth consumer engagement.

If the project has already been defined before consumers are engaged, that is completely fine – just be clear with the consumers you recruit that this is the case.

What if this research is part of a bigger piece of research which is already design with protocols established, how can we address consumer involvement?

When submitting your application, your responses can refer to other areas of a project. For example, you could state the specific area of the larger project that the application is addressing then note the consumer considerations that the main investigator on the larger piece of work has made. If there is no consumer involvement involved in the larger project, this could be a good conversation to have.

What are examples of consumer engagement for biomedical, clinical, public health and health service research?

Type of Research	Key Characteristics	Potential areas of consumer involvement
Biomedical	<ul style="list-style-type: none"> • Laboratory-based • Complex • Controlled experimental designs • Molecular, cellular 	<ul style="list-style-type: none"> • Ethics • Member of a steering committee • Member of the project team • Communicating results broadly, in ways that are meaningful to consumers and community members • Assist with design and implementation of research tools • A consumer representative to understand what consumers need and want to know about this disease to assist with future translation of results • Research Buddies • Consultations with clinicians for planning trials • Consultations with pharmaceutical companies regarding drug developments
Clinical	<ul style="list-style-type: none"> • Laboratory based and/or human subjects • Controlled experimental • Designs • Quantitative methods 	<ul style="list-style-type: none"> • Ethics • Ownership or access to human tissue samples • Identifying areas for further research • Advocacy • Communicating results to participants and wider community in consumer-friendly ways • Member of a steering committee • Member of the project team • Conducting a clinical trial • Focus group of patients to assist in the development and co-design of educational packs and/or interventions • Survey to patient focus group
Public Health	<ul style="list-style-type: none"> • Study of communities or populations • Social setting • Focus on epidemiology, health promotion and prevention, social and behavioural sciences, population-based health interventions • Quantitative and qualitative methods 	<ul style="list-style-type: none"> • Identifying gaps in current knowledge • Identifying need • Contributing consumer focussed research • Advocacy • Informing policy development • Assisting/collaborating in research processes • Networking support and liaison • Communicating results • Translating results into practice • Member of a steering committee • Member of the project team • Developing partnerships with consumer groups
Health Services	<ul style="list-style-type: none"> • Study of health-related institutions, including their operation within the broader system • Systems/policy focus • Complex social settings • Quantitative and qualitative methods 	<ul style="list-style-type: none"> • Identifying breakdown in systems • Feedback about quality, relevance and appropriateness of services • Collaboration in research processes • Contributing consumer focussed research • Research subjects • Member of a steering committee • Member of the project team • Providing consumer perspective on system issues • Networking support and liaison • Advocacy • Communicating results • Implementing results

Table adapted from National Health and Medical Research Council [NHMRC] and Consumers Health Forum of Australia [CHF]. 2004. Resource Pack for Consumer and Community Participation in Health and Medical Research. Canberra. Pp. 15-16

Will researchers be disadvantaged in Heart Foundation funding if they undertake basic science?

Absolutely not. We are investing in research that has a benefit to the Heart Health of all Australians. If your research is of benefit in some way then it should have an end user, the person who is consuming that research.

Top tips the Heart Foundation recommends:

1. Don't over think this – many peoples first thought is to think a consumer is the general public but remember to think about your type of research first
2. Talk to your institutes – they may have a consumer engagement guideline in place
3. Talk to your peers – many researchers are already including consumers in research and can share their experiences

What if the research involves complex terminologies and processes?

It is in the applicant's best interest to explain complex processes or names in simplified terms. Consumers need to get a sense of the wider implications and societal benefits of the research, rather than knowing the complex names. For further assistance, please refer to the 'plain language' document.

Plain language

Writing in plain language is an important skill for researchers to possess. It allows research projects to be accessible to people out of the scientific community. It is important to note that writing in plain language is not simplifying your research project, it is presenting your project in a way that makes it easier to understand. Writing in plain language should be clear, concise, and straightforward, avoiding any unnecessary words.

The Heart Foundation's research program runs predominately on donor money and therefore we have an obligation to ensure we are funding research that is understood by the wider community.

How to write in plain language

- Write as if you are explaining your research to a family member or friend.
- Use simple, common words.
- Avoid technical terminology.
- If you need to use a certain term, define it!
- Use shorter sentences.
- Explain any acronyms or abbreviations used.

Example

How your scientific text might look²

Previous work has shown that pulmonary arterial vascular smooth muscle cells (VSMCs) exhibit cytoskeletal variation. We hypothesise that these translate into VSMC phenotypic differences in contractile properties.

How it might be simplified

We have seen that muscle cells from lung artery walls differ from each other in their 'cytoskeleton' – their structural scaffolding. We believe that these cells have distinct and important individual functions and behaviour.

² <https://www.bhf.org.uk/for-professionals/information-for-researchers/how-to-apply/lay-summaries>



5. Resources

Below is a list of external resources for consumer involvement worth checking out

NHMRC

<https://www.nhmrc.gov.au/about-us/consumer-and-community-engagement>

Consumer and Community Involvement Program

<https://cciprogram.org/>

Health Issues Centre

<https://hic.org.au/consumer-advocates/>

Readable

<https://readable.com/>



Research Program

The Heart Foundation was established in 1959 to help prevent and treat heart disease, and to fund research to take on and defeat our biggest killer. Since then, we have invested more than \$670 million (in today's dollar) into cardiovascular research, leading to important breakthroughs that have helped dramatically reduce the number of deaths from heart disease.

Applying for Funding

Before submitting your funding application, please be aware of the following initial eligibility conditions:

- ➔ Applications must be submitted via the Heart Foundation Research Portal.
- ➔ Applications must be endorsed by the administering institute by 5pm (AEST) on the day of closing to be eligible for review.
- ➔ Research supported by the Heart Foundation must be administered by an NHMRC Administering Institution.
- ➔ All research funded by the Heart Foundation must be conducted primarily in Australia and be related to cardiovascular health.
- ➔ Applicants must be Australian or New Zealand citizens, or permanent residents, or must have applied to become an Australian permanent resident.
- ➔ Ethics clearances (where required) need to be in place for the duration of the award.
- ➔ We don't fund researchers, research groups or institutions that have accepted money from the tobacco industry or persons connected with the tobacco industry.
- ➔ Each award requires applicants to meet specific eligibility criteria. Before applying, please read the **Heart Foundation Funding Guidelines**.

For initial questions about applying, please contact the research office at your institution.

Contact Us:



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[Heart Foundation Website — Research](#)

[Heart Foundation Research Portal](#)

[Alumni LinkedIn Group](#)

[Heart Foundation Twitter](#)

[Heart Foundation Instagram](#)

[Heart Foundation Facebook](#)