Cancer Council NSW Project Grants

Project Grants Consumer Review Guidelines
Grant Round 2026

Contents

1. Background to Cancer Council NSW Consumer Review

The cancer community has a unique insight into the problems faced by those who have been affected by cancer. Consumers are people who have been affected by cancer – patients, survivors, carers, or close family members or friends of someone diagnosed with cancer or when conducting certain kinds of public health research, members of the general community. A consumer is also usually linked to an organised group who voices the perspectives of patients as well as their carers, families, and loved ones; and has been trained to take part in research decision-making processes as a representative of the broader cancer community.

It is important that both the scientific community and the wider community value the research Cancer Council NSW ('Cancer Council') funds. Cancer Council's research funding comes from donations from the general public. Consequently, funding research that is both of significant scientific merit and of value to the community Cancer Council serves and represents, helps to ensure Cancer Council responds to the genuine requirements of the community.

Cancer Council supports the involvement of consumers in the decisions that underlie competitive research funding. Cancer Council has identified consumer involvement as making a fundamental contribution to cancer research. Therefore, it is mandatory for researchers applying for Cancer Council funding to involve consumers in their research work.

In consultation with Cancer Voices NSW, Cancer Council established a formal process to afford consumers a voice in research funding decisions. The *Consumer Involvement in Research Project* resulted in the development of criteria and the training of research consumers in the assessment of research applications on behalf of cancer consumers and the wider community. The Consumer Review Form is designed to enable members of Cancer Council's Consumer Review Panel to assess applications for research funding against five criteria deemed important by consumers.

2. Objectives of the Consumer Review Guidelines

The objectives of the Consumer Review Guidelines are to ensure quality and consistency in the Consumer Review Panel's application of consumer review criteria, and to provide guidance to researchers to facilitate the development of research proposals that meet the expectations of the Consumer Review Panel.

3. Consumer Review Process

The consumer review criteria are assessed by a panel of trained research consumers (the Consumer Review Panel) convened by Cancer Council. The Consumer Review Panel members score Consumer Review Forms independently from the scientific review provided by the NHMRC. Consumer Review Panel members are not provided with the full scientific application, its scientific assessment, ranking or details of the research team.

Responses to the criteria must be written in lay language, in a manner which can be read without reference to information submitted in the scientific application, and in de-identified form. This ensures the Consumer Review Form can be understood by a non-researcher, can be read as a stand-alone document, and it is anonymous to eliminate potential conflicts of interest.

4. Submission of the Consumer Review Form

The Consumer Review Form can be downloaded via the Cancer Council website. Applicants must complete the Consumer Review Form and upload it when prompted as part of the Cancer Council online grant submission form.

4.1 Formatting

Please adhere to the following:

- Do not exceed two pages.
- Do not adjust the margins of the Consumer Review Form, use a minimum font size of Arial 10pt, and submit an electronic copy of the form in Word format.
- Upload the completed Consumer Review Form as a single MS Word file using the following file name convention: App ID_ConsumerForm_CIA Surname, e.g., '123456_ConsumerForm_Smith'

5. Guide to Scoring

Consumer reviewers score independently each of the five consumer review criteria on a scale of 0-7. No half integers are allowed. To derive the overall Consumer Review Panel score for an application, average scores across all individual consumer reviewers are calculated for each criterion and then added together to produce the final score. In combination with the NHMRC score with equal weighting a final score will be derived that determines recommended grants for funding.

The scoring guide below (Table 1) and the detailed description of each criterion (*6. Cancer Council Consumer Review Criteria*) is provided to consumer reviewers.

Table 1 Detailed description of scores.

Score	Description	Detailed Description
7	**Outstanding**	Response is of the highest quality, provides all the information required, is easily understood, and there is no possibility for improvement.
6	**Excellent**	An impressive response that provides all required information clearly and in detail.
5	**Very good**	The response provides most of the information required in a clear and detailed way. Little else could be included.
4	**Good**	The response is sound but could be improved with addition of detail. The response contains minor gaps, or slight confusion in some parts.
3	**Satisfactory**	A barely acceptable response which addresses the criterion but provides minimal detail, causes confusion and/or includes some irrelevant information.
2	**Poor**	The response suffers serious inadequacies such as little or no detail, irrelevant information and/or causes confusion.
1	**Inadequate**	The response does not address the question except in the most fleeting way or is inappropriate to the question. The information provided is very brief or generally irrelevant.
0	**No response**	There is no response, or a response that does not address the question. Nowhere else in the Consumer Review Form is there any information relevant to the question.

6. Cancer Council Consumer Review Criteria

Project Grants applicants need to address five criteria in the Consumer Review Form, which will be assessed by the Consumer Review Panel. Please use language suitable for a non-scientific audience.

6.1 Magnitude of Problem and Extent of Benefit (20% of the total Consumer Review Score)

The criterion *Magnitude of Problem and Extent of Benefit* describes the problem the research is addressing and how the results of this research will have an important positive impact on human lives, including any of the following aspects: cause of the disease, prevention, diagnosis; treatment; physical and/or mental and/or social wellbeing; quality of life, dignity, and survival. This criterion gives the applicant an opportunity to explain the potential for the proposed research to have a direct, beneficial impact on the lives of people affected by cancer.

Consumer Reviewers should consider for the *Magnitude of Problem* how well the response in the Consumer Review Form addresses the following key points:

- Identifying the mechanisms by which cancers arise
- Developing ways to personalise cancer treatments
- Identifying and/or testing effective ways of preventing and/or treating disease. This might include improvements in the environment or individual behaviours.
- Identifying those at high risk of developing cancer
- Improving existing or identifying new cancer care delivery approaches, treatments and/or diagnostic methods
- Improving access to information, and the quality of information available
- Easing physical and/or mental suffering of those affected by cancer
- Maintaining or rebuilding dignity and quality of life.

Consumer Reviewers should consider for the *Extent of Benefit* how well the response in the Consumer Review Form addresses the following key points:

- Has the researcher provided some epidemiological background (for example, how common the cancer is, what the outcomes tend to be, particular population groups who might be affected), to help contextualise the potential benefit?
- Has the researcher explained the extent of the problem and its importance?
- Has the researcher explained how the research will generate tangible benefit/s to human life?
- Are there a number of benefits?
- Has the researcher indicated the probability, magnitude, and/or duration of these potential benefits?
- Has the researcher indicated when in the future the potential benefits might be achieved?
- How important are the benefit(s)?

Example content of a response rated highly by the Consumer Review Panel

Pancreatic cancer (PC) is the fourth leading cause of cancer death in men and women in western societies including NSW, with a 5-year survival rate of less than 5%. Only 10-20% of patients are suitable for surgical treatment at the time of presentation. Chemotherapeutic agents have met with little if any success. Thus the treatment and outcome of PC, apart from improvement in peri-operative care, has not changed for more than 3 decades. Clearly, there is an urgent need for novel approaches to this lethal disease.

This project proposes to examine the role played by the prominent scar tissue (stromal/desmoplastic reaction) in the progression of the disease. We have recently established the identity of the cells responsible for the stromal reaction, as pancreatic stellate cells (PSCs). PSCs are resident cells of the pancreas that maintain normal pancreatic architecture in health. In disease, PSCs are major players in the production of scar tissue (fibrosis) in the pancreas. Importantly, our studies using human PSCs (hPSC) and pancreatic cancer cell lines suggest that PSCs influence local growth and distant spread of pancreatic cancer.

This project will define in detail the role of the stroma in the progression of pancreatic cancer and characterise the processes by which normal stromal cells such as PSCs may influence the development and spread of cancer. An improved understanding of the specific mechanisms involved in this interaction will enable us to develop new ways to interrupt cancer development that do not involve the same sorts of treatments we use now. Such treatments are increasingly being identified and are often less damaging to the body as they are more truly specific for the cancer. The findings of this project may also be applicable to other cancers with prominent stromal elements such as cancer of the breast and prostate.

6.2 Pathway for Realising the Benefit (20% of the total Consumer Review Score)

This criterion should be addressed by providing a clear description of the steps required to reach the stated end benefits of the research. Steps should begin with the aims in the current project and, if necessary, beyond the current project. A timeframe for each of the required steps in the pathway must be included. Please include a timeframe for the research that covers steps within the grant duration and beyond.

Consumers recognise that further steps are often required for the benefits of research to be realised. These steps might include additional laboratory-based research, testing on humans, changes in clinical practice, product development, regulation/law and/or policy changes. For each step to realising the benefit, there are likely to be related investigations, costs and risks.

Consumers also recognise that outcomes achieved in a single body of work may make significant advances to the knowledge of cancer, but not reach a point where a final benefit directly applicable to humans is achieved. Identifying the pathway required to reach an applicable benefit, and highlighting which steps the proposed research will be addressing, will allow the reviewer to judge when and how the results of the proposed research project will be realised.

Applicants are advised that consumers highly regard responses to this criterion which include numbered steps and a timeframe to delineate the pathway for realising the benefit. The pathway should describe the steps required to realise the benefits of the research, rather than the results. These steps should be based on the aims and objectives of the proposed research and extend beyond the requested funding period if appropriate.

Consumer Reviewers should consider for *Pathway for Realising Benefit* how well the response in the Consumer Review Form addresses the following key points:

- Has the researcher provided a description of the broad steps or stages required to reach the stated benefits of the research?
- Do the steps or stages appear reasonable?
- Are the steps or stages achievable?
- Are there any significant gaps in the steps or stages required to reach the stated benefits?
- Has the researcher provided an estimate of broad timeframes for the achievement of each step or stage?
- Do the steps or stages represent significant constraints to achieving the actual benefits of the research?
- Do you understand when in the future the benefits might be achieved?

Example content of a response rated highly by the Consumer Review Panel

1) Test the feasibility of using scar tissue proteins (HSP27 and HSP47) to predict a patient's response to chemotherapy or the severity of disease:

- ***Year 1****. Ethics and access to 900 human pancreatic tumour specimens is approved.*
- *This study will identify sub-groups of patients which may respond better to a particular class of drug.*

2) To understand how HSP27 and HSP47 proteins influence pancreatic stellate cell function:

- ***Year 1****. We will inhibit HSP27/47 in pancreatic stellate cells using our nanoparticle-siRNAs and assess cell survival and scar tissue production; accelerate our therapy from the lab to the clinic.*

3) Test the effect of inhibiting HSP27/47 in pancreatic stellate cells on pancreatic tumour growth and sensitivity to chemotherapy in pre-clinical mouse models of pancreatic cancer:

- ***Years 2-3****. Inhibition of HSP47 reduces pancreatic tumours implanted under the skin of mice, but true clinical relevance requires testing in tumours transplanted in the pancreas. Our lab developed such a model of PC in mice, which resembles human PC i.e. extensive scar tissue.*
- *We will inhibit HSP27 or -47 in pancreatic stellate cells using our nanoparticle-siRNAs and test if we can deplete the scar tissue, reduce tumour growth and increase drug delivery and chemo-sensitivity.*

4) Clinical trial in patients to test our novel nanoparticle-siRNA therapy:

- *If steps 1-3 above are successful, we will apply for additional funding for a clinical trial.*

In the Consumer Review Form applicants must explain how the research in the current study and, if necessary, beyond the current study, will be applied in the real world (over the short, medium or long term) to achieve the stated benefits. The applicants describe the barriers, which need to be addressed to be successful and how they will be addressed, and how the outcomes will be enabled or facilitated.

While research may have the potential to lead to human benefit, it is important to consider whether the benefit can actually be realised in the real world. There will be times when real world hurdles such as resources, technical challenges, public and/or professional acceptability, availability, risks/adverse consequences, process, policy and/or legal barriers and other constraints will affect whether or not the research findings will be put into practice and/or made available to the public.

Applicants are advised consumers highly regard responses to this criterion which clearly address potential for application in each of the short, medium and long terms. They also highly regard a realistic assessment of the potential barriers to application of the findings and may doubt an application that does not evidence appropriately critical and reflective assessment of barriers. In responses to this criterion, consumers are interested in: what the anticipated outcomes entail; how real-world outcomes are to be achieved; how barriers to those outcomes will be overcome; and how the outcomes will be enabled or facilitated.

Consumer Reviewers should consider for *Potential for Application of Finding* how well the response in the Consumer Review Form addresses the following key points:

- How likely is it that the findings of the research will be amenable to translation into practice (in either the short, medium and/or long term)?
- Has the researcher explained how they intend to proceed to facilitate the application of the findings into practice?
- Has the researcher detailed strategies to address any barriers to the application of research findings into practice?
- How compatible are the research findings likely to be with existing laws, public policy, resources etc?
- How will the research findings affect current ways of working (e.g., clinical and other practices)?
- Where relevant, does the researcher include the groups they will work with to overcome barriers to applying the findings of this research?

Example content of a response rated highly by the Consumer Review Panel

Short and medium term: *it is expected that similar response rates will be seen in patients receiving PiggyBac immune cells as those made using other methods (up to 80% complete remission). The results from this trial will enable the further testing of lymphoma and leukaemia specific PiggyBac immune cells in larger numbers of patients in varying clinical circumstances. This would provide an effective therapy where one does not currently exist.*

Long term: *if shown to be an effective alternative to standard therapy, PiggyBac immune cells could then replace toxic second line therapies, becoming a standard of care for high risk, relapsed and refractory leukaemia and lymphoma. The use of the simple, inexpensive PiggyBac system will enable the routine use of these immune cells.*

These studies will pave the way for the cost-effective production and testing of genetically modified immune cells targeting a range of other cancers potentially significantly improving the cure rates of these tumours.

Barriers*: the need for GMP compliant production facilities and large multicentre trials to finally enable ARTG listing. The generation of the PiggyBac immune cells and the supervision of the clinical trials will be carried out by investigators who are members of the Sydney Cell and Gene Therapies group. This is a consortium at our institution which has extensive experience in production of cell and gene therapy products for clinical use and will be utilised to enable appropriate production of clinical products and also to disseminate expertise to other groups embarking on similar projects.*

The investigators will use their connections within the Australian Leukaemia and Lymphoma Group, the Haematology Society of Australia and New Zealand and the Australia and New Zealand Children's Oncology Group to recruit further centres in later phase trials.

6.3 Potential for application of findings (20% of the total Consumer Review Score)

In the Consumer Review Form applicants must explain how the research in the current study and, if necessary, beyond the current study, will be applied in the real world (over the short, medium or long term) to achieve the stated benefits. Describe the barriers you need to address to be successful and how you propose to address them, and how the outcomes will be enabled or facilitated.

While research may have the potential to lead to human benefit, it is important to consider whether the benefit can actually be realised in the real world. There will be times when real world hurdles such as resources, technical challenges, public and/or professional acceptability, availability, risks/adverse consequences, process, policy and/or legal barriers and other constraints will affect whether or not the research findings will be put into practice and/or made available to the public. Applicants are advised consumers highly regard responses to this criterion which clearly address potential for application in each of the short, medium and long terms. They also highly regard a realistic assessment of the potential barriers to application of the findings,and may doubt an application that does not evidence appropriately critical and reflective assessment of barriers. In responses to this criterion, consumers are interested in: what the anticipated outcomes entail; how real-world outcomes are to be achieved; how barriers to those outcomes will be overcome; and how the outcomes will be enabled or facilitated.

Consumer Reviewers should consider for *Potential for application of findings* how well the response in the Consumer Review Form addresses the following key points:

- How likely is it that the findings of the research will be amenable to translation into practice (in either the short, medium and/or long term)?
- Has the researcher explained how they intend to proceed to facilitate the application of the findings into practice?
- Has the researcher detailed strategies to address any barriers to the application of research findings into practice?
- How compatible are the research findings likely to be with existing laws, public policy, resources etc?
- How will the research findings affect current ways of working (e.g., clinical and other practices)?
- Where relevant, does the researcher include the groups they will work with to overcome barriers to applying the findings of this research?

Example content of a response rated highly by the Consumer Review Panel

Short and medium term: *it is expected that similar response rates will be seen in patients receiving PiggyBac immune cells as those made using other methods (up to 80% complete remission). The results from this trial will enable the further testing of lymphoma and leukaemia specific PiggyBac immune cells in larger numbers of patients in varying clinical circumstances. This would provide an effective therapy where one does not currently exist.*

Long term: *if shown to be an effective alternative to standard therapy, PiggyBac immune cells could then replace toxic second line therapies, becoming a standard of care for high risk, relapsed and refractory leukaemia and lymphoma. The use of the simple, inexpensive PiggyBac system will enable the routine use of these immune cells.*

These studies will pave the way for the cost-effective production and testing of genetically modified immune cells targeting a range of other cancers potentially significantly improving the cure rates of these tumours.

Barriers*: the need for GMP compliant production facilities and large multicentre trials to finally enable ARTG listing. The generation of the PiggyBac immune cells and the supervision of the clinical trials will be carried out by investigators who are members of the Sydney Cell and Gene Therapies group. This is a consortium at our institution which has extensive experience in production of cell and gene therapy products for clinical use and will be utilised to enable appropriate production of clinical products and also to disseminate expertise to other groups embarking on similar projects.*

The investigators will use their connections within the Australian Leukaemia and Lymphoma Group, the Haematology Society of Australia and New Zealand and the Australia and New Zealand Children's Oncology Group to recruit further centres in later phase trials.

6.4 Equity (20% of the total Consumer Review Score)

In the Consumer Review Form applicants must justify the selection of the study sample and explain why they have included and excluded particular groups who could potentially benefit from the outcomes of the research. If relevant, the proposal must address an under-studied or under-served population and/or a population with a high burden of disease or poorer outcomes.

Equity in the research context addresses the question ‘who benefits?’ Equity in research is commonly thought of as striving for equal benefit from research. There is no universally accepted best or right answer for how research benefits should be distributed in society, although ideally everyone who could have an opportunity to benefit from research should, and particularly populations with poorer outcomes (which may include patients with particular tumour types or of specific age groups, Aboriginal and/or Torres Strait Islander people, people of culturally and linguistically diverse backgrounds, or patients in regional/rural locations).

For example, for a research project that focuses on a particular cancer or group of people, an explanation should be provided for the rationale behind this focus and how the benefits of the research may be expanded to other groups in the future. It is not the case that a study of, for example, ovarian cancer is inequitable because the benefits do not apply to men, or prostate cancer is inequitable because the benefits do not apply to women. However, a study of ovarian cancer may be inequitable if the results could only benefit women with the resources to access costly treatment delivered in an inner-city facility, and the service delivery model was unlikely to be extended to women from rural/regional and/or less privileged backgrounds. In this example, equity of treatment access may be deemed to be of concern. In addition, along with equity of opportunity, equity of outcome is an important component of the concept of equity. For this reason, consumers highly regard evidence that research results may benefit populations with poorer outcomes.

Consumers tend to assign most responses to this criterion a mid-range score, with lower scores assigned to responses in which the research is perceived to exclude some groups, and higher scores assigned to responses in which the research is seen to particularly benefit groups with poorer outcomes.

Consumer Reviewers should consider for *Equity* how well the response in the Consumer Review Form addresses the following key points:

- Has the researcher explained how the findings could be generalised or applied to other population groups who are not part of the research?
- Does the research have the potential to provide benefit across all relevant persons, groups and/or places?
- Does the research address an under-studied or under-served population?
- Does the research address a population with a high burden of illness or poorer outcomes?

Example content of a response rated highly by the Consumer Review Panel

Initial cognitive studies in cancer patients were largely limited to younger women with breast cancer. Subsequently, cognitive impairment has been seen in cancer survivors with other primary tumour types. For this study, the approach to eligibility ensures study results are generalisable to current oncology practice so have included: (i) male and female survivors (ii) older cancer survivors with no upper age limit (iii) survivors with different primary tumour sites. Key exclusions are inadequate English skills to perform the neuropsychological tests, and pre-existing cognitive impairment prior to cancer diagnosis.

The home-based cognitive programme design ensures the trial is readily accessible to the majority of cancer survivors with self-reported cognitive impairment, regardless of where they live in Australia (79% of Australian homes have internet access). This is important as ~ 30% of cancer survivors live in rural locations in Australia and have limited access to clinical trials and hospital-based interventions.

6.5 Consumer Involvement (20% of the total Consumer Review Score)

Please outline how relevant informed consumers (cancer patients, survivors, carers, family member or friend of someone diagnosed with cancer, or community members) have been involved during the development of the research proposal, and describe the plan for ongoing consumer involvement over the course of the research. Explain how this/these consumer(s) are 'qualified' to be involved.

Scientific peer review identifies research of high quality and the greatest potential for success; it does not necessarily take into account the needs of consumers and the general community.

There are many opportunities for consumer involvement in *all* stages and *all* types of research. 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.

Applicants should consider the following:

- Applicants must include at least one named and qualified consumer in the specific research proposal. Consumer(s) who are involved in the specific project must be named. Applicants should also identify how the consumer(s) is/are qualified to act as consumer representative(s) on this project and specify with which consumer organisation(s) they are networked (e.g. Cancer Voices). Consumer Review Forms that specify these details assure consumer reviewers that the applicants have indeed consulted specific consumers; that these consumers have sufficient knowledge to enable them to provide informed input into the project; and that these consumers have a supportive consumer network around them to facilitate their awareness of the broader issues of concern to cancer consumer groups.* **
- Consumer involvement must be specific to the project that is the subject of the funding application, and must allow for a two-way interaction between the researcher and informed consumer(s), both during the development of the proposal and throughout the conduct of the research. Consumers who sit on institution advisory groups must contribute specifically and directly to the project to meet the Consumer Review Panel's expectations around consumer involvement.
- Applicants are strongly advised to have a trained consumer review their Consumer Review Form to ensure its comprehensibility in terms of both the language used, and as a stand-alone document able to be read without reference to the NHMRC application.
- A plan to disseminate results to consumers does not constitute consumer involvement; the project must receive input from a consumer.

*In some cases, it may not be appropriate to name the involved consumer for privacy reasons. For example, a consumer may wish to remain anonymous to the Consumer Review Panel because their involvement on a specific project is due to an illness they have experienced that they would rather be kept confidential. If so, this should be stated and an additional consumer is needed to fulfill the eligibility criterion of named consumers being involved in the proposed research.

**It may also not be appropriate to list network details for all consumers, specifically in projects where participation of a consumer who has not been affected by cancer is required. For example, in a cancer screening research project in which the input representing the general population is desired, involvement of a consumer with a cancer experience would not be appropriate. In cases such as these, a consumer network may not be available for the consumer to join so would not be required to be listed; however, this should be clearly explained in the Consumer Review Form.

6.5.1 Examples of consumer involvement

There is no single best method of consumer involvement. Even basic science/laboratory-based research can and should incorporate consumer involvement, and it is not acceptable for a researcher to claim otherwise. Some examples of consumer involvement are:

- Provide informed input on strategic priority setting and direction
- Work with researchers to define or refine the research topic
- Provide informed input on research design and proposed methods
- Participate in project advisory committees
- Conduct lay reviews of research proposals
- Participate in recruiting participants to research
- Assist researchers to develop links to hard-to-reach populations
- Conduct reviews of participant information sheets and consent forms
- Assist researchers to pilot a research questionnaire
- Produce newsletters for members of their organisation that chart the progress of research
- Support the development of lay summaries
- Assist in disseminating information to the wider community
- Participate in discussions and decisions around human tissue ownership and access issues.

6.5.2 Consumer training and qualifications

In addressing the consumer involvement criterion, applicants should describe how the consumer(s) involved in the project are qualified to provide input and feedback. Consumers will be deemed qualified if they have completed any of the following:

- Attended Cancer Council's Consumers in Research training, or
- Completed in-house training (e.g. within a consumer advisory group, panel, network, or research institute) that covers topics such as cancer epidemiology; research types, research methods and cycle; and grants and ethics applications, or
- Attended a consumer training program offered by an organisation other than Cancer Council (e.g. Cancer Australia), or
- Worked in the capacity of a consumer in research advisor for ≥3 years, either as a member of an advisory/steering/consumer committee, or as an advisor to individual researchers, or
- Completed the online Consumers in Research training course hosted by Cancer Council Australia[1], and attended face-to-face training (either in-house or through an organisation such as Cancer Council) or intend to attend a face-to-face training session in the first year of the grant.

[1] Online Consumer in Research training is available at **http://www.cancer.org.au/about-us/consumertraining.html**

Applicants should clearly describe the involved consumer's training or experience. If the involved consumer is qualified by in-house training, applicants should specify the content of the training. Likewise, if the involved consumer is qualified by participating as a consumer in research for ≥3 years, the consumer's experiences should be clearly outlined. It is inadequate to merely state the consumer is experienced. Not having at least one named consumer on the proposal will make the application ineligible.

Consumer Reviewers should consider for *Consumer Involvement* how well the response in the Consumer Review Form addresses the following key points:

- Has consumer consultation into the development of this specific project already been undertaken?
- Have the researchers clearly identified the nature of consumer consultation to date?
- Has an individual consumer, or a consumer organisation, agreed to act as the consumer representative on this project?
- Are the consumer(s) named?
- Have the researchers explained what experience or training the consumer(s) have undertaken or been provided which renders them 'qualified' to act as the consumer representative(s)?
- Are the consumer(s) networked as a member of a broader consumer organisation?
- Are there formal processes/structures in place that link the researchers with consumers? For example, consumers might be nominated as members of the project Advisory Group.
- Given the nature of the research, are the extent and type/s of consumer involvement appropriate? For example, it would be expected that consumer involvement in a clinical trial would be more extensive than consumer involvement in a basic science study.
- Is there a plan for ongoing consumer involvement in the research?
- Is the nature of ongoing consumer involvement clearly described, including the matters on which consumers will be consulted and the mechanisms by which this consultation will occur, and is the involvement two-way?
- Have the researchers identified the preferred approach of consumers for ongoing involvement in the research?

Example content of a response rated highly by the Consumer Review Panel

Mr x received consumer in research training through Cancer Council in 2010 and is a member of Cancer Voices. Mr x has been consulted since the early stages of this project and was provided with a two-page outline in December 2011, and CIA discussed the project's aims and plan with him. After taking Mr x's feedback into consideration, the project was further developed and Mr x and CIA met again in February, 2012. Another consumer who is also a prostate cancer survivor, Mr xx, was approached by CIB to comment on the final project outline, and provided further feedback on the proposal.

Mr x will be invited to be a member of the steering committee for this clinical trial, which meets or speaks monthly to specifically discuss progress of the clinical trial. This will include highlighting outcomes and any unexpected findings, discussing the next steps and how the research findings will impact on clinical practice and prostate cancer management.

A newsletter, which will be reviewed by Mr x and Mr xx, will be sent to participants enrolled in the trial and their families explaining in lay terms the results of study. The newsletters and websites from both the xxx Cancer Centre and xxx Institute will also be used as a means to publicise research results to the community at large. Furthermore, through Mr x and the CIA's links to the NSW prostate cancer community, we will present the results at prostate cancer support groups and consumer forums such as the PCFA national support group meeting.

7. Summary for Applicants

- The Consumer Review Panel is a panel of trained cancer patients, survivors, carers, and community members. Using the completed Consumer Review Form, this Panel will assess the value of your proposed research to the cancer community.
- The Consumer Review Panel does not receive the submitted scientific application. Please ensure that the Consumer Review Form can be read as a stand-alone document and that it addresses all the criteria, and is written in language appropriate for a lay reader.
- Applicants do not need to use the maximum allowable word count. Keep your answers to the point, concise and relevant.
- Ask the project specific consumer to assist in answering the questions and to review all answers. If it is not clear to them it will not be clear to the review panel.
- Please do not refer by name to Investigators or laboratories as the Consumer Review Panel reviews anonymised documents.
- To satisfy eligibility requirements, at least one named and qualified consumer must be involved in the research proposal.
- Signatures of consumers involved in the proposal must be obtained in the Consumer Declaration on page 3 of the Consumer Review Form.
- Please read the guidelines closely and ensure you address all criteria in the suggested manner.

- You will be prompted to upload your completed Consumer Review Form as part of the Cancer Council online grant submission form which will be used for online submission of Cancer Council Project Grant applications.

7.1 Resources for Researchers engaging with the community

The NHMRC issued a Toolkit (2020) with a set of resources for researchers, supporting its Statement on Consumer and Community Involvement in Health and Medical Research.
See also Consumer and Community Health Research Network.

7.2 How to find a Consumer

Cancer Voices NSW manages a consumer 'matching service' in which trained consumers are matched to research projects. To apply to have a consumer join your research team, please visit Cancer Voices (http://www.cancervoices.org.au/) and complete the application form found under the heading *Consumer Representation*.