Consumer Involvement in Research Program:  
Frequently Asked Questions

1. What is Cancer Council NSW’s ‘consumer review of research’ process?
All applications for Cancer Council NSW (CCNSW) 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 CCNSW’s Cancer Research Committee in the case of other funding programs. Subsequent to scientific peer review, a panel of specially trained consumers score and rank funding applications using the Consumer Review Form, an appraisal tool developed from research-identified consumer and community values for research funding.

2. What is expected of researchers?
Researchers are required to complete and submit the purpose-designed 2-page Consumer Review Form, addressing each of the five consumer review criteria. Adequate detail in lay terms must be provided. The Consumer Review Form must be completed in a manner which can be read as a stand-alone document and without reference to information provided in the separate, scientific application. Consumers generally do not have a science or research background, and are not expected to read or understand the full research application.

Every consumer 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 0 for that criterion. Cutting and pasting information from the original scientific application into the template is also not acceptable. Lower scores are invariably assigned to responses that attempt to ‘baffle’ consumer reviewers rather than answer in lay terms.

Researchers must substantiate imposing statements provided to consumers just as they would in scientific applications through appropriate referencing. CCNSW staff trained in science, health and research support the Consumer Review Panel. Researchers are advised not to include incorrect information in their Consumer Review Form, as panel members will be advised of such during the review process.

Applications that are assigned low scores in the Consumer Review component of the assessment tend to marked down on Criterion 5, Consumer Involvement. Rather than simply stating that consumers will be involved, it is important for researchers to detail who is to be involved and show that there has been genuine consideration and planning for consumer involvement as an integral part of the research project. A reasonable and appropriate level of consumer involvement may vary, depending on the nature of the research being undertaken, but could include almost any kind of two-way interaction between consumers and researchers. Note that the researchers planning to disseminate their results to consumers does not constitute consumer involvement in a project; the project must receive
input from a consumer. Likewise, consumers who sit on institution advisory group do not constitute consumer involvement in the specific project, which is the Cancer Council NSW requirement.

Researchers are strongly advised to refer to guideline documents outlining frameworks for consumer participation in research, including those produced by the National Health and Medical Research Council (2004; see http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/r33.pdf) and Cancer Voices Australia and Cancer Australia (2011; see http://canceraustralia.gov.au/sites/default/files/publications/national_consumer_framework_web_504af020f2184.pdf) to ensure that they genuinely appreciate who constitutes a consumer and what constitutes legitimate consumer involvement.

3. Will I jeopardise my chance of being funded by CCNSW if I do not adequately address the consumer review criteria?
Yes. Funding decisions are based on both scientific peer reviewer ratings and the CCNSW Consumer Review processes. If you score high in the scientific peer review but poorly during consumer review, it will lower your overall ranked position and your application may be ranked below the number of applications that can be funded by the CCNSW that year. Clearly, scoring and ranking highly in both peer and consumer review provides an application the best chance of being funded. Researchers are advised to address the consumer review criteria as carefully as the scientific methodology.

4. What if the research involves complex processes and terminologies?
It is in researchers’ 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. Consumers 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.

5. What if the funding application is for a small part of a larger research project?
When funding additional to that requested from CCNSW 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.

6. Is lay involvement in ethical review considered consumer 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 consumer involvement. Likewise, the requirement for consumer involvement criterion is not satisfied by the participation of consumers in the research protocol itself. Consumer involvement in research refers to active involvement in the research process, and requires that informed consumers are involved in any or all of the prioritising, planning/design, recruitment, monitoring progress, evaluation and/or dissemination of research findings.
7. Aren’t we all consumers?
Informed consumers are those that understand the views and concerns of wider groups, such as members of Cancer Voices NSW, who keep abreast of current issues faced and the needs of those affected by cancer. Consumers who represent these groups are just as responsible for providing information to assist researchers as they are for feeding information back to their constituency. Research participants, clinicians/hospital staff and/or the researchers themselves are not considered consumers in relation to consumer involvement and should never be described as such in the Consumer Review Form. This practice will ensure that the response to this criterion is scored 0 by consumer review panel members.

8. Can consumers be involved in basic (laboratory) research?
There is a role for consumers in basic research. Information on how to involve consumers in all research disciplines is provided in the reports referenced in the response to FAQ 2, above.

Is your question still not answered?

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