Irish Cancer Society
Research

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

Table of Contents

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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.

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.

Here are some general notes on how to write in plain English:

- People affected by cancer are not scientists (usually) and knowledge should not be assumed. Avoid using technical language or scientific terminology. Use everyday words to communicate your point and explain the science.
- While language should be understandable, it should not be dumbed down - It may be necessary to use scientific words and jargon in order to convey why your research is special, but be sure to explain it thoroughly and be consistent in its use.
- Use short clear sentences.
- Use paragraphs
- Make sure grammar, punctuation, and spelling are accurate.
- Bullet points (like these ones) can make it easy to digest a lot of information

8. Contact

If you have any questions relating to PPI please contact grants@irishcancer.ie.

9. Additional Resources

General resources

- INVOLVE – UK National Institute of Health Research (NIHR) initiative to support PPI. *http://www.invo.org.uk*
- National Standards for Public Involvement. https://www.invo.org.uk/posttypepublication/national-standards-for-public-involvement/
- NALA (National Adult Literacy Agency) *https://www.nala.ie*
- Access to Understanding: Promoting public understanding of biomedical and health research *http://www.access2understanding.org*
- Versus Arthritis: Patient & Public Involvement, A researcher's guide *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/*

10. References

1) INVOLVE. (2018). *What is public involvement in research*? Retrieved from http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2 /. Accessed 07/01/21.
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4) Mockford, C., Staniszewska, S., Griffiths, F., & Herron-Marx, S. (2011). The impact of patient and public involvement on UK NHS health care: a systematic review. *International Journal for Quality in Health Care, 24*(1), 28-38.
5) Thompson, J., Bissell, P., Cooper, C. L., Armitage, C. J., & Barber, R. (2014). Exploring the impact of patient and public involvement in a cancer research setting. Qualitative Health Research, 24(1), 46-54.
6) Froggatt, K., Preston, N., Turner, M., & Kerr, C. (2014). Patient and public involvement in research and the Cancer Experiences Collaborative: benefits and challenges. BMJ Supportive & P Care, 5, 518–521.
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).