

Public & Patient Involvement in Research



What is PPI in Research?

What Do We Mean by PPI?

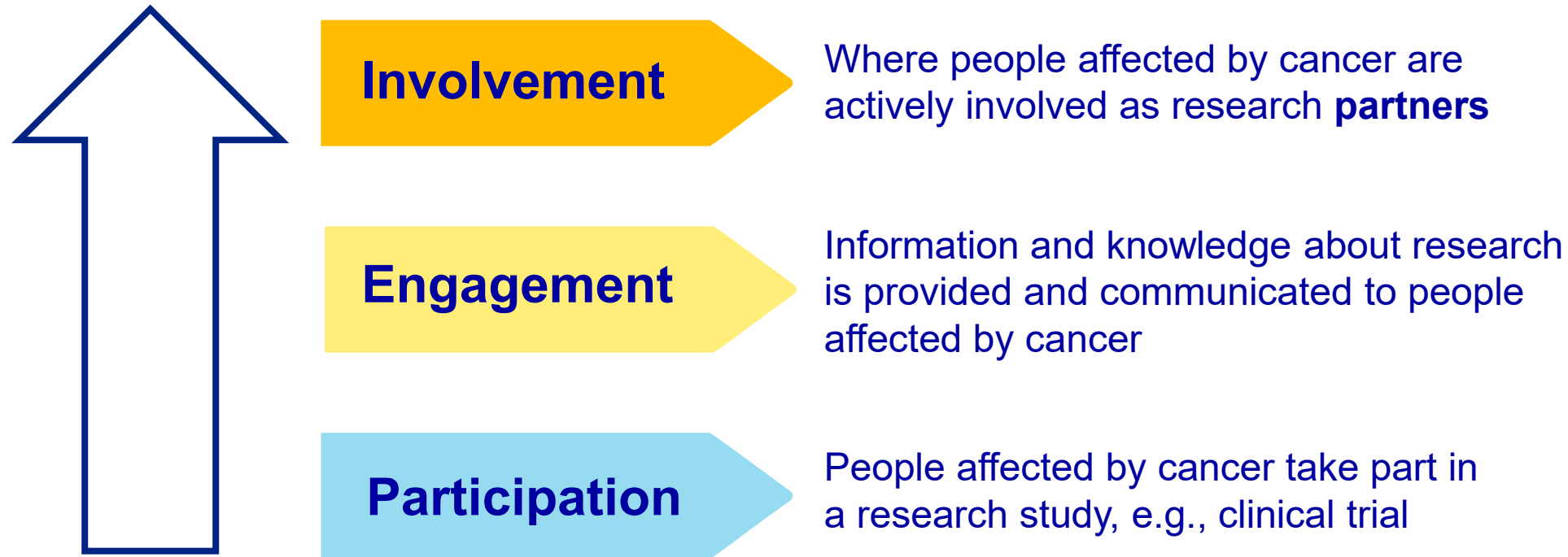
Research being carried out '**with**' or '**by**' members of the public and patients, rather than '**to**', '**about**' or '**for**' them

INVOLVE: <http://www.invo.org.uk/>



Nothing about me, without me.

What Do We Mean by PPI?



Why is PPI Important?

Quality

Relevance

Perspective

Accountability

Empowerment

PPI brings about more rapid, efficient and direct improvement for people affected by the condition they are living with



PPI in research

How and Where to Embed PPI?



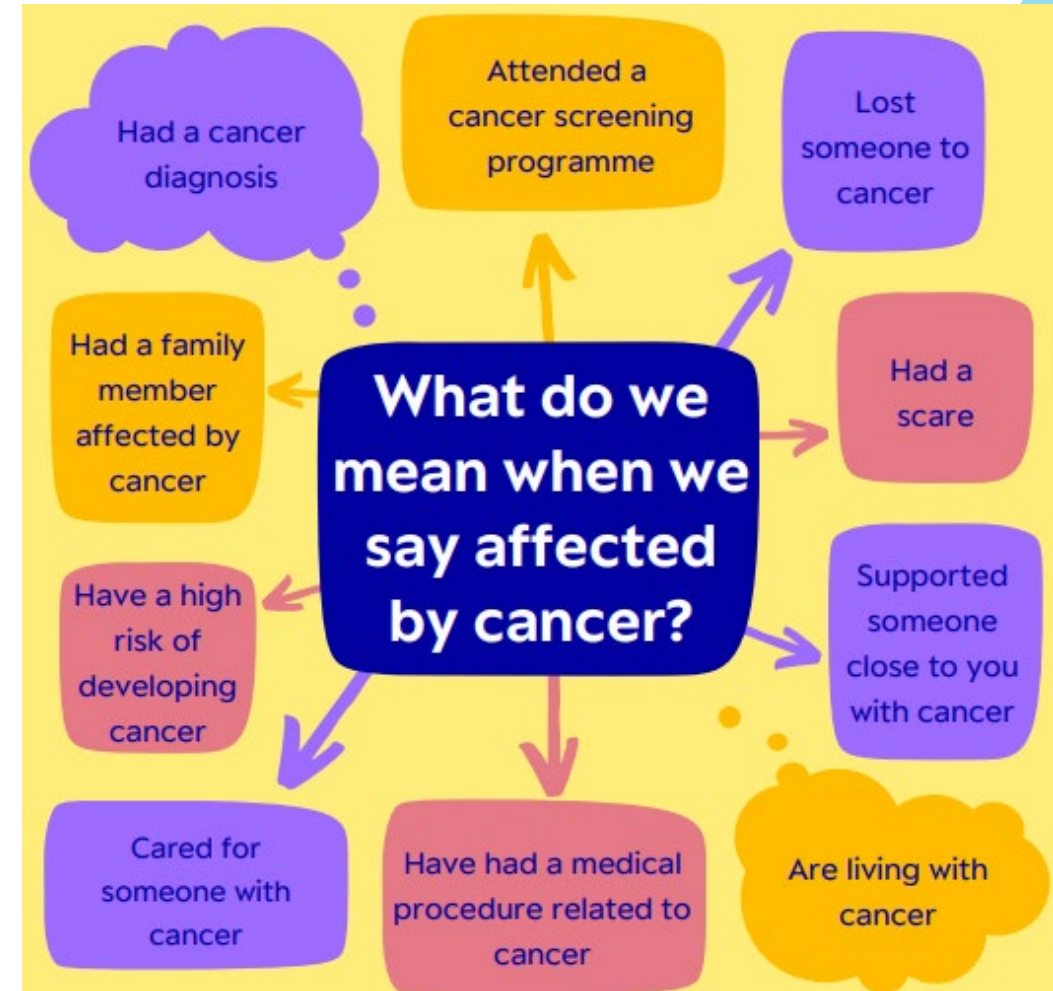
Where do I start?

- **Why** do I want to involve PPI Partner?
- **What** do I want them to do?



Who to involve?

- Consider **scope** for your research
- Are there **specific requirements**?
- Representation and **diversity** are key
- Consider **role description**
- **How many** to involve?



Where to find them?

- Across your network
- Within the clinic
- Through charities or other patient focussed organisations
- Online/Print Media
- Community Engagement



Everyone is welcome.

In particular, we are hoping to better represent marginalised groups, such as:

Travellers

Migrants

Unemployed

People experiencing homelessness or have housing concerns

Refugees

Members of the LGBTQIA+ Community

People with disabilities

Interested?
Have questions?



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How will I facilitate the partnership (methods) ?

- One-to-one discussions
- Advisory / reference groups
- Focus groups and discussion groups
- Steering groups
- Type of contact: Email vs telephone vs online vs in person





Important Considerations

Sufficient Time and Planning

- ✿ Give an appropriate amount of time to developing your PPI plan and building your PPI partnership
- ✿ Be clear on what and how your PPI will practically happen: how often will you meet, where, how?
- ✿ Accessibility & support considerations are very important to build into the plan.



Communication Plan

- ✿ Kick-off questions & expectation management during relationship building phase
- ✿ Information provision throughout the project
- ✿ Building rapport among PPI Partners and the broader research team
- ✿ Consider long term communication from the start



Consider Accessibility

If in person

- What room facilities are needed?
 - Room nearby for people if they get upset
- Consider dietary/accessibility needs
 - Proximity to toilets
- Carers/family members?
- Parking

If online

- Consider accessibility needs
 - Pre meeting tech check-in
 - Inclusion of enough comfort and bathroom breaks?
 - Closed captioning?



Reimbursement

- ✿ Reimbursing PPI is vital to ensure that no individual is left out of pocket by becoming a PPI Partner
- ✿ PPI partner are experts in their experiences.
Acknowledging this is important.
- ✿ Reimbursement helps remove barriers to involvement.



Types of reimbursement

- ✿ Best practice is that PPI partners be reimbursed for their time – check institutional guidance.
- ✿ Take time to develop your PPI budget when doing up your grant application.
- ✿ Consider how PPI Partners should be reimbursed, what will suit them best:
Per hour? Per task? What about travel/food/childcare?



PPI Planning Template

Why are you involving PPI partners in your research?
What do you want your PPI partners to do?
At what stages in the research cycle do you want to involve people in the research project?
What are the characteristics required in the people you wish to involve? How many do you wish to involve, and how will you find them?
How many people will you involve and where will you find them?
What method/s will you use? Type of activities and location
What information/ training/support do you think people might need?
How will you manage any risks ?
How will you share the outcomes of the research with your PPI partners over time?



**What challenges might you
face?**

Tokenistic PPI

- ✿ PPI Partners should be involved as early as possible
- ✿ Can you clearly identify where PPI Partners will have scope to input?
- ✿ Do not pre-develop a plan without PPI Partners



Insufficient PPI Budget

- ✿ Work with your PPI partners to reflect on costs that they might encounter. Childcare? Parking? Travel? Subsistence? Printing? **Time?**
- ✿ As much time should be committed to budgeting for PPI as would be for the broader grant budget.



Confusing PPI with Dissemination or Public Engagement

- ✿ Researchers sometimes complete PPI sections of grant applications and project plans with a focus on **dissemination** of findings to patient groups.
- ✿ This is welcomed as an example of public engagement, but it does **not** constitute PPI.
- ✿ PPI has to actively involve partners (not participants) who have a **meaningful** say throughout the lifecycle of a research project.



Power Imbalance

Often there can be a power imbalance present between researchers and PPI contributors that needs to be overcome:

- ✿ Expectation management for both PPI partners and for researchers (and all other stakeholders)
- ✿ Education on the value of the Expert by Experience
- ✿ Clear meeting etiquette to reduce power imbalance at meetings
- ✿ Reimbursement!



What other challenges do I need to consider?




Summary

Involve a wide range of people if you can

Involvement at an early stage is key

Good communication and expectation management is key to a PPI relationship





We are here to help &
support you on your PPI
journey!

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Resources

- Irish Cancer Society Research Team ppi@irishcancer.ie
- The National PPI Ignite Network <https://ppinetwork.ie/>
- Health Research Charities Ireland PPI tool kit <https://hrci.ie/a-new-ppi-toolkit/>
- Nala tips for writing in plain English <https://www.nala.ie/plain-english/>
- IPOSSI <https://www.ipposi.ie/our-work/research/ppi-clinical-research-2/>
- INVOLVE (www.invo.org.uk)
- NIHR payment guidelines for PPI <https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392>

Case study : Refining a research question



A physiotherapist looking at developing an intervention in men with prostate cancer following surgery

Case study: Refining a research question

Why did she involve people?

To help to plan a clinical trial looking at an exercise intervention of people affected by prostate cancer post-surgery.

Who did she involve ?

5 men who have had a prostatectomy in the last 2 years.

Where?

Hospital nurses within the clinical team

Methods and

Focus groups to discuss feasibility

- When after the surgery?

- How much of a benefit would the men hope to gain?

- How would they promote and monitor compliance to the exercise?

Case study: Writing a grant application



CNS thinking about involving people affected by cancer in writing a grant application looking at the use of an app to support parents of children with cancer

Case study: Writing a grant application

Why did he involve people?

To help develop the PPI sections of the grant application and research project

Who did he involve?

2 parents of children who had previously has cancer (2-5 years ago)

Where?

National children's cancer charity, helped him recruit PPI contributors

Methods

Via email with 1-2 virtual group discussion

They worked together to write the plain English summary & develop a PPI and communication plan for the project.

Case study: Carrying out research



A clinical psychologist involving people affected by cancer in a project to survey depression in people with advanced cancer

Case study: Carrying out research

Why did she involve people?

To ensure the survey is relevant, understandable and acceptable and to maximize recruitment.

Who did she involve?

She recruited 4 people living with advanced cancer who had stable disease

How did she recruit?

She recruited by social media and via ARC cancer support centers

Methods

Project steering group who met quarterly over 1 year

Main role was to develop the appropriate questions and language, design the participant information leaflet, and help with recruitment strategies

Case study: Disseminating results



A clinical researcher who wants to involve patients and carers to help her disseminate her research findings about a melanoma trial

Case study: Disseminating the results

Why did she involve people?

To ensure what was shared was communicated properly to those affected by melanoma

Who did she involve?

2 people with melanoma who were already members of the trial management group

How did she recruit?

Via Irish Cancer Society PPI panel

Methods and how where they involved?

Online discussion with the two PPI Partners to help design draft summaries of results for the public. Interviewed for newspaper for article made about results. Spoke at meetings about results. On a Twitter Q&A panel.

Thank you

**PPI in Survivorship
Research**

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