



# Irish Cancer Society Research

## Appendix 3: Public and Patient Partnership (PPP) 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 Partnership (PPP) in our research processes. The majority of Irish Cancer Society grant calls will require researchers to detail their plans for including PPP in their proposed research. These partnership sections will be reviewed by people affected by cancer (PPP reviewers).

This document is intended as an additional resource on PPP 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 Partnership in research?

Interaction with the public and people affected by cancer can be contextualised in the many different ways people with cancer can interact with research, specifically by means of participation, engagement, and partnership 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.

## Partnership

Partnership, often referred to as Public and Patient Involvement (PPI), is distinct from participation or engagement. Where participation and engagement are conducted 'to', 'about', and 'for' people with cancer, partnership is conducted 'with' or 'by' people with cancer<sup>1</sup>. People with cancer can be involved at any stage of the research process, from conceptualisation to dissemination.

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

## 3. Why is PPP important?

PPP is becoming increasingly important in research. The Irish Cancer Society is committed to expanding the partnership with 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 (2017-2025)<sup>2</sup>, which highlighted:

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

PPP 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, PPP can:

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

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

As such, PPP can be a valuable tool in the research process for both people affected by cancer and researchers, and the Irish Cancer Society aims to continually to build on its PPP work.

#### **4. PPP is a partnership**

PPP 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 PPP.

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 PPP.

Be clear from the outset what will be required from all involved in the partnership activities. A good exercise to do is to complete a role description for PPP contributor along with a description of what your role (the researcher) is with regards to PPP. 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 fundamental for successful PPP. Having an open and respectful relationship is key to successful PPP. It is a good idea to keep in mind this relationship aspect of PPP when designing the PPP plans. A number of different factors are important for a good relationship between the PPP contributor(s) and the researcher(s), examples of these are listed below.

- A good communication, including keeping in touch as needed.
- Showing respect, empathy and understanding.
- Having time for each other and the PPP activities.

#### **5. PPP and the funding process**

Most Irish Cancer Society application forms contain sections relating to PPP. These sections will be reviewed by PPP reviewers and in most instances PP reviewers will contribute to funding decisions along with scientific reviewers. As such, the review of applications is undertaken by scientific and PPP 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.

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

## 6. PPP Sections in the Application

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

These sections will be reviewed by PPP reviewers. For some grant calls the PPP reviewers will score the sections and provide feedback and for other grant calls the PPP 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 PPP panel to effectively evaluate other sections, such as the PPP Plan and Sharing of Research Findings sections.

For some awards, particularly those that include human participants, the PPP 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 language (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 audience and oversimplifying it too much. As such, the summary should be written in clear plain language, 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. PPP plan

The PPP plan should detail how people affected by cancer will be partnered with in the research project. It should be well thought out and as detailed as possible. The PPP 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 PPP Contributors will be involved, how they will be recruited, what exactly they will be doing, etc.

As with any project, we acknowledge that PPP 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 PPP 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 partnership:

Partnership 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 PPP can be incorporated into research includes (but is not limited to):

- Members of an 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 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 PPP, it is important to think about what might go wrong and how you might handle any challenges that arise.
  - A PPI Ready: Researcher Planning Canvas was developed by MacCarthy et al<sup>7</sup>, which researchers may find useful when considering potential challenges and how to address them.
- In some instances, PPP Contributors may need psychological support. It is a good idea to identify supports that could be offered to PPP Contributors should they need it.
- PPP Contributors may also need practical supports to be involved. For example, not all PPP Contributors might 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 PPP

(e.g., PPI Ignite). We strongly recommend that you engage with these local resources when planning how PPP will be integrated into your project.

- Engagement can sometimes be mistaken for partnership (more information on both in Section 2). While engagement activities are important and can often lead to partnership opportunities, it is predominantly partnership that should be outlined in this section. PPP 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 PPP Contributors can be involved in a research project in a meaningful way. However, there are a lot of valuable opportunities to involve PPP Contributors in this type of research. Further guidance on PPP 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 people affected by cancer, 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 it funds. 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 webinars, 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 PPP

The cost of PPP is dependent on how you plan to embed it into your study, i.e., your PPP Plan. As such, it is difficult to prescribe guidelines on how to budget for PPP. However, at a minimum, it is expected that the out-of-pocket expenses of PPP members associated with partnership are covered by the research grant. Please note, certain calls may have set minimum budgets for PPP – please refer to call guidelines for more information.

Before beginning to budget we recommend that you check that the host institution has appropriate systems in place for the payment of PPP costs and expenses. The host institution may also have specific guidelines in place around budget costs and allowable expenses, we recommend that you check this with your institution before completing the budget.

The steps to PPP budgeting are described below:

Step	Activity
Step 1: Framework selection	Select a framework for mapping partnership 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 partnership	Make a plan of the partnership activities you intend to incorporate into your research.
Step 3: What are the costs?	For each partnership 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 partnership activity.  To work out the budget for your study, go to the online cost calculator: <a href="https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/">https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/</a> . Please note the online calculator is in Pound Sterling.
Step 5: Mapping	Map the partnership 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 PPP 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 all costs. Please note this is not an opportunity to elaborate on details of your PPP plan or sharing of research findings plan, all relevant information on these plans must be in the relevant sections.

#### **PPP budgeting costs:**

Costing Category	Related Costs
<b>Payments and rewards</b>	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
<b>Expenses</b>	Travel Subsistence Childcare Carer costs Personal assistants Overnight accommodation Home office costs
<b>Partnership activity</b>	Finding people/advertising Training and learning costs Venues and catering Equipment and books Access to university facilities Conference fees

<b>Partnership staffing</b>	Administrative support Partnership coordinator Independent facilitator Peer researchers/interviewers
<b>Other costs</b>	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

Please see the *worked costing examples* below for guidance on creating and budgeting for the PPP plan.

**Worked costing example for virtual advisory group:**

A researcher wishes to set up a PPP group to advise on dissemination of the research results and assist with writing plain language summaries for grant applications. The researcher is looking for three PPP 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
<b>Virtual Meetings</b>	Online meeting platform used by institution for example Zoom. No cost as institute pays for the licence.	1	€0	€0
<b>Advisory group honorarium</b>	Fee for attending virtual advisory group/workshops	3 x 3= 9 (3 representatives x 3 meetings)	€100	€900
<b>TOTAL COST</b>				€ 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 PPP advisory group to advise on dissemination of the research results and assist with writing plain language summaries for grant applications. The researcher is looking for three PPP Contributors 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	Unit Cost	Total
<b>Travel</b>	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)	€40	€160
<b>Advisory group payment x 2</b>	Fee for attending advisory group meetings)	3 x 3= 9 (3 representatives X 3 meetings)	€100	€900
<b>Virtual Meetings</b>	Online meeting platform used by institution for example Zoom. No costs as institute pays for licence.	1	€0	€0
<b>Venue costs</b>	University meeting room cost No cost as at host institute.	1	€0	€0
<b>Catering costs</b>	Lunch for attendees (€10 per person/per meal	3 x 2= 6 (3 representatives x 2 meetings)	€10	€60
<b>TOTAL COST</b>				€1,136

All costs were calculated using estimated costs for train tickets, hotels, and so on in the Republic of Ireland as of January 2024.

**Please note:** This budget is for specific costs associated with partnership only. If part of your PPP plan is that PPP Contributors 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 language

As outlined in Section 6 the project summary should be written in plain language. There are many online resources available to guide you in writing an effective plain language summary. Some of these resources are listed in Section 9 of this document.

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

- 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 PPP please contact [ppi@irishcancer.ie](mailto:ppi@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 Plain Language 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 Language:

- 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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- 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)