



## General Guidelines for Applicants

### **An Award to Examine the Barriers to Cancer Services for Socially Excluded Groups**

*(Underrepresented Communities Scoping Award 2021)*

Updated: 13.09.2021

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# Irish Cancer Society Research

## 1. Introduction

### 1.1 General information

As the largest voluntary funder of cancer research in Ireland, the Irish Cancer Society is committed to putting patients, families, carers, survivors, supporters and the public at the very heart of what we do. A key priority in the new Irish Cancer Society strategy 2020-2025<sup>1</sup> is to invest in world-class cancer research that will ultimately bring about a positive change to the lives of people affected by cancer. We do this by ensuring that all the research that we fund will have an impact and make a difference to people affected by cancer.

Cancer impacts the lives of everyone, but certain individuals bear a disproportionate burden of cancer when compared with the entire population. Although cancer mortality rates are declining, cancer incidence is still steadily increasing and there are certain groups within Irish society that are much more likely to have poorer outcomes with cancer. Cancer tends to be more common, more advanced, more difficult to treat, and be associated with poorer outcomes among socially excluded\* individuals and communities. Clinically, individuals from these groups are more likely to be diagnosed with cancer at a younger age, at a later stage and are less likely to survive their diagnosis.

The Society envisions that by 2025, three out of every four cancer patients will survive their diagnosis and that everyone affected by cancer will have access to world-class treatment, care and support no matter who you are or where you come from<sup>1</sup>. Therefore, in line with this vision, a key priority of the Irish Cancer Society is to identify ways in which we can overcome the barriers affecting socially excluded individuals and communities, in order to ensure equity of access to cancer care and services.

As an initial step to this priority, we first want to **identify who are these individuals and communities in Ireland that are having poor cancer outcomes**. Nationally and internationally there is very little research defining these socially excluded groups, and the reasons why these groups experience disproportionately poorer survival. Research has shown that there is a correlation between cancer

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<sup>1</sup> Irish Cancer Society Strategic Plan- 2020-2025 (<https://www.cancer.ie/about-us/irish-cancer-society-strategy-2020-2025>)

incidence and socioeconomic disadvantage<sup>2,3</sup>; however, cancer disparities likely reflect an interplay among many social, psychological, and economic determinants.

In the Republic of Ireland, there is limited available information on the patterns of cancer disparity in socially excluded groups. Given this deficit, and in line with the Irish Cancer Society and Irish Cancer Society Strategic Plan, we aim to “*inform and influence public policy*” in relation to all aspects of cancer. With this in mind, the aims of this specific call is to fund a research proposal to scope out and examine the characteristics of people in Ireland who experience especially poor outcomes with cancer and to identify the barriers that exist to accessing cancer services.

*\* As a guide, socially excluded groups may include (but are not limited to), individuals from lower-socioeconomic and educational backgrounds or experiencing poverty, unhoused or homeless individuals, individuals who are discriminated against as a result of their sexual orientation or gender identity, migrants, refugees and ethnic minorities, members of the travelling community or prisoners.*

## 1.2 Purpose

The purpose of this grant call is to fund a scoping research study aimed at identifying the individuals and communities in Ireland that experience significantly poorer cancer outcomes; then, having identified the groups, determine the barriers to accessing diagnosis, treatment and cancer services that exist for these individuals. The study must generate a final report addressing the issues defined and this report will be utilised to inform the needs in this challenging area for the Irish Cancer Society and other stakeholders. Applications for the Underrepresented Communities Scoping Award must address the following questions:

### Areas that must be addressed in a final report from the project:

- Who are the individuals or groups in the Republic of Ireland that have especially poor cancer outcomes? What are the common determinants of their experience?
- What is known of the impact of these common determinants on measures of cancer and its outcome?
- What barriers exist to accessing cancer diagnosis, treatment and services among these socially excluded groups in the Republic of Ireland?

### Additionally, it is desirable that the project might identify the following:

- How can services be adapted to reduce the barriers that prevent socially excluded individuals from accessing them?

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<sup>2</sup> Clegg, L.X., Reichman, M.E., Miller, B.A. *et al.* Impact of socioeconomic status on cancer incidence and stage at diagnosis: selected findings from the surveillance, epidemiology, and end results: National Longitudinal Mortality Study. *Cancer Causes Control* **20**, 417–435 (2009). <https://doi.org/10.1007/s10552-008-9256-0>

<sup>3</sup> Walsh PM, McDevitt J, Deady S, O’Brien K & Comber H (2016) Cancer inequalities in Ireland by deprivation, urban/rural status and age: a report by the National Cancer Registry. National Cancer Registry, Cork, Ireland

In supporting a project in this area we are also seeking to obtain an insight into the common determinants of health, behaviour and the environment of socially excluded individuals as well as the underlying reasons, attitudes, opinions, characteristics, and motivational factors which influence cancer patients and their access to cancer services.

*Please note that the purpose of this award is to provide the Irish Cancer Society with a report, within the time frame agreed to, that will be utilised to inform the activities of the Irish Cancer Society and other key stakeholders. At the end of the funding period, successful applicants will therefore be required to furnish the Society with a technical report detailing the key findings and recommendations. The content of this report will be used on an ongoing basis by the Irish Cancer Society, and in its media communications.*

*\* For the purpose of this award, the research must primarily focus on all socially excluded groups rather than specific groups.*

### **1.3 Applications**

Applications may come from individuals or groups with established expertise in conducting research and synthesising knowledge from this field. For group applications there must be one lead applicant. The lead applicant must be an academic and will be responsible for submitting the application. The lead applicant must be affiliated with a [HRB approved Institution](#) in the Republic of Ireland. Please note, the award must be administered through this HRB approved Institution.

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 principal investigator/lead applicant. An application can only be submitted once\*.

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

### **1.4 Funding**

It is the intention of the Irish Cancer Society to provide funding for one grant in 2021. 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 Underrepresented Communities Scoping Award 2021 will provide funding of up to €50,000 for a project of up to a maximum 12 month duration.

**Multiple interim reports may be provided over this timescale but the project must generate its conclusions no more than 12 months after signing of the award contract inclusive of any external oversight/ethical oversight etc. that might need to be applied for to complete the research.**

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

## 1.5 Key Dates

Monday 13th September 2021	Applications open
<b>Monday 11th October – 3pm</b>	<b>Application Deadline</b>
October/November 2021	Review
November 2021	Awardee selected

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

## 2. Eligibility Criteria

### 2.1 Applicant Eligibility

Applications 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](mailto: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 2-4 years post-doctoral research experience)

Eligible Applicants must fulfil the following criteria:

- The lead applicant must be affiliated with a [HRB approved Institution](#) in the Republic of Ireland. Please note, the award must be administered through this HRB approved Institution
- hold an employment 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

*\* 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](mailto:grants@irishcancer.ie) before applying.*

### 2.2. Project Eligibility

As this is a focused research call, applicants are required, at a minimum, to address the research questions outlined in section 1.2. At a minimum, the research project must use quantitative methods to identify the common determinants of socially excluded groups in the Republic of Ireland\*, the impact of these determinants on their cancer experience and outcome and the barriers to accessing cancer services experienced by these groups. A combination of both quantitative and qualitative

research methodology is also acceptable. There are no stipulations as to how these questions are answered. However, applications will be subjected to expert peer review which will evaluate how robustly the proposed methodology will answer the specified research questions.

*\* As a guide, socially excluded groups may include (but are not limited to), individuals from lower-socioeconomic and educational backgrounds or experiencing poverty, unhoused or homeless individuals, individuals who are discriminated against as a result of their sexual orientation or gender identity, migrants, refugees and ethnic minorities, members of the travelling community or prisoners. For the purpose of this award, the focus must be on identifying determinants of socially excluded groups with the highest cancer burden and what barriers these groups face when accessing cancer services in the Republic of Ireland.*

### **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. 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. Public and Patient Involvement (PPI)**

The Irish Cancer Society is 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. We strongly encourage that applications include involvement by representatives of those affected by the issues that the programme seeks to support and/or their representatives. 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 on how to incorporate PPI are included in Appendix 1.

## **3. Application Procedure**

### **3.1. 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 fields on the registration form.

### **3.2. Overview of the Application Process**

When you enter your login details you will be directed to the Portal Homepage. 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

When you have ensured that all your basic details are entered you can then proceed to apply for a new grant application. This can be done by returning to the Portal Homepage 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 'Underrepresented Communities Scoping Award 2021'.

## 4. 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) Declaration of Support - Head of Department
- h) Budget
- i) Societal Considerations\*
  - Project Summary\*
  - Public and Patient Involvement\*
  - Sharing of Research Findings\*
- j) 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 patient representatives will appraise and give feedback on 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 Underrepresented Communities Scoping Award.

### ***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 2021)
- Duration (maximum 12-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 2-4 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.

#### **Declaration of Support – Mentor:**

Please upload a declaration of support from your mentor (if required). 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. 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.

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).

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

#### ***f) Research Programme***

Please give details of the research project that will be supported by the project grant.

*Basis for research:* Please clearly state the relevant background information for this research proposal **(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 12 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 **(150 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 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, and any other relevant legislation.

*Summary and conclusions:* Please outline the summary and conclusions of your research proposal **(200 words max)**.

*Gantt Chart:* **You must upload a Gantt chart (PDF format) for the proposed research study.** 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) 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.

#### ***h) 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.
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	HSE: <a href="https://www.hse.ie/eng/staff/benefitservices/pay">https://www.hse.ie/eng/staff/benefitservices/pay</a> IUA: <a href="https://www.iua.ie/research-innovation/researcher-salary-scales/">https://www.iua.ie/research-innovation/researcher-salary-scales/</a>
ii. Consumables	Please allow sufficient budget for all materials and consumables required to carry out your research proposal.
iii. 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.
iv. PPI costs	Please describe costs associated with your PPI (Public and Patient Involvement) plan. PPI is <u>optional</u> due to the nature of this award, however, PPI is desired. Guidelines on PPI and budgeting for PPI can be found in Appendix 1.

### ***i) Societal Considerations***

In this section, please provide a summary of your research and an overview of your plan for integrating public and patient involvement into your research project. Please note that public and patient involvement is strongly advised.

This section consists of three sections: Project Summary, Sharing of Research Findings, and Public and Patient Involvement (PPI) Plan. Details on each sections can be found below. Please note that patient 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.**

<b>Project Summary:</b>	Please provide a detailed and structured lay abstract. The language used should be understandable and not scientific. If scientific terms are used, they must be explained. Please detail the following <b>(450 words max)</b> : <ul style="list-style-type: none"> <li>— Briefly outline the background of your research proposal i.e. how and why your research came about, context;</li> <li>— Describe the specific problem, issue, or question that you are asking in your research proposal and describe how you are addressing it (including the variables being measured and why you have chosen these specific variables);</li> <li>— Outline who will take part in your research, how you intend to recruit them into your study, and what they will be expected to do if they take part.</li> </ul>
<b>Public and Patient Involvement Plan:</b>	The public and patient involvement plan should detail how patients will be <i>involved</i> in the research project. It should be well thought out, as detailed as possible, and given as much consideration as the scientific sections in the

	<p>form. Vague plans are to be avoided. When completing this section, please carefully consider the following questions: <b>(300 words max)</b></p> <ul style="list-style-type: none"> <li>— What key patients and stakeholders will be involved and from where will they be identified/recruited?</li> <li>— At what stage will patients be involved in your research project? E.g. planning, design, implementation, management, evaluation, dissemination.</li> <li>— What is the overall goal of involving patients?</li> <li>— How exactly will you involve patients? Give as detailed information as possible, for example numbers of patients involved and how they will be recruited, what exactly will be required from them etc.</li> <li>— What PPI infrastructure is available within your institution and how will it be utilised?</li> <li>— What supports will be in place for patients involved (should they be needed)?</li> <li>— Please identify any challenges that might arise from involving patients in your research, and how any issues will be prevented.</li> </ul>
<p><b>Sharing of Research Findings:</b></p>	<p>As the largest voluntary funder of cancer research in Ireland, the Irish Cancer Society relies on the generous donations from the public in order to fund cancer research. A key priority is, therefore, 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, in particular the public and people affected by cancer. Please describe your plan for sharing your findings. This may include printed or electronic articles, presentations, public engagement events, social media content, etc.</p> <p><b>Please address two areas in this section.</b></p> <p><b>-How</b> you will share your research with the public and people affected by cancer <b>(500 words max)</b>.</p> <p>- 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) and the impact such output is likely to have <b>(300 words max)</b>.</p>

***j) 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. Assessment Procedure

### 5.1. 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.

You can verify that all required sections are complete on the Validation page of the application form. Once validated, 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 proceed to peer review.

### 5.2. Assessment overview

Applications will be reviewed by both international academic reviewers AND PPI representatives. Each reviewer will provide scores and feedback on each application. Sections of the application will be assessed in the following way

	PPI Reviewer	Scientific Reviewer
Application form sections	<ul style="list-style-type: none"> <li>• Societal Considerations:               <ul style="list-style-type: none"> <li>○ Project Summary</li> <li>○ Public and Patient Involvement (PPI) Plan</li> <li>○ Sharing of Research Findings</li> </ul> </li> <li>• Budget*</li> </ul>	<ul style="list-style-type: none"> <li>• Mentor</li> <li>• Applicant Curriculum Vitae</li> <li>• Co-applicant roles and research team</li> <li>• Research Programme</li> <li>• Budget*</li> </ul>

### 5.2. Assessment procedure

Scientific Reviewers are asked to review specific sections of the application and provide a score for each section of the application. Scores will be assigned based on the scientific merit of the proposed research; the likelihood that the proposal will deliver on the required research questions (section 1.2); and the strength of the applicant team and their support structures.

Similarly, the PPI panel will appraise and give feedback on their respective sections, specifically, Project Summary, Public and Patient Involvement (PPI) Plan, and Sharing of Research Findings.

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

Applications will be assessed based on their likelihood to deliver meaningful results that adequately answer the required research questions outlined in Section 1.2.

Both scientific and PPI reviewers will be asked to provide feedback on the feasibility of the budget plan. 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 Irish Cancer Society.

### **5.3. Assessment outcome**

Applicants will be notified of the outcome by email. Feedback from the application review will be made available to candidates. Applicants will be informed of the outcome of review by email.

### **5.4. 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. Application Checklist**

Completed application form submitted online including the upload of:

- Applicant CV
- Gantt Chart
- Declaration of Support – Mentor (if required)
- Declaration of Support - Head of Department/School

The following must be completed **ONLINE by 3pm Wednesday 6th October 2021**.

## **7. Contact**

If you require assistance with the online application system or have any queries about the application which are not currently addressed in the FAQ document, please contact the Irish Cancer Research Team:

Email: [grants@irishcancer.ie](mailto:grants@irishcancer.ie)



# Irish Cancer Society Research

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

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

### 1. Background

The Irish Cancer Society is committed to putting patients, families, survivors, carers, supporters and the public at the very heart of what we do. In keeping with this commitment, we are embedding Patient and Public Involvement (PPI) in our research processes. The majority of Irish Cancer Society grant calls will require researchers to detail their plans for including patients in their proposed research. These involvement sections will be reviewed by people affected by cancer (PPI reviewers).

This document is intended as an additional resource on PPI for researchers planning on submitting a grant application to the Irish Cancer Society.

Information specific to individual grant calls can be found in the Guidelines to Applicants document for each call.

### 2. What is Public and Patient Involvement in research?

Interaction with patients and the public can be contextualised in the many different ways people with cancer can interact with research, specifically by means of *participation*, *engagement*, and *involvement* outlined below.

#### Participation

A person with cancer may be recruited into, and take part in, a research study e.g. a clinical trial, 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<sup>1</sup>. People with cancer can be involved at any stage of the research process, from conceptualisation to dissemination.

Involvement does not refer to researchers raising awareness of research, sharing knowledge or engaging and creating a dialogue with the public. It does also not refer to the recruitment of patients or members of the public as participants in research. However, these different activities – involvement, engagement and participation – are often linked and, although they are distinct, can complement each other<sup>1</sup>.

### **3. Why is PPI important?**

PPI is becoming increasingly important 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)<sup>2</sup>, 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<sup>3</sup>
- Enhance patient trust in researchers<sup>3</sup>
- Improve researchers’ insight into their own research area<sup>3</sup>
- Help researchers identify barriers and come up with solutions to research<sup>3</sup>
- Increase trust and acceptability in the patient community of research findings<sup>3</sup>
- Inform the provision, access, and location of healthcare services<sup>4</sup>
- Improve the dialogue between healthcare professionals and patients<sup>4</sup>

Specific to the cancer setting, PPI may be used by patients as a resource, to make sense of living with a chronic condition<sup>5</sup>. 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)<sup>6</sup>.

As such, PPI can be a valuable tool in the research process for both patients and researchers, and the Irish Cancer Society aims to continually to build on its PPI work.

#### **4. PPI is a partnership**

PPI is about creating a partnership between researchers and people affected by cancer, whereby all contribute collaboratively in varying degrees towards the research process or the research output. Each voice is of equal importance in PPI.

Involving people affected by cancer as early as possible in your planning process, and ensuring on-going clarity about their activities, roles and goals, is crucial to the success of PPI

Be clear from the outset what will be required from all involved in the patient involvement activities. A good exercise to do is to complete a role description for the role of the patient involved along with a description of what your role (the researcher) is with regards to PPI. This is beneficial as it is clear to both the researcher and the person affected by cancer what exactly is involved from both sides from the outset.

Relationship building is key for successful PPI. Having an open and respectful relationship is key to successful PPI. A number of different factors are important for a good relationship between the PPI contributor and the researcher(s), these are listed below.

- A good communicator including keeping in touch as needed
- Shows respect, empathy and understanding
- Has time for each other and the PPI activities

It is a good idea to keep in mind this relationship aspect of PPI when designing the Patient Involvement plans.

## 5. PPI and the funding process

The majority of Irish Cancer Society application forms contain sections relating to patient involvement. These sections will be reviewed by PPI reviewers and in most instances PPI reviewers will contribute to funding decisions along with scientific reviewers. As such, the review of applications is undertaken by scientific and PPI reviewers. In doing this, we ensure that the research we fund is of the highest scientific quality, while being relevant and important to people affected by cancer.

PPI reviewers are people effected by cancer including patients, survivors, family members and carers who have all received appropriate reviewer training.

## 6. PPI Sections in the Application

The following sections give information on PPI sections in application forms. Please note that not all sections outlined below may be in all application forms.

These sections will be reviewed by PPI reviewers. For some grant calls the PPI reviewers will score the sections and provide feedback and for other grant calls the PPI reviewers will give feedback only. This information will be given in the call guidelines.

### 6.1. *Project Summary*

A project summary should provide an overview of the research proposal, written in a format appropriate and understandable to your audience. A good summary should describe what you intend to do, why you intend to do it, and establish context. A clear understanding of the research project will allow the PPI panel to effectively evaluate other sections, such as the Patient Involvement Plan and Sharing of Research Findings sections.

For some awards, particularly those that include human participants, the PPI panel will review the practicalities and feasibility of the project and its relevance to people affected by cancer. Therefore, it is important to be clear and detailed.

Remember, your audience, who will be people affected by cancer, **may not** have a scientific background. Therefore, ensure the project summary is written in plain English (please see Section 6). However, an important consideration when writing the project summary is to determine the right balance between pitching it to the correct lay audience and oversimplifying it too much. As such, the summary should be written in clear plain English, but also adequately conveys the details on the

research question, research plan 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.

## **6.2. Patient involvement plan**

The patient involvement plan should detail how patients will be involved in the research project.

It should be well thought out and as detailed as possible. Vague plans are to be avoided. The patient involvement plan should be given as much consideration as the scientific sections in the application.

It is strongly recommended that plans include specific details such as how many patients will be involved, how these patients will be recruited, what exactly the patients will be doing etc.

As with any project we acknowledge that patient involvement plans may change over the course of an award but detailed plans are still sought at the application stage.

Please note that activities outlined in the Patient Involvement plan are required to be included in the Gantt chart (when a Gantt chart is required as part of the application).

### **Information on types of involvement:**

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

- as members of a patient advisory group for the project-
  - advising on the direction of the research; \*
  - commenting on and developing patient information leaflets, consent forms, questionnaires or other research materials;
  - commenting on and developing dissemination materials (e.g., conference abstracts, posters, presentations);
- user and/or carer researchers carrying out the research e.g. conducting interviews, co-facilitating focus groups, assisting in the interpretation of results.
- Involvement in organising and running public and patient engagement activities;
- Input into grant applications

*\*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*

### Challenges

- When planning how you will involve people, it is important to think about what might go wrong and how you might handle any challenges that arise.
  - A PPI Ready: Researcher Planning Canvas was developed by MacCarthy et al<sup>7</sup>, which researchers may find useful when considering potential challenges and how to address them.
- In some instances, patients may need additional support (emotional), it is a good idea to identify supports that could be offered to patients should they need it.
- Patients may also need practical supports to be involved. For example not all patients will have easy access to a computer. Offer to post printed copies of information and allow for additional time for people to read information and paperwork. Some people may need to use the phone as opposed to a computer to join meetings. These practical needs should be assessed at the start.

### Additional things to consider-

- A number of universities within the Republic of Ireland already have dedicated individuals, infrastructure, training, or programmes in place dedicated to PPI. We strongly recommend that you engage with these local resources when planning how patient involvement will be integrated into your project.
- Engagement can sometimes be mistaken for involvement (more information on both in section 2). While engagement activities are important and can often lead to involvement opportunities, it is predominantly involvement that should be outlined in this section - *Involvement is conducted ‘with’ or ‘by’ people affected by cancer.*
- For translational biomedical laboratory based research it can be difficult to initially envision the practicalities of how patients can be involved in a research project in a meaningful way. However there are a lot of valuable opportunities to involve patients in this type of research. Further guidance on PPI in lab-based research can be found here- <https://sites.google.com/parkinsons.org.uk/ppi-in-lab-based-research/home>

### **6.3. 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 sharing of research findings plan to include communication of their research to **all** relevant audiences including the public and patients. As part of this section of the grant application, researchers are encouraged to carefully consider the different stakeholders that may be interested in their research, and develop a plan for communicating with each of these stakeholder groups.

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.

Some examples of research dissemination and knowledge exchange includes but is not limited to:

- Peer-reviewed journals (open-access is encouraged).
- Dissemination at conferences and meetings
- Non-peer reviewed professional periodicals e.g., The Irish Psychologist, World of Irish Nursing;
- Public engagement talks or events e.g., Irish Cancer Society 'Decoding Cancer', Pint of Science, Science Week events, public university talks, etc.
- Newspapers/media e.g., The Irish Times, thejournal.ie, Newstalk;
- Blog posts e.g., professional blog, Irish Cancer Society website;
- Newsletters
- Online videos and website content

### **6.4. Budgeting for PPI**

The cost of PPI is dependent on how you plan to embed it into your study i.e., your Patient Involvement Plan. As such, it is difficult to prescribe guidelines on how to budget for PPI. However, at a minimum, it is expected that the out of pocket expenses of PPI members associated with involvement are covered by the research grant

Before beginning to budget we recommend that you check that the host institute has appropriate systems in place for the payment of PPI costs and expenses. The host institute may also have specific

guidelines in place around budget costs and allowable expenses, we recommend that you check this with your institute before completing the budget.

The steps to PPI budgeting are described below:

Step	Activity
Step 1: Framework selection	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).
Step 2: Planning your involvement	Make a plan of the involvement activities you intend to incorporate into your research.
Step 3: What are the costs?	For each activity, identify the specific costs for which you will need to budget.
Step 4: How much will it cost?	<p>Estimate the cost or range of costs against each involvement activity.</p> <p>To work out the budget for your study, go to the online cost calculator:</p> <p><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.</p>
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/> . 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.**

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.

Justification must also be given for a costs. Please note this is not an opportunity to elaborate on details of your patient involvement plan or sharing of research findings plan, all relevant information on these plans must be in the relevant sections.

PPI budgeting costs:

<b>Costing category</b>	<b>Related costs</b>
Payments and rewards	<ul style="list-style-type: none"> <li>Fees to individuals</li> <li>Vouchers/tokens for individuals</li> <li>Prize draw awards</li> <li>Fee/donation to a group</li> <li>Funding for additional training and learning</li> <li>Honorary appointment e.g., lay fellow or research partner</li> </ul>
Expenses	<ul style="list-style-type: none"> <li>Travel</li> <li>Subsistence</li> <li>Childcare</li> <li>Carer costs</li> <li>Personal assistants</li> <li>Overnight accommodation</li> <li>Home office costs</li> </ul>
Involvement activity	<ul style="list-style-type: none"> <li>Finding people/advertising</li> <li>Training and learning costs</li> <li>Venues and catering</li> <li>Equipment and books</li> <li>Access to university facilities</li> <li>Conference fees</li> </ul>



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

Working examples:

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

Worked costing example for virtual advisory group:

A researcher wishes to set up a patient advisory group to advise on dissemination of the research results and assist with writing lay summaries for grant applications.

The researcher is looking for three patient representatives to form the advisory group. The group will meet for 3 half day virtual workshops over 2 years.

The estimated costs associated with the advisory group are as follows:

Category	Detail	Quantity	Cost	Total
Virtual Meetings	Online meeting platform used by institution for example Zoom. No cost as institute pays for the licence.	1	€0	€0
Advisory group honorarium	Honorarium for attending virtual advisory group/workshops	3 x 3= 9 (3 representatives x 3 meetings)	€100	€900
<b>TOTAL COST (€1000 from PPI budget)</b>				<b>€ 900</b>

All costs were calculated in the Republic of Ireland as of January 2021.

Worked costing example for in-person advisory group:

A researcher wishes to set up a patient advisory group to advise on dissemination of the research results and assist with writing lay summaries for grant applications.

The researcher is looking for three patient representatives to form the advisory group. The group will meet for 2 half day in-person meetings and 1 virtual meeting over 2 years.

The estimated costs associated with the advisory group are as follows:

Category	Detail	Quantity	UnitCost	Total
Travel	Local travel in Dublin ( 1 representative x 2 meetings)	1 x 2= 2	€8	€16
	Travel from outside of Dublin	2 x 2= 4 (2 representatives x 2 meetings)	€30	€120
Advisory group payment x 2	Honorarium for attending advisory group meetings)	3 x 3= 9 (3 representatives X 3 meetings)	€100	€900
Virtual Meetings	Online meeting platform used by institution for example Zoom. No costs as institute pays for licence.	1	€0	€0
Venue costs	University meeting room cost No cost as at host institute.	1	€0	€0
Catering costs	Lunch for attendees (€10 per person/per meal	3 x 2= 6 (3 representatives x 2 meetings)	€10	€60
<b>TOTAL COST (€1000 from PPI budget and €96 from consumables budget)</b>				<b>€1,096</b>

*All costs were calculated using estimated costs for train tickets, hotels, and so on in the Republic of Ireland as of January 2021.*

**Please note:** This budget is for specific costs associated with involvement only. If part of your PPI plan is that patients will organise an event or dissemination materials, the budget for these must be incorporated into the dissemination category of the main grant budget.

## **7. Writing in plain English**

As outlined in Section 6 the project summary should be written 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 9 of this document.

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

- People affected by cancer 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
- Make sure grammar, punctuation, and spelling are accurate.
- Bullet points (like these ones) can make it easy to digest a lot of information

## **8. Contact**

If you have any questions relating to PPI please contact [grants@irishcancer.ie](mailto:grants@irishcancer.ie).

## 9. Additional Resources

### General resources

- INVOLVE – UK National Institute of Health Research (NIHR) initiative to support PPI.  
<http://www.invo.org.uk>
- National Standards for Public Involvement.  
<https://www.invo.org.uk/posttypepublication/national-standards-for-public-involvement/>
- NALA (National Adult Literacy Agency)  
<https://www.nala.ie>
- Access to Understanding: Promoting public understanding of biomedical and health research  
<http://www.access2understanding.org>
- Versus Arthritis: Patient & Public Involvement, A researcher's guide  
<https://www.versusarthritis.org/media/1373/patient-and-public-involvement-booklet.pdf>

### Writing a Lay Summary

- Duke, M. (2012). How to write a lay summary.  
<http://www.dcc.ac.uk/sites/default/files/documents/publications/HowToLaySummariesDec2012.pdf>

### Communicating to patients

- NHS England. Language Matters: Language and Diabetes.  
<https://www.england.nhs.uk/wp-content/uploads/2018/06/language-matters.pdf>

### Writing in plain English

- NALA (National Adult Literacy Agency). *Writing and Design Tips*. <https://www.nala.ie/wp-content/uploads/2019/08/Writing-and-design-tips.pdf>

### Budgeting for PPI

- INVOLVE PPI Involvement Cost Calculator  
<https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/>

## 10. References

- 1) INVOLVE. (2018). *What is public involvement in research?* Retrieved from <http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/>. Accessed 07/01/21.
- 2) Department of Health. (2017). National Cancer Strategy (2017-2016). Retrieved from <https://health.gov.ie/wp-content/uploads/2017/07/National-Cancer-Strategy-2017-2026.pdf>. Accessed 07/01/21.
- 3) Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C., & Suleman, R. (2014a). A systematic review of the impact of patient and public involvement on service users, researchers and communities. *The Patient-Patient-Centered Outcomes Research*, 7(4), 387-395.
- 4) Mockford, C., Staniszewska, S., Griffiths, F., & Herron-Marx, S. (2011). The impact of patient and public involvement on UK NHS health care: a systematic review. *International Journal for Quality in Health Care*, 24(1), 28-38.
- 5) Thompson, J., Bissell, P., Cooper, C. L., Armitage, C. J., & Barber, R. (2014). Exploring the impact of patient and public involvement in a cancer research setting. *Qualitative Health Research*, 24(1), 46-54.
- 6) Froggatt, K., Preston, N., Turner, M., & Kerr, C. (2014). Patient and public involvement in research and the Cancer Experiences Collaborative: benefits and challenges. *BMJ Supportive & P Care*, 5, 518–521.
- 7) MacCarthy, J., Guerin, S., Wilson, A and Dorris, E. (2019). Facilitating public and patient involvement in basic and preclinical health research. *PLoS One*, 12(5).