

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

### **Welcome to an important role!**

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.

Cancer Voices NSW 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 sought and any other practical details such as meetings times and any out of pocket expenses coverage, and
- provide you with advice and support when needed.

### **Why involve consumers?**

Studies have shown that the quality and content of research benefits a great deal from consumer engagement – in its direction, its applicability to community needs, and its end value for people affected by cancer <sup>(1)</sup>. It will benefit from an informed consumer input at all stages of the research process. Most research funders require evidence that applicants for their funding have engaged in a meaningful way with informed consumers.

**Your role:** Partner with researchers and bring an informed consumer view to the research project, keeping the community and consumers' needs at the forefront of researchers' minds. Some of the questions you can ask researchers are: *"Is this a valuable research objective for people affected by cancer (or a specific cancer)? Could the focus be better directed? When might consumers benefit from this research?"* Your specific role will vary depending on the type of project you have been involved with.

**What you are not:** You are not there as a mini scientist. Nor are you there as a Cancer Voices representative, presenting our organisational view – although you and the researchers are welcome to check our Position Statements at [www.cancervoices.org.au](http://www.cancervoices.org.au)

Cancer Voices' nominees have usually completed the Consumer Research Training Program provided annually by Cancer Council NSW (CCNSW), with Cancer Voices support and input. The training now consists of four online modules and a half day face to face workshop. This gives participants a basic idea of the kinds of cancer research, the stages of research and funding "cycles", what is expected of you by the researcher, and what you should expect yourself.

CCNSW also trains consumers wishing to sit on its Consumer Review Panel. The panel, which includes consumers, reviews applications for research funding to judge their value to the community. Of course, you may choose to serve in both roles. If you are interested in doing the training, email [research@nswcc.org.au](mailto:research@nswcc.org.au)

**The researcher's role:** The researcher/s should take you step-by-step through their project and provide you with documents and other information required for an understanding of their work. 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 on people affected by cancer will be in a way that is easy to comprehend.

### **Some examples of how consumers can be involved in research:**

#### **1. Assisting with a grant application and with a funded project**

For many consumers, their first experience of involvement 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 on the type of research being proposed.

- **Laboratory-based research:** In this kind of research, researchers are working with cells or laboratory animals like mice or rats (sometimes called the 'mouse model') rather than patients. Your involvement is therefore likely to be 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' of their research is clear and easy to understand. Your role in a project that doesn't involve humans will probably be less active.
- **Clinical research, including clinical trials:** Contributing as a consumer representative to this kind of research is likely to be similar to that for laboratory-based research, 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 information is given and recruitment of and support for trial participants. In this role, it will help if you can imagine what it would be like if you were a participant in clinical research – 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 a better experience 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, many will only give you a short time in their rush to submit their application by the deadline. If this is the case, try to make 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 non-medical people to understand and provides a fair representation of what the researcher is trying to do. If funding is awarded, you should expect to continue as the consumer representative for that project.

## 2. Sitting on a grant application review committee

Some research funding organisations have consumers on committees that 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; your job will be 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.

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

If you are invited to join an advisory panel or research team at a research institute, you might do things such as:

- working with practitioners and scientists to identify research priorities;
- providing the consumer perspective on research funding applications or applications for permission to conduct a study that researchers must make to an ethics committee;
- 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.

## 4. 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 be facing, are they being addressed, what improvements could be made in the way treatment is provided?

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**Cancer Voices is here to help:** If you need advice of a generic kind, or are facing any difficulties in your role as a consumer representative, let us know at [info@cancervoices.org.au](mailto:info@cancervoices.org.au)

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 provide advice if required or you could refer to the Australian Clinical Trials Alliance Toolkit at <http://involvementtoolkit.clinicaltrialsalliance.org.au/>



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)

**“nothing about us without us”**

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<sup>(1)</sup> Cancer Voices NSW, *Consumer Involvement in Research. Does it work? An evaluation of Cancer Voices' CIR Program*, 2016