

Irish Cancer Society Research Fellowship 2021 - Social, Nursing, and Allied Health

Expression of Interest (EOI) - Guidelines for Applicants

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1. Introduction

1.1. General information

The Irish Cancer Society is now accepting Expression of Interest (EOI) applications for the Social, Nursing, and Allied Health Sciences (SNAH) Research Fellowship 2021.

The objective of the Irish Cancer Society Social, Nursing, and Allied Health (SNAH) Research Fellowship is to support excellent **early- to mid-stage** (0-6 years' experience post-PhD or equivalent) cancer researchers and clinical professionals (nurses and allied health professionals) to develop as independent researchers. This Fellowship (2 years full time or 3-4 years part time) is specifically intended to fund research that seeks to reduce the burden of cancer and is aligned with the Irish Cancer Society Strategy (2020-2025)¹. Applications in the areas of basic or translational biomedical research are not eligible.

All eligible EOI applications will be reviewed by an international scientific panel and a public and patient involvement (PPI) panel. Shortlisted applicants will be invited to submit a full application. There is funding available for one fellowship in 2021.

Wed 03 February 2021	Opening of call for Expressions of Interest (EOI)
Wed 07 April 2021 @ 15:00	Deadline for online EOI submission
Mid May 2021	Shortlisted applicants invited to submit full application.
Wed 23 June 2021 @ 15:00	Full application deadline
W/O 16 August 2021	Interviews (online)

1.2. Important Dates

Dates are provisional and subject to change. Further details of important dates for the full application stage will be given to shortlisted applicants. Applicants must be available to attend the interview in Dublin.

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

1.3. Funding and Fellowship Duration

The maximum funding granted for this fellowship is €160,000 to be undertaken either 2 years full-time or 3-4 years part-time. A part-time fellowship is allowable for nursing and allied health applicants who hold a concurrent clinical post in their professional field.

Within the total budget, \leq 5,000 is restricted for a Mobility and Capacity Building Element (see Section 1.4. for details). The remaining \leq 155,000 can be used for salary (based on IUA rates or HSE pay scale for nursing and allied health applicants), small equipment items, running costs, training, travel and dissemination (separate from the Mobility and Capacity Building Element), and Public and Patient Involvement costs (a minimum of \leq 1,000 should be budgeted for involvement costs). Budget details are provisional to be confirmed at the full application stage.

Payment to the host institute will only be released on receipt of all necessary institutional ethical approvals. However, a small provision of allocated monies may be made available at the start of the award to facilitate the ethical approval process where necessary.

1.4. Mobility and Capacity Building Element

The Irish Cancer Society SNAH Fellowship provides provision for 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 national/international research group). However, in recognition that extended travel is not always feasible, applicants can nominate either:

- a) Mobility: a substantial mobility element of up to three months in duration at a national or international research group or lab during the first half of the fellowship; or
- b) Non-Mobility Initiative: a substantial and distinct non-mobility initiative which 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

1.5. Public and Patient Involvement (PPI)

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.

It is expected that all applicants will predominantly incorporate patient '*involvement*', activities as part of their plan and will be required to submit a budget and dissemination plan. 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.

The successful recipient will be expected to attend a PPI development workshop during the first year of their fellowship. Please note, people affected by cancer – '*PPI reviewers*' - will review the PPI sections of the application, therefore it is strongly recommended that all applicants carefully review the supporting detail included in our PPI guidance document prior to beginning work on their application, which can be found in Appendix 1.

2. Eligibility

2.1. Applicant eligibility

The objective of the Irish Cancer Society SNAH Research Fellowship is to support excellent **early-stage (0-6 years' experience post-PhD or equivalent*)** cancer researchers to develop as independent researchers in their chosen area of social, nursing, and allied health sciences.

Applications from individuals who do not meet the eligibility criteria will not be assessed. We therefore strongly recommend you read the following criteria carefully to be made aware of requirements for the applicant, mentor, host institution, and research area.

The Irish Cancer Society SNAH Fellowship is open to:

- untenured <u>academic researchers</u> in the social, nursing, or allied health sciences; and
- <u>clinical professionals</u> in a nursing and allied health science.

Academic researchers must:

- possess a PhD or equivalent* in a relevant social, nursing, or allied health sciences field;
- have a no more than 6 years' post-doctoral research experience (from date of graduation);**
- have an established track record in research exemplified by, for example, a history of grant awards, research supervision, peer-review publication, national/international collaboration, presentation at national/international conferences, etc.;
- hold or attain an academic appointment in a higher education institution in the Republic of Ireland for the duration of the proposed study (applicants are not expected to hold this appointment at the time of applying).

Clinical professionals must:

- possess a clinical qualification in a nursing or allied health discipline enabling registration with CORU (e.g. dietetics, physiotherapy, occupational therapy, social work, speech and language therapy) or relevant professional body (e.g. Psychological Society of Ireland, Pharmaceutical Society of Ireland, Nursing and Midwifery Board of Ireland);
- possess a PhD or equivalent* in a relevant social, nursing, or allied health sciences field
- have no more than 6 years' post-doctoral research experience (from date of graduation);**
- have a track record of research involvement exemplified by, for example, recruitment and data collection in research studies, conducting clinical audits, presentation at research meetings or conferences, academic publications, completion of research training, etc.

Part-time applicants must (nurses or allied health professionals only):

• hold a relevant clinical appointment for the duration of the proposed study consisting of substantive clinical contact with cancer patients and/or their families.

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

Applicants must have submitted their final post-viva hard-bound thesis at the time of application and must graduate before commencement of this fellowship.

**<u>Extended Leave</u>: 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, medical, or carer leave. To ensure equity for those who have had to take extended leave in the past, where relevant, applicants may 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.

2.2. Mentor

At least one primary mentor is required for each application. The mentor should be an established senior researcher in an appropriate social, nursing, and allied health field, who will provide guidance and support. They must hold a post, either permanent or on contract basis, at the proposed host institute that covers the entire duration of the research fellowship and provide a letter of support to your application.

2.3. Host institution

The host institution is the organisation that receives and administers grant funding and is responsible for compliance with all general and specific terms and conditions of awards. In order to be eligible to apply for funding, a proposed host institution <u>must</u> be a higher education institution in the Republic of Ireland and <u>must</u> be one of the HRB's approved host institutions: <u>https://www.hrb.ie/funding/funding-schemes/before-you-apply/all-grant-policies/hrb-policy-on-approval-of-host-institutions</u>. Applicants conducting research out of non-approved sites must nominate an approved host institute and all finances must be managed by this institute.

2.4. Eligible research areas

This fellowship is specifically intended to fund research that is aligned with the Irish Cancer Society Strategy (2020-2025). Proposed projects should be in the social, nursing, and allied health sciences and seek to improve the care and outcomes of people affected by cancer. Research projects in the area of basic or translational biomedical science are not eligible for this award.

If considering an intervention-based research study, please ensure that the stage of development of the intervention is appropriate and that previous development phases are complete. If considering a complex intervention, please refer to the Medical Research Council Guidelines² or similar for guidance.

3. Application Procedure

Prior to applying, you <u>must</u> read this document through to completion. You must identify a suitable mentor before completing the application form.

3.1. How to apply

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

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

3.2. Overview of the application process

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

- 1. Update your basic information (please make sure all fields are completed);
- 2. Make a new grant application; and
- 3. Access previous grant applications

3.3. Making an application

When you have ensured that all your basic details are inputted then you can proceed to apply for a new grant application. This can be done by returning to the Portal Home page and clicking to apply for funding from one of our grant streams. Or alternatively through the 'My Applications' tab on the left hand side of the page, and clicking the 'New Application' button.

You will then be asked what Grant Type you would like to apply for. Click 'Apply' for the Grant Type detailed as 'SNAH Fellowship 2021 - EOI.'

² https://mrc.ukri.org/documents/pdf/complex-interventions-guidance/

3.4. 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. The Application Form

Once you have indicated that you meet all eligibility criteria you will then be directed to the application form. There are 8 sections outlined on the left hand side of the page:

- a) Introduction
- b) Project Outline
- c) Applicant Details
- d) Mentorship Details
- e) Organisational Support
- f) Scientific Summary
- g) PPI Summary
- h) Validation Summary

It is recommended that you save the information as you complete each section. This can be done by clicking 'Save' as you go along. Alternatively the information will be saved when you click 'Save and Close'. By clicking 'Previous' you will be brought to the previous section and by clicking 'Next' you will be brought to the next section.

Sections that are required to be filled out have a red circle icon next to them. You will not be able to submit with the application if these sections are not completed.

Further details on each section:

a) Introduction

This section gives overview information on the funding scheme.

b) Project Outline

Details of your application are entered into this section. Input and save the information as required under the following headings:

- Proposed title
- Proposed start date (ideally in October 2021)
- Duration
- Working arrangements/time allocations (clinical applicants only)
- Professional registrations
- Host Institution
- Additional research site details
- Collaboration details
- Cancer type
- Keywords
- Research type
- Discipline

c) Applicant Details

Curriculum Vitae: In this section, you will be asked to complete and upload your CV. The CV should be completed using the template provided (this template is downloadable in this section on the online system or on the website) and be no more than 3 pages long.

Personal Statement: You will be asked to **complete a personal statement**. The personal statement should include only relevant information which will add merit to your application. The following must be covered (**300 words max**):

- Reasons for applying for the fellowship.
- How the proposed fellowship fits into your career plan.
- What you aim to do immediately following the fellowship.
- A demonstrable commitment to a career in research.

d) Mentorship Details

In this section, you must add your mentor to the application and upload CVs and Declarations of Support. You may add more than one formal mentor and detail any informal mentorship that you will receive during the course of your fellowship.

Adding your mentor: At least one primary mentor must be added to each application. Each mentor will have to confirm participation in the application and also approve the application *after* it is submitted by the applicant and *before* it is finally submitted to the Society. Please note that mentor approval must be completed before the application deadline.

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

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

- **Mentor CV:** Please note you must upload a CV from your proposed mentor(s) in PDF format and 3 pages maximum. The CV should be completed using the template provided (this 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:** You must upload a letter of support from any mentor added to the application. The Declaration of Support Template is downloadable from this section of the online system or on the website.

Details of additional mentorship: You may also detail any other mentorship that you will receive (other than your primary mentor) over the course of your fellowship. Please describe the individual, their role and level of involvement, and how they will add value to your fellowship (500 words max).

e) Organisational Support

- Declaration of Support Head of Department at Host Institution: You must also upload a letter of support from the head of department at the proposed host institution. 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.
- **Clinical Letter of Support:** Clinical staff who intend to complete the fellowship on a part-time basis must upload a letter of support from the appropriate person at their clinical site (e.g. Head of Department). The letter must acknowledge that the organisation is aware of, supports the application, and will enable the applicant to fulfil research obligations. This support includes the appointment of new staff or staff to cover the time spent dedicated to research. The letter should describe how this support will be accomplished in the context of providing a clinical service. In addition, the clinical site must agree to provide indemnity cover that may be required by any staff carrying out research at the clinical site.

The declaration of support template is downloadable from this section on the online system or on the Irish Cancer Society website. All letters of support should be completed on headed paper. To upload this letter of support click 'Attach', locate the file to be attached and then click 'Attach'.

f) Scientific Summary

Please give a summary of your proposed research project (**1000 words max** - *Separate space will be given for references*). This should include summary details of the following:

- Background information/existing literature.
- Hypothesis, aims, and/or objectives.
- Methodology.
- Summary and conclusions.

<u>g) PPI Summary</u>

In this section, please provide a project summary of your research and an overview of your plan for integrating patient involvement into your research project.

Please note that patient involvement is a fundamental aspect of the application, a revised patient involvement plan will be required at the full application stage (feedback from the EOI PPI review should be incorporated into the full application). The PPI review panel will review this section. It is strongly recommended that applicants consult Appendix 1 before completing these sections.

Please detail the following:

- **Project Summary:** Please provide a detailed and structured lay abstract. The language used should be understandable and not scientific. If scientific terms are used, they must be explained. Please detail the following **(450 words max):**
 - Briefly outline the background of your research proposal i.e. how and why your research came about, context.
 - Describe the specific problem, issue, or question that you are asking in your research proposal and describe how you are addressing it (including the variables being measured and why you have chosen these specific variables).
 - Outline who will take part in your research, how you intend to recruit them into your study, and what they will be expected to do if they take part.
 - Detail how the proposed research is relevant and important to people affected by cancer.

Patient Involvement Plan: The patient involvement plan should detail how patients will be *involved* in the research project. It should be well thought out, as detailed as possible, and given as much consideration as the scientific sections in the form. Vague plans are to be avoided. The patient involvement plan should. When completing this section, please carefully consider the following questions: (450 words max)

- What is the overall goal of involving patients?
- What key patients and stakeholders will be involved and from where will they be identified/recruited?
- At what stage will patients be involved in your research project? E.g. planning, design, implementation, management, evaluation, dissemination.
- How exactly will you involve patients? Give as detailed information as possible, for example numbers of patients involved and how they will be recruited, what exactly will be required from them etc. Please ensure you are clear about the logistics of the involvement activities here.
- Articulate the challenges that might arise from involving patients in your research and how any issues will be prevented.
- What supports will be in place for the patients involved?

Please note: while patient participation and engagement activities are permitted and encouraged as part of an application and can be detailed as part of the patient involvement plan, the Society will only fund applicants who predominately include "involvement" activities as part of their plan. Please see Appendix 1 for further details and examples.

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 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**).

h) Validation Summary

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

5. Submission of the Application

The application is ready for submission once:

- It has been verified that all required questions are answered in the correct manner on the application form; and
- Your mentor(s) has confirmed their participation. An email will be sent your mentor requesting their participation when they are added to the application.

The application will be received by the society once:

- The application is submitted by the applicant; and
- The application is approved by the mentor. Your mentor will be notified by email once you have submitted the application inviting them to approve your application.

Please note that signatories have the capacity to approve or reject the application. The applicant will be notified by email if the application has been approved by signatories. Rejected applications will be returned to the applicant.

Applications that have been submitted by the lead applicant but not approved by the signatories 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. Please ensure that the application is submitted with sufficient time allowed for each signatory to approve.

EOI Application Checklist

Completed application form, including the upload of:

- CVs for the mentor(s)
- Declaration of Support from mentor(s)
- Declaration of Support from the Head of Department at the host institution
- Declaration of Support from clinical employer (for nurses and allied health professionals only)

6. Assessment Procedure

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

6.1. Conflicts of Interest

We will endeavour to ensure that the reviewers chosen do not have any conflicts of interest regarding the applications they are assessing.

6.2. Assessment Procedure

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

	Patient Reviewer	Scientific Reviewer	
EOI	 Project Outline PPI Summary: Project Summary PPI Plan Sharing of Research Findings 	 Project Outline Applicant Details Mentorship Scientific Summary 	
Full Application	Full review of PPI sections	Full review of scientific sections	
Interviews	Present	Present	

Scientific reviewers will evaluate applications based on the scientific merit of the proposed research; the strength of the applicant and the applicant's commitment to cancer research; and the strength of mentorship. PPI reviewers will evaluate applications based on their practical feasibility, potential impact, and relevance to people affected by cancer. Additionally, PPI reviewers will evaluate the strength of patient *involvement* and dissemination plans.

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

6.3. Assessment outcome

Applicants will be informed of the outcome of review by email. Shortlisted applicants will be invited to submit a full application.

7. Next Stage: Full Application

Applicants whose EOIs are shortlisted will be invited to submit a full application. For the full application, you will be required to provide greater detail on all aspects of the proposal including a revised PPI summary, research programme, research environment, mobility & capacity building element plan, training and career development plan, and references letters. You will also be required to respond to feedback provided at the EOI stage by the scientific and PPI reviewers.

The top applicants from the Full Application stage will be invited to attend a virtual interview in July 2021. The final funding decision will be co-decided by academic experts and PPI reviewers.

8. Contact

If you require assistance with the online application system or have any queries about the application which are not currently addressed in the FAQ document, please contact us at **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.

<u>Engagement</u>

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

Appendix One

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 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 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 al⁷, 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-<u>https://sites.google.com/parkinsons.org.uk/ppi-in-lab-based-research/home</u>

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, thejournal.ie, Newstalk;
- Blog posts e.g., professional blog, Irish Cancer Society website;
- Newsletters
- Online videos and website content

6.4. Budgeting for PPI

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

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

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

The steps to PPI budgeting are described below:

Step	Activity
Step 1: Framework selection	Select a framework for mapping involvement costs. This might be the research project cycle (i.e., the step-by-step research process/procedure) or a project timeline (e.g., Gantt chart).
Step 2: Planning your involvement	Make a plan of the involvement activities you intend to incorporate into your research.
Step 3: What are the costs?	For each activity, identify the specific costs for which you will need to budget.
Step 4: How much will it cost?	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 Insti	tute for Health Research, Budgeting for Involvement (2013)

An online calculator is available on the NIHR Involve website: <u>https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/</u>. 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)			€ <mark>900</mark>	

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. <u>https://www.invo.org.uk/posttypepublication/national-standards-for-public-involvement/</u>
- NALA (National Adult Literacy Agency)
 <u>https://www.nala.ie</u>
- 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. <u>http://www.dcc.ac.uk/sites/default/files/documents/publications/HowToLaySummariesD</u> <u>ec2012.pdf</u>

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. <u>https://www.nala.ie/wp-</u> content/uploads/2019/08/Writing-and-design-tips.pdf

Budgeting for PPI

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

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).