Guidelines for Applicants

Increasing Bowel Screening Uptake Research Award 2019

Updated: 16/10/19

1 Introduction

1.1 General information

Bowel Cancer in Ireland

Bowel cancer (colorectal cancer) is one of the most common types of cancer diagnosed in Ireland. An average of 2775 cases of bowel cancer were diagnosed each year in Ireland during 2015-2017 (1). An average of 1000 people died dying from the disease in Ireland each year during 2014-2016 (1). Bowel cancer is the second most commonly diagnosed cancer among males (after prostate cancer) and the third most commonly diagnosed among females (after breast and lung cancer). Annual numbers of cases of bowel cancer are projected to increase by approximately 100% by 2045 compared to 2015 (2). Identification of precancerous lesions will usually mean cure without further treatment and if bowel cancer is detected at an early-stage, it is easier to treat and there is a better chance of recovery often curable.

BowelScreen

In 2012 the National Screening Service introduced BowelScreen, the National Colorectal Cancer Screening Programme. The aim of BowelScreen is to detect signs of bowel cancer at an early stage, where there are no symptoms. BowelScreen offers free bowel screening to men and women aged 60-69 through a home test kit known as the faecal immunochemical test (FIT). Screening is offered every two years. In the small number of cases where blood is found in the test sample, a colonoscopy will be performed as part of the BowelScreen programme. The colonoscopy will take place in a screening colonoscopy unit in a hospital.

Eligible men and women who indicate they wish to take part in the screening programme are sent a FIT. This simple and easy-to-use kit includes step-by-step instructions for self-administration of the
test at home. The test is returned in a special Freepost envelope to a laboratory contracted by the NSS for analysis. Results are provided within four weeks. From 2021, it is planned to extend the programme to all aged between 55 and 74 years.

Analysis has shown that in an eligible population in Ireland uptake of bowel screening following invitation was 40.2% in the prevalent round of screening (round one 2012-2015) (3). For the period between 1 January and 31 December 2016 the uptake of bowel screening following invitation was 39.8% (4). This is substantially lower than the percentage uptake of breast screening (76.2% in Jan-Jun 2018) and cervical screening (79.8% in Jan-Jun 2018) (5).

The literature has identified a number of different barriers hindering the uptake of bowel screening in Ireland (3,6). In particular research has shown that men have a significantly lower uptake when compared to women and there was significantly lower uptake in disadvantaged areas as opposed to affluent areas (6).

The Irish Cancer Society and the National Screening Service are committed to increasing the uptake of bowel screening in Ireland. Therefore, the aim of this award is to fund a project that identifies and pilots an intervention designed to overcome these barriers and increase bowel screening uptake.

References


5 Department of Health. National Cancer Strategy 2017-2026
6


**1.2 Purpose and requirements**

The purpose of this grant call is to fund research that produces **tangible results** in increasing bowel screening uptake in eligible populations in Ireland.

The project **must identify and pilot an intervention(s) designed to increase bowel screening uptake in Ireland**. It should be clear how the intervention has been designed taking into account the current literature in this area. It is encouraged that the intervention is completed and the results analysed during the 24 month funding period.

It is required that applicants **link in with the National Screening Service (NSS)** at pre-application stage. As the national body overseeing BowelScreen the NSS will be integral in facilitating the research and potentially implementing the research findings into the programme.

NSS Contact- Dr Therese Mooney, Head of Programme Evaluation Unit- Therese.Mooney@screeningservice.ie.

**1.3 Applications**

Both individual and group applications are acceptable. For group applications there must be one lead applicant. The lead applicant must be an academic and will be responsible for submitting the application. Should the application be successful, the lead applicant will be responsible for overseeing the award. This award is not intended to fund a Masters or PhD student.

For this award any group members will be considered as **co-applicants*** (maximum of 5 co-applicants plus 1 lead applicant). Co-applicants must have a well-defined and substantial role in the proposed plan.

Only one application can be submitted per applicant. An application can only be submitted once**.

* Co-applicants must be academics (e.g., principal investigators/clinicians active in research/post-doctoral research fellows/PhD students).

** Applicants that submit multiple applications will be rejected. Applications submitted more than once by different applicants will be rejected.

**1.4 Funding**

The funding provided jointly by the National Screening Service and the Irish Cancer Society. There is funding available for one grant in 2019. This will be subject to the submitted grant proposals meeting
the required standard as assessed by international peer review. Any application that does not meet this required standard will be eliminated from the application process. The Increasing Bowel Screening Uptake Research Award 2019 will provide funding of up to €160,000 for a project of up to a maximum of 24 months duration.

Only proposals with the potential to deliver excellent, informative, and impactful research within the timeframe of the grant will be considered for funding.

1.5. Key Dates

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tuesday 15th October 2019</td>
<td>Applications open</td>
</tr>
<tr>
<td>Tuesday 12 November 2019 – 3pm</td>
<td>Application Deadline</td>
</tr>
<tr>
<td>November/December 2019</td>
<td>Review</td>
</tr>
<tr>
<td>December 2019</td>
<td>Awardee selected</td>
</tr>
</tbody>
</table>

*Please note: that the above dates are subject to change at the discretion of the Irish Cancer Society.*

2 Eligibility Criteria

2.1. Applicant Eligibility

Applications from individuals that do not meet the eligibility criteria will not be assessed. We therefore strongly recommend you read the following requirements carefully. If you are unsure of your eligibility, please contact grants@irishcancer.ie.

**Lead applicants must have:**
- a doctoral degree by research (or equivalent*) in a field relevant to the proposed research programme
- a minimum of two years post-doctoral research experience
- have a mentor (only required for lead applicants with less than 4 years post-doctoral research experience)

**Eligible Applicants must fulfil the following criteria:**
- be based at an Institution in the Republic of Ireland
- hold a contract that covers the duration of the award

**Co-applicants must fulfil the following criteria:**
- have well-defined and substantial roles in the proposed project
- hold academic contracts that covers the duration of the award

*PhD equivalent is defined as three or more senior (first, joint-first, or last) author publications in peer-reviewed academic journals or 4 years full time research experience. Alternative research outputs may be considered eligible e.g., monographs. In such instances, candidates should contact grants@irishcancer.ie before applying.*
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. 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.

4 Stakeholder Steering Group

The Irish Cancer Society is committed to ensuring representation from key stakeholders in helping to guide and shape how best to deliver continued improvements in patient outcomes. In particular, the Irish Cancer Society is dedicated to putting patients, families, survivors, supporters, and the public at the very heart of what we do.

It is therefore a requirement of this award that provision for public and patient stakeholder engagement through an overarching Stakeholder Steering Group be included as part of this project proposal. The steering group will include people who can input key perspectives on an ongoing basis into the project and must include public and patients’ representatives for their insight. Bearing in mind that screening is focussed on an otherwise healthy public, at a minimum, it is expected that one representative representing the perspective of general members of the public will sit on the group.

Such a group may be consulted throughout the duration of the proposed project to inform on key methodologies such as stakeholder recruitment, design of materials (e.g., questionnaires/interview scripts), interpretation of results, and advise on dissemination plans across the various stakeholder networks.

5. Application Procedure

5.1 How to Apply

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

When registering please fill out all the fields on the registration form.

5.2 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

5.3 Making an application

When you have ensured that all your basic details are entered then you can proceed to apply for a new grant application. This can be done by returning to the Portal Home page and clicking to apply for funding from one of our grant streams. Or alternatively through the ‘My Applications’ tab on the left hand side of the page, and clicking 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 ‘Alternative Therapy Scoping Award 2019’.

6. The Application Form

There are 10 sections outlined on the left hand side of the page:

a) Introduction
b) Project Outline
c) Mentor
d) Applicant Curriculum Vitae
e) Co-applicant roles and research team
f) Research Programme
g) Sustainability
h) Declaration of Support - Head of Department
i) Budget
j) Societal Considerations *
   - Interaction with Study Participants*
   - Stakeholder Steering Group*
   - Sharing of Findings*
k) Validation Summary

These sections are to be viewed and completed. 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 PPI (public and/or patients) 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 the overview information of the Increasing Bowel Screening Uptake 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 February 2020)
- Duration (max 24 months)
- Applicant details
- Proposed host institution
- Cancer type
- Keywords
- Research type
- Discipline

c) Mentor
Please indicate if you have at least 4 years post-PhD research experience. A mentor is required for all applicants with less than 4 years of post-PhD research experience. If the application is submitted as a group and neither the lead applicant nor the co-applicants have 4 years of post-PhD research experience then a mentor is required.

**Mentor:**
You must add your Mentor to the application. Your mentor will have to confirm participation in the application and also approve the application after you submit it and before it is finally submitted to the Society.

To add your Mentor you can search for them by entering their surname. If the Mentor has already created an account then they will appear on the list. To add them as your Mentor click ‘Select’. Please note that on saving, the contact will be added to the Application as a Mentor and they will receive a notification of this via email.

If your Mentor does not already have an account you can click ‘Add a New Contact’ and enter their name and email address. Please note that on saving, the contact will be added to the Application as a Mentor. They will receive a notification of this via email.

**Mentor CV**
Please upload your Mentor’s CV. The CV template is downloadable from this section on the online system or on the website.

**Declaration of Support – Mentor:**

Please upload a declaration of support from your mentor. The Declaration of Support Template is downloadable from this section on the online system or on the website. This must be completed on headed paper.

**d) Applicant Curriculum Vitae**

In this section you are required to upload your CV, completed using the associated CV template. To upload the CVs click ‘Attach’ then locate the file to be attached, then click ‘Attach’.

**e) Co-applicant roles and research team**

More than one applicant may be listed on each application. This may be in the form of a) co-applicants, or b) where a junior applicant (2-4 years post-doctoral experience) requires a mentor. Co-applicants must confirm participation in the application and also approve the application before you submit it.

A mentor is a signatory who is required to approve the application after you have submitted it, before it is finally submitted to the Society for review. Please note mentor information is required in another section of the application form (outlined in Section C).

To add a co-applicant you can search for them by entering their surname. If the individual has already created an account then they will appear on the list. To add them to the application, click ‘Select’. Please note that on saving, the contact will be added to the application and they will receive a notification of this via email.

If the co-applicant does not already have an account you can click ‘Add a New Contact’ and enter their name and email address. Please note that on saving, the contact will be added to the application and will receive a notification of this via email.

**Co-applicants:** If there are co-applicants please explain their roles in the plan delivery (maximum of 5 co-applicants) (100 words max per co-applicant).

In this section it is required to upload the CVs of co-applicants, completed using the associated CV template. To upload the CVs click ‘Attach’ then locate the file to be attached, then click ‘Attach’.

**Research team:** If there are additional research team members please explain their roles in the plan delivery (150 words max).

**f) Research Programme**

Please give details of the research project that will be supported by the project grant.
National Screening Service (NSS)

Please outline the communication that has occurred with the NSS and how they will be included in this application (200 words max).

Basis for research: Please clearly state the relevant background information for this research proposal. It is very important that a knowledge of the current research in bowel screening internationally and in Ireland is demonstrated (400 words max).

Hypothesis, aims and objectives: Please outline the hypothesis and the aims of your research proposal and how these correspond to the purpose of this project grant outlined in section 1.2.

In this section you need to set out a series of strategic and logical objectives that you hope to achieve in the 24 months of the project. The objectives should be precise and concise statements, with a projected date for completion. In some cases, you can enter alternatives in case a pitfall arises (200 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 public/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 of your proposal. Where appropriate, describe informed consent procedures, with consideration of anonymisation (200 words max).

In addition, applicants should ensure to follow data protection legislation in all respects including the General Data Protection Regulations (GDPR) which came into effect on the 25th May 2018.

Dissemination and output: In addition to the brief mid-way report and the detailed end of study technical report, please describe the likely output from your proposal (e.g., peer-reviewed articles, policy documents, public engagement event) and the impact such output is likely to have (300 words max).

Summary and conclusions: Please outline the summary and conclusions of your research proposal (200 words max).
**Gantt Chart and Research Images:** You must upload a Gantt chart (PDF format) 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.

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

**g) Sustainability**

It is expected that the intervention funded as part of this award would be implemented on a larger scale following the end of the award, should the results show the intervention increased uptake.

The ability to leverage additional sources of funding and support is critical to this happening.

Please outline the following (200 words max):

- The steps that would need to be taken to implement the intervention on a larger scale.
- Any organisations that you would need to work with and how you plan on linking in with them during the grant period
- What additional funding will be leveraged and how this will be achieved
- Optional: Detail of confirmed other sources of co-funding/leveraged investments in kind (supporting document(s) required).

**h) Declarations of Support – Head of Department**

Please upload a declaration of support letter from the head of department at your host institution. The declaration of support template is downloadable from this section on the online system. 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’. If your research will take place at any additional sites (e.g., public hospital), you must upload a declaration of support from a relevant person within this organisation.

**i) Budget**

A full detailed breakdown of costs and justification for all costs must be provided in your application. Final approval of all budgeted costs is at the discretion of the Irish Cancer Society.

Funds may be requested for the following:

| i. Salary costs | All salary costs and staff should be detailed and justified, with costs calculated using the appropriate HSE or IUA scales and inclusive of employer PRSI and appropriate pension contributions. HSE: https://www.hse.ie/eng/staff/benefitsservices/pay |

---

Increasing Bowel Screening Uptake Research Award 2019  Page 10 of 14
<table>
<thead>
<tr>
<th>Section</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ii. Consumables</td>
<td>Please allow sufficient budget for all materials and consumables required to carry out your research proposal.</td>
</tr>
<tr>
<td>iii. Travel and dissemination costs</td>
<td>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.</td>
</tr>
<tr>
<td>iv. Stakeholder Steering Group</td>
<td>Please describe costs associated with your Stakeholder Steering Group including costs relating to patient and public involvement in the group. Guidelines on patient and public involvement and budgeting for patient and public involvement can be found in Appendix 1.</td>
</tr>
<tr>
<td>v. Leveraged Funding</td>
<td>Please describe the funding that has been leveraged and the associated costs.</td>
</tr>
</tbody>
</table>

**j) Societal Considerations**

The sections consist of three sections: Interaction with Participants, Stakeholder Steering Group and Sharing of Findings. Details on each sections can be found below. Please note that PPI reviewers will appraise these sections and it is very important that these sections are written in plain English and are understandable to a non-scientific audience.

**Interaction with Study Participants**

Please provide an overview summary of the proposed project intervention (100 words max).

A major part of this application will be interacting with and recruiting members of the general population to assess the barriers to bowel screen or “Study participants”. In the below section please describe the interaction with the participants as follows: (450 words max)

- Each stage of the project that participants will be interacted with and why
- How the participants will be recruited
- What the interaction involves
- What is expected of participants
- The process of providing feedback to participants about the project

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

The Irish Cancer Society is committed to ensuring representation from key stakeholders in helping to guide and shape how best to deliver continued improvements in patient outcomes. In particular the Society is dedicated to putting patients, families, survivors, supporters, and the public at the very heart of what we do. It is therefore a requirement of this award that provision for public and patient stakeholder engagement through an overarching Stakeholder Steering Group be included as part of this project proposal.

In this section, **please provide a detailed description of the Stakeholder Steering Group (300 words max)**.

When responding to this question, please address the following:
- What key stakeholders will be approached and from where?
- What aspects (e.g., recruitment, assessment, dissemination) of the proposed research will include the Stakeholder Steering Group?
- What is the procedure for integrating the Stakeholder Steering Group into these aspects?
- What steps will be taken to ensure that the input of the Stakeholder Steering Group is not tokenistic?

Before completing these sections the Society asks that all applicants carefully read Appendix 1 of these guidelines, which provides general guidance on public and patient involvement. Any plan which includes participation or engagement activities in lieu of involvement in the steering group will not be funded.

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

**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. **(200 words max).**

*External PPI 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) 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.
6 Assessment Procedure

6.1 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.

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

6.2 Assessment overview

Applications will be reviewed by both international academic reviewers AND PPI representatives. International academic reviewers will score and provide feedback for each application. PPI representatives will provide feedback on the application. Sections of the application will be reviewed in the following way:

<table>
<thead>
<tr>
<th>PPI Reviewers</th>
<th>Scientific Reviewers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Application form</td>
<td></td>
</tr>
<tr>
<td>• Interaction with Study Participants</td>
<td>• Project outline</td>
</tr>
<tr>
<td>• Stakeholder Steering Group</td>
<td>• Applicant Curriculum Vitae</td>
</tr>
<tr>
<td>• Sharing of Findings</td>
<td>• Mentor suitability (where relevant)</td>
</tr>
<tr>
<td></td>
<td>• Co-applicants suitability</td>
</tr>
<tr>
<td></td>
<td>• Research Programme</td>
</tr>
<tr>
<td></td>
<td>• Stakeholder Steering Group</td>
</tr>
<tr>
<td></td>
<td>• Declarations of Support</td>
</tr>
</tbody>
</table>

Please note it is vital that the sections reviewed by patient representatives are written in accessible plain English.

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.

6.3 Conflicts of Interest

We will endeavour to ensure that the international peer review panel chosen do not have any conflicts of interest regarding the applications they are assessing.
6.4 Assessment outcome

Applicants will be informed of the outcome of review by email.

7 Application Checklist

- Completed application form submitted online including the upload of:
  - Applicant CV
  - Mentor CV (if required)
  - Co-applicants CV(s)
  - Gantt Chart and research images
  - Declaration of Support – Mentor (if required)
  - Declaration of Support - Head of Department

The following must be completed **ONLINE by 3pm Tuesday 12\textsuperscript{th} November 2019.**

8 Contact

If you require assistance with the online application system or have any queries about the application, please contact the Irish Cancer Research Team, email: grants@irishcancer.ie
Appendix 1: Public and Patient Involvement (PPI) in Research Guidelines

Table of Contents

1. What is Public and Patient Involvement in research? ................................................................. 2
2. Why is PPI important? ......................................................................................................................... 2
3. PPI and the funding process ............................................................................................................. 3
   3.1. Lay Summary .............................................................................................................................. 4
   3.2. Sharing of research findings ....................................................................................................... 7
   3.3. PPI and the research process ..................................................................................................... 7
4. Budgeting for PPI ............................................................................................................................. 8
5. Writing in plain English .................................................................................................................. 10
6. Additional Resources ....................................................................................................................... 11
7. References ....................................................................................................................................... 12
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 involvement¹.

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)\(^2\), which highlighted:

>“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\(^3\)
- Enhance patient trust in researchers\(^3\)
- Improve researchers’ insight into their own research area\(^3\)
- Help researchers identify barriers and come up with solutions to research\(^3\)
- Increase trust and acceptability in the patient community of research findings\(^3\)
- Inform the provision, access, and location of healthcare services\(^4\)
- Improve the dialogue between healthcare professionals and patients\(^4\)

Specific to the cancer setting, PPI may be used by patients as a resource, to make sense of living with chronic condition\(^5\). 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)\(^6\).

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. 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>PPI Reviewer</th>
<th>Scientific Reviewer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Application form</td>
<td>• Lay summary</td>
</tr>
<tr>
<td></td>
<td>• Sharing of Findings</td>
</tr>
<tr>
<td></td>
<td>• Public and Patient Involvement</td>
</tr>
<tr>
<td></td>
<td>• Project Outline</td>
</tr>
<tr>
<td></td>
<td>• Research Programme</td>
</tr>
<tr>
<td></td>
<td>• Applicants’ CVs</td>
</tr>
<tr>
<td></td>
<td>• Research Partnership</td>
</tr>
<tr>
<td></td>
<td>• Research Sustainability</td>
</tr>
<tr>
<td></td>
<td>• Organisational Support</td>
</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 PPI reviewers. To do this, it is vital that application form sections allocated to PPI reviewers are written in plain, non-technical language.

PPI reviewers will review their allocated sections and therefore significantly contribute to the funding decision-making process. Scientific and PPI reviewers 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. 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).

3.3. 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. 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>
<tr>
<td>Step 4: How much will it cost?</td>
<td>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: <a href="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/</a>. Please note the online calculator is in Pound Sterling.</td>
</tr>
<tr>
<td>Step 5: Mapping</td>
<td>Map the involvement activities onto your selected project framework so that you know exactly when in the project timeline costs are allocated.</td>
</tr>
</tbody>
</table>

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

*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>Travel</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>Focus group payment</td>
<td>Payment for attending focus group/workshop</td>
<td>5</td>
<td>€100</td>
<td>€500</td>
</tr>
<tr>
<td>Venue costs</td>
<td>University meeting room cost</td>
<td>1</td>
<td>€0</td>
<td>€0</td>
</tr>
<tr>
<td>Catering costs</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>Advertising</td>
<td>Newspaper advertisement (for 2 weeks)</td>
<td>1</td>
<td>€70</td>
<td>€70</td>
</tr>
<tr>
<td>Dissemination</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>Public Event costs</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>
<tr>
<td><strong>TOTAL COST</strong></td>
<td></td>
<td></td>
<td><strong>€1,651</strong></td>
<td><strong>€1,651</strong></td>
</tr>
</tbody>
</table>

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


