Cancer Council NSW Project Grants

Project Grants Lived Experience Review Guidelines
Grant Round 2027

Contents

1. Background to Cancer Council NSW Lived Experience Review

It is important that both the scientific 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. The cancer community has a unique insight into the problems faced by those who have been affected by cancer.

People with lived experience are people who have been affected by cancer – patients, survivors, carers, or close family members or friends of someone diagnosed with cancer (former *Consumer*). A trained person with lived experience is a person who underwent specific training or has experience as a research advisor for a specific amount of time to take part in research decision-making processes as a representative of the broader cancer community (see 7.5.2).

Cancer Council supports the involvement of Lived Experience in the decisions that underlie competitive research funding and is committed to ensure Lived Experience contributions and opinions are fundamental contributions to cancer research. Therefore, it is mandatory for researchers applying for Cancer Council funding to involve people with lived experience in their research work.

In consultation with Cancer Voices NSW, Cancer Council established a formal process to afford Lived Experience a voice in research funding decisions. The *Consumer Involvement in Research Project* resulted in the development of criteria and the training of people with lived experience in the assessment of research applications on behalf of the community. The *Lived Experience targeted questions* are filled in by the researcher, and it is strongly advised that the respective person(s) with lived experience is involved in this process. The Lived Experience targeted questions are designed to enable members of Cancer Council's Lived Experience Review Panel (Panel) to assess applications for research funding against five criteria deemed important by the community.

2. Objectives of the Lived Experience Review Guidelines

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

3. Lived Experience Review Process

Only the Lived Experience review criteria are assessed by the Lived Experience Review Panel, which consists of trained people with lived experience and is convened by Cancer Council. The Panel members score *Lived Experience targeted questions* independently from the scientific review provided by the *National Health and Medical Research Council* (NHMRC). The Panel members are not provided with the full scientific application, its scientific assessment, ranking or details of the research team. It is important to remember that the scientific validity of a proposed research project is not to be scored or judged as this is done by the subject matter experts in the independent NHMRC process.

Responses to the *Lived Experience targeted questions* must be written in lay language and in a manner which can be read without reference to information submitted in the scientific application. This ensures that the *questions* can be understood by a non-researcher and can be read as a stand-alone document.
Following providing scores and comments the Panel meets for the Lived Experience Review Panel Meeting, which is chaired by a pre-selected panel member, to discuss the applications and to recommend a ranked list of applications to the Cancer Research Committee for funding. Final approval for the application will be sought from Cancer Council's Board.

4. Submission of the *Lived Experience targeted questions*

The *Lived Experience targeted questions* are included in the Project Grant application, which is accessible in Cancer Council NSW's Grants Portal when the grant round is open. Applicants must complete the *Lived Experience targeted questions* in collaboration with the respective person(s) with lived experience as part of the Cancer Council online grant submission form.

Applicants must adhere to the requirements given in Cancer Council NSW's Grants Portal.

5. Conflicts of Interest

The Panel members must ensure that the application review process is conducted effectively and is free from conflict of interest. Panel members must declare their conflict of interest in Cancer Council NSW's Grants Portal (see 9). There are several situations where a conflict of interest may arise, two general circumstances are:

- *Financial interests*: an interest must be declared with an application as a potential conflict when benefits or losses either in money or in kind have occurred or may occur at a level that might reasonably be perceived to affect a person's judgement in relation to fair decisions and participation in group decision making; and

- *Other relationships*: an interest must be declared as a potential conflict when a strong position or prejudice or familial connection or other relationship held by a person could reasonably, or be perceived to, affect a person's judgement in relation to fair decisions or their participation in group decision making. This might be, for example, where a Lived Experience Review Panel member recognises a research application to be one with which they are personally involved, or which involves a researcher who is their own or a family member's health care provider.

Panel members have the responsibilities to identify and report an interest that is in potential or actual conflict. Where it is unclear that a conflict of interest exists, it should be declared and discussed with Research Strategy & Operations team by emailing research@nswcc.org.au.

6. Guide to Assessment

6.1 General

Panel members must score from the perspective Lived Experience. The scientific merit of the application and whether the project will work on a technical level has been managed by the scientific reviewers and the application has been deemed scientifically sound. Due to the condensed information the Panel member receives, compared to the full application, many scientific details omitted or simplified for the review and the Panel will assess how the research outcomes will serve the cancer community only.

When scoring the form, Panel members must score based on the Lived Experience Review Guidelines. Sections further down below assist during assessment for each of the five criteria.

Assessment of the *Lived Experience targeted questions* should be impartial and based only on the information provided.

6.2 Scoring and comments

The Panel members will be prompted to score applications they are not conflicted with in Cancer Council NSW's Grants Portal. Alongside the score, Panel members must provide a rationale for the respective score. One-word comments are not sufficient and will be returned by the Research Strategy & Operations team. In the rationale the Panel member must

- give information on what was missing from the application or what was described in a sufficient way;
- speak in terms of the guidelines, rather than comparing to other applications
- where possible, temper negative feedback with good feedback.

Lived Experience Review Panel members score independently each of the five Lived Experience review criteria on a scale of 0-7. No half integers are allowed. To derive the overall Panel score for an application, average scores across all individual Panel members 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 Lived Experience Review Criteria*) is provided to Panel members. The Panel members are encouraged to use the score descriptors in their comments for the panel discussions to ensure alignment of scores across all criteria.

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. There is information not relevant to the *Lived Experience targeted questions*.

7. Cancer Council Lived Experience Review Criteria

Project Grants applicants need to address five criteria in the *Lived Experience targeted questions*, which will be assessed by the Lived Experience Review Panel. The applicants are requested to use non-scientific lay language throughout.

7.1 Magnitude of Problem and Extent of Benefit (20% of the total Lived Experience 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 the community, including any of the following aspects: cause and underlying mechanisms 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 beneficial impact on the lives of people affected by cancer.

Panel members should not score rare cancer research lower than research about the most common cancer. Cancer Council supports research into all cancers and Panel members should assess only if the information about how many people are affected by this cancer has been included and if the benefits for affected people warrant funding.

Short: What is the problem, what is the extent of the problem and how will it be solved?

Panel members should consider for the *Magnitude of Problem* how well the response in the *Lived Experience targeted questions* addresses any of the following key points:

- Identifying the mechanisms by which cancers arise
- Developing ways to improve existing or develop new 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.

Panel members should consider for the *Extent of Benefit* how well the response in the *Lived Experience targeted questions* 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?
- Is the research outcome applicable across multiple cancers?
- How important are the benefit(s)?

Example content of a response rated highly by the* Lived Experience *Review Panel

Pancreatic cancer (PC) is the third leading cause of cancer death in Australia, with a 5-year survival rate of less than 14%. 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.

7.2 Pathway for Realising the Benefit (20% of the total Lived Experience 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. The applicant should include a timeframe for the research that covers steps within the grant duration and beyond and should ensure that challenges and solutions are addressed as well as direct outcomes to be realized to ensure step-by-step progression.

Panel members 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.

Panel members 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. Simply stating that clinical trials with subsequent approval of new drugs are planned are not sufficient.

Applicants are advised that Panel members 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.

Short: When and how will the research be translated into the real world?

Panel members should consider for *Pathway for Realising Benefit* how well the response in the *Lived Experience targeted questions* 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 addressed challenges and proposed practical solutions along the way?
- 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 Lived Experience 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) Laying the groundwork for future translation

- *If steps 1-3 above show strong potential, the findings will guide our next steps in advancing this new therapy toward real-world use.*
- *The long-term goal is to create a treatment that reduces tumour scarring, improves drug delivery, and ultimately leads to better outcomes for people with pancreatic cancer.*

7.3 Potential for application of findings (20% of the total Lived Experience Review Score)

In the *Lived Experience targeted questions* 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.

Panel members 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, Panel members 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.

Short: How likely will the results lead to community benefit in the next 5, 10 or 20 years?

Panel members should consider for *Potential for application of findings* how well the response in the *Lived Experience targeted questions* 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 Lived Experience 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.

7.4 Equity (20% of the total Lived Experience Review Score)

In the *Lived Experience targeted questions* 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). Additionally, to benefit from research equally, research needs to be inclusive to the extend feasible. This means including research materials from groups expected to be addressed (e.g. using mice of both genders in animal experiments if relevant or enrolling the right patients into a clinical trial).

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, Panel members highly regard evidence that research results may benefit populations with poorer outcomes and that equity considerations are applied across all questions.

Research into a specific cancer that affects some populations more than others is not automatically in itself research that addresses equity if the disadvantaged population is not directly addressed in the proposal.

Short: Who will benefit from the research?

Panel members should consider for *Equity* how well the response in the *Lived Experience targeted questions* 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? Or, why this may not be possible?
- Has the researcher ensured that relevant data or materials that address equity are included in as far as feasible?
- 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 directly and targeted rather than in general (e.g. research in liver cancer does not automatically address the equity component solely because some populations are affected more than other by the disease)?
- Does the research directly and specifically address a population with a high burden of illness or poorer outcomes?

Example content of a response rated highly by the Lived Experience 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.

7.5 Consumer Involvement (20% of the total Lived Experience Review Score)

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

In this section the applicant needs to outline how relevant informed people with lived experience have been involved during the development of the research proposal and describe the plan for ongoing consumer involvement over the course of the research. It must be explained how this/these people with lived experience are 'qualified' to be involved. It is important to ensure active engagement throughout the project and ensure that Lived Experience opinions and ideas are considered and integrated into the research where possible and feasible. Lived Experience should form an active part of the research team and is asked to contribute to progress and outcome reporting.

There are many opportunities for people with lived experience involvement in *all* stages and *all* types of research. A reasonable and appropriate level of Lived Experience involvement may vary, depending on the nature of the research being undertaken, but could include almost any kind of two-way interaction between people with lived experience and researchers.

Applicants should consider the following:

- Applicants must include at least one named and qualified person with lived experience in the specific research proposal and people with lived experience who are involved in the specific project must be named. Having more than one named and qualified person with lived experience will not lead to a higher score in the criterion. We encourage participants to consider how their research progression is communicated to community throughout the lifetime of the project. Applicants should also identify how the people with lived experience are qualified to act as Lived Experience representative(s) on this project and specify with which Lived Experience organisation(s) they are networked (e.g. Cancer Voices). *Lived Experience targeted questions* 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.* **
- Lived Experience involvement must be specific to the project that is the subject of the funding application and must ensure a two-way interaction between the researcher and informed Lived Experience, both during the development of the proposal and throughout the conduct of the research. People with lived experience sitting on institution advisory groups must contribute specifically and directly to the project to meet the Panel's expectations around Lived Experience involvement.
- Applicants are strongly advised to have a trained person with lived experience to formulate their *Lived Experience targeted questions* to ensure its comprehensibility in terms of both the language used, and its ability to be understood as a stand-alone document without reference to the NHMRC application.
- A plan to disseminate results to the community alone does not constitute Lived Experience involvement; the project must receive input from a person with lived experience.

*In some cases, it may not be appropriate to name the involved person with lived experience for privacy reasons. For example, a person with lived experience may wish to remain anonymous to the Lived Experience 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 person with lived experience is needed to fulfill the eligibility criterion of named people with lived experience being involved in the proposed research.

**It may also not be appropriate to list network details for Lived Experience, specifically in projects where participation of community not 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 Lived Experience with cancer would not be appropriate. In cases such as these, a Lived Experience network may not be available for community to join and would not be required to be listed; however, this should be clearly explained in the *Lived Experience targeted questions*.

7.5.1 Examples of Lived Experience involvement

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

7.5.2 Lived Experience training and qualifications

In addressing the Lived Experience involvement criterion, applicants should describe how Lived Experience is involved in the project and how it qualifies to provide input and feedback. Lived Experience will be deemed qualified if they have completed any of the following:

- Completed the Consumer Research Training entailing online modules and the Lived Experience in Research Workshop facilitated in collaboration with Cancer Voices NSW;
- Completed the online modules and attended face-to-face training (either in-house or through an organisation such as Cancer Council) or intends to attend a face-to-face training session in the first year of the grant;
- Completed in-house training (e.g. within a Lived Experience 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;

- Attended a Lived Experience training program offered by an organisation other than Cancer Council (e.g. Cancer Australia), or
- Worked in a Lived Experience capacity as in research advisor for ≥3 years, either as a member of an advisory/steering/Lived Experience committee, or as an advisor to individual researchers.

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

Panel members should consider for *Lived Experience Involvement* how well the response in the *Lived Experience targeted questions* addresses the following key points:

- Has at least one person with lived experience, or a Lived Experience organisation, agreed to act as the Lived Experience representative on this project?
- Is the person with lived experience named?
- Has Lived Experience consultation into the development of this specific project already been undertaken?
- Have the researchers clearly identified the nature of Lived Experience consultation to date?
- Have the researchers explained what experience or training the person with lived experience has undertaken or been provided which renders them 'qualified' to act as the Lived Experience representative(s)?
- Is the person with lived experience networked as a member of a broader Lived Experience organisation?
- Are there formal processes/structures in place that link the researchers with Lived Experience? For example, person with lived experience might be nominated as members of the project Advisory Group.
- Given the nature of the research, are the extent and type/s of Lived Experience involvement appropriate? For example, it would be expected that Lived Experience involvement in a clinical trial would be more extensive than Lived Experience involvement in a basic science study.
- Is there a plan for ongoing Lived Experience involvement in the research?
- Is the person with lived experience aware that direct participation in progress and outcome reporting will be part of the research?
- Is the nature of ongoing Lived Experience involvement clearly described, including the matters on which Lived Experience 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 their named person with lived experience 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 2023 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 2025, 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, 2026. 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.

8. Financial recognition

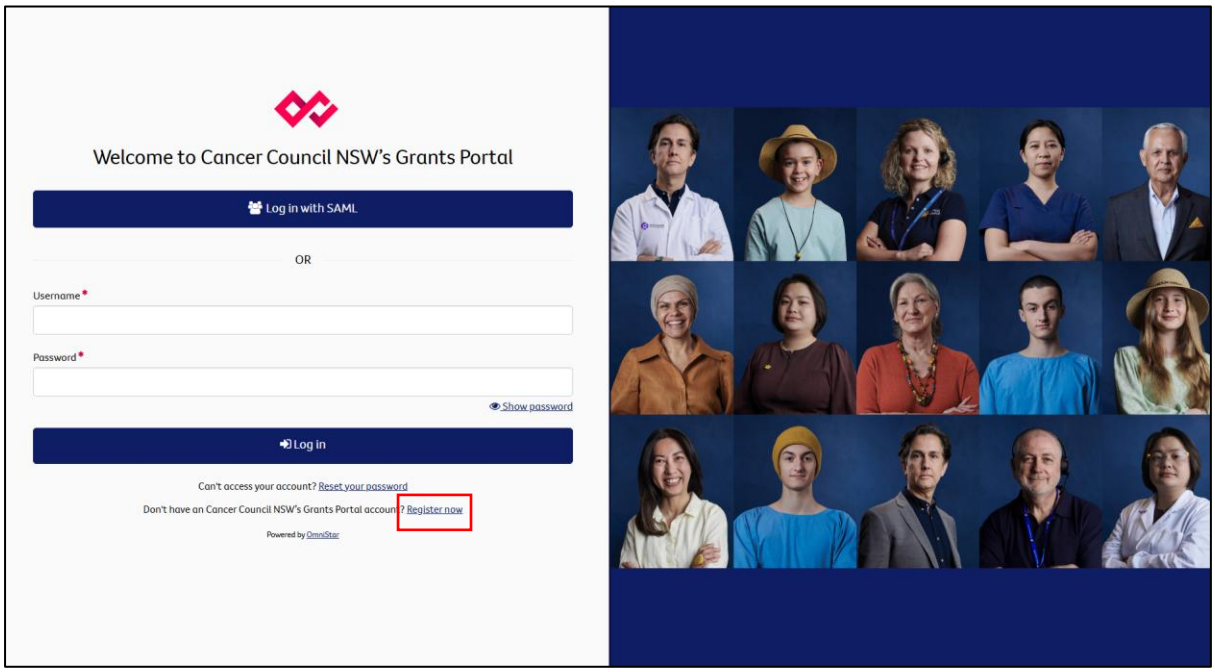
Cancer Council encourages researchers to include appropriate financial recognition for the project-specific involvement of people with lived experience in their proposed research budgets.

Lived Experience reviewers participating in the Lived Experience Review Panel will be financial recognised and reimbursed for reasonable costs associated with the review process by Cancer Council.

9. Cancer Council's Grants Portal

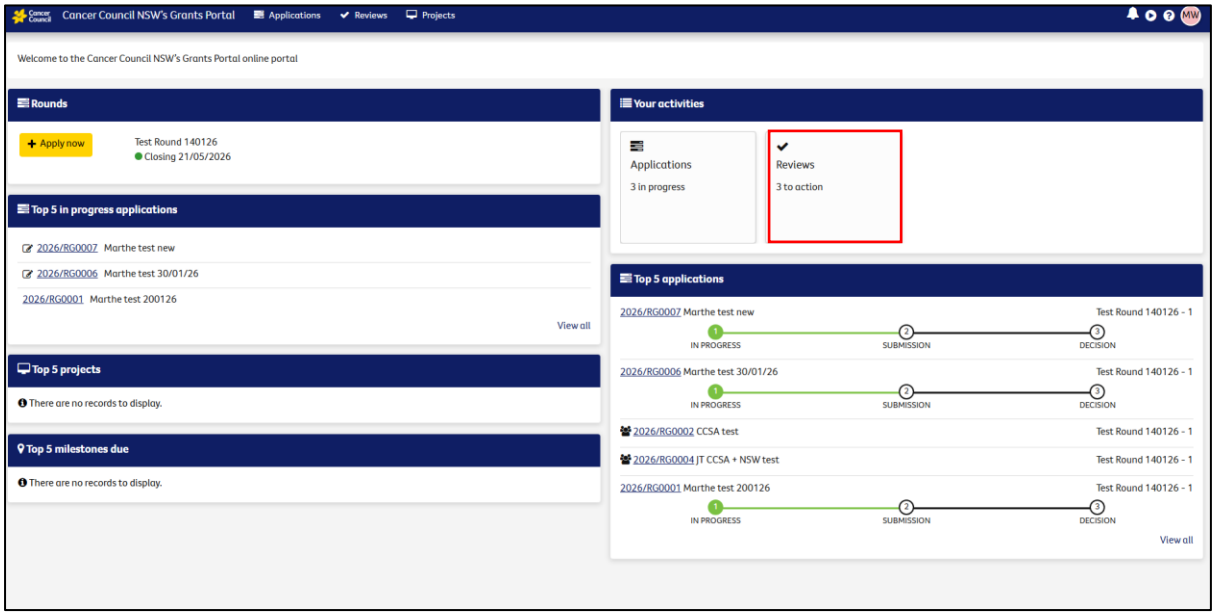
9.1 Sign up as a user

Navigate to Cancer Council NSW's Grants Portal and register under *Register now* with your email address (see below). If successful you will receive an email to the respective email account for confirmation purpose only and you can log into the portal.



9.2 How to access the Lived Experience Review Form

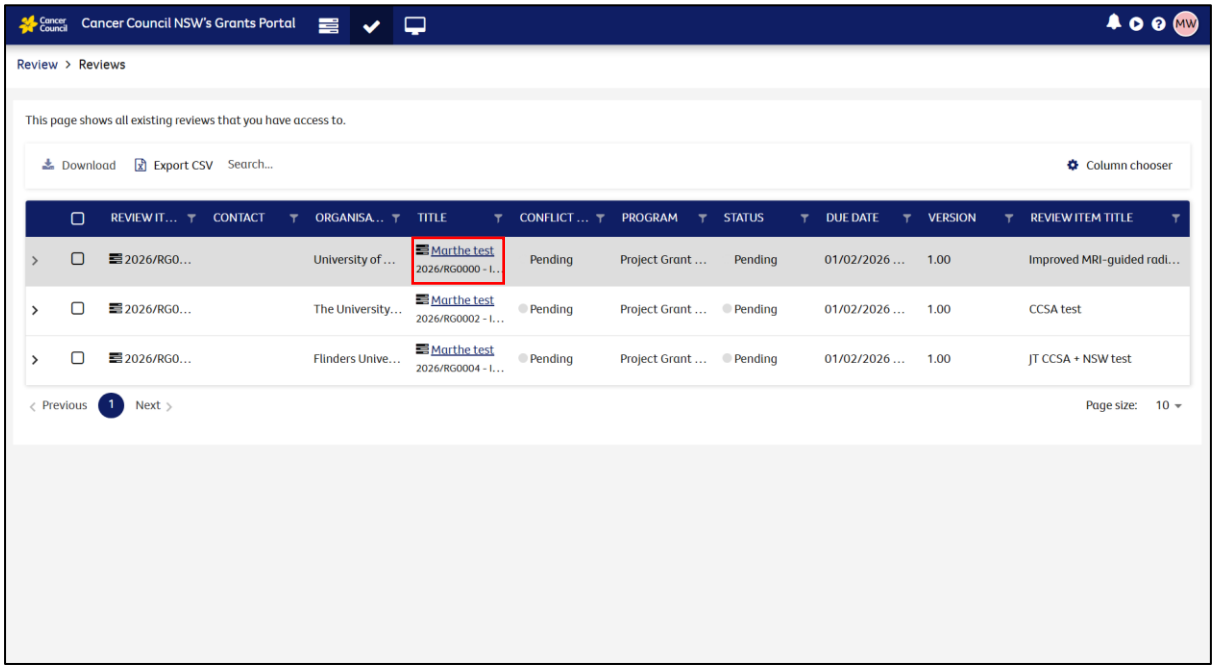
The Research Strategy & Operations team will reach out to the Panel members when the Lived Experience Review Form is available in Cancer Council NSW's Grants Portal. The Panel Member will also receive an email indicating that the assessment has been assigned. Following log in the Panel member can navigate to different areas. Under *Your activities* the assigned reviews can be found (see below, indicated in red).



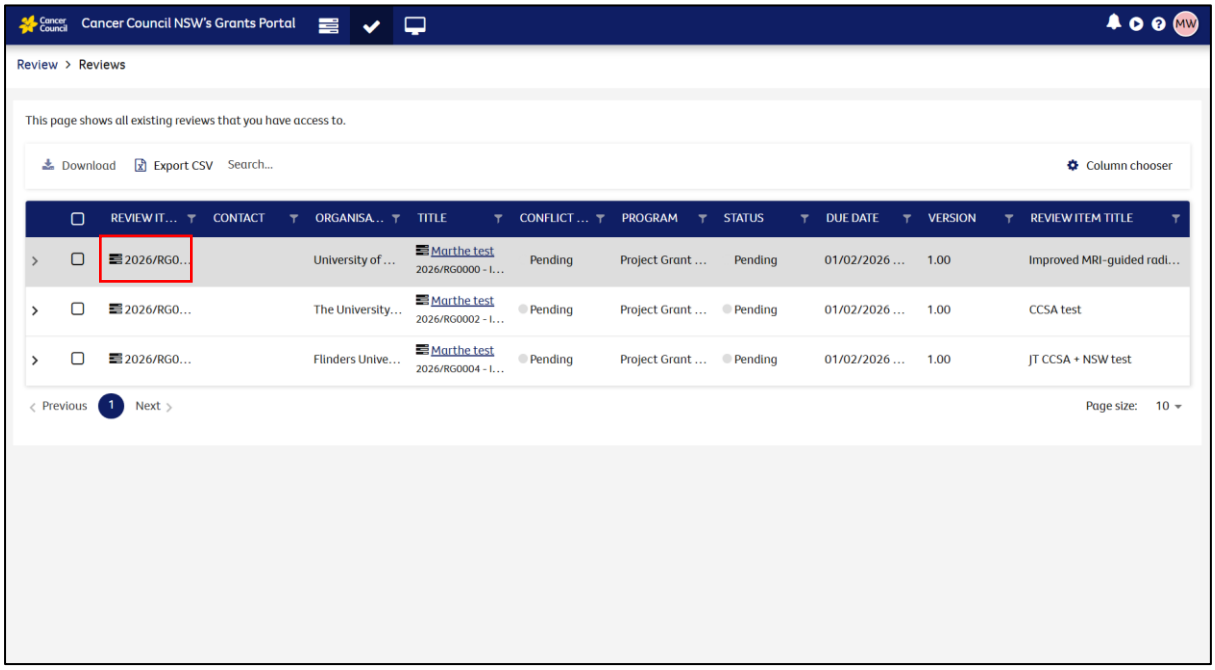
9.3 Filling in the Lived Experience Review Form

The Panel Member accesses the assigned reviews by clicking on *Reviews*. All assigned applications will be listed (see below). There are two ways to review the application.

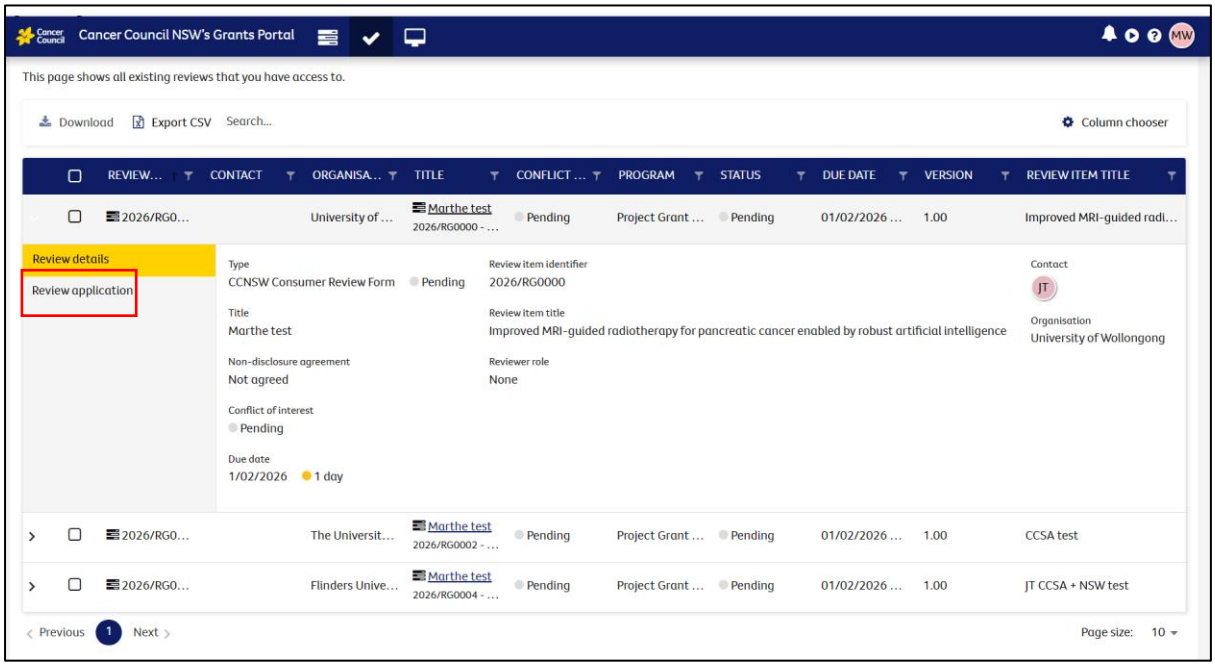
1. Clicking on the application name will directly navigate the reviewer to this particular application.



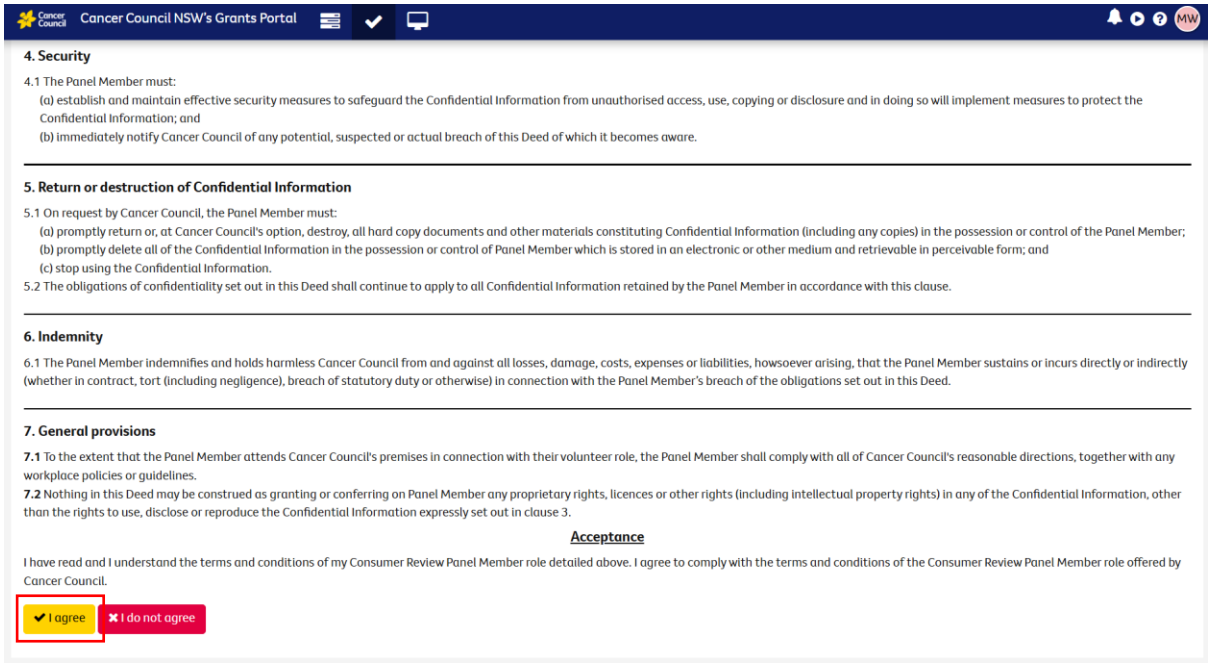
2. Clicking on the review ID (see below).



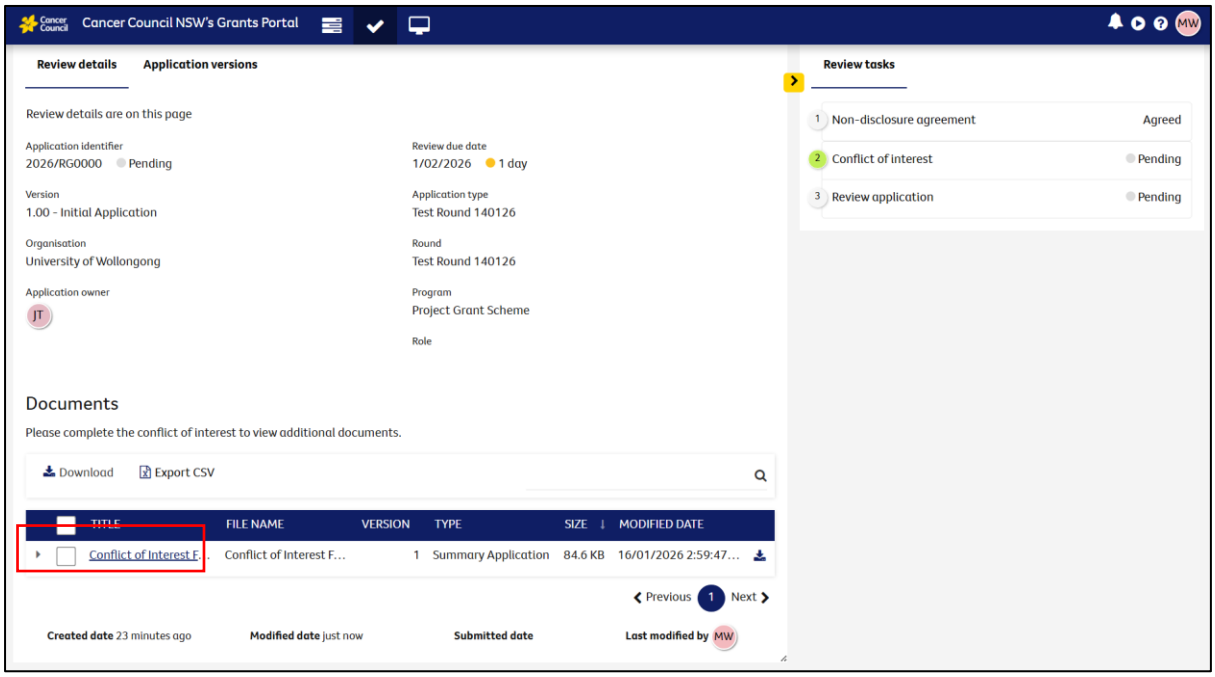
The reviewer can see the review details and must then click on *Review application*.



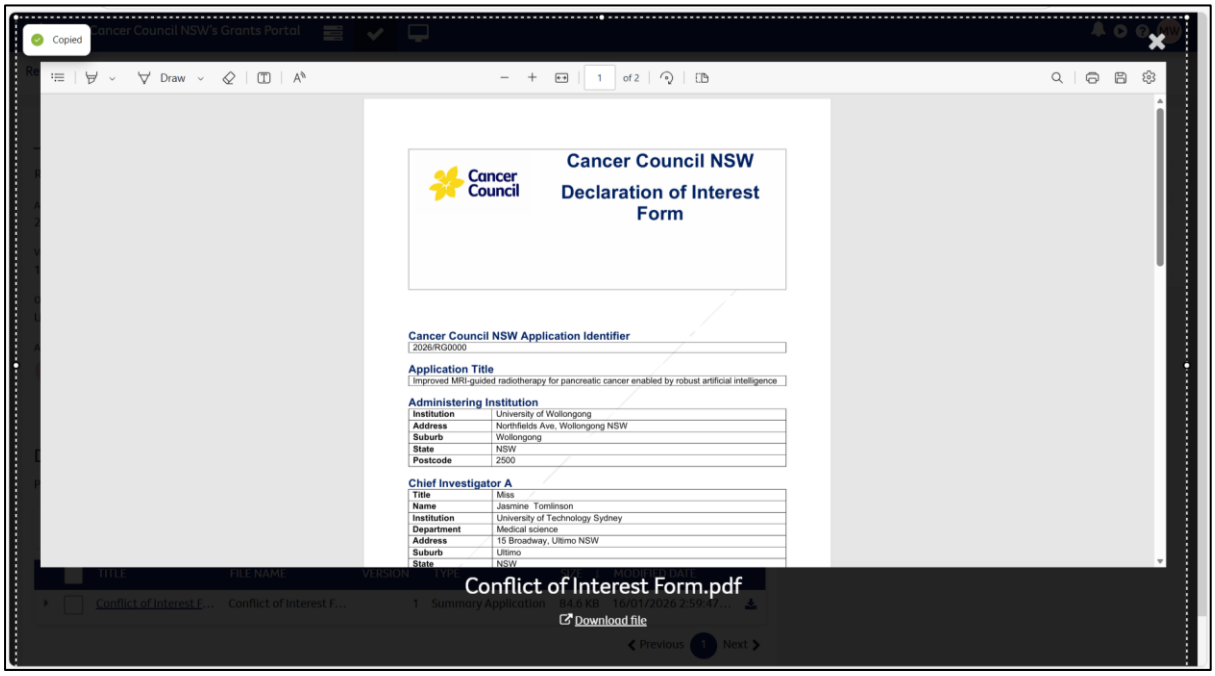
Both options will lead to the following screen (see below).



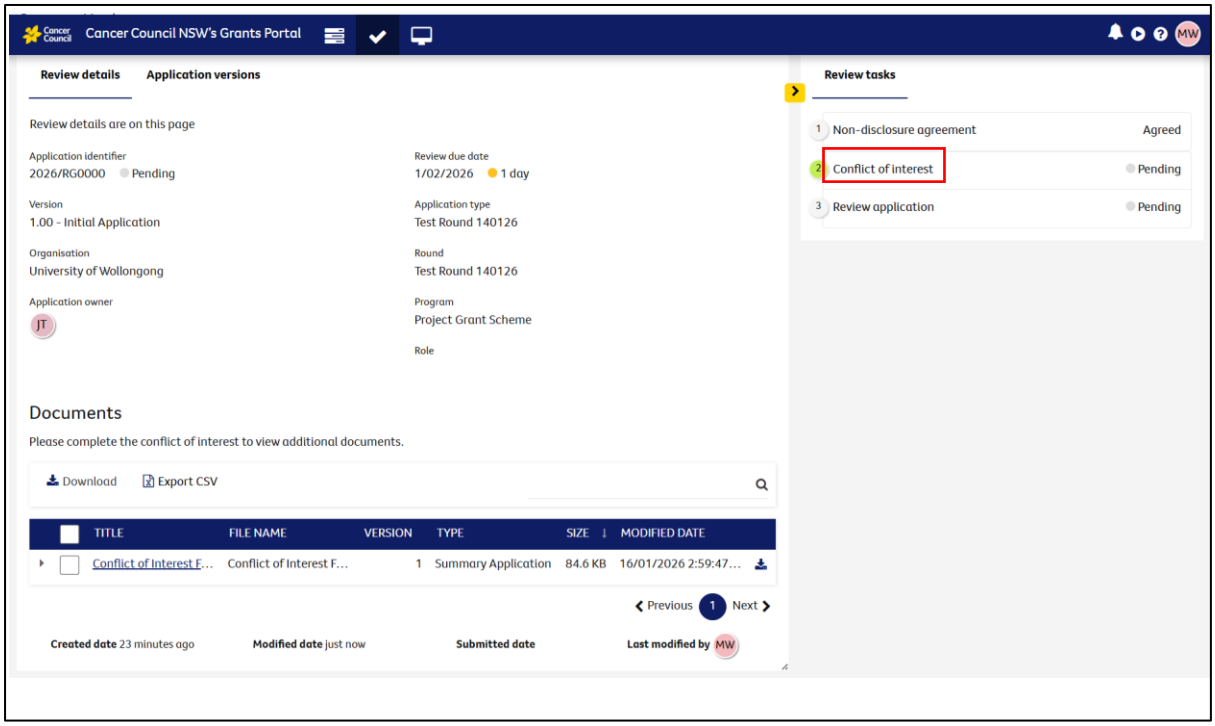
Every Panel Member must agree to the non-disclosure agreement by clicking on *I agree*. This will lead to the Conflict-of-Interest declaration. The Panel Member can now navigate to the application (see below).



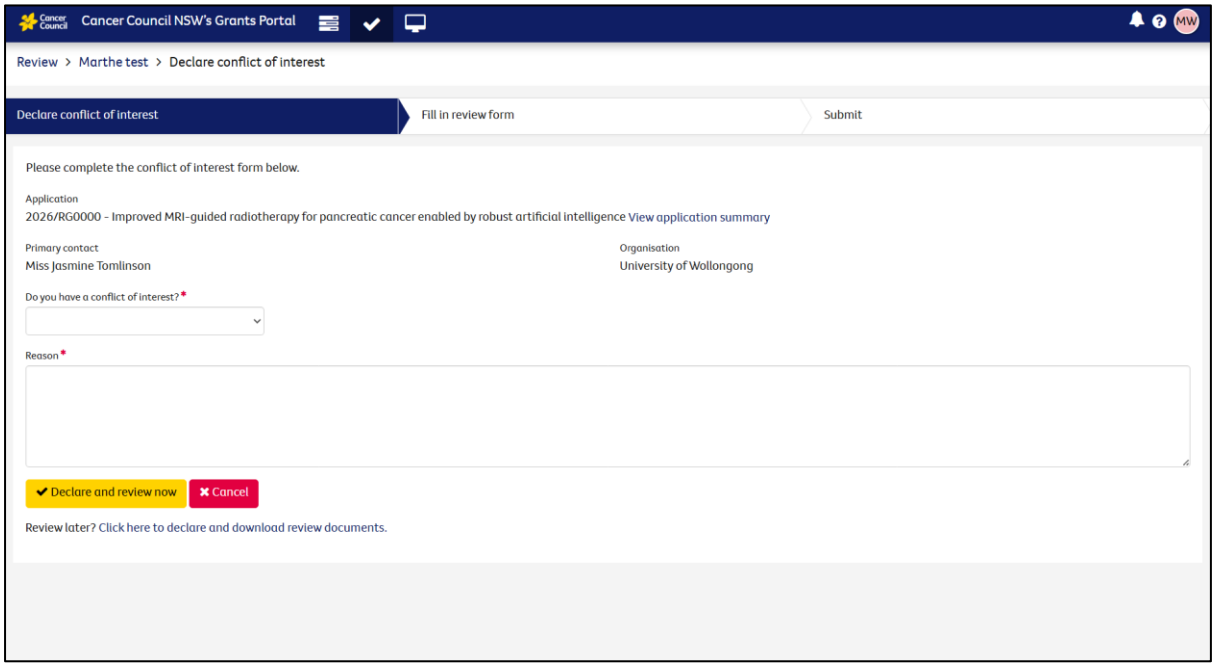
By clicking on the application, the Panel Member will have access to the Conflict-of-Interest form for this particular application (see below). This form can also be downloaded.



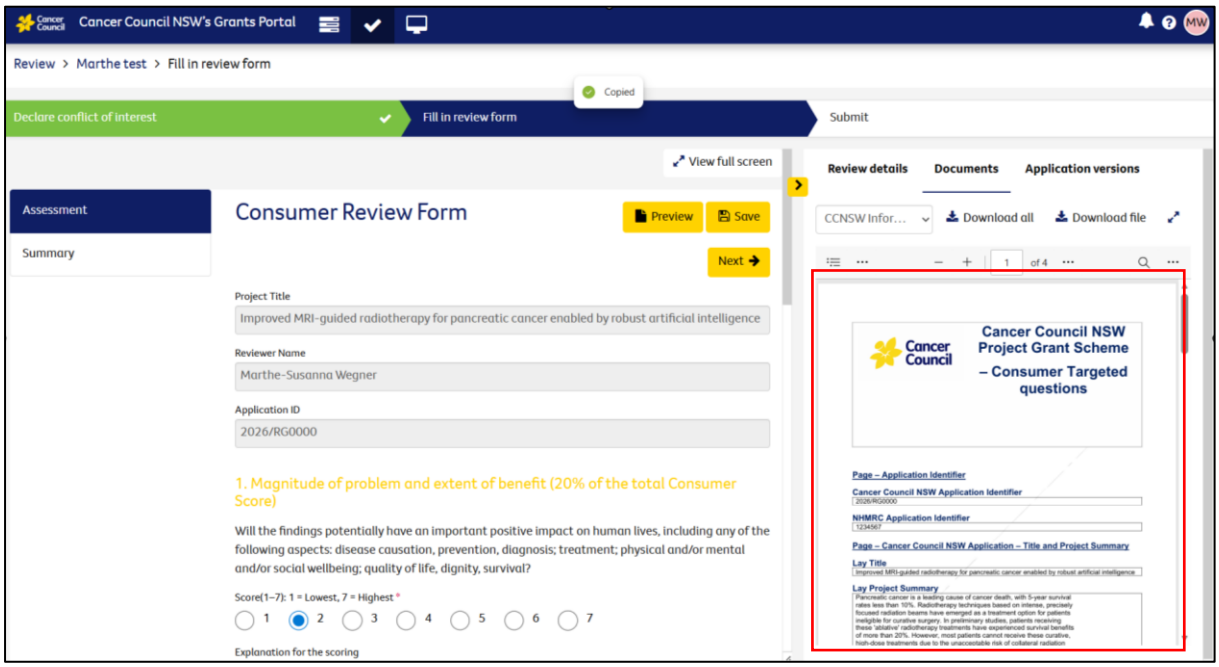
Following review of the Administering Institution and Investigators being involved, the reviewer can declare a conflict if applicable by navigating to *Conflict of Interest* (see below).



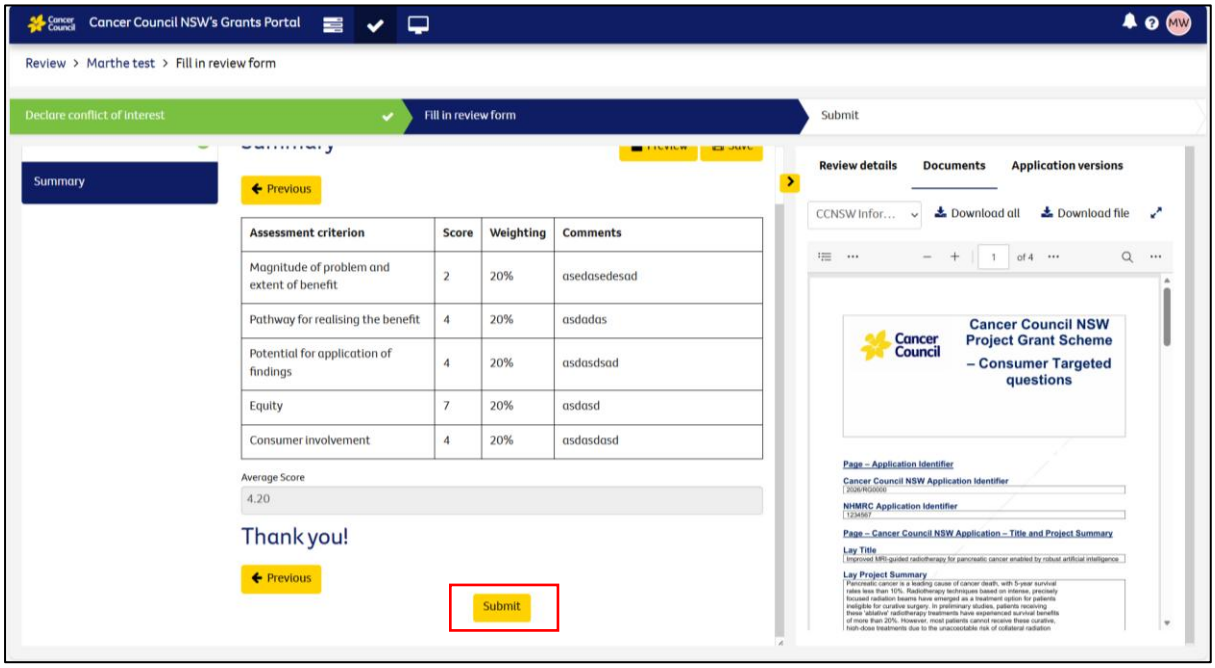
Declare if you have a conflict or not by using the dropdown menu and provide a reason if your answer is yes (see below).



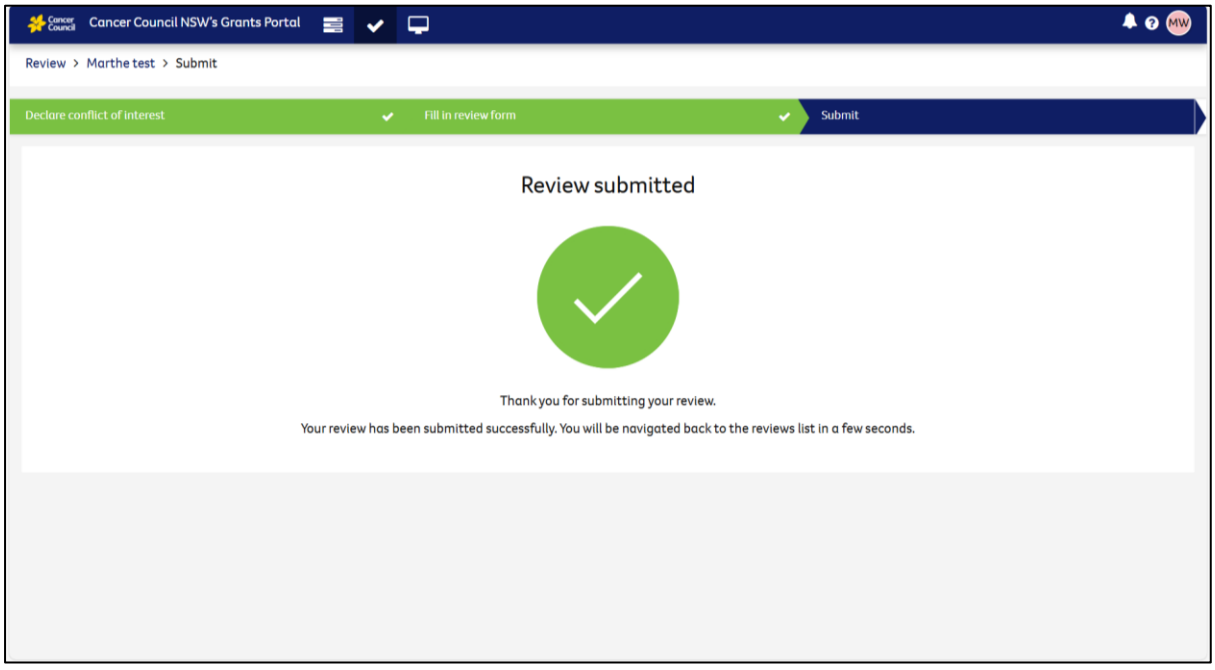
If you have declared no conflict, the reviewer can proceed and score the application including commenting on the reasoning for the score (see below). On the right-hand sight the Lived Experience targeted questions, filled in by the applicant can be found. There is also the option to download the respective documents.



The review is submitted by clicking on Submit (see below).



A confirmation of the review submitted will be displayed if submission is successful (see below). The Panel member can log off or proceed with the review of additional applications. If a conflict is declared, the reviewer will receive a prompt that the application cannot be reviewed. An automated email will also be sent to the reviewer.



10. Summary for Applicants

- The Lived Experience Review Panel is a panel of trained cancer patients, survivors, carers, and community members. Using the completed *Lived Experience targeted questions*, this Panel will assess the value of the proposed research to the cancer community.

- The Panel does not receive the submitted scientific application. It must be ensured that the *Lived Experience targeted questions* 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.
- Fill in *Lived Experience targeted questions* together with the project specific person with lived experience, who also must sign the online application form in the *Lived Experience targeted questions* section (please see *Project Grants Guidelines*).
- Use plain lay language to ensure the text can be understood by non-scientific audience. If it is not clear to the project specific involved Lived Experience it will not be clear to the Panel.
- To satisfy eligibility requirements, at least one named and qualified person with lived experience must be involved in the research proposal.
- Please read the guidelines closely and ensure you address all criteria in the suggested manner. If one of the five Lived Experience review criteria is not addressed, the application will be deemed ineligible.
- Review the current Project Grants Guidelines to receive more information.

10.1 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.
- Consumer Involvement in Research - The Daffodil Centre

10.2 How to find a person with lived experience

Cancer Voices NSW manages a consumer 'matching service' across all Australia in which trained Lived Experience are matched to research projects. To apply to have Lived Experience (former *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*.