

Translational Research Fellowship Programme

Expression of Interest

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Translational Research Fellowship Programme

EOI applicant guidelines
Updated: 07/02/2022

1. Introduction

1.1 Timelines*

Milestone	Date
Expression of Interest (EOI) Applications Open	Tuesday 8 February
EOI online submission Deadline	Tuesday 22 March 3pm
Review of EOI applications for shortlisting	March – April 2022
Shortlisted applicants invited to submit full application	April 2022
Full Application deadline	May 2022
Review of full applications	May – June 2022
	Iviay – Julie 2022
Shortlisted applicants Invited to Interview	June 2022

^{*}Please note: the above dates are provisional, and subject to change at the discretion of the Irish Cancer Society. Further details of important dates for the Full Application stage will be given to shortlisted applicants.

1.2 Background

The Irish Cancer Society is now accepting Expression of Interest applications for the Translational Research Fellowship Scheme 2022.

The objective of the Irish Cancer Society Translational Research Fellowship Programme is to support excellent **early-stage** (0-5 years' experience post-PhD) translational cancer researchers to develop as independent researchers. There is fellowship funding available for one applicant of the highest calibre to focus on research within areas of high strategic priority¹ for the Irish Cancer Society. This applicant must have a **background in biomedical sciences**, **pharmaceutical sciences**, **life sciences or medicine**.

All eligible EOI applications will be reviewed by an international scientific panel and Public and Patient Involvement (PPI) panel. Shortlisted applicants will be invited to submit a full application. Applications are accessible through the Irish Cancer Society Gateway Grant Tracker online system.

1.3 Research Themes

This fellowship is specifically intended to fund research that is aligned with the <u>Society's Strategy (2020-2025)</u> and <u>Research Roadmap.</u> It is anticipated that the applicant will undertake a project likely within the a) translational biomedical research b) clinical trials and/or d) strategic priorities themes. All Society thematic areas are described below in greater detail (See Figure 1 below).

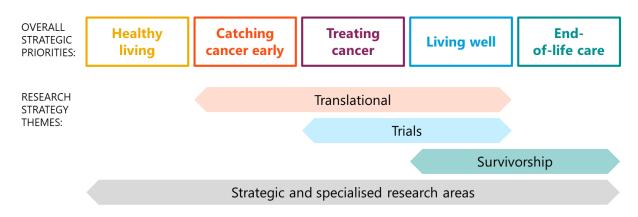


Figure 1. Irish Cancer Society Strategic Research Themes

a. Translational biomedical research can be defined as 'bench to bedside' or patient-focused biomedical research, the aim of which is to translate existing knowledge about cancer biology into techniques and tools that will accelerate progress towards patient treatment. Research in this area will build upon basic biological discoveries

¹ https://www.cancer.ie/about-us/irish-cancer-society-strategy-2020-2025

and improves their translational potential through pre-clinical studies. Much of the outputs of translational research naturally merge into trials, the next area of focus.

Applications in drug design, SAR (structure—activity relationship) analysis, drug-screening or basic biomedical research are not considered eligible.

- b. Clinical trials are organised investigations in people to examine the benefits of new approaches to treatment and care. For example, looking to see if a new medicine can improve survival for a particular form of cancer. As well as funding these drug-based trials (so called IMP trials), the Irish Cancer Society is also interested in funding non-drug based trials (non-IMP trials) in areas such as diagnostics, technology, radiotherapy, surgery, psycho-oncology, exercise, nutrition, and combinations of these.
- c. **Survivorship** covers the period from diagnosis to treatment outcome (including palliative and end-of-life care). Survivorship research seeks to improve the care and outcomes experienced by people living with and beyond cancer. This includes: prevention and early detection of recurrent cancer; long term effects of cancer and its treatment; quality and experience of treatment and care; psycho-social effects of cancer and its treatment; self-management; health information and literacy; genetic risk and counselling; physical and practical needs e.g. financial, employment, mobility; etc. **Projects in this area are not considered eligible for this award.**
- d. **Strategic priorities** is a crosscutting theme, which seeks to specifically foster and grow research into areas of high unmet need in cancer. For example, cancers which have not benefited from the huge strides in outcome seen in some malignancies, such as metastatic disease, rare cancers and cancers with poor response or outcomes; the unmet needs of children, adolescents, and young adults affected by cancer; tackling misinformation and disinformation in cancer; addressing the needs of underrepresented groups of people (e.g. Travelling community, ethnic and language minority communities, migrant communities, communities with socio-economic or mental health challenges, or any other socially excluded group).

It is the responsibility of the applicant to ensure that the project fulfils the project eligibility criteria for this scheme. If you are uncertain about your project's eligibility, please contact Dr Niamh McCabe (grants@irishcancer.ie) in advance of preparing your application.

1.4 Funding and Duration

The maximum funding granted for a Fellowship is €235,000 over two to three years. A mandatory provision of **a minimum** €1,000 is included within this budget to support Public and Patient Involvement (PPI) in the proposed research project*.

An additional mobility and capacity building funding of a maximum €5,000 will be available. Further details can be found in section 1.5 of this document; a mobility and capacity building plan will only be sought from shortlisted candidates at the full application stage.

Details on the Budget will also only be sought from shortlisted candidates at the full application stage.

*Please note that the €1,000 available for PPI may be supplemented with funds remaining from the fellow's annual budget. However, the annual budget may not be supplemented with the PPI fund.

Example of Eligible Costings	Details*	
Salary	Applicants must use the most up-to-date Irish University Association (IUA) salary scales for academic researchers (https://www.iua.ie/research-innovation/researcher-salary-scales/). All salaries should be inclusive of PRSI, pension and increases.	
Equipment	Please note: this is not a start-up grant. The Irish Cancer Society will allow researchers to purchase small equipment items up to a maximum value of €3,000.	
Consumables	Please allow sufficient budget for all materials and consumables required to carry out your research proposal.	
Training and Dissemination	To cover costs of attending training (if outside your host institution), meetings and conferences during your Research Fellowship. Please also detail the costs of disseminating your research: printing, posters, publications etc.	
Public and Patient Involvement costs	A minimum of €1,000 must be allocated to support PPI activities. Please refer to the PPI Guidelines (Appendix 1) for guidance on completing this section.	

^{*}The details provided are provisional. Further information on the proposed budget will be provided to shortlisted candidates at the full application stage.

1.5 Mobility and Capacity Building Element

An additional mobility/capacity building funding of up to a maximum of €5000 will be available*. This important element is intended to provide the awardee experience that goes beyond the traditional research environment in developing the fellow, their career, and the wider research environment. In order to encourage well-rounded researchers with varied experiences, applicants are required to develop a Mobility and Capacity Building Element plan.

The aims of Mobility and Capacity Building Element are to:

- i. Facilitate academic and clinical networking.
- ii. Encourage national and/or international cooperation and collaboration.
- iii. Promote the development of new skills and/or perspectives.

Traditionally, these aims would be achieved through mobility funding alone (i.e. travel to a national/international research group). However, in recognition that extended travel is not always feasible, applicants can nominate either:

- Option A) Mobility: a substantial mobility element of up to 3 months in duration at a national or international research group or lab during the fellowship.
- Option B) Non-Mobility Initiative: a substantial and distinct non-mobility project-based initiative that facilitates academic and clinical networking; encourages national and/or international cooperation and collaboration; and promotes the development of new skills and/or perspectives.

Details on the Mobility and Capacity Building Element will only be sought at the full application stage.

*Please note: Funding for this proposed mobility or capacity building element will not be automatically available to successful applicants. Successful applicants will be required to reapply for this mobility funding at least three months in advance of the element start date.

2. Eligibility

2.1 Applicant Eligibility

Applications from individuals that do not meet the eligibility criteria will not be assessed. The objective of the Irish Cancer Society Translational Research Fellowship Scheme is to support excellent early-stage (0-5 years' experience post-PhD) cancer researchers with a background in biomedical sciences, pharmaceutical sciences, life sciences or medicine, to develop as independent researchers in their chosen area of cancer research.

Lead Applicant Minimum Eligibility Criteria:

The Research Fellowship scheme is open to:

- untenured early-stage postdoctoral scientists
- non-consultant hospital doctors

Applicants must:

have graduated with a Doctoral Degree,

OR

be certified as having fulfilled the requirements for the award of a Doctoral Degree, including the successful completion of a viva, but have not yet graduated by the Fellowship EOI submission date*

- have a maximum <u>five years</u>* research experience following graduation from their doctoral degree
- have a background in the areas of biomedical sciences, pharmaceutical sciences, life sciences or medicine
- not be tenured for a lectureship position at the time of applying for the Research Fellowship
- have a strong commitment to progress their career in academic cancer research

^{*}Applicants must have submitted their final post-viva hard-bound thesis at the time of full application. If there are any eligibility queries associated with e.g. expected delays, please contact <u>grants@irishcancer.ie</u> prior to submission.

^{**}Extended leave: The Society recognises that applicants may have had to take a period of extended leave from their careers for a number of reasons including maternity, paternity, adoptive, parental, carer's, and medical leave. To ensure equity for those who have had to take extended leave in the past, where relevant, there will be an opportunity for applicants to extend their period of eligibility for this award or justify reasonable shortcomings in their application portfolio commensurate with these circumstances to the external reviewers. Please contact grants@irishcancer.ie for more information. Extended leave will also be taken into consideration during the assessment of applicants.

It is the responsibility of the applicant to ensure that they fulfil the eligibility criteria for this scheme. If you are uncertain about your eligibility to this scheme, please contact Dr Niamh McCabe at grants@irishcancer.ie in advance of preparing your application.

2.2 Mentor and Research Team Eligibility Mentor(s)

- At least one primary mentor is required for each application. A mentor should be an established senior researcher who will guide and support the applicant.
- They must hold a post either permanent or on contract basis at the proposed research institute that covers the entire duration of the Research Fellowship.

2.3 Host Institution Eligibility

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 based in the Republic of Ireland and must be listed as an approved host institution on the Health Research Board's website:

https://www.hrb.ie/funding/funding-schemes/before-you-apply/all-grant-policies/hrb-policy-on-approval-of-host-institutions

Applicants conducting research out of non-approved sites (e.g. a hospital) must nominate an approved host institution, and all finances must be managed by this institution.

2.4 Public and Patient Involvement

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. 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 expected that all applicants include a detailed PPI plan (and the associated minimum €1,000 budget allocation) within their application. It is strongly recommended that applicants read Appendix 1 'Public and Patient Involvement (PPI) in Research' Guidelines prior to beginning work on an application.

Details of planned PPI is expected at Expression of Interest stage. All applicants that are shortlisted to progress to full application will be required to incorporate comments from the PPI reviewers, where relevant, and provide a revised PPI plan, a PPI budget, and sharing of research findings plan in their full application.

3. Application Procedure

3.1 Application Overview

There are 3 stages to the application process:

- i. Expression of interest (EOI) stage
- ii. Full application stage
- iii. Interviews

The structure of the application and review process is designed to allow for an iterative development and improvement of applications, to maximise their potential.

Stage	Description
Stage 1: Expression of	The Expression of Interest stage allows applicants to present an initial outline of their proposal.
Interest	Only those EOI applications that are recommended by the independent scientific review panel and PPI review panel to have achieved an appropriate level of quality, will be invited to submit a full application (Stage 2). EOI applications that do not meet the appropriate level of excellence will not be invited to submit a full application and will not proceed further in the evaluation process.
	Constructive feedback from the review panel is made available to all applicants upon request.
Stage 2: Full Application	The full application allows applicants to a) expand on the information provided in the EOI stage, and b) revise and improve their application in response to reviewer feedback.
	The same review panels (scientific and PPI) as at the EOI stage will evaluate the full application submissions. As before, applications will be evaluated based on their quality, and how the applicant responded to feedback.
	Applications that are of the highest quality will be shortlisted to the next stage (stage 3). Reviewer feedback will be made available to all applicants.
Stage 3: Interviews	Interviews are conducted between shortlisted applicants and the review panel (scientific and PPI). Feedback from the full application stage should be used to further improve the application in advance of the interviews.

3.2 How to Apply

Applications must be completed and submitted through the Irish Cancer Society online grant management 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.

When you enter your login details, you will be directed to the portal homepage. From here, you can:

- 1. Update your basic information (please make sure all fields are completed)
- 2. Make a new grant application
- 3. Access previous grant applications
- 4. Manage any active grants

When you have entered your basic details, you will be able to create a new application from the portal homepage. Alternatively, select 'New Application' from the 'My Applications' tab.

Next, click 'Apply' for the Grant Type detailed as 'Translational Research Fellowship - EOI 2022''.

4. Application Form

There are 8 sections outlined on the left-hand side of the page:

- 1. Project Outline
- 2. Applicant Details
 - a. Applicant CV
 - b. Personal Statement
- 3. Mentor details and Institutional Support
 - a. Add mentor
 - b. Mentor CV
 - c. Declaration of Support- Mentor
 - d. Declaration of Support- Head of Department
- 4. Project Summary
- 5. Alignment with Irish Cancer Society Priority Research Areas
- 6. Public and Patient Involvement plan
- 7. Sharing of Research Findings
- 8. Validation Summary

Saving your progress regularly is strongly recommended by clicking 'Save' as you go through the application form. 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.

Mandatory sections are marked with a red circle icon. You will not be able to submit the application if these sections are incomplete.

1. Project Outline

In this section, you will be asked to provide basic information about your application. Input and save the information as required under the following headings:

- Proposed Fellowship Title
- Proposed Start Date (must be in Q4 2022)
- Duration must be between 24 36 months
- Applicant Details
- Proposed Host Institution
- Cancer Type(s)
- Research Type(s)
- Discipline(s)
- Keywords
- Research Theme
- Has the proposed project been submitted elsewhere?

2. Applicant Details

Applicant Curriculum Vitae

Please upload your CV - completed using the template provided (the template is downloadable in this section on the online system or on the website). More information on each section is given in the template.

Personal Statement

It is expected that the successful fellow will plan on pursuing a long-term career in academic research.

Please outline why you are applying to the Fellowship Scheme and how it fits into your long-term plan of pursuing a career in academic research. (300 words max).

3. Mentor Details and Institutional Support

Add mentor

You must add at least one primary 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 email address. If the mentor has already created an account then they will appear on the list. To add them as your mentor click 'Select'. Please note that on saving, the contact will be added to the application as a mentor and they will receive a notification of this via email.

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

Mentor CV

Please upload a CV from your proposed mentor using the template provided (the template is downloadable in this section on the online system or on the website).

Please ensure that you first have the permission from your mentor to upload their CV.

Declaration of Support - Mentor

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

Declaration of Support - Head of Department

Please upload a Declaration of Support from the Head of Department (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.

The Declaration of Support required from the Head of Department is a standard letter stating that they are aware of and support the application.

4. Project Summary

Please give a summary of your proposed research fellowship project (1000 words max).

This should include summary details of the following:

- Background information/existing literature
- The hypothesis and the objectives
- Methodology
- Why the research is important and how the research will benefit people affected by cancer
- Summary and conclusions

5. Alignment with Irish Cancer Society Priority Research Areas

Please outline how the proposed research aligns with one or more of the Irish Cancer Society research themes (Section 1.3 a, b and/or d). Please note- if the proposed research project does not align with the strategic goals of the Society, it will not be eligible for funding **(250 words max)**.

6. Public and Patient Involvement Plan Summary

The Irish Cancer Society is dedicated to putting patients, families, survivors, carers, supporters, and the public at the very heart of what we do.

In this section, please provide an accessible summary of the proposed study and your plan for co-developing and integrating clearly identifiable public and patient involvement. An expert PPI Panel will review this section. As such, please use plain accessible language and if technical terms are used, they must be explained. Public and patient involvement and partnership is a fundamental aspect of the application. **Please consult Appendix 1 before completing these sections.**

Project Summary: this section will be used to set the context for the PPI reviewers.

Please provide a detailed and structured lay abstract, detailing the following **(300 words max)**:

- The background of your research proposal i.e. how and why your proposal came about and the context in which your proposal will take place.
- What is the overall aim of your research project?

- 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).
- Detail how the proposed research is relevant and important to people affected by cancer.

Public and Patient Involvement Plan: The public and patient involvement plan should detail how people affected by cancer and any other relevant stakeholder will be *involved* in the study as partners. It should be well thought out, as detailed as possible, and given as much consideration as the scientific sections in the form. Vague plans are to be avoided. When completing this section, please detail the following (**350 words max**):

- What is the overall goal of your PPI plan i.e. of involving patients?
- At what stage of the research programme will patients and other stakeholders be involved e.g. planning, design, implementation, management, evaluation, dissemination?
- What will be expected of the patients and stakeholders who become involved? What
 is the burden of involvement and how will people's time and expenses be
 compensated?
- Please describe any patient or stakeholder involvement that has occurred to date in the development of the proposal.
- How will the planned involvement activities influence the research and how will you
 ensure that the involvement activities are not tokenistic?
- What key patients and stakeholders will be involved, how many will be recruited, and from where will they be identified?
- Articulate the challenges that might arise from involving patients in your research and how any issues will be prevented or overcome.
- What, if any, supports or training will be available to those involved?
- What PPI supports are available to you locally or nationally, and how will these supports be utilised?

Please note: while patient participation and engagement activities are encouraged as part of an application and can be detailed as part of this plan, the Society will only fund applications that predominantly include *involvement* or *partnership* activities. Please see Appendix 1 for further details and examples.

7. Sharing of Research Findings

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, sharing research findings with 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. **(250 words max)**

8. Validation Summary

Any required fields in the application form that have not been completed will be detailed in this section. You will not be able to submit the application until all required fields are completed.

5. Submission of the Application

Final submission can only occur after the signatory (mentor) approves the application. Please see below for more information.

The application is ready for submission for signatory approval once:

- Your mentor has confirmed their participation.
 An email will be sent to your mentor requesting their participation when they are added to the application.
- It has been verified that all mandatory sections are completed on the application form.

The application is ready for final submission to the Irish Cancer Society once:

- The application submitted by the applicant is approved by the signatory (Mentor). The mentor will be notified by email once the applicant has submitted the application.
- The signatories will be able to see the full application in PDF format on their online portal. The signatory may approve or reject at this stage.
- The applicant will be notified of both approval and rejection of the application. Rejected applications will be returned to the applicant.

Applications that have been submitted by the lead applicant but not approved by the signatory before the deadline, will not be considered. It is the responsibility of the applicant to ensure that each signatory approves the application before the deadline.

Application Checklist

- Completed Application form.
 - Including the upload of:
 - Applicant CV
 - Mentor CV
 - Declaration of Support from mentor(s)
 - Declaration of Support- Head of Department

The application must be submitted to the Irish Cancer Society **ONLINE by 3pm Tuesday 22**March 2022.

6. Application Assessment

The Irish Cancer Society bases its funding decisions on the recommendations of an external review panel. However, the Society withholds the right to reject any funding application at its own discretion.

Incomplete, ineligible, or late applications will be rejected by the Society and may not proceed to external review.

6.1. Conflicts of Interest

The Society endeavours to ensure that external reviewers are free of any conflicts of interest that might unduly bias the decision-making process.

6.2. Assessment Procedure*

Applications are reviewed by a panel of international academic/clinical experts (scientific panel) **AND** a panel of experts by experience (PPI panel). The scientific panel will consist of experts in the areas of cancer research. The PPI panel will be made up of individuals with a lived experience of cancer. Sections of the application will be assessed in the following way:

	PPI Panel	Scientific Panel
Expression of Interest	 Project Summary – will be used to set context for PPI and Sharing of Research Findings plans Public and Patient Involvement (PPI) Plan Sharing of Research Findings Plan Alignment with research themes The panel will have the opportunity to provide feedback on the entire application, if they wish 	 Applicant CV Mentor CV Project Summary Personal Statement Declaration of Support- Mentor
Full Application	Full review of PPI sections and the provision of optional feedback on the entire proposal	Full review of scientific sections
Interviews	Present	Present

^{*}Please note that this is for guidance purposes only. Applicants however, will be notified of any changes to the review process.

The Scientific Panel will not be formally assessing any of the PPI panel's sections, and vice versa. As such, it is vital that the sections reviewed by the PPI panel are written in **plain accessible English**. Failure to do this may result in the PPI experts being unable to accurately score and provide feedback on these sections of your application. The review panel will be asked to provide feedback on the budget at full application stage, which the Society will take into consideration. The approval of all grant budget items is at the discretion of the Irish Cancer Society.

Both Scientific and PPI reviewers will have access to the entire application and while they won't be scoring the sections that they are not tasked with reviewing, they may provide optional feedback on other sections if they wish*.

Scientific reviewers will score applications based on:

- The academic merit and personal achievements of the applicant.
- The strength and suitability of the research mentor(s) in supporting the applicant in their research and career progression.
- The scientific merit of the proposed research, including feasibility of the proposed research.
- The applicant's demonstrable commitment to cancer research.

PPI reviewers will score each application based on:

- Rationale for research and its relative importance to people affected by cancer
- Feasibility of the proposed interactions with patient partners i.e. will the research work in practice
- Clarity and feasibility of the PPI plan e.g. use of local resources, tokenism of plan, inclusion of all relevant stakeholders, timelines etc.
- A clear understanding by the researcher of the value of involving patients in their research project
- Whether the PPI activities constitute true involvement and not participation/engagement
- How the proposed research aligns with the strategic research themes outlined by the
 Irish Cancer Society

*Please note: It is vital that the sections reviewed by the PPI Panel are written in accessible **plain English**. Failure to do this may result in the PPI representatives not being able to accurately review and score these sections of your application.

6.3. Assessment Outcome

Review scores and comments will be collated and all applications will be discussed at a review panel meeting. The review panel will select which applications should proceed to the next stage (Full Application Stage). Applicants will be informed of the outcome by email. Reviewer feedback will be available to all applicants upon request.

7. Next Stage: Full Application

Applications shortlisted at the EOI stage will be invited by email to submit a full application. The full application will allow applicants to expand on information provided in the EOI stage and respond to the review panel's feedback. You will also be asked to provide greater detail on all aspects of the proposal including: Research programme (including basis for research, research details, aims, methods, ethical approval, contingency plan, Gantt chart, public and patient involvement plan, sharing of research findings, research environment,

mobility/capacity building plan), the budget, and impact plan. The full application will be reviewed by the same international scientific reviewers (research programme, mobility, budgets) and PPI reviewers (public and patient involvement plan, sharing of research findings, and PPI plan budget) as from EOI stage.

The top applications at full application stage, will be invited to interview. There is funding available for **one fellowship**.

8. Contact

If you require assistance with the online grant management system or have any questions about the grant call, please contact the Irish Cancer Society Research Department:

Email: grants@irishcancer.ie

FAO: Dr Niamh McCabe



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.

<u>Involvement</u>

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 cancer¹. 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 other¹.

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)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 a 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 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

<u>Challenges</u>

- 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 ⁷, 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 which 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, the journal.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	Make a plan of the involvement activities you intend to	
involvement	incorporate into your research.	
Step 3: What are the costs?	For each activity, identify the specific costs for which you	
Step 3. What are the costs:	To reach activity, identity 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 Pound Sterling.		
Step 5: Mapping	Map the involvement activities onto your selected project framework so that you know exactly when in the project timeline costs are allocated.		
Adapted from the UK National Institute for Health Research, Budgeting for Involveme (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:

Related costs
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
Travel
Subsistence
Childcare
Carer costs
Personal assistants
Overnight accommodation
Home office costs
Finding people/advertising
Training and learning costs
Venues and catering
Equipment and books
Access to university facilities
Conference fees
Administrative support
Involvement coordinator
Independent facilitator
Peer researchers/interviewers
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
TOTAL COST (€1000 from PPI budget)			€ 900	

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
	Local travel in Dublin (1 representative x 2 meetings)	1 x 2= 2	€8	€16
Travel	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
TOTAL COST (€1000 from PPI budget and €96 from consumables budget)			€1,096	

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.

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
 <u>https://www.versusarthritis.org/media/1373/patient-and-public-involvement-booklet.pdf</u>

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

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- 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.
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- 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).