

Consumer Involvement in the Research Funding Program: Frequently Asked Questions

1. What is Cancer Council WA's 'community review of research' process?

Applications for Cancer Council WA's research funding undergo a two-stage review process. The first is scientific peer review, which is managed either by the National Health and Medical Research Council (NHMRC) in the case of applications for Project Grant funding, or by the academic members of Cancer Council WA's Research Grants Advisory Committee (or the relevant sub-committee) in the case of other programs.

In addition to scientific peer review, a panel of specially trained community representatives score funding applications using the Community Review Criteria, an appraisal tool developed from research-identified consumer and community values for research funding. These two scores are combined to give the final ranking of applications.

For Cancer Council WA student vacation scholarships, there isn't a separate community review section of the application. For these applications each criteria is assessed by the academic and / or community representatives of the committee as appropriate.

2. How are community representatives on the Research Grants Advisory Committees selected and trained?

Community members interested in becoming a community representative complete an expression of interest form. Volunteers must have a personal connection to cancer. Community representatives must be able to impart an impartial community perspective and so cannot be an active cancer researcher, or work in a cancer research-related area (including research management) at any of the institutions we fund, or be associated with the alcohol or tobacco industries.

Eligible volunteers complete a 2-day training course, which covers general background on cancer, cancer research and research ethics, as well as in-depth training on the community criteria used to assess applications. The training includes completing several mock reviews of research grants, which gives candidates a chance to develop their review skills and for Cancer Council WA to assess whether candidates have the attributes to impartially review applications and to contribute effectively to committee discussions. After the training, those participants who are still interested in becoming a community representative complete an application form. Final selection is based on the information in the applications and performance at the mock panels.

Cancer Council WA staff provide ongoing support to the community representatives to ensure the review process is conducted to a high standard.

3. What is expected of applicants?

Application forms for Cancer Council WA project grants, fellowships (including early career grants) and PhD Top Up and Honours Scholarships will now include a plain language summary and a community review criteria section. For all grants except the Project Grants, researchers are required to complete and submit these sections along with the rest of the application. For the Project Grants, specific instructions will be given about how to submit these sections.

The plain language summary and community review criteria must be completed in a manner which can be read as a stand-alone document and without reference to information provided in the rest of the application. Adequate detail must be provided in plain language. Community representatives

generally do not have a science or research background, and are not expected to read or understand the full research application.

Every community review criterion must be addressed. A response of not applicable (N/A) is unacceptable, and applicants who respond in this way, or who leave a response completely blank, will automatically be scored zero for that criterion. Researchers must substantiate imposing statements provided to consumers just as they would in scientific applications through appropriate referencing. Cancer Council WA staff trained in science, health and research support the community review process. Researchers are advised not to include incorrect information in their Community Criteria responses, as community representatives will be advised of such during the review process.

For more information, please see the 'Community Review Criteria for Cancer Council WA Research Grants: Guide for Applicants', available on our website: www.cancerwa.asn.au/research/funding/

4. Will I jeopardise my chance of being funded by Cancer Council WA if I do not adequately address the community review criteria?

Yes. Funding decisions are based on both scientific peer reviewer ratings and the community criteria scores. If you score high in the scientific peer review but poorly on the community review criteria, it will lower your overall ranked position and your application may be ranked below the number of applications that can be funded that year.

Clearly, scoring and ranking highly in both scientific and community criteria provides an application the best chance of being funded. Researchers are advised to address the community review criteria as carefully as the scientific methodology, **this is especially important as the community reviewers do not see the scientific section of your application.**

5. How much of the total score are the community criteria worth?

The community criteria are worth 30% of the final score, with the scientific criteria contributing the remaining 70%.

6. What if the research involves complex processes and terminologies?

It is in applicants' best interest to explain complex processes or names in simple ways, for example, 'the cell protein' rather than the full scientific name, code or classification for the protein. Community representatives need to get a sense for the wider implications and societal benefits of the research rather than knowing the complex names or systems of particular molecular or other structures.

For more guidance see our plain language summary guide, available on our website: www.cancerwa.asn.au/research/funding/

7. What if the funding application is for a small part of a larger research project?

When funding additional to that requested from Cancer Council WA will be required to complete a research project, researchers should provide detail on the way in which the first stage of the research will, in and of itself, benefit society. Otherwise they leave themselves open to speculation that if future funding cannot be found it would be a waste of money to fund only the first stage.

8. What is the difference between a community representative and a consumer?

Nothing. We have chosen to use the term 'community representative' rather than 'consumer' as we feel it is better understood by the wider community.

9. What is the definition of a community representative?

The NHMRC definition of a community representative is:

'Patients and potential patients, carers, organisations representing consumers' interests, members of the public who are targets of health promotion programs and groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services'.

Some organisations use a narrower definition, such as 'people who have had cancer or have cared for someone with cancer'. For the purposes of our research committees, we are defining community representatives as 'someone with a personal connection to cancer, e.g. experience of cancer or caring for someone with cancer, a family member or close friend diagnosed with cancer, volunteering for a cancer-related organisation'.

You can use any one of these definitions. If you feel an alternative definition is more appropriate for your research, we suggest you check with us first to make sure it meets requirements (see the answer to Q10 below too).

10. Aren't we all community members?

Community representatives need to be able to provide an impartial community perspective. Therefore clinicians / hospital staff involved in the research and / or the researchers themselves cannot act as community representatives and should never be described as such in the community review criteria form. This practice will ensure that the response to this criterion is scored zero.

The subjects (participants) in a research project are not considered to be community representatives. Sometimes some participants in a research project may also act as community representatives e.g. on a steering group. Whether this is appropriate requires careful consideration of issues around ethics, confidentiality and potential bias.

For more information on identifying appropriate community representatives see fact sheet p04 <https://www.involvingpeopleinresearch.org.au/find-out-more/our-resources/fact-sheets-series/>

11. Can clinicians act as community representatives?

While we would encourage you to involve clinicians in your research if appropriate, clinicians acting in their professional role do not count as community representatives. However, if someone who has a personal experience / connection with cancer happens to coincidentally work as a clinician and their work is not connected to your research, then they can act as a community representative. See also the answer to question 10.

12. Is lay involvement in ethical review considered community involvement?

A Research Ethics Committee constituted according to the NHMRC's *National Statement on the Ethical Conduct of Research* must include a layperson representative. However, ethical review and approval are not accepted as a mode of community involvement. Community involvement in research refers to active involvement in the research process, and requires that informed community representatives are involved in any or all of the prioritising, planning / design, recruitment, monitoring progress, evaluation and / or dissemination of research findings.

13. My research is on a pediatric cancer, who can I use as community representatives?

It is possible to involve children and young people as community representatives. If the cancer you are studying affects young children, you could consider involving adolescents or young adults who have survived the cancer. The parents of children with cancer could also be used.

14. My research is on a rare cancer or a cancer with poor prognosis so there aren't many survivors. Can I use people who have had other cancers as my community representatives?

Yes you can. You can also use people who have cared for someone with the cancer you are studying.

15. What is a carer?

A carer is someone who looks after a friend or family member with cancer. This is often a spouse, but can also be a parent, child, other relative or someone not related. It is not a professional, paid carer such as a nurse.

16. Can community members be involved in basic (laboratory) research?

There is a role for consumers in basic research, but involvement may look different to what would be appropriate in a clinical trial. For example, community representatives could help with making sure your plain language summaries are easy to understand, how to communicate the value of your research to the wider public and / or communicating the results of your research to interested parties. You may want to consider having a 'research buddy' – see fact sheet 7 - <https://www.involvingpeopleinresearch.org.au/find-out-more/our-resources/fact-sheets-series/>

More examples of ways to involve community representatives in different kinds of research can be found in https://www.involvingpeopleinresearch.org.au/wp-content/uploads/2018/07/PURPLE_PLANNING_BOOK_271015.pdf

17. Do community representatives on my research project need to be trained and networked?

Ideally, community representatives should have had some training to give them the skills, knowledge and confidence to contribute in a meaningful way. This training could be conducted by an outside organisation, or if that is not possible you could provide your own training.

In many cases, it is helpful if community representatives are part of a larger network or organisation as this can help them understand and represent the views and concerns of wider groups. This could include disease specific patient organisations or wider umbrella groups such as the Health Consumers Council or the Participation Network. Community representatives who are members of such groups can assist researchers by providing information that doesn't just reflect their own experience and can also feed information back to their constituency. However, we recognise that the value of community representatives being networked will vary depending on the type of research and community involvement, and also that it may not always be possible to find formally networked community representatives.

We do encourage all researchers and community representatives to join the Participation Network (www.involvingpeopleinresearch.org.au/join-our-network). The Participation Network is a group of people who share an interest in consumer and community participation in research. It is a resource

for consumers, community members and researchers and provides links between these different groups.

18. How do I find trained community representatives?

Contact: www.involvingpeopleinresearch.org.au/

Please allow plenty of time as finding appropriate representatives can take a while.

Is your question still not answered?

Contact:

Anna Nankivell

Research Development Coordinator

Cancer Council WA

Ph: (08) 9388 4354 or email: anankivell@cancerwa.asn.au