

Cancer Voices' Consumer Involvement in Research (CIR) Program

Being a consumer advisor to cancer researchers

Welcome to an important job!

Thank you for agreeing to assist cancer researchers by contributing the essential consumer perspective to their research. Ideally this will start as the research concept begins to take shape – often our views are most valuable at the beginning.

As your nominator, via this “matching” process, Cancer Voices will:

- introduce you to the requesting researcher, with full contact details and location
- provide you with the description of the project for which your assistance is required and other practical details, meetings times and any out of pocket expenses coverage.
- provide you with advice and support when needed.

WHY? Studies in this relatively new area have shown that the quality and content of research benefit a great deal from consumer engagement – in its direction, in its applicability to community needs, and its end value for people affected by cancer... even if it's a mouse model, or molecular biology study, the end object will benefit from an informed consumer view. Research funders are now convinced and most require evidence that applicants for their funding have engaged in a meaningful way with informed consumers.

YOUR Role: Cancer Voices' nominees are usually “graduates” of the Consumer Research Training Program held annually by Cancer Council NSW, with Cancer Voices support and input. This gives participants a basic idea of the kinds of cancer research, the stages of research and funding “cycles”, what is expected of you and what you should expect yourself. It also trains consumers wishing to sit on Cancer Council NSW's (or other funders') Consumer Review Panels. These are groups of consumers who review applications for research funding from the consumer perspective, to judge its value to the community. Of course, you may choose to serve in both roles. If you have not received the training and would be interested in it, email research@nswcc.org.au.

Your aim is to consider issues from as broad and as objective a viewpoint as you can – eg is this a valuable research objective for people affected by cancer (or a specific cancer)? Could its focus be better directed? Your role is NOT to act as a mini scientist, but as a consumer who can bring a broad, informed view to the project, and who can keep community needs at the forefront of researchers' minds. Your specific roles will vary depending on the type of project you have been nominated to.

You are not on board as a Cancer Voices representative, presenting our organisational view – although you, and the researchers, are welcome to check our Position Statements on the website. Most nominees are already Cancer Voices members, which gives them the benefit of being a part of a network, and knowing the priorities of other consumers as well as their own.

THEIR Role: The researchers should provide you with the documents and other information required for an understanding of their work, and take you, step by step, through their project. If the project is more than a proposal, they will usually invite you for at least one face to face meeting so you become familiar with the team and get an idea of who does what. They

should answer and consider any questions you may have about the topic, methods, impact, and eventual dissemination of the study results. You are not expected to have or to gain an in-depth understanding of the science behind the research – what’s more important is that they can explain what its impact will be.

Some examples of consumers being involved in research:

Assisting with a grant application and with a funded project

For many consumers, their first experience of being an advisor will be to assist with an application for research funding (a grant). Your role here is to provide the consumer perspective on the research, ensure the researchers have considered its impact and how the community will be informed about the results. What you’re looking for will depend partially on the type of research you’re looking at.

Laboratory-based research: Because in this kind of research, researchers are working with cells or laboratory animals like mice or rats rather than patients, your involvement is relatively simple. Ask them how their research will eventually impact on real patients. Make sure they have a plan for having consumers involved if they are awarded funding. Finally, make sure the ‘lay summary’ or ‘media summary’ of their research is clear and easy to understand. Your role in a project that doesn’t involve humans will be less active.

Clinical research, including clinical trials: Acting as a consumer representative in this kind of research is likely to involve all of the above, but because the researchers are working with cancer patients, there are additional questions to think about. You should make sure that their plans take the patients’ needs and problems into account, and are sensitive to the issues that surround a cancer diagnosis and the experience of cancer treatment. For clinical trials, your work may range from reviewing and commenting on the criteria about who can participate, to reviewing questionnaires or other information to be given, the way it is given and support for trial participants. In this role, imagine what it would be like if you were a participant – what sort of information would you be looking for, how will it work in practical terms, what support might you need. Your perspective here can be really useful to make a trial or study experience a better one for cancer patients and their families.

Some researchers will give you plenty of time to consider their research proposal and the documents to be submitted with their grant application. Unfortunately, however, most will only give you a short time in their rush to submit their application by the deadline. Still, take the time to understand what the project will be and to make sure that at least the consumer summary is in language which is easy for other consumers to understand and provides a fair represents what the researcher is trying to do. If funding is awarded, you should expect to continue as the consumer representative for that project.

Sitting on a grant application review committee

Some research funding organisations have consumers on committees which determine which applications should be funded. They should give you all the information you need to do your job – if not, ask. They will usually have their own set of assessment criteria; and your job is to consider each application against those criteria. You should not add other information to your consideration beyond that provided in the application. That would be unfair to that applicant and to other applicants who have not benefited from additional information beyond the application form. You should also try to take personal views out of your consideration. Be as objective as you can and try to provide, an independent, objective perspective.

Other committee work

You might be asked to sit on other kinds of committees, for example, a committee that is reviewing treatment guidelines or examining ways services are delivered. Again, your job is to take as broad and objective a view as possible and consider the issues from the perspective of consumers – what issues will patients likely to be facing, are they being addressed etc.

Helping a research team on their “in-house” consumer advisory panel (CAP)

If you are invited to join a particular team at a research institute, you might do things like:

- Work with practitioners and scientists to identify research priorities
- Provide the consumer perspective on research funding applications or applications for permission to conduct a study that researchers must make to Ethics Committees
- Reviewing draft information sheets and questionnaires to make sure they are easy to understand

In this role, you should be invited to attend regular update presentations on the Institute’s research, and contribute feedback from an objective viewpoint.

Cancer Voices is here to help: If you need advice of a generic kind, or are facing any difficulties in your role, let us know. This engagement is often a first time for the researchers as well as for the consumer, and expectations may not always match. Cancer Voices can give you advice on how to speak to researchers about the limitations of your role, and if necessary can step in to help you out (although it is best to have a go and talk to them about it yourself first). Enjoy your important job!

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Cancer Voices Australia is the independent, 100% volunteer voice of people affected by cancer, working to improve the cancer experience for Australians, their families and friends. We are active in the areas around diagnosis, information, treatment, research, support, care, survivorship and policy.

To achieve this we work with decision-makers, ensuring the patient perspective is heard.

Cancer Voices has led the cancer consumer movement in Australia since 2000. The CVA network works together on national issues identified as important by their members, with consumers working to help others affected by cancer.

