

Cancer Voices' Consumer Involvement in Research (CIR Program)

Researchers working with consumer representatives

Thank you for including and valuing the consumer view in your project.

This Advisory Sheet is to help you make the most of this experience, to outline the reasons for including consumer input, to clarify your role and theirs and to suggest practical ways you can connect with informed consumers.

What is Consumer Involvement in Research (CIR)?

Many cancer research funders now require evidence in grant applications that the applicant has *engaged meaningfully with a consumer group / informed consumer in the development of their study, and intends to maintain this collaboration throughout project execution*. This applies to all types of cancer research – from the laboratory to clinical through to psychosocial and epidemiological research. Involving consumers means that your research will have benefited from the essential perspective of the ultimate beneficiaries – people affected by cancer and more widely, the general population.

Benefits

Studies in this area have shown that the quality and content of research benefits a great deal from consumer engagement – in its direction and in its applicability to the real needs of real people.¹ Researchers themselves report improvements, not only in meeting requirements of funders, but in the value and structure of work which has benefitted from consumer input².

What service does Cancer Voices provide?

Cancer Voices, for NSW and nationally, offers a free service to researchers to connect them with trained, networked consumers. We believe this is the most valuable kind of input, but recognise that some research organisations prefer to develop “in-house” consumer advisory groups. For the latter, more care must be exercised to address potential conflicts of interest. To use the matching service, please fill out the [form](#) on the Cancer Voices website, which asks for information about your research project and your requirements.

Through the “matching” process, Cancer Voices will:

- On receipt of your Request Form via the website, introduce you to a suitable, trained consumer and provide their contact details. This may take a few days or up to several weeks depending on the nature of your request and the “supply” of trained consumers available.
- Provide both consumer and researcher with information to clarify their respective roles and reasonable expectations.

YOUR Role: Once matched, you are expected to contact your consumer representative to introduce yourself and your project. Information provided by you on the Request Form will have been forwarded to your consumer. To obtain the greatest benefit from their involvement, it's best to begin working with your consumer representative early in the cycle. It's advisable to arrange a face to face meeting as soon as a practicable to familiarise the consumer with the project and the team. Reimbursement of out of pocket expenses for attending meetings should be offered as a matter of course. Essential documents should be

¹Wyatt, K., et al Family Practice,(2008), 25(3): 154-161

² Tallon, D., Chard, J., BMJ (2000), 320(7231):380

sent for review and input, and updates on progress provided with opportunities to provide meaningful input. Make sure you allow the consumer adequate time to do this. The collaborations are most productive and effective when both parties take the consumer role seriously.

How you will work together will depend on the type of research you conduct and the point at which you engage with your consumer representative. Ideally, you will have involved a consumer from the formative stages of the research, so they can take part in initial discussions about the idea, the research design, the funding application and throughout every step of the project until its conclusion. It is not enough to simply use a consumer to help complete forms when you are applying for a grant. The principle to keep in mind is that a consumer is the conduit between you and the potential end beneficiaries of your work. If you are doing lab-based research, this means that their main contribution will be to give you the informed consumer perspective, and to help you tell the community about your results. For more clinical work, consumers can assist with how you interact with patients, survivors and carers. Consumers can be meaningfully involved in all research.

Please remember that the consumers we nominate, and Cancer Voices members who provide the matching service, are volunteers, doing this work because they believe in its importance.

Here are some tips to get the most out of the relationship:

- Start with an in-person conversation about your research. If it's not possible to meet in person, then talk on the phone.
- Make sure they understand what you are proposing to study, the methods you will use to do so, and the potential implications of your findings. This is essential – they will not be able to give meaningful input if they do not have a good grasp of the research. A lay summary or grant proposal is often insufficient to impart an understanding of the work – you will need to talk them through the research or give them more information, and answer their questions.
- Seek their input on the lay summary to ensure that your research is comprehensible, accessible and relevant to the lay person.
- Remember they are not scientists, and they are not there to provide scientific input. Their role is to provide the informed consumer view. It is helpful if you explain any processes you need to go through as part of your proposed study.
- Clearly set out what you expect from your consumer representative, and when. Ensure they are comfortable with meeting those expectations and the proposed deadlines. Ensure that you are both happy with the tasks they agree to undertake to help with your project.

The Consumer's Role: Your consumer representative will help ensure that your research is comprehensible, accessible and relevant. They will consider the documents provided and/or the proposals and methods of your research from as broad and as objective a viewpoint as they can. Most will have done a short training course covering an introduction to the range of cancer research, the stages of research and funding “cycles” and their own role. That role is NOT to act as a mini scientist, or as a proponent of the Cancer Voices’ organisational view. Most nominees are Cancer Voices members, which gives them the benefit of being a part of a network, knowing the priorities, views and needs of others, not just their own. Cancer Voices, the voice of people affected by cancer, is independent and membership is free. Members are regularly linked by informative quarterly newsletters (which are all available on our website), our website, Facebook and Twitter.