Cancer Nursing Research Award 2019

Application Guidelines

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Appendix 1: Public and Patient Involvement (PPI) in Research Guidelines
1. General

1.1. Introduction
The Irish Cancer Society, in collaboration with the Health Research Board (HRB), the National Cancer Control Programme (NCCP), and the Office of the Nursing & Midwifery Services Director (ONMSD), wishes to invite research teams led by eligible nursing professionals to submit an application for the Cancer Nursing Research Award 2019.

The aim of this award is to stimulate, develop, and support cancer nursing research in the Republic of Ireland. As such, this award will fund a nurse-led partnership-based research project between Irish nursing professionals and academic researchers. Clinical-academic partnerships encourage research that is of the highest quality and clinical relevance, while expediting the translation of research into practice.

This is intended to be a transformative investment in a nursing individual who demonstrates great potential in driving and leading clinically-relevant and innovative cancer research in Ireland. This research will focus on areas which will impact positively on patient care outcomes and should be aligned to recommendations in the National Cancer Strategy 2017-2026.

Key Dates

<table>
<thead>
<tr>
<th>Event</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Call opens</td>
<td>Thursday 9 May 2019</td>
</tr>
<tr>
<td>Application deadline</td>
<td>Tuesday 2 July 2019</td>
</tr>
<tr>
<td>Interviews</td>
<td>First week of September 2019</td>
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</tbody>
</table>

1.2. Partnership Structure
The Cancer Nursing Research Award 2019 will fund one applicant team to undertake a nurse-led partnership-based research project. A team of at least two co-applicants will undertake a body of research work over a two-year period. The team must, at a minimum, have a nursing professional working in a clinical oncology role (Clinical Nurse Lead) and a researcher working in an academic role (Academic Research Lead). Though the application is a clinical-academic partnership, the research must be nurse-led. The research may be carried out either by the Clinical Nurse Lead (with time backfilled through the award – this is the preferable option) or by dedicated research staff supervised jointly by the Clinical Nurse Lead and the Academic Research Lead.

1.3. Public and Patient Involvement (PPI)
The Irish Cancer Society, the HRB, the NCCP, and the ONMSD are dedicated to involving patients, families, survivors, supporters, and the public in research. Public and Patient Involvement (PPI) in the research process ensures that research is meaningful and of benefit to those affected by cancer. As such, all applications are required to incorporate PPI into their proposal. PPI can be involved at any stage of a research project, from development and design to interpretation and dissemination. Ideally, PPI will feature throughout the project. Further details of PPI are included in Appendix 1.

1.4. Funding
The maximum total funding available is €160,000. The minimum funding period is 18 months and the maximum is 24 months. Payment to the host institute will only be released on receipt of all necessary institutional ethical approvals. However, a small provision (€7,500) of allocated monies may be made available at the start of the award to facilitate the ethical approval process where necessary.

2. Eligibility Criteria
Applications must be made by at least two co-applicant partners.

2.1. Applicant eligibility
The Clinical Nurse Lead must:

- Hold a professional qualification in nursing and be currently listed on the Nursing and Midwifery Board of Ireland’s register of Nurses and Midwives
- Currently hold a nursing appointment in the Republic of Ireland during which clinical time is spent working with people with cancer;
• Have a track record of research involvement exemplified by, for example, recruitment and data collection in research studies, conducting clinical audits, presentation at research meetings or conferences, publications, completion of research training, etc.
• The Clinical Nurse Lead will act as a clinical advisor to the project for the duration of the award. There must be clear evidence of this role through-out the application and for the duration of the award.

The Academic Research Lead must:

• Currently be resident and hold an academic appointment in a higher education institution in the Republic of Ireland for the duration of the award. This higher education institution will act as the host institution for the duration of the award;
• Possess a PhD or equivalent* in an academic field appropriate to the proposed project;
• Have a minimum of 5 first or senior authorships in peer-reviewed publications;
• Demonstrate a clear and strong level of support from their host institution;
• Have an established track record in research exemplified by, for example, a history of principal investigator roles, history or grant awards, involvement in clinical trials, research supervision, national/international research partnership development, presentation at national/international conferences, etc.;
• Demonstrate a commitment to ensuring the highest research standard of the proposed body of work;
• Act as a scientific advisor to the project and support the Clinical Nurse Lead for the duration of the award. There must be clear evidence of this active role through-out the application and for the duration of the award.

*PhD equivalent is defined as 4 or more years’ full-time postgraduate research experience.

2.2. Eligible research areas
Proposed projects should be in any area relevant to cancer nursing and focus on positively impacting cancer care and outcomes. Proposed projects must be aligned to the goals of the National Cancer Strategy and completed within the timeframe of the award.

Research projects in the area of basic or translational science are not eligible. If considering an interventions-based research study, please ensure that the stage of development of the intervention is appropriate and that previous development phases are complete. The award will not fund multiple phases of developing and delivering an intervention. If considering a complex intervention, please refer to the MRC Guidelines².

2.3. Host institution
The host institution is the organisation that receives and administers grant funding and is responsible for compliance with all general and specific terms and conditions of awards. Detailed letters of support will be required from the host institute (see Section 4). In order to be eligible to apply for funding, a proposed host institution must be a higher education institution in the Republic of Ireland and must be one of the HRB’s approved host institutions: https://www.hrb.ie/funding/funding-schemes/before-you-apply/all-grant-policies/hrb-policy-on-approval-of-host-institutions.

2.4. Clinical Site
Organisational support for the Clinical Nurse Lead is very important for this award. The clinical site may require staffing rearrangements (e.g., to cover the protected research time, if budgeted) or the hiring of research staff. A detailed letter of support is required from the clinical site outlining its commitment to support the Clinical Nurse Lead in all relevant activities within the proposed body of work. Further information regarding the letter of support is provided in Section 4.

2.5. Postgraduate Training
The Clinical Nurse Lead will be entitled to pursue a postgraduate research-based degree qualification as part of the award. Degrees must be completed within the timeframe of the award. Qualifications that are primarily clinically focused are not eligible for funding.

3. Application Process
Prior to applying, applicants must read this document through to completion. The research project should be designed and jointly written by both applicant Leads. The application must NOT be written by the Academic Research Lead or the Clinical Nurse Lead alone. For applications shortlisted for interview, both applicants will be expected to attend and both will be expected to display an in-depth knowledge of the proposed research project.

Either applicant partner may initiate an application. The second applicant partner is added to the application on the ‘Project Outline’ page. For instance, the Clinical Nurse Lead may create the application initially and add the Academic Research Lead to the application. The Academic Research Lead will then have access to the form, with editing capabilities.
3.1. How to apply

Applications must be completed and submitted through the Irish Cancer Society Gateway Grant Tracker online system. In order to submit an online application you are required to register at the following address: https://grants.cancer.ie.

The Clinical Nurse Lead and the Academic Research Lead will be joint lead applicants on the online application form. Both applicants will be required to approve the online application before it is submitted.

In addition to the Clinical Nurse Lead and Academic Research Lead, additional and appropriate co-applicants including PPI contributors may be added to the application.

3.2. Overview of the application process

When you enter your login details you will be directed to the Portal home page. From here you can:

- Update your basic information (please make sure all fields are completed)
- Make a new grant application
- Access previous grant applications

3.3. Making an application

To make a new grant application click on the ‘My Applications’ tab on the left-hand side of the page and click the ‘New Application’ button.

You will then be asked what Grant Type you would like to apply for. Click ‘Apply’ for the Grant Type detailed as ‘Cancer Nursing Research Award 2019’.

4. Application Form

Once you have confirmed that you meet all the eligibility criteria you will be directed to the application page.

There are 13 sections in the application form:

a) Introduction
b) Project Outline
c) Research Programme
d) Applicants’ Curriculum Vitae
e) Research Partnership
It is recommended that you save the information as you complete each section. This can be done by clicking ‘Save’ as you go along. Alternatively the information will be saved when you click ‘Save and Close’. By clicking ‘Previous’ you will be brought to the previous section and by clicking ‘Next’ you will be brought to the next section.

As you proceed through the sections you will see a small blue question mark icon next to some of the sections. By clicking on this icon you will get more information on the section to be completed.

Sections that are required to be filled out have a red circle icon next to them. You will not be able to proceed with the application if these sections are not completed.

*Note: External patient representatives will appraise the sections marked by an asterisk. It is very important that these sections are written in plain English and are accessible to a non-scientific audience.

Please see information from the Irish Cancer Society on Public and Patient Involvement (PPI) in Research Guidelines (Appendix 1) for more information.

a) Introduction

This section gives an overview of the Cancer Nursing Research Award 2019.

b) Project outline

Details of your application are entered into this section. Input and save the information as required under the following headings:
- Proposed title
- Proposed start date (must not be before December 2019)
- Duration (18-24 months)
- Clinical Nurse Lead details
- Academic Research Lead details
- Any other co-applicants
- Proposed host institution
- Cancer type
- Keywords
- Research type
- Discipline

c) Research Programme

**Basis for research**: Please describe the previous research which forms the basis of your research proposal. You may include research carried out by the applicants’ research team (400 words max).

**Hypothesis and/or Aims**: Please outline the hypothesis, research questions, and/or aims of your research proposal. Please ensure that the aims are realistic and achievable in the time frame (250 words max).

**Methods of Research**: Please describe and justify the methods, procedures, and experimental design you will use to conduct your research (800 words max).

For quantitative research, please provide statistical analysis for each part of your experimental plan; power calculations, numbers of samples, number of matched controls, and strategy of different controls to be used should all be discussed. Additionally, please discuss the feasibility of obtaining/accessing sufficient numbers of patient participants and controls that will result in statistically meaningful results.

For qualitative research, please describe the planned sample size and rationale, data collection methodologies (e.g., interviews, focus groups, and transcription procedures), analytic framework(s), and sources of bias. Additionally, please discuss the methodology and feasibility of recruiting the planned sample size.
**Ethical Considerations and Data Protection:** Please describe relevant ethical considerations for this project, including; Potential risks of participation and how they will be minimised, Research Ethics Committee application procedures, data protection considerations with respect to GDPR legislation, etc. *(250 words max).*

**References:** Please cite any literature referenced in the sections above.

**Gantt Chart and Research Images:** You must upload a Gantt chart for the proposed research study. You may upload up to four additional research images. All uploads must be in PDF format. Please ensure that figures are legible when uploading. Illegible figures may be difficult for the peer review panel to assess and could detract from your application.

**d) Applicants’ Curriculum Vitae**

In this section you are required to upload the Clinical Nurse Lead CV and the Academic Research Lead CV, completed using the associated CV templates. To upload the CVs click ‘Attach’ then locate the file to be attached, then click ‘Attach’.

**e) Research Partnership**

The partnership between the Clinical Nurse Lead and the Academic Research Lead is a core aspect of this award. It is expected that partners will work closely together to ensure the success of this project and reciprocally learn from each other’s expertise. In this section, you should describe the nature of the partnership, including, where relevant *(500 words max):*

- Details on whether the co-applicants have previously worked together and the nature of this previous partnership
- An overview of how the partnership will work practically over the course of the study (including information such as number and format of interactions, etc.)
- Details of the knowledge-sharing that will reciprocally occur between the Clinical Nurse Lead and the Academic Research Lead;

Please note, the successful applicants will be expected to provide evidence of this research partnership through-out the award as part of the reporting process.
f) Research Sustainability

Priority will be given to applicants who can demonstrate a clear plan to conduct further research and leverage further funding. Please describe your research sustainability plan, including the following (400 words max):

a) How this award would be transformative to the Clinical Nurse Lead’s career and establish them as a leader in research;
b) The next steps following the completion of the proposed research programme, where relevant;
c) Please identify any specific programme(s) and research funding body/bodies to which a future proposal(s) might be submitted.

g) Organisational Support

Organisational support is very important for this award, for both the Clinical Nurse Lead and the Academic Research Lead. Indeed, assessment of applications will favour those with the strongest letters of support.

The award must be processed through a higher host institution approved by the Health Research Board (www.hrb.ie/funding/funding-schemes/before-you-apply/all-grant-policies/hrb-policy-on-approval-of-host-institutions). Therefore, the academic institution of the Academic Research Lead must be aware of, and support, the application and agree to process the award.

Additionally, the organisation of the Clinical Nurse Lead may need to support research on-site. For projects which budget the part-time or full-time buy-out time of clinical staff, the supporting hospital is explicitly undertaking to use the award to backfill the staff time.

In this section the Clinical Nurse Lead is required to answer the following question (max 300 words):

- Please detail the steps that would need to be taken to ensure hospital sign-off for this award (and making necessary arrangements) should you be successful.

  If you have academic commitments these must also be considered.

Also required is an unequivocal and strong Organisational Letter of Support from both the organisation of the Clinical Nurse Lead and the higher education institute of the Academic Research Lead. Letters must be on headed paper and signed by the relevant person within each organisation.
- The Clinical Nurse Lead’s organisational letter of support should be from the applicant’s Director of Nursing, or similar. The letter must acknowledge that the Director of Nursing, and the organisation more generally, is aware of supports the application and will enable the applicant to fulfil research obligations. This support includes the appointment of new staff, or staff to cover any budgeted buy-out time (if relevant). The letter should describe how this support will be accomplished in the context of providing a clinical service. In addition, the clinical site must agree to provide indemnity cover that may be required by any staff carrying out research at the clinical site.

- The Academic Research Lead’s organisational letter of support must include acknowledgement that the organisation is aware of the application and will act as host institution should the applicant team be successful. This letter should also include acknowledgement that they will provide the staff of the award with research space, access to resources, and the appropriate insurance cover.

Letters of support should be written on headed paper and signed. To upload this letter of support click ‘Attach’, locate the file to be attached and then click ‘Attach’.

**h) Budget**

A full detailed breakdown of costs and justification for all costs must be provided for each budget heading in your application.

*Please note, preference may be given to applications that have leveraged additional external investment to support this research project.*

Funds may be requested for the following:

<table>
<thead>
<tr>
<th>i. Salary costs</th>
<th>All salary costs and staff should be detailed and robustly justified, with costs calculated using the appropriate HSE or IUA scales and inclusive of employer PRSI and appropriate pension contributions. Buy-out time for the Clinical Nurse Lead may be budgeted. However, salary costs for the Academic Research Lead cannot be budgeted. There are two options for hiring staff. Firstly, a backfill for a proportion of the Clinical Nurse Leads time can be funded by the award to buy out time to undertake the research. Preference will be given to this option. Secondly, the hiring of research/support staff is allowable where the Clinical</th>
</tr>
</thead>
</table>
| Nurse Lead is not in a position to carry out the research himself/herself. Research staff will be supervised jointly by the Clinical Nurse Lead and the Academic Research Lead. 
If research staff are to be hired, both partners should be able to demonstrate that they possess the necessary skills or experience to act in a supervisory capacity.  
HSE: https://www.hse.ie/eng/staff/benefitsservices/pay  
IUA:https://www.iua.ie/research-innovation/researcher-salary-scales/ |
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<tr>
<td>ii. Consumables</td>
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| iii. Training and education costs | Please provide details of costs involved in the lead applicants or research staff attending training and education modules (including those at research institutions other than host institution). 
If the Clinical Nurse Lead intend on pursuing an academic qualification during the award period, please justify and detail the associated costs. Please ensure that the fee amount budgeted here will suffice to cover the entire duration of the award. Registration fees may increase from year to year and it is your responsibility to ensure you have budgeted accordingly. |
| iv. Travel and dissemination costs | Please detail the dissemination costs for the research study e.g. printing, posters, publication costs, and public awareness lectures.  
Please also detail costs associated with the lead applicants or research staff attending academic meetings and conferences e.g., registration fees, travel, accommodation. |
| v. PPI costs | Please describe costs associated with your PPI (Public and Patient Involvement) plan. PPI is a requirement of this award. 
Guidelines on PPI and budgeting for PPI can be found in the appendices. |
i) Lay Summary

Please briefly detail the following: **(450 words max)**

- Outline the background of your research proposal, i.e. how and why your research came about. It is not sufficient to just state that 'this is an interesting area that we have been researching'.
- Describe the specific problem, issue, or question that you are asking in your research proposal, and describe how you are addressing it*.
- Describe the partnership between the co-applicants and how this award will contribute to the research career of the Clinical Nurse Lead.

*Note: It can be difficult to find the optimum “balance” between too much context and too little context. Therefore, we recommended that you veer towards giving more context than less.

External patient representatives will review this section. Please see information from the Irish Cancer Society on Public and Patient Involvement (PPI) in Research Guidelines (Appendix 1).

j) Impact

Research should be meaningful and of benefit to those affected by cancer (please see Appendix 1 for discussion of impact).

Please describe the impact your research is likely to have **(200 words max)**.

**Note:** You must articulate the realistic impact of your research project. You must not overstate or exaggerate the potential impact of your research

External patient representatives will review this section. Please see information from the Irish Cancer Society on Public and Patient Involvement (PPI) in Research Guidelines (Appendix 1).

k) Sharing of Findings

A key priority of the funders is to ensure that the public (including people affected by cancer) are kept up to date on research. In line with this, it is a requirement that all applicants produce a dissemination plan to include communication of their research to all relevant audiences (including the public and people affected by cancer).
Please describe your plan for sharing your findings. Dissemination may include printed or electronic articles, presentations, public engagement events, etc. (max 200 words).

External patient representatives will review this section. Please see information from the Irish Cancer Society on Public and Patient Involvement (PPI) in Research Guidelines (Appendix 1).

I) Public and Patient Involvement

The Irish Cancer Society, HRB, NCCP, and ONMSD are dedicated to putting patients, families, survivors, supporters, and the public at the very heart of what we do. In this section, please provide a detailed description of your plan for integrating Public and Patient Involvement (PPI) into your research project. Please note that PPI is a fundamental aspect of the application and will be integral in the selection of the successful applicant.

When completing this section, please carefully consider the following questions: (300 words max)

- What key stakeholders will be approached and from where?
- What aspects (e.g., recruitment, assessment, dissemination) of the proposed research will include PPI?
- What is the procedure for integrating PPI into these aspects?
- What steps will be taken to ensure PPI is not tokenistic?
- What PPI infrastructure is available within your university and how will it be utilised?

External patient representatives will review this section. Please see information from the Irish Cancer Society on Public and Patient Involvement (PPI) in Research Guidelines (Appendix 1).

m) Validation Summary

In this section, any required fields in the application form that have not been completed will be detailed. You will not be able to submit the application until all required fields are completed.
5. Submission of the Application

Once it has been verified that all required questions are answered in the correct manner on the application then the application can be submitted.

In the Validation section of the application please click "Save and Close" and then click on the "Submit" button in the right hand side of the Application Summary page.

The application deadline is 2 July 2019 at 3pm.

6. Application Assessment

Incomplete and ineligible applications and those submitted after the deadline will not be assessed.

6.1. Overview

Applications will be reviewed by both international academic reviewers AND patient representatives. Sections of the application will be assessed in the following way:

<table>
<thead>
<tr>
<th>Patient Reviewers</th>
<th>Scientific Reviewers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Application form</td>
<td></td>
</tr>
<tr>
<td>• Lay summary</td>
<td>• Project Outline</td>
</tr>
<tr>
<td>• Impact</td>
<td>• Research Programme</td>
</tr>
<tr>
<td>• Sharing of Findings</td>
<td>• Applicants’ CVs</td>
</tr>
<tr>
<td>• Public and Patient Involvement</td>
<td>• Research Partnership</td>
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<td></td>
<td>• Research Sustainability</td>
</tr>
<tr>
<td></td>
<td>• Organisational Support</td>
</tr>
</tbody>
</table>

Interview | Attending | Attending

Please note, the scientific reviewers will not be assessing any of the patient review sections, and vice versa. As such, it is vital that the sections reviewed by patient representatives are written in accessible **plain English**. Failure to do this may result in the patient representatives not being able to accurately score these sections of your application.

The budget will also be reviewed by the Irish Cancer Society to ensure that it is feasible and that all maximum limits have been adhered to. Final approval of all budgeted costs is at the discretion of the funders.
6.2. Assessment Procedure
Scientific Reviewers are asked to review each section of the application and provide a score for a) the Research Programme, b) Applicants’ CVs, c) Research Partnership, d) Research Sustainability, and e) Organisational Support. These sections will be assigned scores based on the strength of the applicants, their support structures, and the scientific merit of the proposed research.

Preference will be given to applications which demonstrate a clear benefit to the research skills, capacity, or career of the Clinical Nurse Lead.

Similarly, the patient panel will review and score their respective sections, specifically a) Lay summary, b) Impact, c) Sharing of Findings, and d) Public and Patient Involvement.

Scores from reviewers will be combined; both patient and scientific reviewers. Each patient reviewer will have an equal say (provide an equal score) to the scientific reviewers.

A teleconference with all reviewers will be held to decide which applicants will be invited to attend an interview. This decision will take into account the total score and ranking of each application.

6.3. Outcome
Applicants will be notified if they have been shortlisted for interview by email. Interviews are taking place the first week of September (date to be confirmed) in Dublin. Both applicant partners must be available on the interview on this date.

The interview panel will consist of scientific and patient reviewers. All reviewers will have an equal vote.

Feedback from the application review will be provided to shortlisted candidates in advance of the interview.

7. Application Checklist
The following must be completed ONLINE by 2 July 2019 at 3pm:

1. Completed Application Form
2. Uploaded CV of applicants
3. Uploaded Gantt Chart
4. Uploaded unequivocal and strong statements of organisational support for the application (on headed paper and signed by the relevant person within each organisation).
8. Contact

If you require assistance with the online application system or have any queries about the application, please contact the Irish Cancer Society:

Email: grants@irishcancer.ie

Telephone: +353 1 2310 583
Appendix 1: Public and Patient Involvement (PPI) in Research Guidelines

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Appendix 1: Public and Patient Involvement (PPI) in Research Guidelines

Please note: This document is intended for researchers planning to submit applications to an Irish Cancer Society research grant. For general information regarding the Irish Cancer Society’s Public and Patient Involvement, please contact ppi@irishcancer.ie

1. What is Public and Patient Involvement in research?
The Irish Cancer Society is committed to putting patients, families, survivors, supporters and the public at the very heart of what we do. In keeping with this commitment, we are working to embed Patient and Public Involvement (PPI) in our research processes. PPI can be contextualised in the many different ways people with cancer can interact with research, specifically by means of participation, engagement, and involvement\(^1\).

**Participation**
A person with cancer may be recruited into, and take part in, a research study and provide data of some form.

**Engagement**
Engagement is when the researcher communicates and disseminates research information, for example, at science festivals, public talks, television programmes, or radio.

**Involvement**
Involvement is distinct from participation or engagement. Where participation and engagement are conducted ‘to’, ‘about’, and ‘for’ people with cancer, involvement is conducted ‘with’ or ‘by’ people with cancer. People with cancer can be involved at any stage of the research process, from conceptualisation to dissemination.
2. Why is PPI important?
PPI is becoming increasingly common in research. The Irish Cancer Society is committed to expanding the involvement of those affected by cancer in the research that the Society funds, and in the funding decision-making process. This commitment is reinforced by the Irish Governments’ National Cancer Strategy (2017-2026)

“Patient involvement in cancer research improves the relevance of research questions, the quality, acceptability and feasibility of research conduct and the likelihood of uptake of research outputs.”

PPI creates a partnership between people affected by cancer and researchers. It is more than a tokenistic gesture to comply with policy, but can provide a real and substantial benefit to all key stakeholders. While not without its challenges, PPI can:

- Promote a sense of empowerment and value among patients
- Enhance patient trust in researchers
- Improve researchers’ insight into their own research area
- Help researchers identify barriers and come up with solutions to research
- Increase trust and acceptability in the patient community of research findings
- Inform the provision, access, and location of healthcare services
- Improve the dialogue between healthcare professionals and patients

Specific to the cancer setting, PPI may be used by patients as a resource, to make sense of living with chronic condition. People with cancer report feeling enhanced knowledge and skills from taking part in PPI, as well as feeling they contributed to research by providing a lay perspective (i.e., practical knowledge about being a patient with cancer).

As such, PPI can be a valuable tool in the research process for both patients and researchers, and the Irish Cancer Society aims to expand its PPI work over the coming years.
3. PPI and the funding process
The Irish Cancer Society aims to embed PPI in its grant review process and funding decisions. As such, the selection of award recipients is co-decided by scientific and patient reviewers. In doing so, the research we fund is of the highest scientific quality, while being relevant and important to people affected by cancer.

To accommodate PPI in the funding process, the application form comprises of sections that are reviewed by the scientific panel only and sections that are reviewed by the patient panel only.

Review sections will typically be allocated in the following way:

<table>
<thead>
<tr>
<th>Application form</th>
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</tr>
</thead>
<tbody>
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<td></td>
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</tr>
</tbody>
</table>

As the ultimate stakeholders in any future improvements of cancer care, advances in cancer research is of the most impact to patients. The Irish Cancer Society, therefore, encourages all applicants to use the PPI sections as an opportunity to connect with the patient reviewers. To do this, it is vital that application form sections allocated to patient reviewers are written in plain, non-technical language.

Patient reviewers will score their allocated sections and therefore significantly contribute to the funding decision-making process. Scientific and patient reviewers will form the interview panel and each panel member will have an equal vote.

3.1. Lay Summary
A lay summary should provide a brief overview of the research proposal, written in a format appropriate and understandable to your audience. Remember, your audience, who will be patients, may not have a scientific background. Therefore, ensure the lay summary is written in plain English (please see Section 5). However, an important consideration when writing a lay abstract is to determine the right balance between pitching it to the correct lay audience and oversimplifying it too much. As such, the abstract should be written in clear plain English, but also adequately conveys the research question and what makes that particular research project important. The abstract may still
have some “jargon” or scientific names when necessary, once they are clearly defined in
understandable terms.

Please see below for sample answers for the Lay Summary Section:

**Example 1: Technical language used. Poor abstract with very little context. Please note, the
project described in this example has been created for the purpose of providing guidelines.**

**Background of the research proposal:**
Our group was the first group to establish and publish research on Trastuzumab-resistant cell line
variants. At present, to our knowledge, we are the only group researching the role of Hypoxia-
inducible factor 1-alpha (HIF-1α) in Trastuzumab drug resistance in HER2+ breast cancer. This is a
very interesting area that we have been researching. This research may also be beneficial in other
HER2 targeted therapies.

**Overall problem:**
The focus of this project is on a drug called Trastuzumab. The problem that we are addressing is
Trastuzumab drug resistance. The question we are asking is why do some patients respond to
Trastuzumab treatment and why do some patients not respond to Trastuzumab treatment?

Trastuzumab is a monoclonal antibody that prevents HER2-mediated signalling. Trastuzumab is
approved for the treatment of HER2-positive breast cancer. Trastuzumab is showing promise in the
clinic but, like most therapies, the issue of innate and de novo resistance prevails. Our research
focuses on investigating the mechanisms of drug resistance, finding ways to overcome this
resistance and finding predictive and/or prognostic biomarkers for this breast cancer treatment.

**How are we addressing the problem of Trastuzumab resistance?**
In the laboratory, we have Trastuzumab-sensitive breast cancer cell line variants and we have
developed Trastuzumab-resistant breast cancer cell line variants. We are comparing the proteins in
drug-resistant cells to the drug-sensitive cells to try to find statistically significant differences
between the two. We have identified HIF-1α as a potential protein involved in the mechanism of
Trastuzumab resistance.

**What is HIF-1α and what are our next steps?**
HIF-1α is one of the major transcription factors that regulates tissue response to low oxygen
tension. HIF heterodimers bind to hypoxic response elements (HREs) in the genome, this results in
activation of pathways involved in angiogenesis, pH regulation, metabolism and apoptosis.

We have shown in the laboratory that increased expression of HIF-1α directly correlates with
increased resistance to Trastuzumab treatment. We are interested in further investigating if HIF-1α
plays a role in initiating and/or promoting Trastuzumab drug resistance. If awarded this grant, we
will have the opportunity to expand this research and to test these findings in other breast cancer
models.
Example 2: Understandable lay abstract with good level of research context given. Plain language used. Please note, the project described in this example has been created for the purpose of providing guidelines.

Overall problem:
Trastuzumab is a drug used to treat a certain type of breast cancer called HER2+ breast cancer. This drug has been very successful in treating breast cancer. However, unfortunately, while Trastuzumab destroys a lot of breast cancer cells, there are some cancer cells that can still stay alive. When treatment does not kill all cancer cells, this is called drug resistance.

Background of the research proposal:
With the issue of Trastuzumab drug resistance in mind, we previously developed two types of breast cancer cells in the laboratory that represent the different ways that patients respond to Trastuzumab. One type being cells that die after Trastuzumab treatment and the other type are cells that do not die after Trastuzumab treatment. We previously compared hundreds of different ingredients in these two different types of cells. We found one particular ingredient that we believe to be involved in stopping Trastuzumab working.

What is the specific ingredient?
We found that the breast cancer cells that are resistant to Trastuzumab treatment are the only ones that produce large amounts of the “Hypoxia-inducible factor-1-alpha (HIF-1α)” ingredient. We need to see if HIF-1α is the “brains-of-the-operation” when it comes to Trastuzumab resistance.

What is HIF-1α?
Tumours can grow very fast, but, sometimes the walls surrounding the tumour cannot grow at the same speed and are faulty. Because of this, the tumours can become patchy and “leaky”. When this happens, oxygen can leak out of the tumour causing the conditions in the tumour and nearby area to become very harsh and unfavourable. But, cancer cells cleverly find ways to avoid the harsh conditions and they can become stronger and survive better. Cancer cells use HIF-1α to make these unfavourable conditions within a tumour less harsh.

How are we addressing this problem?
Our next steps are to find out why the resistant cells are producing large amounts of HIF-1α. We believe that Trastuzumab will work again if we stop the cells producing large amounts of this specific ingredient. We will test different drugs to shutdown HIF-1α in the resistant cells. When we find the best drug to shut down HIF-1α we will then test Trastuzumab’s ability to kill the cells. If Trastuzumab works again we will test the two drugs together to see if they work better together as a “double therapy”. The next step will be to try the two drugs in mouse models of HER2 breast cancer. Mice with resistant cancer tumours will be given either Trastuzumab alone or the two drugs together to see if the “double therapy” works best.

Our research will focus on trying to stop drug resistance occurring in patients in the first place and to try and make Trastuzumab better at treating breast cancer.
3.2. Impact

Broadly speaking impact is the demonstrable contribution that research makes to society. Impact is defined as research being used to bring about a positive change to the lives of people affected by cancer. The impact research has is specific to each project and therefore, impact is varied and can occur over different timescales, from the short to long term.

Some of the key areas of research impact include:

- academic impact
- health and health systems/services impact
- health-related and societal impact
- influence on policy making
- economic impact

It is vital that applicants describe their research project honestly, and do not overstate the impact of a research project. Rather, goals should be realistic, as should the potential impact that the project can have.

It is recognised that for some research there will be no direct impact on the lives of people affected by cancer in the short or medium term. However, the research will contribute to a wider conversation on cancer with the view to eventually directly impacting the lives of people affected by cancer.

The inclusion of academic impact is also an important consideration when measuring research impact, as it demonstrates the contribution that a particular research project has made towards the advancement of science, and to the cancer research knowledgebase. These academic advances can be measured in terms of primary research related outputs and includes research publications, knowledge dissemination, capacity building, and collaborations.

Please note, when communicating the impact of your research, it is also useful to identify and articulate the different routes to impact - which are the means by which you aim for your research to be impactful.
3.3. Sharing of research findings

The Irish Cancer Society is the largest voluntary funder of cancer research in Ireland. Research is conducted primarily for the benefit of patients, therefore, a key priority of the Irish Cancer Society is to ensure that the public (including people affected by cancer) are kept up to date on research that is funded by the Society. In line with this, it is a requirement that all applicants produce a dissemination plan to include communication of their research to all relevant audiences (including the public). It is important to note that while peer-reviewed journals are an important means of communicating research findings to academic researchers, members of the public are less likely to access academic journals.

Research dissemination and knowledge exchange includes:

- Public engagement talks or events e.g., Irish Cancer Society ‘Decoding Cancer’, Pint of Science, Science Week events, public university talks, etc.;
- Non-peer reviewed professional periodicals e.g., The Irish Psychologist, World of Irish Nursing;
- Newspapers/media e.g., The Irish Times, thejournal.ie, Newstalk;
- Blog posts e.g., professional blog, Irish Cancer Society website;
- Peer-reviewed journals (open-access).

4. PPI and the research process

PPI can be incorporated into almost any stage of the research process, which should be planned from the very beginning of study design. Examples of how PPI can be incorporated into research includes (but is not limited to):

- as members of a patient advisory group for the project;*
- commenting on and developing patient information leaflets, consent forms, questionnaires or other research materials;
- user and/or carer researchers carrying out the research;
- commenting on and developing dissemination materials (e.g., conference abstracts, posters, presentations);
- Involvement in organising and running public and patient engagement activities.
In general, when, where, and how PPI will be included in studies should be decided early in the research process. The PPI plan must detail the PPI activities that will be organised during the project.

Please note, a number of universities within the Republic of Ireland already have dedicated individuals, infrastructure, training, or programmes (e.g., the HRB ‘PPI Ignite Award’) in place dedicated to PPI. We recommend that you engage with these local resources when planning how PPI will be integrated into your project.

*Any post-award significant alterations to study design or protocol suggested by the patient advisory group would need to be approved in advance by the Irish Cancer Society throughout the duration of the research project.*

### 4.1. Budgeting for PPI

The cost of PPI is dependent on how you plan to embed it into your study i.e., your ‘PPI Plan’. As such, it is difficult to prescribe guidelines on how to budget for PPI. However, **at a minimum, it is expected that the cost to PPI members associated with involvement are covered by the research grant** e.g., bus/train fares, mileage, parking charges, and subsistence (if appropriate).

The steps to PPI budgeting are described below:

<table>
<thead>
<tr>
<th>Step</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1: Framework selection</td>
<td>Select a framework for mapping involvement costs. This might be the research project cycle (i.e., the step-by-step research process/procedure) or a project timeline (e.g., Gantt chart).</td>
</tr>
<tr>
<td>Step 2: Planning your involvement</td>
<td>Make a plan of the involvement activities you intend to incorporate into your research.</td>
</tr>
<tr>
<td>Step 3: What are the costs?</td>
<td>For each activity, identify the specific costs for which you will need to budget.</td>
</tr>
</tbody>
</table>
| Step 4: How much will it cost? | Estimate the cost or range of costs against each involvement activity.  
To work out the budget for your study, go to the online cost calculator: [https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/](https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/). Please note the online calculator is in Pound Sterling. |
| Step 5: Mapping | Map the involvement activities onto your selected project framework so that you know exactly when in the project timeline costs are allocated. |

*Adapted from the UK National Institute for Health Research, Budgeting for Involvement (2013)*
An online calculator is available on the NIHR Involve website: [https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator](https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator). Please note the online calculator is in pound sterling (£), euro conversion rates will apply. The online calculator is a guiding tool, all costs must be appropriate to costing in the Republic of Ireland and all researchers must verify the costs associated with their PPI plan. Please check that the host institute has appropriate systems in place for the payment of PPI costs and expenses. Costings from all categories of the online calculator will be eligible (see below). However, please note that final approval of all costs is at the discretion of the Irish Cancer Society.

Please see the worked costing example below for guidance on creating and budgeting for the PPI plan.

**PPI budgeting costs:**

<table>
<thead>
<tr>
<th>Costing category</th>
<th>Related costs</th>
</tr>
</thead>
</table>
| Payments and rewards      | • Fees to individuals  
• Vouchers/tokens for individuals  
• Prize draw awards  
• Fee/donation to a group  
• Funding for additional training and learning  
• Honorary appointment e.g., lay fellow or research partner |
| Expenses                  | • Travel  
• Subsistence  
• Childcare  
• Carer costs  
• Personal assistants  
• Overnight accommodation  
• Home office costs |
| Involvement activity      | • Finding people/advertising  
• Training and learning costs  
• Venues and catering  
• Equipment and books  
• Access to university facilities  
• Conference fees |
| Involvement staffing      | • Administrative support  
• Involvement coordinator  
• Independent facilitator  
• Peer researchers/interviewers |
| Other costs               | • Disclosure and barring service  
• Language translation and interpretation costs  
• Support for people with impairments |

*Adapted from the UK National Institute for Health Research, Involvement Cost Calculator*
**Worked costing example:** A researcher wishes to set up a patient advisory group to guide the dissemination of findings. The aim is to ensure the research findings are communicated as widely and efficiently as possible, are accessible to a lay audience, and are engaging to the general public. To achieve this aim, the researcher hopes to host a public engagement event.

The researcher is looking for five patient representatives to form the advisory group. The group will meet for a half day workshop to design the public engagement event, creating information booklets, and educational project posters. All information booklets and educational videos will be accessible on the researcher’s website.

The estimated costs associated with setting up the advisory group and the costs associated with the public event are as follows:

<table>
<thead>
<tr>
<th>Category</th>
<th>Detail</th>
<th>Quantity</th>
<th>Cost</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Travel</strong></td>
<td>Local travel in Dublin</td>
<td>3</td>
<td>€7</td>
<td>€21</td>
</tr>
<tr>
<td></td>
<td>Travel from outside of Dublin</td>
<td>2</td>
<td>€30</td>
<td>€60</td>
</tr>
<tr>
<td><strong>Focus group</strong></td>
<td>Payment for attending focus group/workshop</td>
<td>5</td>
<td>€100</td>
<td>€500</td>
</tr>
<tr>
<td><strong>Venue costs</strong></td>
<td>University meeting room cost</td>
<td>1</td>
<td>€0</td>
<td>€0</td>
</tr>
<tr>
<td><strong>Catering costs</strong></td>
<td>Breakfast and lunch for attendees (€10 per person/per meal)</td>
<td>5</td>
<td>€20</td>
<td>€100</td>
</tr>
<tr>
<td><strong>Advertising</strong></td>
<td>Newspaper advertisement (for 2 weeks)</td>
<td>1</td>
<td>€70</td>
<td>€70</td>
</tr>
<tr>
<td><strong>Dissemination</strong></td>
<td>Printing of 12-page booklets</td>
<td>250</td>
<td>€0.96</td>
<td>€240</td>
</tr>
<tr>
<td></td>
<td>And educational posters:</td>
<td>5</td>
<td>€32</td>
<td>€160</td>
</tr>
<tr>
<td><strong>Public Event costs</strong></td>
<td>Costs for university venue (1/2 day)</td>
<td>1</td>
<td>€150</td>
<td>€150</td>
</tr>
<tr>
<td></td>
<td>Catering (tea and biscuits) (€3.50 per person)</td>
<td>100</td>
<td>€3.50</td>
<td>€350</td>
</tr>
</tbody>
</table>

**TOTAL COST** (€1000 from PPI budget and €651 from consumables budget) **€1,651**

*All costs were calculated using estimated costs for train tickets, hotels, and so on in the Republic of Ireland as of March 2019.*
5. Writing in plain English
There are many online resources available to guide you in writing an effective plain English summary. Some of these resources are listed in Section 6 of this document.

Here are some general notes on how to write in plain English:

- Patients are not scientists (usually) and knowledge should not be assumed. Avoid using technical language or scientific terminology. Use everyday words to communicate your point and explain the science. While language should be understandable, it should not be dumbed down - It may be necessary to use scientific words and jargon in order to convey why your research is special, but be sure to explain it thoroughly and be consistent in its use.
- Use short clear sentences.
- Use paragraphs
- Use an active voice, and place the person/group/thing doing the action at the beginning e.g., ‘We ran an experiment,’ rather than, ‘The experiment was run.’
- Don’t use ‘don’t’. You can write in plain English without becoming too casual/unprofessional.
- Use an appropriate tone. This is not a newspaper article, and its purpose is not to entertain.
- Make sure grammar, punctuation, and spelling are accurate.
- Bullet points (like these ones) can make it easy to digest a lot of information

6. Additional Resources
General resources

- INVOLVE – UK National Institute of Health Research (NIHR) initiative to support PPI.
  http://www.invo.org.uk
- NALA (National Adult Literacy Agency)
  https://www.nala.ie
- Access to Understanding: Promoting public understanding of biomedical and health research
  http://www.access2understanding.org

Writing a Lay Summary

Communicating to patients


Writing in plain English

• NALA (National Adult Literacy Agency). Writing and Design Tips.

Budgeting for PPI

• INVOLVE PPI Involvement Cost Calculator

7. References


