

## ***Cancer Voices' Consumer Involvement in Research (CIR) Program***

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

This information is intended to

- help you make the most of this experience
- outline the reasons for including consumer input
- clarify your role and that of the consumer, and
- suggest practical ways you can connect with informed consumers.

### **What is Consumer Involvement in Research (CIR)?**

Most cancer research funders now require evidence in grant applications that the applicant has *engaged meaningfully with a consumer group / informed consumers 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.

### **Why involve consumers?**

Consumers can be meaningfully involved in all types of research. The quality and content of research benefit a great deal from consumer engagement – in its direction, and in its applicability to needs of real people <sup>(1)</sup>. Researchers themselves report improvements, not only in meeting the requirements of funders, but in the value and structure of work which has benefited from consumer input.

### **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 service, complete the [form](#) on the Cancer Voices website [www.cancervoices.org.au](http://www.cancervoices.org.au), which asks for details of your research project and your requirements.

Cancer Voices will then:

- introduce you to a suitable, trained consumer and provide their contact details. How long this takes will depend on the nature of your request and the availability of suitable consumers.

- provide you and your consumer with information to clarify your respective roles and reasonable expectations.

**Your Role:** 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 research cycle. It's advisable, where possible, to arrange a face-to-face meeting as soon as 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 sent for review and input, and updates on progress provided with opportunities to provide meaningful input. If the documentation is extensive (say more than 8-10 pages), consider providing them in hard copy to help minimise your consumer's personal financial expenditure. Make sure you allow the consumer adequate time to do this. Your collaborations will be 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. 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.

Please remember that the consumers we nominate, and Cancer Voices members who manage and coordinate the CIR program are volunteers doing this work because they believe in its importance.

**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 objective a viewpoint as they can.

Most will have completed the Consumer Research Training Program provided by Cancer Council NSW (CCNSW), with Cancer Voices support and input. The training consists of four online modules and a half-day face-to-face workshop. The training provides an introduction to the range of cancer research, the stages of research and funding “cycles”, what is likely to be expected of them by the researcher, and what they can expect in carrying out their own role as a consumer in research.

Their 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 available on our website), Facebook and Twitter.

#### Some tips to get the most out of the relationship:

- Get to know each other. 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.
- Be patient with your consumer. 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 clearly explain any processes you need to go through as part of your proposed study.
- Discuss what you expect from your consumer representative and what they can expect from you. Ensure they are comfortable with meeting your expectations and the proposed deadlines. Ensure that you are both happy with the tasks they agree to undertake to help with your project.
- Be flexible in arranging meetings. Offer refreshments or a parking voucher if relevant and reimbursement of out-of-pocket expenses for attending meetings should be offered as a matter of course.
- Keep in touch with them - even during periods of inactivity or slow progress.

- Introduce them to your entire team and offer a tour of the laboratory, if relevant. The more a consumer knows about what you do the greater their value will be.
- Further information on involving consumers can be found in the Australian Clinical Trials tool kit at <https://involvementtoolkit.clinicaltrialsalliance.org.au/>

#### A few tips on what not to do:

- ✗ Don’t make assumptions about what your consumer knows or might be interested in. All consumers are volunteers giving their time freely to help others. Treat them with respect and dignity.
- ✗ Try not to use jargon and if you absolutely must, make sure you explain what it means.
- ✗ Don’t treat the relationship as a “tick-the-box” exercise – something you have to do to apply for a grant. And don’t send your grant application to the consumer at the very last minute.



#### What is Cancer Voices NSW?

Cancer Voices NSW provides the independent voice of people affected by cancer in NSW, to improve the cancer experience of the over 48,000 people who are diagnosed each year.

Established in 2000, we are active in the areas of diagnosis, information, treatment, research, support and care.

To achieve this, we work in partnership with decision makers and providers of these services, ensuring that the patient perspective is heard from planning to delivery.

Membership is free. Members are linked via a regular newsletter, website and Facebook

Join today using the electronic form on our website at [www.cancervoices.org.au](http://www.cancervoices.org.au)

If you have any queries, please contact us at [info@cancervoices.org.au](mailto:info@cancervoices.org.au)



#### Consumers Included – a logo “seal of approval” A Cancer Voices initiative

The purpose of the Consumers Included (Ci) logo is to encourage and acknowledge organisations which enable consumers to participate in conferences, meetings and other events which are of interest to them and which will benefit from their involvement.

Further information can be found on the Consumers Included website at <http://consumersincluded.wordpress.com/> which advises applicants on how to apply for its use, as well as listing those who have been awarded approval to use the logo.

If you have any queries contact: [info@consumersincluded.org.au](mailto:info@consumersincluded.org.au) or go to the Ci tab on Cancer Voices Australia’s website [www.cancervoicesaustralia.org.au](http://www.cancervoicesaustralia.org.au)

*“nothing about us without us”*