Irish Cancer Society Research

General Guidelines for Applicants

Improved Supports for Underserved Communities Award 2023
Timely Access to Early Diagnosis

Updated: 11.09.2023

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1. Introduction

1.1 Overview

The Irish Cancer Society's vision is that by 2025 three out of every four cancer patients in Ireland will survive their diagnosis and, in future, no one in Ireland will die from the disease. Timely access to cancer diagnostics is a key component of making this vision a reality.

As part of our strategic pillar to support and address unmet needs of cancer patients, the Irish Cancer Society plans to undertake research which will help identify the enablers and barriers to the timely diagnosis of cancer on both the supply (healthcare providers) side and the demand (public) side. The Improved Supports for Underserved Communities Award will provide funding of up to €100,000 for a project of up to a maximum of 12 months.

Importance of early detection

Timely diagnosis of cancer is important for a variety of reasons, including ensuring a good quality of life for people during and after treatment. The earlier cancer is detected the better. To illustrate, 4 in 5 people will survive to five years post-diagnosis when colorectal (95%), breast (94%) and ovarian (83%) cancers are detected at Stage 1. Unfortunately, survival falls to under 1 in 5 people for the same cancer types when diagnosed at Stage 4 (colorectal: 10%; breast: 19%; ovarian: 15%).[i]

Time is crucial for reducing cancer mortality. For instance, delays of 4 weeks in accessing treatments, such as chemotherapy, radiotherapy and surgery, can affect mortality.[ii] In October 2022 then-Taoiseach, Micheál Martin, warned of a 'frightening wave' of delayed cancer diagnoses in 2023. [iii] Between 2020 and 2021, 1 in 12 (8%) fewer cancers were registered compared to projections.[iv]

To build an evidence base in the Irish context, the Irish Cancer Society are focusing a research project on cancer detection amongst the following groups of people: adults aged 65+; people living with an intellectual disability; people living with a physical disability.

Advocacy and research on early detection of cancer

Through our work, the Irish Cancer Society seeks to support people affected by cancer and bring their voice into policy discussions. The Irish Cancer Society advocates for resources and infrastructure to support the earlier detection of cancer, including but not limited to:

- Advocacy through the Pre-Budget Submission Process

- Submissions of evidence to the Joint Committee on Health

- *Your Health Matters* Roadshow

- Media discussions

Research on underserved communities

Through the public's generous support, the Irish Cancer Society funds research in line with our mission to ensure fewer people get cancer and those that do have better outcomes. We always keep people affected by cancer at the heart of everything we do. Since 2021, The Society has been funding research specifically looking at improving cancer outcomes and supports for socially excluded and underserved communities in Ireland. This research intends to inform not only the Irish Cancer Society, but also government, policy makers and the wider public so we can make healthcare more accessible and equitable for all. The data generated from the Improved Supports for Underserved Communities funding call will also inform future research.

1.2 Purpose

The overarching objective of this funding call is **to learn about the barriers and enablers towards timely access to diagnostics to detect cancer**, relating to both patients/public and in the healthcare system. The research project will examine detection amongst the following groups of people:

- People aged 65+.
- People living with a physical disability.
- People living with an intellectual disability.

The term diagnostics refers to the pathway where investigations for pre-cancer and cancer begins. Diagnostics, therefore, include a range of tests necessary to making a final diagnosis or excluding the possibility of cancer, e.g. a mammogram does not detect cancer directly, but is often a necessary step towards indicating signs of cancer and would be considered a diagnostic tool on the diagnostic pathway for the purposes of this study. A non-exhaustive list includes, cervical/HPV test, access to rapid access clinics and their services, access to medical imaging services, colonoscopy, access to a prostate-specific antigen test, biopsy, etc.

The diagnostic pathway to be examined includes:

- Patients/public
  - outline the enablers and barriers towards getting a cancer diagnosis, including awareness of signs and symptoms, access to healthcare services, healthcare practitioner management of symptoms, number of visits before diagnostic referral, etc.
  - provide an understanding of group specific needs
  - gather perspectives and experiences relating to late detection of cancer
- Healthcare practitioners

- o outline the enablers and barriers at community and general practice level, including assessing awareness of signs and symptoms of cancer, awareness of referral guidelines, access to diagnostic services, training needs, etc.
- o understand the systemic issues within the healthcare system after GP referral to diagnostics, which could delay diagnosis. To the extent possible, we would like to capture referrals to both public and private services.
- o Learn about the impact of early and late detection on community and general practice management of patients.
- Analysis, lessons learned and conclusions
  - o examine the current and long-term ability of the healthcare system to cope with the projected growth in demand for diagnostics services.
  - o reflections on what works well and what does not work well.
  - o provide national/international examples of good or best practices on interventions encouraging the public to access services for early detection of cancer AND for the public healthcare service and primary care in meeting the demand for diagnostics.
- Recommendations
  - o provide action points for the Irish Cancer Society, the Government, the HSE and other cancer policy stakeholders

1.3 Research Methods

When outlining their proposed methodology, applicants should consider the most appropriate methods to meet our objectives and respond to the research questions. We anticipate that the research will require a mixed methods interdisciplinary approach.

Any proposed methods should take into consideration the following; how to include the voices of people aged 65+, people living with an intellectual disability, people living with a physical disability and carers/family members. Researchers should also consider how to include the voices of healthcare practitioners and allied health professionals.

- The study should rely on quantitative and qualitative data.

- There is a need to collect new representative data to fill gaps and bring our existing knowledge up to date.

- It is important to reflect stories and give voice to lived experience. We would like for the study to capture stories (through thematic case studies, or through individual case studies).

- To the extent possible, the study should also be designed to identify statistically significant findings.

- Research will be limited to healthcare services in the Republic of Ireland and, where possible, data should preferably be broken down by region/province, depending on sample size of respondents.

- The study should be designed appropriately to ensure that it is powered to provide robust qualitative and quantitative data to be presented to key stakeholders such as Government departments, Oireachtas Members and the media.

1.4 Applications

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

For this award any group members will be considered as co-applicants (maximum of 10 co-applicants plus 1 lead applicant). Co-applicants must have a well-defined and substantial role in the proposed plan.

Only **one** application can be submitted per principal investigator/lead applicant. An application can only be submitted once*.

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

1.5 How the research will be used by the Irish Cancer Society

The purpose of this piece of work is to develop a knowledge- and evidence-base to understand the barriers and enablers towards timely diagnosis of cancer and potential impacts for people aged 65+, people with intellectual disabilities and people with physical disabilities.

Primarily, this research will be used to help us identify new solutions and inform their development. Importantly, the evidence produced from this project will illustrate the general and unique challenges and impacts associated with access to diagnostics for the specified-groups, which need to be addressed by a range of stakeholders. Additionally, the evidence-base will help us to track progress over time, in relation to our advocacy work.

We will require the results of this research to be summarised in a narrative report, which can be used for influencing, campaigning and media work. The report should also provide disaggregation, where possible, outlining how people may be differently impacted based on a variety of factors, for example (but not limited to) socio-economic status, ethnicity, residence, employment status, proximity to services, location/county/region, etc.

Specifically, this research will be used to:

- build on our existing advocacy work to enhance early detection of cancer

- prioritise and develop potential lobbying and/or service solutions

- provide evidence for campaigning and media work on access to diagnostics

- provide evidence on the needs of healthcare and other professionals in relation to service provision

- inform the work of the Irish Cancer Society, right across the organisation

1.6 Funding

It is the intention of the Irish Cancer Society to provide funding for one grant in 2023. This will be subject to the submitted grant proposals meeting the required standard, as assessed by international peer review. Any application that does not meet this required standard will be eliminated from the application process.

The Improved Supports for Underserved Communities Award 2023 will provide funding of up to €100,000 for a project of up to a maximum 12-month duration.

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

1.7 Key Dates

Tuesday 12th September 2023	Applications open
Monday 9th October – 3pm	**Application Deadline**
October/November 2023	Review
November 2023	Awardee selected

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

2. Eligibility Criteria

2.1 Applicant Eligibility

Applications that do not meet the eligibility criteria will not be assessed. We therefore strongly recommend you read the following requirements carefully. If you are unsure of your eligibility, please contact grants@irishcancer.ie.

Lead applicants must have:

- a doctoral degree by research (or equivalent*) in a field relevant to the proposed research programme
- a minimum of two years post-doctoral research experience
- have a mentor (only required for lead applicants with 2-4 years post-doctoral research experience)

Eligible Applicants must fulfil the following criteria:

- The lead applicant must be affiliated with a HRB approved Institution in the Republic of Ireland. Please note, the award must be administered through this HRB approved Institution
- hold an employment contract that covers the duration of the award

 Co-applicants must fulfil the following criteria:
- have well-defined and substantial roles in the proposed project

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

2.2. Project Eligibility

As this is a focused research call, applicants are required, at a minimum, to address the key research questions outlined in Appendix 1: Key Research Questions. There are no stipulations as to *how* these questions are answered. However, applications will be subjected to expert peer review which will evaluate how robustly the proposed methodology will answer the specified research questions. Please see section 5.2 for details of the evaluation criteria.

Research aims:

- To provide the Irish Cancer Society with a robust, up-to-date evidence-base to inform campaigning and advocacy work as well as providing key information to our fundraising and service departments; and against which future changes can be measured.
- To surface problems and challenges facing the public and the healthcare services, including the personal, financial and social costs of late detection, of which the Irish Cancer Society are unaware.
- To demonstrate how different groups of people (cancer patients and their families) are uniquely impacted (e.g. socio-economic status, cancer type, age, gender, county/region, etc.).

2.3. Host institution

The host institution is the organisation that receives and administers grant funding and is responsible for compliance with all general and specific terms and conditions of awards. In order to be eligible to apply for funding, a proposed host institution must be a higher education institution in the Republic of Ireland and must be one of the HRB's approved host institutions: https://www.hrb.ie/funding/funding-schemes/before-you-apply/all-grant-policies/hrb-policy-on-approval-of-host-institutions.

2.4. Public and Patient Involvement (PPI)

The Irish Cancer Society is dedicated to involving patients, families, survivors, supporters, and the public in research. Public and Patient Involvement (PPI) in the research process ensures that research is meaningful and of benefit to those affected by cancer. We strongly encourage that applications include involvement by representatives of those affected by the issues that the programme seeks to support and/or their representatives. PPI can be involved at any sage of a research project, from development and design to interpretation and dissemination. Ideally, PPI will feature throughout the project. Further details on how to incorporate PPI are included in Appendix 2.

3. Application Procedure

3.1. How to Apply

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

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

3.2. Overview of the Application Process

When you enter your login details you will be directed to the Portal Homepage. From here you can:

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

3.3. Making an application

When you have ensured that all your basic details are entered you can then proceed to apply for a new grant application. This can be done by returning to the Portal Homepage and clicking to apply for funding from one of our grant streams. Or alternatively through the 'My Applications' tab on the left-hand side of the page and clicking the 'New Application' button. You will then be asked what Grant Type you would like to apply for. Click 'Apply' for the Grant Type detailed as 'Improved Supports for Underserved Communities Award'.

4. The Application Form

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

a) Project Outline
b) Mentor
c) Applicant Curriculum Vitae
d) Co-applicant roles and research team
e) Research Programme
f) Declaration of Support - Head of Department
g) Budget
h) Public and Patient Involvement*
   - Project Summary*
   - Public and Patient Involvement*
   - Sharing of Research Findings*
i) Validation Summary

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

As you proceed through the sections you will see a small blue question mark icon next to some of the sections. By clicking on this icon you will get more information on the section to be completed.

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

*Note: External patient representatives will appraise and give feedback on the sections marked by an asterisk. It is very important that these sections are written in plain English and are accessible to a non-scientific audience.

Please see information from the Irish Cancer Society on Public and Patient Involvement (PPI) in Research Guidelines (Appendix 2) for more information.

a) Project Outline

Details of your application are entered into this section. Input and save the information as required under the following headings:
– Proposed title
– Proposed start date (must not be before December 2023)
– Duration (maximum 12-months)
– Applicant details
– Proposed host institution
– Cancer type
– Keywords
– Research type
– Discipline

b) Mentor

Please indicate if you have at least 4 years post-PhD research experience. A mentor is required for all applicants 2-4 years of post-PhD research experience. If the application is submitted as a group and neither the lead applicant nor the co-applicants have 4 years of post-PhD research experience, then a mentor is required.

Mentor:

You must add your Mentor to the application. Your mentor will have to confirm participation in the application and also approve the application after you submit it and before it is finally submitted to the Society.

To add your Mentor you can search for them by entering their surname. If the Mentor has already created an account then they will appear on the list. To add them as your Mentor click

'Select'. Please note that on saving, the contact will be added to the Application as a Mentor and they will receive a notification of this via email.

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

Declaration of Support – Mentor:

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

c) Applicant Curriculum Vitae

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

d) Co-applicant roles and research team

More than one applicant may be listed on each application. This may be in the form of a) co-applicants, or b) where a junior applicant (2-4 years post-doctoral experience) requires a mentor. Co-applicants must confirm participation in the application. A mentor is a signatory who is required to approve the application after you have submitted it, before it is finally submitted to the Society for review.

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

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

Co-applicants: If there are co-applicants please explain their roles in the plan delivery (maximum of 10 co-applicants).

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

e) Research Programme

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

Basis for research: Please clearly state the relevant background information for this research proposal **(400 words max)**.

Hypothesis, aims and objectives: Please outline the hypothesis and the aims of your research proposal and how these correspond to the purpose of this project grant outlined in section 1.2. In this section you need to set out a series of strategic and logical objectives that you hope to achieve in the 12 months of the project. The objectives should be precise and concise statements, with a projected date for completion. In some cases, you can enter alternatives in case a pitfall arises **(250 words max)**.

Methods of Research: Please describe and justify the methods, procedures, and experimental design you will use to conduct your research **(100 words max).**

For quantitative research, please provide statistical analysis for each part of your experimental plan; power calculations, numbers of samples, number of matched controls, and strategy of different controls to be used should all be discussed. Additionally, please discuss the feasibility of obtaining/accessing sufficient numbers of patient participants and controls that will result in statistically meaningful results.

For qualitative research, please describe the planned sample size and rationale, data collection methodologies (e.g., interviews, focus groups, and transcription procedures), analytic framework(s), and sources of bias. Additionally, please discuss the methodology and feasibility of recruiting the planned sample size.

Ethical Considerations and Data Protection: Please describe relevant ethical considerations of your proposal. Where appropriate, describe informed consent procedures, with consideration of anonymisation **(400 words max)**.

In addition, applicants should ensure to follow data protection legislation in all respects including the General Data Protection Regulations (GDPR) which came into effect on the 25th May 2018, and any other relevant legislation.

Summary and conclusions: Please outline the summary and conclusions of your research proposal **(300 words max)**.

Gantt Chart: **You must upload a Gantt chart (PDF format) for the proposed research study**. All uploads must be in PDF format. Please ensure that figures are legible when uploading.

Illegible figures may be difficult for the peer review panel to assess and could detract from your application.

References: Please cite any literature referenced in the sections above.

f) Declarations of Support – Head of Department

Please upload a declaration of support letter from the head of department at your host institution. The declaration of support template is downloadable from this section on the online system. Letters of support should be written on headed paper and signed. To upload this letter of support click 'Attach', locate the file to be attached and then click 'Attach'. If your research will take place at any additional sites (e.g., public hospital), you must upload a declaration of support from a relevant person within this organisation.

g) Budget

A full detailed breakdown of costs and justification for all costs must be provided in your application. Final approval of all budgeted costs is at the discretion of the Irish Cancer Society. Please refer to Appendix 3: Irish Cancer Society Research Budget & Expenses Policy when completing your budget.

Funds may be requested for the following:

i. Salary costs	All salary costs and staff should be detailed and justified, with costs calculated using the appropriate HSE or IUA scales and inclusive of employer PRSI and appropriate pension contributions. HSE: https://www.hse.ie/eng/staff/benefitsservices/pay IUA:https://www.iua.ie/research-innovation/researcher-salary-scales/
ii. Consumables	Please allow sufficient budget for all materials and consumables required to carry out your research proposal.
iii. Travel and dissemination costs	Please detail the dissemination costs for the research study e.g. printing, posters, publication costs, and public awareness lectures. Please also detail costs associated with the lead applicants or research staff attending academic meetings and conferences e.g., registration fees, travel, accommodation.
iv. PPI costs	Please describe costs associated with your PPI (Public and Patient Involvement) plan. PPI is optional due to the nature of this award, however, PPI is desired.

	Guidelines on PPI and budgeting for PPI can be found in Appendix 2.

h) Public and Patient Involvement

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

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

Please note that patient reviewers will appraise these sections **and it is very important that these sections are written in plain English and are understandable to a non-scientific audience.**

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.
Public and Patient Involvement Plan:	The public and 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. When completing this section, please carefully consider the following questions: (**300 words max**) — 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.

	— What is the overall goal of involving patients?
	— 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.
	— What PPI infrastructure is available within your institution and how will it be utilised?
	— What supports will be in place for patients involved (should they be needed)?
	— Please identify any challenges that might arise from involving patients in your research, and how any issues will be prevented.
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.
	Please address two areas in this section.
	-How you will share your research with the public and people affected by cancer (**500 words max**).
	- In addition to the brief mid-way report and the detailed end of study technical report, please describe the likely output from your proposal (e.g., peer-reviewed articles, policy documents) and the impact such output is likely to have **(300 words max)**.

i) 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.

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5. Assessment Procedure

5.1. Submission of the Application

Once it has been verified that all required questions are answered in the correct manner on the application then the application can be submitted.

You can verify that all required sections are complete on the Validation page of the application form. Once validated, please click "Save and Close" and then click on the "Submit" button in the right-hand side of the Application Summary page.

Incomplete and ineligible applications and those submitted after the deadline will not proceed to peer review.

5.2. Assessment overview

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

	PPI Reviewer	Scientific Reviewer

Application form sections	• Public and Patient Involvement:
	   o Project Summary
	   o Public and Patient Involvement (PPI) Plan
	   o Sharing of Research Findings
	• Budget*
	• Overall comment
		• Mentor
		• Applicant Curriculum Vitae
		• Co-applicant roles and research team
		• Research Programme
		• Budget*

* Both scientific and PPI reviewers will be asked to provide feedback on the feasibility of the budget plan. The budget will also be reviewed by the Irish Cancer Society to ensure that it is feasible and that all maximum limits have been adhered to. Final approval of all budgeted costs is at the discretion of the Irish Cancer Society.

5.3. Assessment procedure

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

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

Please note, the scientific reviewers will not be assessing any of the PPI review sections, and vice versa. However, the PPI panel will be providing comments to the panel on **the overall project proposal.** Therefore, it is recommended that all sections are accessible as possible. It is vital that the sections appraised by patient representatives are written in accessible plain English. Failure to do this may result in the patient representatives not being able to accurately give feedback on these sections of your application. The score and comments will be utilised when making the final decision.

Applications will be assessed based on their likelihood to deliver meaningful results that adequately answer the required research questions outlined in Sections 1.2, 2.2 and appendix 1.

Specifically, applications will be assessed using the following criteria:

- How the proposal meets the aims and objectives of the research

- Understanding of the context and purpose of the research

- Value for money

- Ability to engage with the target audience within the timescales specified

- Experience of the team and resources available

The final funding decision is at the discretion of the Irish Cancer Society.

5.3. Assessment outcome

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

5.4. Conflicts of Interest

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

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6. Application Checklist

Completed application form submitted online including the upload of:

- Applicant CV

- Gantt Chart

- Declaration of Support – Mentor (if required)

- Declaration of Support - Head of Department/School

The following must be completed **ONLINE at https://grants.cancer.ie by 3pm, Monday 9th October 2023**.

7. Contact

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

Email: grants@irishcancer.ie

References:

[i] Health Service Executive. 2022a. "Early diagnosis key step in improving cancer survival." Available here: hse.ie/eng/about/our-health-service/making-it-better/early-diagnosis-key-step-in-improving-cancer-survival.html

[ii] Hanna, T. P., King, W. D., Thibodeau, S., Paulin, G. A., Harvey-Jones, E., O'Sullivan, D. E., Booth, C. M., Sullivan, R., & Aggarwal, A. 2020. "Mortality due to cancer treatment delay: systematic review and meta-analysis." BMJ. 2020;371

[iii] McConnell, D. 2022. "Taoiseach warns of 'frightening' wave of delayed cancer diagnoses next year." 31 October. Irish Examiner. Available: irishexaminer.com/news/arid-40995386.html

[iv] https://www.ncri.ie/sites/ncri/files/pubs/NCRI_COVIDImpactIncidence2021_Report2023.pdf

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Appendix 1: Key Research Questions and Deliverables

Key research questions

Researchers should respond to the research questions specifically in relation to the following groups of people:

- People aged 65+.
- People living with a physical disability.
- People living with an intellectual disability.

The Irish Cancer Society is interested in learning about the experiences of people who have been diagnosed with cancer, as well as the perspectives of healthcare providers. We would like for these experiences to be analysed in the context of the current set-up and performance of services available in Ireland, and against current knowledge of the importance of early detection. Researchers should also consider good/best practice examples of timely access to diagnostics and mechanisms for raising awareness amongst the general population. Responses to the research objectives should refer to the diversity amongst the public and patients, survivors and their families, e.g. by cancer types, age at diagnosis, gender, whether a person has a disability or requires specific accommodations when seeking access to healthcare, as well as other factors. The successful applicant should conduct research to respond to the following questions.

General

- What is the current context in terms of incidence, stage at diagnosis, survival, etc.?
- What are the benefits of early diagnosis?
- What are the financial, health and social, etc. costs associated with late and with early diagnosis?

- What are the financial, health and social, etc. benefits associated with timely access to diagnostics?
- What is the current performance against waiting list times and National Cancer Strategy key performance indicators which support early detection of cancer?

Public Perceptions

- What are the main barriers and enablers (e.g. service-level, personal, circumstantial, etc.) reported by the specified-groups or their carers (who may or may not be affected by cancer) associated with accessing diagnostic services?
    - How were these barriers overcome?
    - Are any of the enablers transferrable and sustainable?
- What do the public believe is needed to overcome identified barriers?
- Do people in the specified-groups, or their carers, feel they have enough information on signs and symptoms of cancer to know when to seek medical attention? Did people diagnosed with cancer in the specified-groups, or their carers, feel they had enough information on signs and symptoms of cancer to seek medical attention? What is the initial point of contact for health concerns or to access health information? E.g. community resources, pharmacist, internet, GP, Irish Cancer Society information, etc.
- How many times have people with a subsequent cancer diagnosis in the specified-groups had to attend a GP before getting a referral to cancer diagnostics?
- Diversity of impact: Which groups are particularly affected by lack of timely access to diagnostics services (e.g. by socio-economic group, type of cancer, age, disability, need for specific accommodations, gender, household composition, county/region, etc.)? Such impact can include emotional, financial, social, etc.

System level – healthcare practitioners and allied health professionals
Healthcare practitioners and allied health professionals include a range of roles for the purposes of this study, including but not limited to, GPs, nurses, non-consultant hospital doctors, consultant doctors, advanced nurse practitioners, radiologists (diagnostic imaging professionals), dentists, etc.

- What are the barriers and enablers to access to diagnostics in general and in particular for the specified-groups as reported by general practitioners and other healthcare practitioners?
    - How can the reported barriers be overcome?
    - How can the reported enablers be replicated and sustained?
    - What are the emotional, financial, social, etc. impacts of such barriers on healthcare professionals and allied health professionals?
- What works well in terms of a) identifying the need for diagnostics, b) ensuring access to diagnostic services for patients?
- What does not work well in terms of a) identifying the need for diagnostics, b) ensuring access to diagnostic services for patients?

The research should consider what is already known about early detection, perceptions and attitudes towards access to healthcare services, health service data, etc., and further build upon existing knowledge. The successful research team should consider that the Irish Cancer Society would like to take a solutions-focused approach towards addressing the findings from the research to use in our advocacy and other work to support the specified-groups on their cancer journey.

Solutions

- What are the solutions (based on existing or potential solutions) in ensuring greater access to timely diagnostics for the specified-groups?
- What practices exist in Ireland or elsewhere which are conducive to early/timely detection amongst the specified-groups, e.g. focusing on initiatives for the public and/or innovations or initiatives implemented within healthcare services?
- What supports are required (at community level, primary care level, hospital level, regional level, etc.) to enhance and improve access to health services, and by extension access to timely diagnostics, for the specified-groups?

Lessons learned

- To support Irish Cancer Society cancer information, cancer awareness and advocacy activities, we would like to further our understanding of public needs in terms of timely access to diagnostics for the specified-groups. For example, are there areas where people need additional information before seeing a GP?
- To support Irish Cancer Society advocacy activities, what do the specified-groups, their carers, and health care practitioners feel can be changed and how?

Deliverables and project activities

Phase	Description	Type	Timeline
Inception	A kick off meeting to discuss the project, timeline, methods, data sources, and subsequent report priorities.	Activity	TBC
	Inception report outlining final methodological approach, updated work plan (and timeline) and deliverables against which the project will be managed, etc., including an annex with a research and analysis framework	Deliverable 1	TBC
Continuous communication	Fortnightly phone calls with the Society on project progress and contract deliverables	Activity	TBC

Implementation	Implementation of research activities	Activity	TBC
Reporting	Mid-point meeting including presentation of findings to date, and discussion of work conducted to date, as well as how the work will be finalised	Deliverable 2	TBC
	End of research meeting including presentation of findings, and discussion of reporting structure	Deliverable 3a	TBC
	Draft report	Deliverable 3b	TBC
	Final report	Deliverable 3c	TBC

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

Appendix 2: 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[1]. 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[1].

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 patients[3]
- Enhance patient trust in researchers[3]
- Improve researchers' insight into their own research area[3]
- Help researchers identify barriers and come up with solutions to research[3]
- Increase trust and acceptability in the patient community of research findings[3]
- Inform the provision, access, and location of healthcare services[4]
- Improve the dialogue between healthcare professionals and patients[4]

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

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

4. PPI is a partnership

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

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

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

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

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

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

5. PPI and the funding process

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

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

6. PPI Sections in the Application

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

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

6.1. Project Summary

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

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

Remember, your audience, who will be people affected by cancer, **may not** have a scientific background. Therefore, ensure the project summary is written in plain English (please see Section 6). However, an important consideration when writing the project summary is to determine the right balance between pitching it to the correct lay audience and oversimplifying it too much. As such, the summary should be written in clear plain English, but also adequately conveys the details on the research question, research plan and what makes that particular research project important. The abstract may still have some "jargon" or scientific names when necessary, once they are clearly defined in understandable terms.

6.2. Patient involvement plan

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

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

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

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

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

Information on types of involvement:

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

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

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

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 [7], which researchers may find useful when considering potential challenges and how to address them.
- In some instances, patients may need additional support (emotional), it is a good idea to identify supports that could be offered to patients should they need it.
- Patients may also need practical supports to be involved. For example, not all patients will have easy access to a computer. Offer to post printed copies of information and allow for additional time for people to read information and paperwork. Some people may need to use the phone as opposed to a computer to join meetings. These practical needs should be assessed at the start.

Additional things to consider-

- A number of universities within the Republic of Ireland already have dedicated individuals, infrastructure, training, or programmes in place dedicated to PPI. We strongly recommend that you engage with these local resources when planning how patient involvement will be integrated into your project.

- Engagement can sometimes be mistaken for involvement (more information on both in section 2). While engagement activities are important and can often lead to involvement opportunities, it is predominantly involvement that should be outlined in this section - *Involvement is conducted 'with' or 'by' people affected by cancer.*

- For translational biomedical laboratory based research it can be difficult to initially envision the practicalities of how patients can be involved in a research project in a meaningful way. However, there are a lot of valuable opportunities to involve patients in this type of research. Further guidance on PPI in lab-based research can be found here- https://sites.google.com/parkinsons.org.uk/ppi-in-lab-based-research/home

6.3. Sharing of research findings

The Irish Cancer Society is the largest voluntary funder of cancer research in Ireland. Research is conducted primarily for the benefit of patients, therefore, a key priority of the Irish Cancer Society is to ensure that the public (including people affected by cancer) are kept up to date on research that is funded by the Society. In line with this, it is a requirement that all applicants produce a sharing of research findings plan to include communication of their research to **all** relevant audiences including the public and patients. As part of this section of the grant application, researchers are encouraged to carefully consider the different stakeholders that may be interested in their research, and develop a plan for communicating which each of these stakeholder groups.

It is important to note that while peer-reviewed journals are an important means of communicating research findings to academic researchers, members of the public are less likely to access academic journals.

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

- Peer-reviewed journals (open-access is encouraged).
- Dissemination at conferences and meetings
- Non-peer reviewed professional periodicals e.g., The Irish Psychologist, World of Irish Nursing;
- Public engagement talks or events e.g., Irish Cancer Society 'Decoding Cancer', Pint of Science, Science Week events, public university talks, etc.
- Newspapers/media e.g., The Irish Times, 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 Institute for Health Research, Budgeting for Involvement (2013)	

An online calculator is available on the NIHR Involve website: https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/ . Please note the online calculator is in pound sterling (£), euro conversion rates will apply. **The online calculator is a guiding tool, all costs must be appropriate to costing in the Republic of Ireland and all researchers must verify the costs associated with their PPI plan**.

Costings from all categories of the online calculator will be eligible (see below). However, please note that final approval of all costs is at the discretion of the Irish Cancer Society.

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

PPI budgeting costs:

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)				€ 900

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

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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)				€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.

<u>Here are some general notes on how to write in plain English:</u>

- 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.

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9. Additional Resources

General resources

- INVOLVE – UK National Institute of Health Research (NIHR) initiative to support PPI. *http://www.invo.org.uk*
- National Standards for Public Involvement.

https://www.invo.org.uk/posttypepublication/national-standards-for-public-involvement/

- NALA (National Adult Literacy Agency)

https://www.nala.ie

- Access to Understanding: Promoting public understanding of biomedical and health research

http://www.access2understanding.org

- Versus Arthritis: Patient & Public Involvement, A researcher's guide

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

Writing a Lay Summary

- Duke, M. (2012). How to write a lay summary.

http://www.dcc.ac.uk/sites/default/files/documents/publications/HowToLaySummariesDec2012.pdf

Communicating to patients

- NHS England. Language Matters: Language and Diabetes.

https://www.england.nhs.uk/wp-content/uploads/2018/06/language-matters.pdf

Writing in plain English

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

Budgeting for PPI

- INVOLVE PPI Involvement Cost Calculator

https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/

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5) Thompson, J., Bissell, P., Cooper, C. L., Armitage, C. J., & Barber, R. (2014). Exploring the impact of patient and public involvement in a cancer research setting. Qualitative Health Research, 24(1), 46-54.

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6) Froggatt, K., Preston, N., Turner, M., & Kerr, C. (2014). Patient and public involvement in research and the Cancer Experiences Collaborative: benefits and challenges. BMJ Supportive & P Care, 5, 518–521.

7) MacCarthy, J., Guerin, S., Wilson., A and Dorris, E. (2019). Facilitating public and patient involvement in basic and preclinical health research. PLoS One, 12(5).

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Appendix 3:

Irish Cancer Society Research Budget & Expenses Policy

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1. Introduction

The Irish Cancer Society is the largest voluntary funder of cancer research in Ireland. The majority of the Society's funds are raised from public donations and we are therefore committed to ensuring that all funds are budgeted for and used sensibly in line with donor's expectations and the scientific goals of the work. This policy describes the Society's requirements for drafting budgets as part of the research grant submission process, as well as our expenses policy for research grant expenditure. This document should be consulted when completing Irish Cancer Society grant applications or grant variations. Bearing in mind that funding from the Society comes from the enormous effort, sacrifice and generosity of the general public it should be a general principle of all budgeting to get the most value and minimise costs in every way that is reasonable and justifiable.

Please note:

- These guiding principles are not an automatic approval for the use of funds from any grant. The Society reserves the right to review expenditure for reasonableness at any time during the research project.

- These guidelines describe the overall general budget and expenses guidelines for our awards. More specific rules may apply for some bespoke awards, and these rules will be included in the call documentation and/or contract specific for that award.

- Each research grant has a defined, agreed budget to help carry out the agreed Research Project. It is the responsibility of the research institution to ensure that all monies claimed and paid are allowable, necessary and reasonable for the conduct of the Research Project.

- The Society acknowledge that an approved budget may require modifications over the course of an award. Budget reallocations may be permitted during the lifetime of award provided they are adequately justified on an Irish Cancer Society budget reallocation form. Approval of such reallocations is at the sole discretion of the Society. Details of the budget reallocation process can be found here on the Irish Cancer Society website.

- It is expected that an internal financial governance structure will be in place to monitor and review allocation of funds for the Research Project.

- Annual and interim financial reports sought by the Society must include a detailed breakdown of costs claimed. The Society reserves the right to request independent verification of costs charged to a research grant.

- The Society reserves the right to refuse the payment of costs, which are deemed contrary to the guiding principles contained herein.

- The Society reserves the right, as often as it may reasonably require, to arrange for an audit to be conducted into the use of funds provided.

- As an Irish charity, The Irish Cancer Society will fund eligible direct costs only. The Society do not pay any overhead contribution to host universities.

This guidance document does not represent an exhaustive list and where queries arise that fall outside of the guidance herein, prior authorisation from the society should be sought by emailing grants@research.ie

2. Budgeting for Personnel Costs

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

It is expected that all applicants will budget for salary to include employers' PRSI and pension contributions in accordance with the appropriate salary scale and host institution. Where an applicant is budgeting for a part-time position, salaries should only be budgeted for the percentage full-time equivalent (FTE) that the employee will spend working on that specific research project. Please note The Irish Cancer Society may ask the employee to provide evidence (e.g. records or timesheets etc.) for specific time spent on the funded research project. For all positions, the Irish Cancer Society will allow a staff member to move up a point on the scale every 12 months. This **must** be incorporated into the original budget application.

2.1. Academic Research Staff

The Irish Cancer Society will fund the direct salaries of academic research members according to the IUA Researcher Salary Scale. The scale, point, and full salary (including employer's PRSI and pension contribution) must be included within all salary budgets. Therefore, it is recommended that applicants use the 'RESEARCHER SALARY SCALES AND EMPLOYMENT COSTS' attachment on the IUA scale website.

The IUA scales are continually updated, therefore, it is important to utilise the most up to date scale according to the time period in which the anticipated staff member is due to commence employment. The IUA scales are continually changing, therefore if the IUA scale does not cover the funding period in question, a salary contingency of 2.5% per annum should be applied.

2.1.1. Research Assistant

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

2.1.2. Postdoctoral Researcher

The Irish Cancer Society will fund the salary of a postdoctoral researcher starting at the minimum point of PD1, Point 1 of the IUA Scale (early stage post-doctoral researcher). It would be expected at this level that the postdoctoral fellow would hold a minimum of PhD or equivalent* research experience. For higher points on the scale, the individual would be expected to hold the required number of years (depending on the point) postdoctoral and/or industry experience. For PD2 of the IUA scale, it would be expected that the postdoctoral researcher has significant post-doctoral research experience, this would need to be thoroughly justified in grant applications.

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

2.1.3. Research Fellow

The Irish Cancer Society will only fund the salary of a research fellow if it is expressly stated in the call guidance document and pre-approved by the Society prior to application submission. A research fellow will be required to hold at least 4-6 years post-doctoral and/or industrial research experience and must have a significant track record of high-quality peer reviewed publication and/ or other equivalent outputs based on the norms of their discipline. In addition, it will be expected that the research fellow has previously obtained independent competitive peer-reviewed research grants, and is capable of leading and managing independent research projects. Research fellows should be appointed at point 1 of the research fellow IUA scale, and a strong justification will be required to appoint at other points on the scale.

For larger programmatic award, the salary of senior research fellows may be permitted if it is robustly justified, and only if it is expressly stated in the call guidance document. Such individuals must have a central role in leading a significant portion of the funded research

programme and must not already be in receipt of a full-time permanent position within the host institution. Senior research fellows should be appointed at point 1 of the senior research fellow IUA scale.

2.1.4. Postgraduate Student

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

Fees: The Irish Cancer Society will make a contribution of up to €8,500 towards the annual costs of EU or non-EU postgraduate registration fees for up to four years. Some host institutions provide a reduction of fees in the latter years of the postgraduate degree (e.g. a 50% reduction in year 4 of a PhD) and this should be taken into account when calculating the total registration fees over the four years. The Society is not in a position to fully fund the full registration fees of non-EU applicants. In this instance, it would be the responsibility of the host institution to cover the remaining fee shortfall.

2.2. Nursing and Allied Health Professionals

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

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

2.3. Research Support Staff

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

3. Budgeting Non-Personnel Costs

3.1. Research Running Costs

These are all the day-to-day costs associated with the running of the research project. The Irish Cancer Society will allow the payment of reasonable running costs relevant to the specific project. Such costs may include but are not limited to: materials and consumables, research sample costs, access costs, survey costs, costs associated with research participants, transcription costs, data management costs, bench fees etc. Please note, any travel-based costs specifically associated with the running of the research project e.g. travel costs associated with research participants should be outlined in this section and not in the travel and dissemination section. All costs must be inclusive of VAT, where applicable. All running costs should be itemised within the application budget section and suitably justified.

3.1.1. Small Equipment items

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

3.1.2. Computer/Laptop Equipment

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

3.1.3. Mobile Phone Budget

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

Please refer to Section 4.6 for further detail on allowable expenditure for mobile phone use.

3.2. Training and Education Budget

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

For some awards, the Irish Cancer Society will cover the cost of further education to allow researchers funded by the Society to pursue formal education opportunities as part of their grant programme e.g. taught post-graduate diploma or masters programmes etc. Provision for these opportunities will be outlined in the specific call document if relevant.

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

3.3. Travel and Dissemination Budget

3.3.1. Travel

These are the costs relating to the travel of the grant applicant and/or other Irish Cancer Society funded team members for dissemination and networking purposes. Such costs must be directly related to events as part of the research programme and only funded researchers will be eligible to claim these expenses. Any travel costs that are part of the direct day-to-day running of the research programme e.g. travel costs associated with research participants should be budgeted under running costs (Section 3.1). As a charitable organisation, we would expect that all costs in relation to travel be reasonable, and must be clearly justified. Please note that the Irish Cancer Society will fund Economy-Class flights only. Please refer to Section 4.1 for further detail on permitted costs.

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

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

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

3.3.2. Dissemination

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

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

3.3.3. Open Access Publication:

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

3.4. PPI Budget

The Irish Cancer Society is dedicated to putting patients, families, survivors, supporters, and the public at the very heart of what we do. Public and Patient Involvement (PPI) in the research process ensures that research is meaningful and of benefit to those affected by cancer and other relevant stakeholders. PPI can be involved at any stage of a research project, from development and design to interpretation and dissemination.

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

A mandatory minimum provision for specifically costing PPI activities into grant applications is included in the majority of Irish Cancer Society funding calls, and will be outlined in the

specific call documentation. At the very minimum it is expected that that all costs to patient members associated with involvement are covered by the research grant e.g. bus/train fares, mileage, parking charges, and subsistence. These costs should be outlined as part of the PPI section of your grant application. Universities will have their own specific rules and policies regarding budgeting and expenditure in relation to PPI costs. We therefore strongly encourage all researchers to consult with their host university and local PPI resource (e.g. PPI Ignite) when completing the PPI section of their application budget.

3.5. Mobility and Capacity Building Element Budget

As part of our scholarship and fellowship research awards, applicants are given the opportunity to request either A) a mobility initiative for travel to a national or international research institution in furtherance of advancement of their research project aims, or B) a 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. The specific details, amount and duration of funding for this element will be outlined in the specific grant call documentation.

Details of the mobility and capacity building element funding is requested at the application stage and the main standard budget grant categories should be used in developing a mobility and capacity building element. However, please note that this funding is separate to the funding amount requested as part of the main application. In recognition that mobility plans can often change through-out the course of the research project, all successful applicants must reapply for this funding closer to the period of travel (at least three months in advance of the initiative commencement). Applicants therefore have the opportunity to change the details of the mobility element during the research award. However, final approval of all changes is at the discretion of the Irish Cancer Society. For further details on allowable costs as part of the Mobility and Capacity Building Element, please refer to Section 4.7.

Post-award applications for the mobility and capacity building element can be made through the online grant management system: http://grants.cancer.ie.

4. Research Grant Expenses

The Irish Cancer Society are committed to ensuring that all funds included within budget are used sensibly and appropriately. Reasonable travel, accommodation, subsistence, and other expenses incurred by a researcher in the execution of activities directly related to the research project will be reimbursed.

Reasonable expenses are defined as those that are cost effective weighed against the purpose of the activity. Researchers should be sensitive to what is perceived as reasonable at all times.

It is not possible to set out rules for every situation and so you are required to exercise judgment to ensure that all claims made are within the spirit of the guidelines.

Please note, an awardee will be required to submit a detailed statement of income and expenditure as part of their annual report process. As part of this reporting, the Irish Cancer Society may request copies of the original receipts associated with any travel on their grant. Failure to supply a receipt or any underspend on any travel bursaries must be reimbursed in full to the Society

If there is any uncertainty as to whether something is reasonable or not, then a query should be addressed to the Society by emailing grants@irishcancer.ie in advance of incurring such expenditure.

4.1 Travel Expenses

- Travel should be by the most economical means and the Society expressly encourages that public transport be used whenever possible, when this is the cheapest option. Tickets for public transport should be booked in advance where possible and should be standard class or economy class only.

- Taxis may be used but are the least preferred method of transport. Taxis should be shared where possible and incur no additional fees i.e. waiting time charges or tips.

- In situations where conferences/meetings in Ireland are not accessible by means of public transport, researchers may use their own vehicle to travel to and from the conference/meeting. A standard motor travel rate of **€0.35 cent per kilometre** is permitted in instances where this is necessary. Higher mileage rates permitted by the research institution will not be covered by the Society. The motor travel rate paid is deemed to cover all expenses incurred in running the car e.g. insurance, tax, running costs, etc.

4.2. Accommodation Expenses

- The cost of accommodation should be reasonable and in line with the duration of the event.

- For travel to conferences/meetings, researchers must endeavour to book accommodation not exceeding a 4-star rating.

- For accommodation in Ireland, **a rate not exceeding €140 per night** (B&B; standard room) should be sought.

- For international accommodation, rates will vary depending on the city and country; therefore, it is difficult to give a guiding rate. However, accommodation rates that are reasonable and in line with the average daily hotel rate for the specific location should be sought.

- Accommodation costs for travelling partners will not be covered.

- In situations where a research institution has agreed a discounted rate for accommodation, which exceeds a 4-star rating, prior approval must be sought from the Society in order to proceed with any booking.

- Facilities and services which are not provided free of charge by the hotel are not permitted (e.g. Wi-Fi costs, room service, newspapers, etc.).

4.3. Subsistence

- All subsistence expenses must be vouched expenses. The Irish Cancer Society does not permit any researchers to claim standard subsistence rates that may be outlined by their individual research institutions.

- Breakfast, lunch, and dinner costs to a value of €10, €12, and €25 per person respectively would be deemed reasonable.

- An added tip or discretionary service charge of up to 15% on bills is deemed reasonable in countries where such charges are expected and are standard practice.

4.4. Costs Associated with Meetings and Events

In furthering the research interests of the Society, researchers on Irish Cancer Society-funded grants may occasionally host meetings or events between researchers, members of the public, patients and/or scientific advisory groups.

- Expenditure for events such as these should be kept as low as possible, compatible with the occasion.

- Where possible, room hire for any events should ideally be in locations that are free of charge. However, the Society do acknowledge that depending on the type of event and location that this is not always possible.

- For bookings associated with national or international guest speakers, the travel and accommodation rates set out in Section 4.1 and 4.2 of this policy must be adhered to.

- The number of hosts accompanying a guest for lunch or dinner should be dependent on a necessary requirement to attend and should not be perceived as a reward for attendees.

- Lunch and dinner costs to a value of €12 and €25 per person respectively would be deemed reasonable. This includes the costs associated with the provision of catering for events.

- An added tip or discretionary service charge of up to 15% on bills is deemed reasonable in countries where such charges are expected and are standard practice.

- For events that utilise internal and external suppliers, it is expected that the most economical supplier be utilised.

4.5. Alcohol and Entertainment

It is the Irish Cancer Society's policy not to fund alcohol for any events or meals or any form of entertainment.

4.6. Mobile Phone Expenses

The Irish Cancer Society do not generally permit the use of funds to cover the cost of a mobile phone or mobile phone bill. However, we do recognise that in certain circumstances exceptions may apply. In this case, mobile phone expenses must be robustly justified and pre-approved by the Society at the post-award budget negotiation stage prior to contract signing.

The researcher must use the most economical and cost-effective means for purchasing a phone and bill-pay call plan. The Society will cover mobile phone bill costs associated specifically with the funded research project up to a maximum of €40 per month only. No expenditure outside of the researcher's standard call plan allowance will be permitted to be charged to the Irish Cancer Society Research Grant. Please note, mobile phones can only be used for specific research purposes only and expenditure will be carefully scrutinised upon submission of the annual financial reports. It is at the discretion of the Society to request copies of all mobile phone bills and justification of call.

4.7. Mobility Element & Capacity Building Expenses

Allowable expenses associated with the mobility and capacity building element include travel, networking or workshop registration fees, accommodation, and running costs associated with the mobility or capacity building elements. Payments will only be made by the Irish Cancer Society upon approval of a successful mobility and capacity building element application.

Please provide a summary of the costs requested and justification of each amount requested.

For costs associated with travel, quotes detailing the estimated average cost for travel and accommodation must be attached the mobility application. Eligible travel costs are those that involve return travel from your location of origin to your mobility or capacity building element destination only. Local travel required day-to-day to get to your place of work will not be covered i.e. public transport, mileage, parking charges, tolls etc.

All researchers are advised to be as economical as possible when making accommodation arrangements as part of the mobility and capacity building element award. Hotel bookings can often be much more expensive when booked for long durations of time, therefore, this may mean booking Airbnb or other self-catering accommodation for your stay.

During the mobility and capacity building element period, all researchers will continue to receive their standard monthly salary from their research institution. It is therefore the policy of the Irish Cancer Society that the researcher uses their own salaries to cover subsistence costs such as food. Costs for subsistence will only be allowed under exceptional circumstances and to a maximum value of €200 per month.