



General Guidelines for Applicants

Misinformation and Disinformation in Cancer: An Intervention Development Award

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Key Dates

09 September 2020	Call opens to applicants
10 November 2020 @ 3pm	Application deadline
November/December 2020	Review
January 2021	Right to respond
Early February 2021	Outcome announced

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



Irish Cancer Society Research

1. Introduction

1.1. Overview

The purpose of this award is to fund an intervention development study designed to better enable those impacted by cancer to be more resilient in the face of misinformation/disinformation and false claims about alternative treatments that they will often experience. The Misinformation and Disinformation in Cancer Intervention Development Award will provide up to €65,000 for a project of up to 18 months duration. We are looking for an ambitious but achievable project focused on the emerging challenges faced both by patients and the healthcare professionals seeking to support them in the modern clinical environment and cognisant of the practicalities of operational issues, such as ethical approval, which might impact the commencement and delivery of the work.

1.2. Background and Aims

Despite increasing survival rates associated with evidence-based medical advances, false, partially false, or misleading information about cancer treatments are common. Misinformation is “information that is false, but not created with the intention of causing harm”, whereas, disinformation is “information that is false and deliberately created to harm a person, social group, organisation or country.”¹

Belief in health misinformation/disinformation may negatively alter a person’s cancer trajectory by influencing their medical decision making. For instance, use of alternative cancer therapies, defined as ‘*non-mainstream practices used in place of conventional medicine*^{2*}, can complicate the doctor-patient and doctor-carer relationships, and pose serious risk to health and life. Initial research suggests that the mortality rate for people with cancer can be up to 5 times higher among those taken in by misinformation/disinformation and who end up using alternative cancer therapies³. Hence, it is incumbent on us to develop new ways to ensure that patients are empowered to protect themselves

¹ Wardle, C., & Derakhshan, H. (2017). *Information disorder: Toward an interdisciplinary framework for research and policy making*. Council of Europe report, 27.

² National Center for Complementary and Integrative Health, *Complementary, alternative, or integrative health: what's in a name?* <https://nccih.nih.gov/health/integrative-health>.

³ Johnson SB et.al. *Use of Alternative Medicine for Cancer and Its Impact on Survival*. PMID: 28922780.

from being manipulated to make decisions by those promoting false and misleading information about cancer.

In the Republic of Ireland, there is limited available information on the patterns of alternative cancer therapy use. A key priority of the Irish Cancer Society Strategy (2020 - 2025) is to *“increase the number of people surviving cancer and improve the quality of that survival.”* We are already funding research to examine the extent of the challenge in our community and hence we now wish to examine and quantitate the opportunities to help those impacted by cancer and their loved ones protect themselves from misinformation/disinformation that can have negative economic, psychological, and health consequences.

With this in mind, the purpose of this call is to fund an intervention development study designed to better prepare those affected by a cancer diagnosis and reduce the numbers and extent to which they are potential victims of those touting false and misleading claims.

1.3. Funding

It is the intention of the Irish Cancer Society to provide funding for one grant, subject to grant proposals meeting the required standard as assessed by external review. The award will provide funding of up to €65,000 for a project of up to a maximum of 18 months duration, which includes a mandatory provision of €1,000 to support Patient and Stakeholder Involvement.

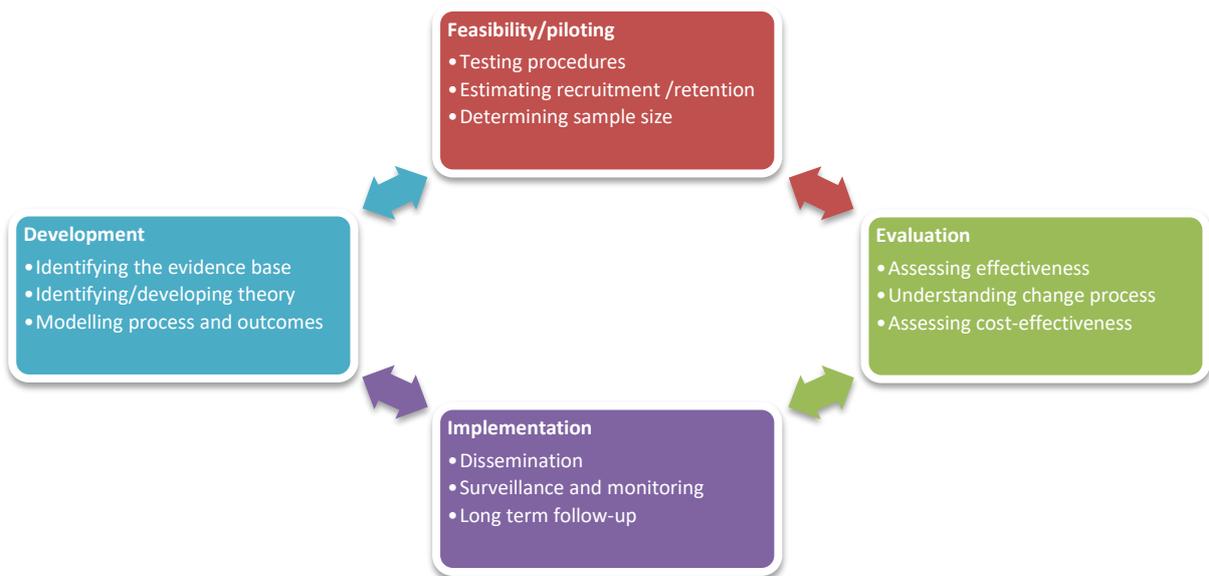
The Society will be happy to consider opportunities where applicants have leveraged additional funding or ‘in-kind’ supports which might make for a larger total fund to undertake the award. For example, co-investment from other institutions, funding agencies, protected time made available etc.

2. Eligibility Criteria

2.1. Project Eligibility

The purpose of this award is to develop a theory-driven and evidence-based intervention aimed at making those affected by a cancer diagnosis more resilient to the misinformation/disinformation they will likely experience over the course of their treatment and beyond. Such an improvement should be quantifiable in nature.

Proposals should be based on internationally accepted procedures for complex intervention development, for example, the Medical Research Council’s (MRC) Guidelines on Developing and Evaluating Complex Interventions.



Craig, et al. (2013). Developing and evaluating complex interventions: the new Medical Research Council guidance.

At a minimum, it is expected that by the end of the study the awardee will produce a complete testable intervention.

Aspects of misinformation/disinformation may include: inappropriate promotion of non-evidence based diets, supplements, extracts, healing, and diagnostics or misinformation/disinformation about existing and proven evidence-based treatments and diagnostics by individuals operating outside of a clinical scope of practice or conventional professional clinical guidance.

Applications which identify interventions at any stage of the diagnosis, treatment, recovery and/or palliative journey are eligible for consideration for this award.

2.2. 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.

Lead applicants must:

- have a doctoral degree by research (or equivalent*) in a field relevant to the proposed research programme;
- have 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);
- be based at an eligible host institution in the Republic of Ireland; *and*
- hold a contract at the eligible host institution that covers the duration of the award

Co-applicants must:

- have well-defined and substantial roles in the proposed project; *or*
- be a member of the project steering/working group.

** 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.*

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>.

Lead applicants are required to possess a formal affiliation with a HRB-approved host institution. This is not a requirement for co-applicants.

2.4. Patient and Stakeholder Involvement

Each application must be directed by a lead applicant who must have an affiliation with a HRB-approved host institution (<https://www.hrb.ie/funding/funding-schemes/before-you-apply/all-grant-policies/approval-of-host-institutions/>). The lead applicant will be responsible for submitting the application. Should the application be successful, the lead applicant will be responsible for overseeing the award.

The Irish Cancer Society is committed to ensuring representation from key stakeholders in guiding and shaping continued improvements in patient outcomes and to bolster the success of any new interventions. 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 expected that projects will be guided by *multidisciplinary* groups, with representation from clinical professionals, academic researchers, patient advocates, and any other stakeholder relevant to the intervention's development or subsequent delivery. Such a group may be consulted throughout the duration of the proposed project to inform on key decisions and methodologies such as study design, interpretation of results, and dissemination plans.

Stakeholder involvement should be achieved by the development of a Stakeholder Steering and/or Working Group. If members of this group are identified prior to submission, they may be added as co-applicants.

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 the 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 Home page. From here you can:

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

3.3. Making an application

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 'Misinformation and Disinformation in Cancer Intervention Development Award'.

4. The Application Form

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

- a) Introduction
- b) Project Outline
- c) Applicant Curriculum Vitae
- d) Project Team
- e) Research Programme
- f) Declarations of Support
- g) Budget
- h) Lay Research Pitch*
 - Project Summary*
 - Public and Patient Involvement*
 - Sharing of Findings*
- i) 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 (PPI reviewers) 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 provides overview information about the 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 (commencing in Q2/Q3 of 2021)
- Duration (max 18 months)
- Lead Applicant details
- Proposed host institution
- Cancer type
- Keywords
- Research type
- Discipline

c) Applicant Curriculum Vitae

In this section you are required to upload your CV, completed using the associated CV template (3 pages max). To upload the CV click 'Attach' then locate the file to be attached, then click 'Attach'.

d) Project Team

Mentor:

A mentor is required for all applicants with fewer than 4 years of post-PhD research experience.

If you have fewer than four year post-PhD research experience, you must add a mentor to the application. The mentor should be an established senior researcher in a field appropriate 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 for review.

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. 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.

You must upload a CV from your mentor (3-page maximum). CVs must be completed using the CV template provided, downloadable from the page. To upload a CV click 'Attach' then locate the file to be attached, then click 'Attach'.

You will also be asked to upload a declaration of support from your mentor in the Declarations of Support section of the application. Please see section F for more details.

Co-Applicants:

You may add up to 10 co-applicants to the project. Co-applicants must have a well-defined and substantial role in the proposed plan e.g. significant input into study design, data collection, or analysis and interpretation, or be a member of the steering/working group. Co-applicants must confirm their participation and approve the application prior to it being finally submitted for review.

Please provide a role description for each co-applicant and indicate whether they form part of your steering/working group. If patient representatives and other stakeholders were involved in the planning and drafting of this research application, please also provide details of their contribution.

Collaborators:

If your application includes collaborations with individuals or organisations, please describe the collaboration here.

e) 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, including any theoretical frameworks which underpin the proposal **(750 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 timeframe 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 **(300 words max)**.

Methods of Research: Please describe and justify the methods, procedures, and experimental design you will use to conduct your research **(750 words max)**.

For quantitative methods, 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 methods, 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.

Research in context: Please summarise how this proposal fits within a framework for complex intervention development. This description should highlight how the proposed research builds on previous work and what the next phase of research would entail **(500 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 for the proposed research study (Excel or PDF format)**. You may upload up to four additional research images. Research images 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.

f) Declarations of Support

Declarations of support are required from:

- from the head of department at your host institution.
- from your mentor (if applicable)

- a relevant person within any additional research site (e.g. public hospital) other than the 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. Please note that digital signatures are acceptable where original signatures are not possible.

g) Budget

The total budget available is €65,000. 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:

- Salary costs (including clinical buy-out time)
- Running costs
- Travel and dissemination
- Patient and stakeholder involvement (PPI) costs

Please refer to the Irish Cancer Society budget guidelines (Appendix 2) when developing your budget.

Please note that a mandatory provision of €1,000 has been allocated to support Patient and Stakeholder Involvement. This provision may be supplemented with funds from the remaining core (€64,000) budget. However, the core budget may not be supplemented with the Patient and Stakeholder Involvement fund.

Please note, given the COVID-19 travel restrictions that are currently in place, traditional travel to conferences and meetings may not be feasible within the timeframe of this award. Applicants may therefore want to consider alternative plans for networking opportunities and disseminating their research findings and network.

h) Lay Research Pitch

The sections consists of three sections: Project Summary, Sharing of Findings, and a Patient and Stakeholder Involvement Plan. 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-technical audience.**

Project Summary: Please provide a detailed and structured lay abstract. Do not use scientific or technical language. Please detail the following (**500 words max**):

- Briefly outline the background of your research proposal i.e. how and why your research came about, context;

- 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);
- Outline who will take part in your research, how you intend to recruit them into your study (where relevant), and what they will be expected to do if they take part.

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

Patient and Stakeholder Involvement Plan: Representation from clinical professionals, academic researchers, patient advocates, and any other stakeholder relevant to the intervention’s development or subsequent delivery is a requirement of this award. Please outline your patient and stakeholder involvement plan. Please carefully review the recommendations outlined for patient involvement in light of the current COVID-19 pandemic, in section 4 of Appendix 1. When completing this section, please carefully consider the following questions: **(300 words max)**

- What key patients and stakeholders will be approached and why?
- How do you intend to recruit patient and stakeholder representatives?
- What aspects (e.g. recruitment, assessment, dissemination) of the proposed research will involve patients and stakeholders?
- What is the procedure for integrating patient and stakeholder involvement into these aspects?
- What steps will be taken to ensure the patient and stakeholder involvement is not tokenistic?
- What infrastructure is available to involve patients and stakeholders within your university and how will it be utilised?

Sharing of Findings: 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. In line with this, it is a requirement that all applicants produce a dissemination plan to include communication of their research to all relevant audiences (including the public and people affected by cancer).

Please describe your plan for sharing your findings. Dissemination may include printed or electronic articles, presentations, public engagement events, etc. **(max 200 words).**

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.

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.

The application deadline is **3pm on 10 Nov 2020**.

5.2. Assessment overview

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

	Patient Reviewers	Scientific Reviewers
Application form	<ul style="list-style-type: none">• Co-Applicants (from Project Team page)• Project summary• Patient and Stakeholder Involvement Plan• Sharing of Findings• Feasibility of PPI budget	<ul style="list-style-type: none">• Project Outline• Project Team• Applicant Curriculum Vitae• Research Programme• Feasibility of scientific budget

Scientific reviewers will not be assessing any of the PPI review sections, and vice versa. As such, it is vital that the sections reviewed by PPI reviewers are written in accessible **plain English** and do not assume knowledge of other sections. Failure to do this may result in the review panel being unable to accurately assess your application.

The budget will also be reviewed by the Irish Cancer Society to ensure that it is feasible and that all maximum limits have been adhered to. Reviewers will not provide a score for the budget sections of the grant application, but will be asked to comment on budget feasibility for the relevant sections. Final approval of all budgeted costs is at the discretion of the funder.

5.3. Assessment procedure

The assessment of each application will include a paper review, right to reply, and panel meeting.

Step 1 Paper review: Scientific peer reviewers will review their relevant sections of the application and provide a score for a) the Research Programme, b) Applicants' CVs, and c) Declarations of Support. These sections will be assigned scores based on: the suitability of the applicant, project team, and the

patient and stakeholder involvement group; the scientific merit of the proposed research; and the likelihood that the proposal will deliver on the aim of the funding call. Similarly, the PPI panel will review and score their respective sections, a) Co-Applicant and Stakeholders summary (from Project Team page), b) Project summary, c) Patient and Stakeholder Involvement Plan, and d) Sharing of Findings. The PPI panel will evaluate proposals based on the practical feasibility of the proposal (as appropriate); the completeness of the dissemination plan; and strength of the Public and Stakeholder Involvement plan.

Each reviewer will also provide comment on the feasibility of the budget.

Step 2 Right to Reply: Review comments will be provided to applicants in advance of the panel meeting, allowing applicants the opportunity to address reviewer remarks. Applicants' responses will be used to inform the panel funding decision.

Step 3 Panel Decision: Scores from reviewers will be combined; both patient and scientific reviewers. The funding decision will be based on review scores and applicants' Right to Reply submission.

5.4. Conflicts of Interest

The Irish Cancer Society will endeavour to ensure that the both the scientific and PPI review panel chosen do not have any conflicts of interest regarding the applications they are assessing.

5.5. Assessment outcome

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

6. Application Checklist

Completed application form submitted online including the upload of:

- CV – Lead Applicant
- Gantt Chart
- CV - Mentor CV (if required)
- Declaration of Support – Mentor (if required)
- Declaration of Support – Head of Department
- Declaration of Support – Additional Research Sites (if required)

The following must be completed **ONLINE by 3pm on 10 Nov 2020.**

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 guidance document, please contact the Irish Cancer Research Team:

Email: grants@irishcancer.ie



Irish Cancer Society Research

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

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Irish Cancer Society Research

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

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

1. What is Public and Patient Involvement in research?

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

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

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

Involvement: Involvement is distinct from participation or engagement. Where participation and engagement are conducted 'to', 'about', and 'for' people with cancer, involvement is conducted 'with' or 'by' people with cancer. People with cancer can be involved at any stage of the research process, from conceptualisation to dissemination.

2. Why is PPI important?

PPI is becoming increasingly common in research. The Irish Cancer Society is committed to expanding the involvement of those affected by cancer in the research that the Society funds, and in the funding decision-making process. This commitment is reinforced by the Irish Governments' National Cancer Strategy (2017-2026)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 patients³
- Enhance patient trust in researchers³
- Improve researchers' insight into their own research area³
- Help researchers identify barriers and come up with solutions to research³
- Increase trust and acceptability in the patient community of research findings³
- Inform the provision, access, and location of healthcare services⁴
- Improve the dialogue between healthcare professionals and patients⁴

Specific to the cancer setting, PPI may be used by patients as a resource, to make sense of living with chronic condition⁵. 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. As such, the selection of award recipients is co-decided by scientific and patient reviewers. In doing so, the research we fund is of the highest scientific quality, while being relevant and important to people affected by cancer.

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

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

Scientific and patient reviewers will form the interview panel (if relevant) and each panel member will have an equal voice.

3.1. Project Summary

The PPI reviewers are expert by experience, meaning they can provide valuable insights into the practicalities of a proposed research study. For instance, is the research worth doing; are the researchers measuring the correct variables; will the recruitment or experimental plan work in practice? It is also important for the PPI reviewers to know details on your project to be able to adequately review the Patient Involvement Plan and Sharing of Research Findings sections.

When completing this section, please outline: **(150 words max)**

- the background of your research proposal i.e. how and why your research came about, context;
- 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);
- who will take part in your research, how you intend to recruit them into your study (where relevant), and what they will be expected to do if they take part.

The project summary should be 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 project 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, the steps in the project 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.

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).

4. PPI and the research process

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

- as members of a patient advisory group for the project;
- commenting on and developing patient information leaflets, consent forms, questionnaires or other research materials;
- user and/or carer researchers carrying out the research;
- commenting on and developing dissemination materials (e.g., conference abstracts, posters, presentations);
- Involvement in organising and running public and patient engagement activities.

In general, when, where, and how PPI will be included in studies should be decided early in the research process. The PPI plan must detail the PPI activities that will be organised during the project.

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.

Please note that only PPI plans which include **involvement** will be funded. Any plan which includes participation or engagement activities in lieu of involvement will not be funded.

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

4.1 PPI and COVID-19

Please note that in light of the ongoing COVID-19 pandemic, the risks involved for all members of the public, and in particular those in at risk categories, we strongly recommend that you consult the latest government advice when developing a PPI and dissemination plan. All applicants should minimise the use of face-to-face methods of communication where possible, or build in contingency plans to allow for alternative methods of communication. Activities that predominately incorporate online or virtual methods are encouraged and all

activities must be in line with the current government advice and recommendations at the time at which they occur. Please see <https://www.gov.ie/en/campaigns/c36c85-covid-19-coronavirus/> for further information.

4.2. 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 out of pocket expenses of PPI members associated with involvement are covered by the research grant**

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?	Estimate the cost or range of costs against each involvement activity. To work out the budget for your study, go to the online cost calculator: https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/ . Please note the online calculator is in Pound Sterling.
Step 5: Mapping	Map the involvement activities onto your selected project framework so that you know exactly when in the project timeline costs are allocated.
<i>Adapted from the UK National Institute for Health Research, Budgeting for Involvement (2013)</i>	

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. 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 examples below for guidance on creating and budgeting for the PPI plan.

PPI budgeting costs:

Costing category	Related costs
Payments and rewards	<ul style="list-style-type: none"> • Fees to individuals • Vouchers/tokens for individuals • Prize draw awards • Fee/donation to a group • Funding for additional training and learning • Honorary appointment e.g., lay fellow or research partner
Expenses	<ul style="list-style-type: none"> • Travel • Subsistence • Childcare • Carer costs • Personal assistants • Overnight accommodation • Home office costs
Involvement activity	<ul style="list-style-type: none"> • Finding people/advertising • Training and learning costs • Venues and catering • Equipment and books • Access to university facilities • Conference fees
Involvement staffing	<ul style="list-style-type: none"> • Administrative support • Involvement coordinator • Independent facilitator • Peer researchers/interviewers
Other costs	<ul style="list-style-type: none"> • Disclosure and barring service • Language translation and interpretation costs • Support for people with impairments

Adapted from the UK National Institute for Health Research, Involvement Cost Calculator

Worked costing example for virtual event: 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 virtual public engagement event.

The researcher is looking for five patient representatives to form the advisory group. The group will meet for a half day virtual 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 public event will then be held virtually.

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

Category	Detail	Quantity	Cost	Total
Virtual Meetings	Online meeting platform used by institution for example Zoom	1	€0	€0
Focus group payment	Payment for attending virtual focus group/workshop	5	€100	€500
Advertising	Newspaper advertisement (for 2 weeks)	1	€70	€70
Dissemination	Printing of 12-page booklets	250	€0.96	€240
	And educational posters:	5	€32	€160
Virtual Public Event costs	Zoom Webinar licence (one off, month long usage)	1	€37	€37
TOTAL COST (€1000 from PPI budget and €7 from consumables budget)				€1007

All costs were calculated using estimated costs for train tickets, hotels, and so on in the Republic of Ireland as of September 2020.

Worked costing example non-virtual event:

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:

Category	Detail	Quantity	Cost	Total
Travel	Local travel in Dublin	3	€7	€21
	Travel from outside of Dublin	2	€30	€60
Focus group payment	Payment for attending focus group/workshop	5	€100	€500
Venue costs	University meeting room cost	1	€0	€0
Catering costs	Breakfast and lunch for attendees (€10 per person/per meal)	5	€20	€100
Advertising	Newspaper advertisement (for 2 weeks)	1	€70	€70
Dissemination	Printing of 12-page booklets	250	€0.96	€240
	And educational posters:	5	€32	€160
Public Event costs	Costs for university venue (1/2 day)	1	€150	€150
	Catering (tea and biscuits) (€3.50 per person)	100	€3.50	€350
TOTAL COST (€1000 from PPI budget and €651 from consumables budget)				€1,651

All costs were calculated using estimated costs for train tickets, hotels, and so on in the Republic of Ireland as of September 2020.

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

- 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/sites/default/files/publications/Writing%20and%20Design%20Tips%202011_1.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/>

7. 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 2/08/2018.
- 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 28/08/2018.
- 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-Centred 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.



Irish Cancer Society Research

Appendix 2: Irish Cancer Society Research Budget Guidelines

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1. Introduction

The Irish Cancer Society is the largest voluntary funder of cancer research in Ireland. The majority of the Society's funds are raised from public donations and we are therefore committed to ensuring that all funds are budgeted for and used sensibly in line with donor's expectations and the scientific goals of the work. This policy describes the Society's requirements for drafting budgets as part of the research grant submission process.

Please note:

- These guiding principles are not an automatic approval for the use of funds from any grant. The Society reserves the right to review expenditure for reasonableness at any time during the research project.
- These guidelines describe the overall general budget guidelines for our awards. More specific budget rules may apply for some bespoke awards, and these rules will be included in the call documentation specific for that award.
- Each research grant has a defined, agreed budget to help carry out the agreed Research Project. It is the responsibility of the research institution to ensure that all monies claimed and paid are allowable, necessary and reasonable for the conduct of the Research Project.
- The Society acknowledge that an approved budget may require modifications over the course of an award. Budget reallocations may be permitted during the lifetime of award provided they are adequately justified on an Irish Cancer Society budget reallocation form. Approval of such reallocations is at the sole discretion of the Society. Details of the budget reallocation process can be found [here](#) on the Irish Cancer Society website.
- It is expected that an internal financial governance structure will be in place to monitor and review allocation of funds for the Research Project.
- Annual and interim financial reports sought by the Society must include a detailed breakdown of costs claimed. The Society reserves the right to request independent verification of costs charged to a research grant.
- The Society reserves the right to refuse the payment of costs which are deemed contrary to the guiding principles contained herein.
- The Society reserves the right, as often as it may reasonably require, to arrange for an audit to be conducted into the use of funds provided.
- As an Irish charity, The Irish Cancer Society will fund eligible direct costs only. The Society do not pay any overhead contribution to host universities

2. Budgeting for Personnel Costs

The Irish Cancer Society will only fund the direct salaries of staff working on Irish Cancer Society research projects provided it is expressly stated in the call documentation specific to a particular funding award. For the majority of awards, the Irish Cancer Society will not provide funding for the salaries of applicants already employed by their host-institution on a full-time permanent basis. Exceptions may be made in certain research calls or applicant cohorts that allow for the provision of buy-out time. In addition, the Irish Cancer Society will not contribute to the salaries of any project mentors or collaborators included on a grant application.

It is expected that all applicants will budget for salary to include employers' PRSI and pension contributions in accordance with the appropriate salary scale and research institution. Where an

applicant is budgeting for a part-time position, salaries should only be budgeted for the % full-time equivalent (FTE) that the employee will spend working on that specific research project. Please note The Irish Cancer Society may ask the employee to provide evidence (e.g. records or timesheets etc.) for specific time spent on the funded research project. For all positions, the Irish Cancer Society will allow a staff member to move up a point on the scale every 12 months. This **must** be incorporated into the original budget application.

2.1. Academic Research Staff

The Irish Cancer Society will fund the direct salaries of academic research members according to the IUA Researcher Salary Scale. The scale, point and full salary (including employers PRSI and pension contribution) must be included within all salary budgets. Please note the IUA scales are continually updated, therefore, it is important to utilise the most up to date scale according to the time period in which the anticipated staff member is due to commence employment. The IUA scales are continually changing, therefore if the IUA scale does not cover the funding period in question, a salary contingency of 2.5% per annum should be applied.

2.1.1. Research Assistant:

The Irish Cancer Society will fund the salary of a Research Assistant starting at the entry level position of Level 1, Point 1 of the IUA Scale, which is the minimum point on the scale. It would be expected at this level that the Research Assistant would hold a primary degree but would likely have little or no research experience. For higher points on the scale, the individual would be expected to hold a secondary degree (Masters/PhD) and/or some research experience. Higher points on the scale would need to be thoroughly justified in grant applications.

2.1.2. Postdoctoral Fellow:

The Irish Cancer Society will fund the salary of a Postdoctoral Researcher starting at the minimum point of Level 2, Point 1 of the IUA Scale. It would be expected at this level that the postdoctoral fellow would hold a minimum of PhD or equivalent* research experience. For higher points on the scale, the individual would be expected to hold a number of years (depending on the point) postdoctoral and/or industry experience. Higher points on the scale would need to be thoroughly justified in grant applications.

**Please note that PhD equivalency is only permitted for certain grant calls, and will be specifically outlined in the grant call guidelines. The Irish Cancer Society defines PhD equivalence as three or more senior (first, joint-first, or last) author publications in peer-reviewed academic journals or 4 years' full-time research experience post-primary degree. Alternative research outputs may be considered eligible e.g. monographs. In such instances, candidates should contact grants@irishcancer.ie before applying.*

2.1.3. Research Fellow:

The Irish Cancer Society will only fund the salary of a Research Fellow if it is expressly stated in the call guidance document. A Research Fellow will be required to hold at least 4 years post-doctoral and/or industrial research experience and must have a significant track record of high-quality peer reviewed publication and/ or other equivalent outputs based on the norms of their discipline. In addition, it will

be expected that the Research Fellow has previously obtained independent competitive peer-reviewed research grants, and is capable of leading and managing independent research projects. Research Fellows should be appointed at Level 3, point 1 of the IUA scale, and a strong justification will be required to appoint at other points on the scale.

2.1.4. Postgraduate Student:

Stipend: The Irish Cancer Society will fund the stipend of postgraduate students (PhD and MSc) at a flat rate of €18,500 per year for up to four years' full time (in the case of PhD Scholar's) or up to two years full-time (in the case of MSc students). The funding of part-time post-graduate students over longer periods of time may be permitted depending on the specific funding call.

Fees: The Irish Cancer Society will make a contribution of up to €8000 towards the annual costs of EU or non-EU postgraduate registration fees for up to four years. Some host institutions provide a reduction of fees in the latter years of the postgraduate degree (e.g. a 50% reduction in Year 4 of a PhD) and this should be taken into account when calculating the total registration fees over the four years. The Society is not in a position to fully fund the full registration fees of non-EU applicants. In this instance it would be the responsibility of the host institution to cover the remaining fee's shortfall.

2.2. Nursing and Allied Health Professionals

The Irish Cancer Society will fund the direct salaries of nurses and allied health professionals (AHPs) either via the IUA Researcher Salary Scale or via buy-out time on the HSE salary scale, whichever is the most appropriate for the call and/ or applicant. For appointments on the IUA Researcher salary scale, applicants should follow the guidelines outlined in Section 2.1.

For applicants seeking buy-out using the HSE salary scales, a maximum of 0.5 FTE buy-out time will be permitted for applicants who will hold a concurrent clinical post in their professional field. Only applicants that are permanently employed by the HSE may use this salary scale. Applicants should use the scale and salary point most relevant for their role and experience within the HSE. A strong justification will be required as to why specific salary points were chosen.

2.3. Research Support Staff

For large programmatic awards, the Irish Cancer Society will, in certain circumstances, allow for the budgeting of research support staff (project managers, project officers, project admin staff etc.). In this instance, salaries should be aligned to the most appropriate administrator scale for the specific research institution. Strong justification on all scales and salary points will be required.

3. Guiding Principles for Budgeting for Non Personnel Costs

3.1. Research Running Costs

These are the day to day costs associated with the running of the research project. The Irish Cancer Society will allow the purchase of reasonable running costs relevant to the specific project. Such costs

may include but are not limited to: materials and consumables, research sample costs, access costs, survey costs, costs associated with research participants, transcription costs, data management costs, bench fees etc. All costs must be inclusive of VAT, where applicable. All running costs should be itemised within the application budget section and suitably justified.

3.1.1. Small Equipment items

The Irish Cancer Society will allow researchers to purchase small equipment items up to a maximum total value of €3,000. A strong justification must be provided for each equipment item, and a rationale must be given as to why this item is not already available to the researcher at their host institution. Only equipment items that are **specific** to the applicant's research project will be allowed. All costs must be inclusive of VAT, where applicable.

3.1.2. Computer/Laptop Equipment:

The purchase of computer equipment as part of an Irish Cancer Society funding award will be considered for any grant of over 24 months' duration, provided a strong rationale is given at the time of grant application. The maximum allowed budget for the purchase of a computer or laptop is €1,500. For funding awards of less than 24 months' duration, the purchase of computer equipment will only be permitted in exceptional circumstances. Any computer or laptop purchased as part of an Irish Cancer Society award is the property of the host institution, and any use of such equipment by the researcher or research team beyond the end date of the Irish Cancer Society grant is at their discretion.

3.1.3. Mobile phone expenses:

The Irish Cancer Society will not generally cover mobile phone expenses of any researcher working on a Society-funded project. However, the Society do acknowledge that for exceptional cases only, the provision of a phone for specific research projects may be required.

In this case, the researcher must use the most economical and cost-effective means for purchasing a phone and bill-pay call plan. The Society will cover mobile phone charges verifiably associated with the research work up to a maximum of €40 per month only. Please refer to the Irish Cancer Society Researcher Expenses Policy for further detail.

3.2. Training

These are the costs associated with the education and training of the grant applicant and/or other Irish Cancer Society team members. These include costs relating to technical skills training specific to the research project e.g. animal handling, statistical analysis etc. In addition, costs relating to the long-term career development of the researchers will also be permitted e.g. personal and professional development training etc. providing it relates to their future research career aspirations.

All costs relating to training must be outlined and justified as part of the researcher's application budget. When justifying these costs, it is important to provide details on the training type, location and rationale. Please note, for any training elements where travel is required, please detail the travel costs as part of the Travel and Dissemination budget (Section 3.4).

3.3. Travel and Dissemination

3.3.1. Travel:

These are the costs relating to the travel of the grant applicant and/or other Irish Cancer Society funded team members. Such costs must be directly related to events as part of the research programme and only funded researchers will be eligible to claim these expenses. As a charitable organisation, we would expect that all costs in relation to travel be reasonable, and must be clearly justified. Please note that the Irish Cancer Society will fund Economy-Class flights only. Please refer to the Irish Cancer Society Researcher Expenses Policy for further detail on permitted costs.

An example of permitted travel includes but is not limited to: costs associated with attendance at meetings, conferences, patient engagement events, workshops, fostering collaborations etc.

Reimbursement for costs associated with conference attendance will only be provided if the recipient is presenting their specific Society-funded research project in poster and/or oral format. Exceptions may apply for post-graduate students in the first year of study, whom would benefit from attendance at a national conference.

The applicant should provide as much detail as possible at the application stage. For example, if planning to attend a conference: the name, location and dates (where possible) of the conference should be detailed, in addition to the reason for attendance.

3.3.2. Dissemination:

These are the costs associated with the communication and reporting of your research results. A key priority of the Society is to ensure that research findings are communicated to all relevant stakeholders. In particular, we are committed to ensuring that the public (particularly people affected by cancer) are kept up to date on our research that is funded. In line with this, we require that all applicants produce a dissemination plan that includes communication of their research not only to the academic community but to **all relevant** audiences.

Dissemination costs should be clearly planned and articulated as part of your research budget. Such costs may include printing, posters, generation of leaflets, publication costs, costs associated and hosting of public awareness events etc. All costs must be inclusive of VAT, where applicable.

3.3.3. Open Access Publication:

The Irish Cancer Society encourage publication in open-access journals and will provide a contribution of up to €2,000 towards open-access publication costs. Please note, the Irish Cancer Society will not fund any research published in so called “predatory journals”. We therefore ask that all researchers be aware of predatory publishers and exercise caution in this regard when publishing their research.

3.4. PPI costs

The Irish Cancer Society is dedicated to putting patients, families, survivors, supporters, and the public at the very heart of what we do. Public and Patient Involvement (PPI) in the research process ensures that research is meaningful and of benefit to those affected by cancer and other relevant stakeholders.

PPI can be involved at any stage of a research project, from development and design to interpretation and dissemination.

In line with this commitment, it is encouraged that all applicants include PPI within their application where relevant, and guidelines on this will be outlined within the guidance documentation specific to each call. The Irish Cancer Society have specific documentation in place for developing a PPI Budget and these can be found in Appendix 1 of all call document guidelines.

A mandatory provision for specifically costing PPI activities into grant applications is included in the majority of Irish Cancer Society funding calls, and will be outlined in the specific call documentation. At the very minimum it is expected that that all costs to patient members associated with involvement are covered by the research grant e.g. bus/train fares, mileage, parking charges, and subsistence. These costs should be outlined as part of the PPI section of your grant application.

3.5. Mobility Element

As part of our Scholarship and Fellowship Research Awards, applicants are given the opportunity to request mobility funding for travel to a national or (preferably) international research institution in furtherance of advancement of their research project aims. This is considered separate to the general travel and dissemination budget outlined in the main project application. The specific details, amount and duration of mobility funding will be outlined in the specific grant call documentation.

Details of mobility funding is requested at the application stage. However, please note that this funding is separate to the funding amount requested as part of the main application. In recognition that mobility plans can often change through-out the course of the research project, all successful applicants must reapply for this funding closer to the period of travel (at least three months in advance of travelling). Applicants therefore have the opportunity to change the details of the mobility element during the research award. However, final approval of all changes is at the discretion of the Irish Cancer Society.

Allowable mobility costs include travel, subsistence, accommodation, and running costs. Mobility payments will only be made by the Irish Cancer Society upon approval of a successful mobility application. Further guidance on expenses permitted as part of the mobility award are detailed in the Irish Cancer Society Researcher Expenses Policy or by contacting grants@irishcancer.ie.