

# **Translational Research Scholarship Programme**

#### EOI applicant guidelines

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# Translational Researcher Scholarship Programme

EOI applicant guidelines
Updated: 12/01/2022

# 1. Introduction

#### 1.1. Indicative Timelines

Date
Thursday 13 January
Tuesday 22 February 3pm
March
Late March
Early May
May
Early to mid-June
Late June
Early July

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

#### 1.2. Background

The Irish Cancer Society is now accepting Expression of Interest (EOI) applications for the Translational Research Scholarship Programme 2022.

The objective of the Irish Cancer Society Research Scholarship Programme is to offer excellent graduates the opportunity to undertake postgraduate training in world class cancer research. There is scholarship funding available for one applicant of the highest calibre to focus on research within areas of high strategic priority<sup>1</sup> for the Irish Cancer Society.

During the four-year programme, Scholars will undertake general and cancer-specific training while participating in structured PhD programmes, and will have the opportunity to gain experience at an international research institution through a mobility/capacity building element. This will be subject to ongoing restrictions related to the Covid-19 pandemic.

All eligible EOI applications will be reviewed by an international panel and shortlisted applicants will be invited to submit a full application. Applications to the Translational Research Scholarships are accessible through the Irish Cancer Society Gateway Grant Tracker online system.

There are two scholarship award strands available: A Translational Biomedical Researcher Scholarship and a Social Science, Nursing, and Allied Health Researcher Scholarship. This guidance document gives instructions on completing the translational biomedical researcher Scholarship only i.e. for those individuals with a background in biomedical, life sciences or medicine. Applicants can only apply for one type of Scholarship award. For instructions on applying for the Social Science, Nursing and Allied Health Scholarship, please review the associated guidelines.

Please ensure that you are using the correct application that is relevant to the specific field of your research proposal. Applicants that submit applications to both awards or apply using the incorrect application form will be rejected. If you are unsure of which award category is applicable to your project, please contact grants@irishcancer.ie.

#### 1.3. Research Themes

This scholarship is specifically intended to fund research that is aligned with the <u>Society's Strategy (2020-2025)</u> and its <u>Research Roadmap</u>. Proposed projects can be in any of the following areas: a) translational biomedical research, b) clinical trials, c) survivorship, or d) strategic priorities. These areas are described below in greater detail (See Figure 1 below).

<sup>&</sup>lt;sup>1</sup> https://www.cancer.ie/about-us/irish-cancer-society-strategy-2020-2025

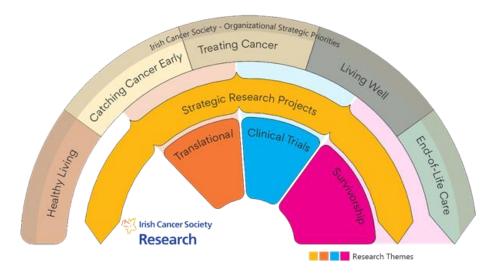


Figure 1. Irish Cancer Society Strategic Research Themes

- 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 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.
  - Please note, applications in drug design, SAR (structure—activity relationship) analysis, drug screening or basic biomedical research will not be considered at this time.
- 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. it 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.

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 (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 under-represented 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).

#### 1.4. Funding and Duration

The total value of the Irish Cancer Society Research Scholarship covering stipend, fees, materials and dissemination will be €155,000 for a maximum of four years.

A mandatory provision of at least €1,000 is included within this budget to support Public and Patient Involvement (PPI) in the proposed research project\*.

Costing	Details*
Stipend	o An annual stipend of €18,500 @ 100% FTE.
University registration fees	A maximum of €8,500 per annum may be allocated for university registration fees.
Running costs	Costs associated with conducting the research, for example, consumables, materials, small equipment items.
Travel and Dissemination	To cover costs of disseminating the research.
Public and Patient Involvement costs	A minimum of €1,000 must be allocated to support PPI activities.

<sup>\*</sup>Details provided are provisional. Information on the proposed budget will only be sought 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 awardees experience that goes beyond the traditional research environment in developing the scholar, 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 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 first half of 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.

# 2. Eligibility

# 2.1. Applicant Eligibility

Applications from individuals that do not meet the eligibility criteria will not be assessed. This award is open to biomedical sciences, pharmaceutical sciences, life sciences or medicine graduates.

#### **Lead Applicant:**

#### **Minimum Eligibility Criteria**

At a **minimum**, the applicants must meet the following criteria:

- You must have obtained (or be about to obtain) a first class honours or upper second class honours bachelor degree or equivalent\* in the biomedical sciences, pharmaceutical sciences, life sciences or medicine. If examination results are not known at the time of application, the Irish Cancer Society may make a provisional offer on condition that the applicant's final grade for their bachelor's (or equivalent) degree is a first class or upper second-class honours.
- \* If you did not receive a first class honours or upper second class honours bachelor degree but received (or are about to obtain) distinction- or merit-level in a master's degree you are eligible to apply.
  - You must not be registered for a PhD prior to application. This funding is for a four
    year PhD only, therefore individuals undertaking a masters degree in their chosen
    project will not be eligible to use this funding to transfer onto the PhD register.
  - This must be your first PhD.
  - You must complete the PhD at an Institution in the Republic of Ireland. This must be one of the <u>HRB's approved host institutions</u>.

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 us at <a href="mailto:grants@irishcancer.ie">grants@irishcancer.ie</a> in advance of preparing your application. It is also the responsibility of the applicant to ensure they meet the minimum PhD entry requirements of the proposed host institution.

# **Supervisor and Research Team Eligibility Criteria Supervisors**

The proposed PhD project must have at least two Supervisors, both of who are active in the supervision of the work.

- One Supervisor must be based at the proposed host institute and have a minimum of 5 years post-doctoral experience and hold a contract that covers the period proposed for the PhD.
- The other supervisor must have a minimum of 1-year post-doctoral experience or equivalent\*.

Ideally both supervisors should hold a contract that covers the duration of the PhD.
 However, given one of the supervisors is only required to have 1-year post-doctoral experience, we will consider any co-supervisor who can demonstrate their commitment to the supervision of the student throughout the whole period.

We recommend applicants ensure that their supervisors also meet the host institution's requirements for a research supervisor. Please refer to the guidelines for supervisors specific to their research organisation.

\*Please Note: We are allowing one supervisor to have a minimum of 1-year post-doctoral experience to strongly encourage more junior researchers to act as a PhD supervisor. The proposed supervisor's stage of career will be taken into account when reviewing each supervisor's CV.

#### 2.2. 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. hospital) must nominate an approved host institute and all finances must be managed by this institute.

#### 2.3. Patient and Stakeholder 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.

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 patient involvement plan and sharing of research findings plan in their full application.

#### 2.4. Eligible Research Area

All grants must be aligned with the Society's Strategy (2020-2025) and its Research Roadmap. Proposed projects must meet the requirements set out in section 1.3.

If considering an intervention development study, the proposed stage of development must be appropriate with all previous development phases complete. Intervention proposals should favour a single development phase rather than attempting to complete the entire development life cycle within a single project. Applicants should not attempt to develop a novel intervention where a similar intervention already exists, unless there is robust justification of need.

If considering a complex intervention, please refer to the <u>Medical Research Guidelines</u> or similar for guidance.

# 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 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.

Stage	Description
	Constructive feedback from the review panel is made available to all applications.
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 panel as with the expression of interest 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, interviews. Reviewer feedback will be made available to all applicants.
Stage 3: Interviews	Interviews are conducted between shortlisted applicants and the review panel. 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: <a href="https://grants.cancer.ie">https://grants.cancer.ie</a>. 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 home page. 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 home page. Alternatively, select 'New Application' from the 'My Applications' tab.

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

#### 3.3. Eligibility Criteria

Once you click 'Apply' you will be required to tick that you meet all of the eligibility criteria before you can proceed to make an application. If you do not meet all criteria then you will be unable to make an application.

# 4. Application Form

There are 9 sections outlined on the left hand side of the page:

- a. Introduction
- b. Project Outline
- c. Applicant Details
- d. Supervisors
- e. Scientific Summary
- f. Alignment with Irish Cancer Society Priority Research Areas
- g. Public Patient Involvement plan
- h. Declaration of Support Head of Department
- i. 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 with the application if these sections are incomplete.

#### Further details on each section of the application form:

#### a) Introduction

This section gives overview information on the scholarship programme.

#### b) 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 PhD Title
- Research Theme
- Has the proposed project been submitted elsewhere?
- Proposed Start Date Must not be before 01/09/22
- Duration Must be 48 months
- Proposed Host Institute

- Cancer Type (s)
- Research Type (s)
- Discipline(s)
- Keywords

#### c) Applicant Details

#### **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.

- Name
- Contact details
- Academic qualifications

Please complete a table for each year of your qualification. For example, one table for Year 1, another table for Year 2, etc.

Example of a completed academic qualifications table for one year:

Degree/Qualification	BSc Genetics
Year	1
From	01/09/17
То	01/06/18
Subjects	Molecular Genetics, Emerging Therapies,
	Drug Discovery and Development, etc
Institute	University College Dublin (UCD)
Department/School/Division	Pharmacology
Country	Ireland
Grade	70% or GPA 3.1 (First Class)

- Research experience
- Employment
- Publications
- Research grants

#### **Personal Statement**

The personal statement section should include only relevant information which will add merit to your application (300 words max).

The following must be covered:

- Reasons for pursuing a PhD in cancer research
- Reasons for choosing the proposed research centre and supervisors
- Future career plans

#### d) Supervision

#### **Add supervisors**

You must add your two proposed supervisors to the application. Your supervisors will have to confirm participation in the application and also approve the application after you complete it and before it is finally submitted to the Society.

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

If your supervisor 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 Supervisor. They will receive a notification of this via email. Please note you must upload a CV from each of your proposed supervisors.

#### **Supervisors' CVs**

Please upload the CVs of your two proposed primary supervisors. These CVs must be completed using the template provided (this template\* is downloadable in this section on the online system or on the website).

\*Please note this template is different to the Applicant CV Template.

Please ensure that you first have the permission from your supervisors to upload their CVs.

#### **Declaration of Support - Supervisors**

Please upload a declaration of support from each of your two proposed primary supervisors. 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.

Please note, reviewers will use this declaration of support to help assess supervisory support and the research environment.

#### e) Scientific Summary

Please give a summary of your proposed research project (1000 words max). This should include summary details of the following:

Background information/existing literature/preliminary results

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

#### f) 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). 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).

#### g) PPI Summary

In this section, please provide an accessible summary of the proposed study and your plan for co-developing and integrating clearly identifiable 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. Patient involvement and partnership is a fundamental aspect of the application. Please consult Appendix 1 before completing these sections.

**Project Summary:** Please provide a detailed and structured lay abstract, detailing the following **(200 words max)**:

- Briefly outline 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.

**Involvement Plan:** The 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?
- What are the aims and objectives of your PPI plan?
- 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 national 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 predominately include *involvement* or *partnership* activities. Please see Appendix 1 for further details and examples.

#### h) 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 simply a standard letter stating that they are aware of and support the application.

#### i) Validation Summary

The validation summary page will notify you of any incomplete required. You will not be able to submit the application until all required fields are complete.

# 5. Submission of the Application

The application is ready for submission once the form has been validated on the validation summary page. This will also highlight any supervisors who have yet to confirm their participation. Once the application has been validated, it may be submitted by the <u>lead applicant</u>.

The application will then be routed to any required signatories. The application will not be received by the Society until all signatories have approved it, in this case, once the **two** 

**supervisors have approved the application.** All signatories must approve the application before the application deadline. It is the responsibility of the lead applicant to ensure that signatories are given sufficient time to approve the application before the deadline.

Applications must be received by the Society prior to the deadline. Late or incomplete applications will not be accepted.

#### **Application Checklist**

- Completed Application form.
  - Including the upload of:
    - Applicant's CV
    - Both proposed Supervisors' CVs
    - Declaration of Support from both Supervisors
    - Declaration of Support- Head of Department

The application must be submitted to the Irish Cancer Society **ONLINE by 3pm Tuesday 22 February 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 translational biomedical science. 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	<ul> <li>Project Summary –         will be used to set         context for PPI plans</li> <li>Patient Involvement         (PPI) Plan</li> <li>Alignment with         research themes</li> </ul>	<ul> <li>Applicant CV</li> <li>Supervisors' CVs</li> <li>Scientific Summary</li> <li>Personal Statement</li> <li>Declaration of Support- Supervisors</li> </ul>
Full Application	Full review of PPI sections	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 representatives 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, 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.

Scientific reviewers will score applications based on:

- The academic merit and personal achievements of the applicant.
- The strength and suitability of the research supervisors 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.
- The strength of endorsement from the applicant's referees and how well-known the applicant is to them.

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 participants 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 that the 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 the PPI Panel are written in accessible **plain English**. Failure to do this may result in the PPI representatives not being able to accurately 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.

# 7. Next Stage: Full Application

Applications shortlisted at the EOI stage will be invited to Full application by email. The full application will allow applicants to expand on information provided in the EOI stage and respond to the review panel's feedback. You also will 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) budget and impact plan. The full application will be reviewed by international scientific reviewers (research programme, mobility, budgets) and PPI reviewers (full public and patient involvement plan, sharing of research findings, and involvement plan budget).

#### 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



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

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

#### 1. Background

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

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

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

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

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

#### **Participation**

A person with cancer may be recruited into, and take part in, a research study e.g. a clinical trial, and provide data of some form.

#### **Engagement**

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

#### Involvement

Involvement is distinct from participation or engagement. Where participation and engagement are conducted 'to', 'about', and 'for' people with cancer, involvement is conducted 'with' or 'by' people with cancer<sup>1</sup>. People with cancer can be involved at any stage of the research process, from conceptualisation to dissemination.

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

#### 3. Why is PPI important?

PPI is becoming increasingly important in research. The Irish Cancer Society is committed to expanding the involvement of those affected by cancer in the research that the Society funds, and in the funding decision-making process. This commitment is reinforced by the Irish Governments' National Cancer Strategy (2017-2026)<sup>2</sup>, which highlighted:

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

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

- Promote a sense of empowerment and value among patients<sup>3</sup>
- Enhance patient trust in researchers<sup>3</sup>
- Improve researchers' insight into their own research area<sup>3</sup>
- Help researchers identify barriers and come up with solutions to research<sup>3</sup>
- Increase trust and acceptability in the patient community of research findings<sup>3</sup>
- Inform the provision, access, and location of healthcare services<sup>4</sup>
- Improve the dialogue between healthcare professionals and patients<sup>4</sup>

Specific to the cancer setting, PPI may be used by patients as a resource, to make sense of living with a chronic condition<sup>5</sup>. People with cancer report feeling enhanced knowledge and skills from taking part in PPI, as well as feeling they contributed to research by providing a lay perspective (i.e., practical knowledge about being a patient with cancer)<sup>6</sup>.

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

#### 4. PPI is a partnership

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

Involving people affected by cancer as early as possible in your planning process, and ensuring ongoing 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, cofacilitating focus groups, assisting in the interpretation of results.
- Involvement in organising and running public and patient engagement activities;
- Input into grant applications

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

#### **Challenges**

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

#### Additional things to consider-

- A number of universities within the Republic of Ireland already have dedicated individuals, infrastructure, training, or programmes in place dedicated to PPI. We strongly recommend that you engage with these local resources when planning how patient involvement will be integrated into your project.
- Engagement can sometimes be mistaken for involvement (more information on both in section
   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 herehttps://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 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.
Adapted from the UK National Institute for Health Research, Budgeting for Involvement (2013)	

An online calculator is available on the NIHR Involve website: <a href="https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/">https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/</a>. Please note the online calculator is in pound sterling (£), 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:

Costing category	Related costs
Payments and rewards	Fees to individuals
	Vouchers/tokens for individuals
	Prize draw awards
	Fee/donation to a group
	Funding for additional training and learning
	Honorary appointment e.g., lay fellow or research partner
Expenses	Travel
	Subsistence
	Childcare
	Carer costs
	Personal assistants
	Overnight accommodation
	Home office costs
Involvement activity	Finding people/advertising
	Training and learning costs
	Venues and catering
	Equipment and books
	Access to university facilities
	Conference fees

Involvement staffing	Administrative support
	Involvement coordinator
	Independent facilitator
	Peer researchers/interviewers
Other costs	Disclosure and barring service
	Language translation and interpretation costs
	Support for people with impairments

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

#### 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)				

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

#### Worked costing example for in-person advisory group:

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

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

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

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

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.
   <a href="https://www.invo.org.uk/posttypepublication/national-standards-for-public-involvement/">https://www.invo.org.uk/posttypepublication/national-standards-for-public-involvement/</a>
- 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.
 <a href="http://www.dcc.ac.uk/sites/default/files/documents/publications/HowToLaySummariesD">http://www.dcc.ac.uk/sites/default/files/documents/publications/HowToLaySummariesD</a>
 ec2012.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. <a href="https://www.nala.ie/wp-content/uploads/2019/08/Writing-and-design-tips.pdf">https://www.nala.ie/wp-content/uploads/2019/08/Writing-and-design-tips.pdf</a>

#### **Budgeting for PPI**

#### 10. References

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- 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).