



**Irish Cancer Society**  
Research

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# **PPI in Cancer Network: Report from Kick-Off Event**

# Introduction

Public and Patient Involvement (PPI) is fast becoming a pillar of research. PPI refers to ways in which the public and patients can become involved in research, beyond acting as participants, and help to set the agenda.

PPI in cancer creates a partnership between people affected by cancer and researchers. It is more than a tokenistic gesture to comply with policy; it can provide a meaningful and substantial benefit to all stakeholders.

People affected by cancer report gaining enhanced knowledge and skills from taking part in PPI, as well as feeling they actively contributed to research by providing a different perspective (i.e., practical knowledge about being affected by cancer). PPI can be a valuable tool in the research process for both patients and researchers.

## While not without its challenges, PPI can:

- ▶ Promote a sense of empowerment and value among patients.
- ▶ Improve researchers' insights into their own research area through mutual learning with patients.
- ▶ Help researchers identify barriers and come up with impactful solutions to their research questions.
- ▶ Increase patient trust in researchers and acceptability of research findings in the patient community.
- ▶ Inform the provision, access, and location of healthcare services.
- ▶ Improve the dialogue between healthcare professionals and patients.

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.

Republic of Ireland  
National Cancer Strategy  
(2017-2026)

## This report defines PPI Contributors in cancer to include, but not be exclusive to:

- ▶ People who have had a cancer diagnosis.
- ▶ People who are living with cancer.
- ▶ People who are the significant others to those with a cancer diagnosis.
- ▶ People who are the carers to those with a cancer diagnosis.
- ▶ People who have a higher risk of developing cancer due to a genetic predisposition.
- ▶ People who have attended cancer screening programmes.
- ▶ People who have had a family member or friend with cancer.
- ▶ People who have lost someone due to cancer.
- ▶ People who have had a cancer 'scare'.

As put forward in the cancer strategies for both the Republic of Ireland and Northern Ireland, PPI is vital across the cancer research landscape.

PPI in cancer research feeds into improved service delivery. The Republic of Ireland Health Service Executive's book entitled *Better Together: The Health Services Patient Engagement Roadmap* highlights that:

"Patients have a unique perspective which makes them invaluable partners in how we design, deliver and evaluate our health services.

The involvement of patients requires us to view care from a patient perspective. Their insight is a largely untapped resource and one of the ways of harnessing this resource is through patient engagement.

Patient engagement is positively associated with improved health outcomes and improved satisfaction for patients and their families. It is essential that health services put processes in place to involve patients, their families and the public. Patient Engagement should be for every patient, every day by every member of staff".

It is paramount that we optimise the involvement of people affected by cancer in formulating and developing research proposals.

Northern Ireland  
Cancer Strategy  
(2023-2032)

## Purpose of the Event

The overarching goal of this event was to bring together everyone on the island of Ireland engaged with PPI and cancer to discuss if and how a National PPI in Cancer Network should be established. The event served as a meeting point for those who are experienced in PPI, as well as novices and those who wished to learn more.

Event details were widely circulated between stakeholders across Northern Ireland and the Republic of Ireland. These included PPI contributors affected by cancer, researchers working in the cancer field, clinicians, charities involved in funding cancer research, and research funding bodies.

By bringing together various stakeholders we sought to answer what the goals and scope of the network should be, and who should drive it forward.

### Details of the Event

The event was hosted by the Irish Cancer Society, during the PPI Ignite PPI Festival (October 2023).

An online event was held, chaired by Michael Foley of PPI Ignite (Trinity College Dublin). A brief introduction was given by Claire Kilty (Irish Cancer Society), who provided some context to the organisation of the event. Following this, the attendees were split into breakout rooms.

Each breakout room had a facilitator from various backgrounds (e.g., PPI contributor, PPI Ignite leads) and a scribe present. Groups were mixed to hold a variety of voices in each group.

Each group was asked to work through two of the following three questions:

1. What are the ultimate goals of the Network?
2. What are the expectations and limitations of the Network?
3. Who should drive it forward and how should it run?

Breakout rooms provided feedback to the wider group on the outcome of their discussions, and additional notes were captured through scribes.

Following the event, feedback forms were circulated to evaluate the event and for people to provide further input on the above three questions. The survey was also open to those who did not attend the event, to allow further voices to be heard in this process.

The survey feedback and notes from the breakout rooms have been collated and are presented in the 'Findings' section of this report.

## Findings

The outcome of the discussions have been categorised under the following headings:

- ▶ Increasing the Profile and Uptake of PPI in Cancer Research.
- ▶ Collaborating on a Centralised Resource.
- ▶ Training and Support.
- ▶ Running the Network.
- ▶ Membership of the Network.

### Increasing the Profile and Uptake of PPI in Cancer Research

The existence of one all-island network for PPI in cancer research was suggested to help build the profile of PPI in cancer in Ireland. It was noted that at present, there is no clear entity to engage with should an individual want to get involved with PPI in cancer.

The network was seen as an ideal conduit to develop a 'registry' for people affected by cancer – whereby they could sign up to be notified about PPI opportunities across the island of Ireland. It was suggested that this may act as a means of capturing voices that are not currently well represented in PPI in cancer research, closing the circle between various stakeholders

and reducing the over-reliance on individual PPI contributors.

The network was considered to be well suited to collate and disseminate evidence on the benefit and impact of incorporating meaningful PPI into cancer research or policy and service development.

As such, it was put forward that the network should have a role in advocating for and raising awareness of PPI in cancer research at national levels (in Northern Ireland and the Republic of Ireland).

### Collaborating on a Centralised Resource

Ultimately, the network should provide an all-island centralised hub where people involved in PPI and cancer – be they researchers, PPI contributors, clinicians, policy makers – can go to find best practice guidelines and advice, regardless of experience. It was posited that this would encourage PPI to be at the helm of cancer research, or policy and service development, and ensure a standardised approach to PPI.



Co-producing standard operating procedures for various aspects of PPI would streamline the PPI process. This would ensure that PPI contributors involved in cancer research would be treated the same way, regardless of the project, location, or team they were involved with. This may reduce the risk of tokenistic PPI.

Standardising of payment was discussed; however, this may be unfeasible given that various entities and institutions manage finances and reimbursing PPI differently. While standardisation may not be possible in the near future, this issue remain a priority for the network. It was highlighted that it is important that the network engages with the pre-established PPI Ignite network and aligns with European and global cancer networks also.

### Training and Support

The network was seen as having a core role in providing training and support to individuals involved in PPI in cancer research on the island of Ireland.

The provision of training should be prioritised by the network, to ensure that people involved in PPI in cancer research are knowledgeable and educated on the topic. This could be presented as online content that

is interactive, easily accessible, and specific to a cancer context. Those working in lab-based research were highlighted as a cohort with unmet educational needs in the PPI context.

Providing support for PPI contributors, policy and service developers, and researchers was noted as an area the network could feed into. This encapsulated providing mediation where needed between PPI contributors and researchers, advice, training, and an annual conference or webinars.

It was highlighted that it would not be within the scope of the network to manage or provide governance over specific research projects. Some individuals felt training was not the responsibility of the network, however, the majority of individuals did voice that the network would be ideally placed to develop new training and signpost to pre-established training options already available, such as from organisations like PPI Ignite and IPPOSI.

### Running the Network

Consensus was not reached on who should run the network.

Those affected by cancer were seen as being at the core of any network, with a few suggesting that a rotating executive with PPI contributors acting as a majority stakeholder would be a preferred format within this.

The role of chair for the executive was a discordant topic. Some individuals felt that this should be a rotating role, such that no one group, or individual could remain as chair for a long period. Others felt this role was best suited as a permanent position, held by an independent individual with experience in PPI in cancer research.

The need for regular stakeholder mapping was noted to ensure regular recruitment and representation in the network. Aligned with this, ensuring the use of accessible language was highlighted by many.

The importance of reaching across both Northern Ireland and the Republic of Ireland was emphasised.

The need for salaried positions, such as a program manager, to be available to ensure the network is set up and run efficiently was highlighted. The importance of the running of the network not becoming a part of voluntary, unpaid workload faced by many was noted. This raised the issue of where such funds would come from.

### Membership of the Network

It was widely agreed that one of the core underpinnings of the network should be to promote genuine inclusivity. This was highlighted within the remit of including those from marginalised groups, ensuring that the sexes are equally represented, incorporating the voice of people affected by cancer across all treatment modalities, cancer sites, and timelines, carers, significant others, and that there is no urban and rural divide.

It was deemed important that established PPI groups would not be subsumed but would rather join and become a part of the network. Local and cancer-site specific groups were considered important to maintain. This was reiterated as a means through which the network could increase diversity of membership, while working collaboratively alongside organisations such as Cancer Trials Ireland.

Some were unsure on how well a network could represent a multitude of stakeholders, such as researchers, academics, health care professionals, PPI contributors, and those working in policy and service delivery. There were discussions on whether the network should focus on cancer in general, or cancer research specifically.

While advocating for better and more genuine PPI was noted as a priority for the network, advocacy for other issues impacting people affected by cancer was not deemed to fall within the remit of the network.

It was strongly felt that the network should play no role in decision making on individual patient care.

Queries were also raised about how industry representatives, such as individuals working in pharmaceutical companies, who have an interest in PPI in cancer research would be managed. This was particularly relevant when considering sources of funding for running the network.

### ► Running the Network.

Recommendation that such a network requires a salaried member of staff and a rotating executive, with PPI contributors acting as a majority stakeholder.

### ► Membership of the Network.

Recommendations for an inclusive network that is representative of the diverse community of people affected by cancer across the island of Ireland.

## Conclusions

The Irish Cancer Society carried out this report to showcase the breadth of the needs of PPI in cancer on the island of Ireland. The network should focus on PPI in cancer research, which will in turn support the improvement of cancer service delivery.

There is a clear need to develop a centralised network which brings together ongoing work within PPI in cancer research, and to act as a trusted source of information pertaining to PPI.

The recommendations from this report would be best actioned by an organisation with wide-reaching scope across cancer research, taking a cross-border approach.

These findings are not unique to the cancer community, and the above recommendations may be applicable to other disease types.

## Recommendations

### ► Increasing the Profile and Uptake of PPI in Cancer Research.

Recommendations for a network that highlights PPI in cancer research and brings potential PPI contributors together.

### ► Collaborating on a Centralised Resource.

Recommendations for a network that sets the standard for PPI in cancer research across the island of Ireland.

### ► Training and Support.

Recommendations for a network that provides training and further support for anyone currently involved in, or wanting to get involved in, PPI in cancer research.

# Acknowledgements

We would like to thank everyone who took part in the event and filled out the feedback form.

Thank you to Michael Foley (PPI Ignite, TCD), who chaired the session and provided excellent feedback.

### Thank you to the facilitators of the breakout rooms:

- Simon Dunne (School of Psychology, DCU)
- Jennifer Feighan (PPI Contributor)
- Rosemary Gannon (All-Island Cancer Research Institute)
- Claire Kilty (Irish Cancer Society)
- Aidan McCormick (Northern Ireland Cancer Research Consumer Forum)
- Edel Murphy (PPI Ignite, UG/national)
- Yvonne O'Meara (School of Medicine, UCD)
- Elaine Quinn (Patient Voice in Cancer Research)
- John Wall (Cancer Advocate)

### Thank you to the breakout room scribes:

- Itunu Adebomi (Irish Cancer Society)
- Rebecca Amet (Irish Cancer Society)
- Croí Buckley (Irish Cancer Society)
- Adele Connor (School of Biology and Environmental Science, UCD)
- Natalia Ferreyra-Carroll (Irish Cancer Society)
- Claire Hughes (School of Biology and Environmental Science, UCD)

- Chloe Moore (School of Psychology, DCU)
- Deirdre Murphy (Irish Cancer Society)
- Nikolett Warner (Irish Cancer Society)

### Thank you to those who helped drafting the report:

- Rebecca Amet (Irish Cancer Society)
- Jennifer Feighan (PPI Contributor)
- Claire Kilty (Irish Cancer Society)
- Aidan McCormick (Northern Ireland Cancer Research Consumer Forum)
- Sarah McLoughlin (Cancer Trials Ireland)
- Sarah Tighe (Irish Cancer Society)
- Martin Sweeney (PPI Contributor)
- Nikolett Warner (Irish Cancer Society)



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