

General guidance on including PPI in your research proposal

Introduction

Public and Patient Involvement (PPI) is the term for public involvement and co-production frequently used within the disciplines of health and social care research. PPI is a research practice that involves public(s) and patients in decision-making, prioritising, planning, conducting and communicating research with the overall goal of improving research relevance and impact.

It is defined as ***research carried out with or by patients and those who have experience of a condition, rather than for, to, or about them.***

It is the concept of involving people, who are not researchers, in the research and seeking their input to shape and guide it. It is about moving their role from one of participant to one of partnership.

In an effort to clarify what is meant by involvement, Irish Universities Association's **Campus Engage** differentiates between three different ways in which people can become a part of the research process:

- **Participation:** Being recruited as study participants is defined as participation in research;
- **Engagement:** Efforts aimed at raising awareness among the public around research, such as newspaper articles, or outreach activities such as open days in research facilities can be described as engagement. Engagement activities are required for both participation and involvement;
- **Involvement:** Refers to co-created and co-produced research with a focus on collaboration

(Ref: https://www.tcd.ie/tcaid/assets/pdf/MakingAStart_PPIToolkit.pdf
MAKING A START: A toolkit for research charities to begin a PPI relationship)

What PPI is:

- PPI describes a whole variety of ways that researchers engage with people for whom their research holds relevance.
- PPI plays an important role in ensuring that patients are informed about research that is relevant to them. This is likely to result in increased patient support for research and the improved likelihood of patient involvement in the case of clinical research.
- PPI is an important step in ensuring that the real-life experiences of patients are considered in decision-making processes around research.
- PPI is key to ensuring that patients and their families have the opportunity to express the questions and needs that matter most to them, which is likely to improve the relevance of research.

- PPI helps to ensure that studies involving patients are designed to be sensitive to the needs of the study participants.

What PPI is NOT:

- PPI is not an attempt to make amateur scientists out of lay people. It is well recognised that, in general, it is not appropriate to ask lay people to assess the validity or methodology of an avenue of research.
- The use of PPI is not intended to focus research on short-term health goals. Patients, in particular, often have great understanding of the need for research at all stages of the spectrum, from basic to applied.
- The adoption of PPI into funding and policy processes is not meant to imply that researchers have no empathy or understanding of the needs of patients.
- The use of PPI is not intended to confuse or provide false hope to people who are vulnerable.

(Ref: Irish Health Research Forum, https://859556ce-4d33-4b82-be63-d48940ba7029.filesusr.com/ugd/75eae6_5ee17a6102544c3c8119362d36bb751b.pdf)

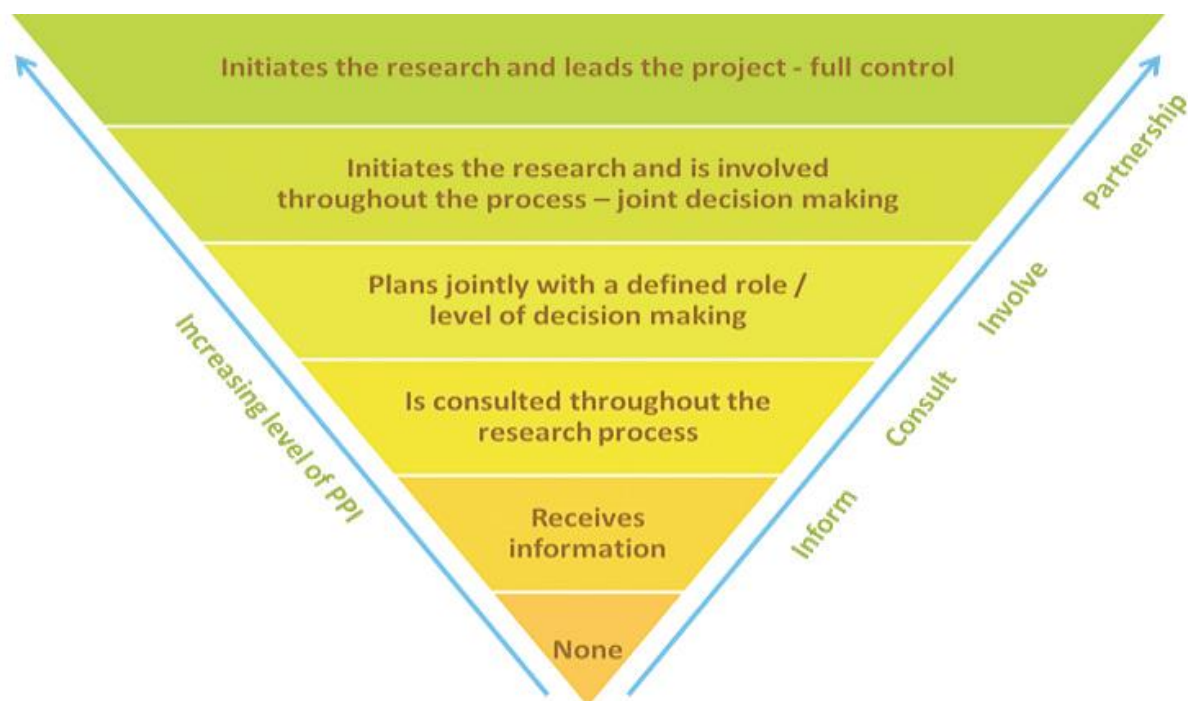
Why do PPI?

Involving patients and the public in research is seen as a marker of good research practice because it leads to research that is relevant, better designed, with clearer outcomes, and a faster uptake of new evidence.

It is important to realise that Patients/Public can be involved in research in a number of different ways;

1. As co-applicants on a research project.
2. Involvement in identifying research priorities (at a national, institutional or charity level).
3. As members of a project advisory or steering group.
4. Assisting with the developing of patient information leaflets or other research materials.
5. Carrying out the research.
6. Dissemination and implementation of the research outcomes

The spectrum of ways in which a patient or members of the public might be involved in research:



Ref: *Public and Patient Involvement (PPI) in Research: Irish Health Research Forum*
https://859556ce-4d33-4b82-be63-d48940ba7029.filesusr.com/ugd/75eae6_5ee17a6102544c3c8119362d36bb751b.pdf

How to start

Planning PPI Templates:

Activity	Role for PPI?	PPI approach?
Agree the research question – what is the most important thing to address right now, with the resources and time we have available?		
What data will you need to answer this question?		
Where will you find that data (if already collected)? <i>And/or</i> Who will provide the data (these are study participants)?		
Will you need ethical approval to collect data? If yes, list the steps involved:		
How will you collect data (this is study methodology and protocol)?		
How will you analyse the data?		
How will you report on and share the results?		
What is the next step when you have shared the results?		

Ref: PPI Ignite @ NUI Galway

Here are a few questions to help you to work out what roles PPI contributors will play.

Stage	What role will PPI contributors play*?	What PPI activities are needed to help them play a role?	How does this benefit the research, its impact or the team?
Identifying & Prioritising stage			
Design stage			
Undertaking & Management stage			
Analysing & Interpreting stage			
Dissemination stage			
Implementation & Impact stage			




Ref: PPI Ignite at Trinity College Dublin (<https://www.tcd.ie/tcaid/ignite/>)

Research Planning Canvas

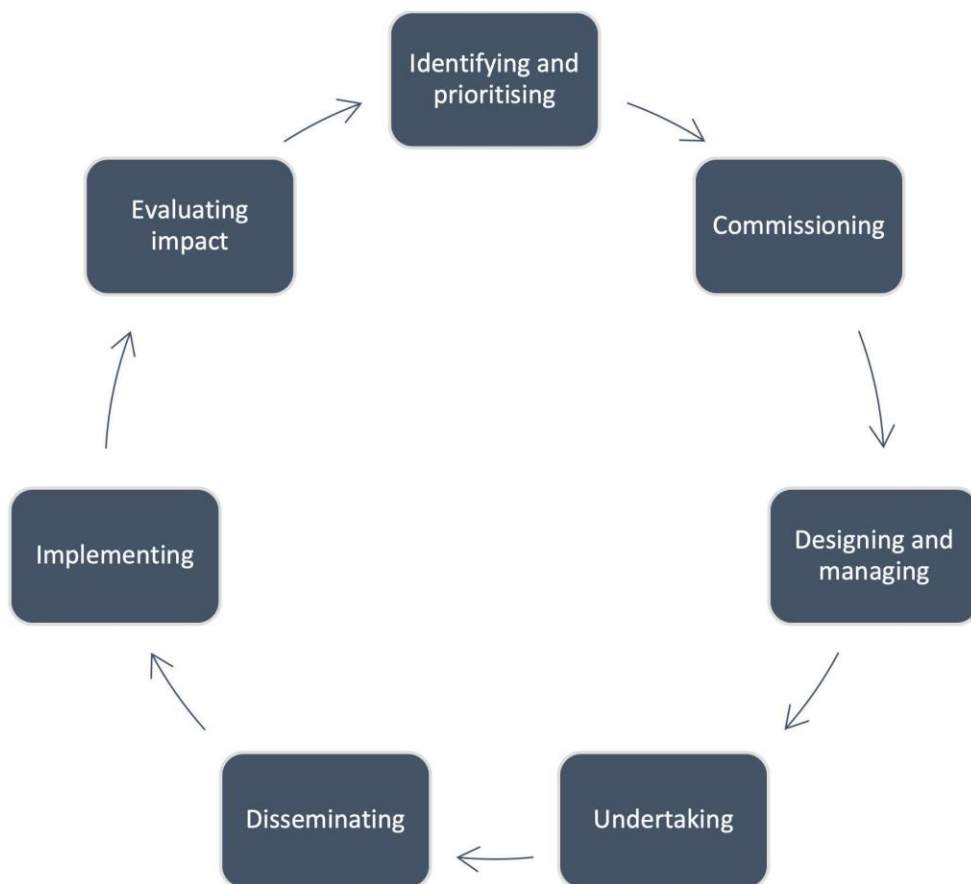
To make a strategic, considered plan for the involvement of patients and public(s) throughout all stages of research, the PPI planning canvas is a useful resource.

Ref: <https://www.ucd.ie/research/portal/outcomesandimpacts/publicengagementandengagedresearch/>.

PPI Researcher Planning Canvas

PPI Researcher Planning Canvas		
CHALLENGE	RESPONSE	VALUE
Barriers Institutional policies, procedures or situations that my hinder PPI		What additional benefit will PPI bring to your research
Worries Personal hurdles that cause anxiety or unease about PPI		IMPACT What effect on impact will inclusion of PPI bring? (Cultural, economic, health, political, social, knowledge etc.)
Concerns Perceived impediments to research value or practice		
Time Related timeframes to prepare for PPI		Funding Your funding roadmap to enable preparation for PPI

PPI participants can make contributions at every stage of the Research Process.



Source: INVOLVE (2012) Briefing notes for researchers.

How do I cost it?

The following proposed PPI budget template is a TCD PPI Ignite tool reminder of the types of costs that often occur for PPI activities.

Budget Item	Per er item cost	Total Cost
PERSONNEL		
PPI specific team member ¹	€ per day	
PPI Office support time	€ per day + prep time	
External facilitator	€ per day + prep time	
NGO facilitator	€ per day + prep time	
ACTIVITY COSTS (including induction and training)		
Room hire for activities	€ per event	
Tea / Coffee	€ per PPI contributor + other attendees	
Lunch	€ per PPI contributor + other attendees	
Train, Bus, Taxi per event	€ to and from	
Mileage (if permissible)	€ per km	
Overnights (if required)	€ bed-night + breakfast	
Stationery, materials	€ per event	
Data Costs (for online contributors)	€ per hour	
Fees for Conference or Event attendance	€ per Contributor per event	
CONTRIBUTOR ACKNOWLEDGEMENT		
PPI Contributor payment (if permissible)	€ per day per contributor	
PPI honorarium	€ per contributor	
ACCESSIBILITY COSTS		
Sign Language Interpreter	€ per event	
Assistive technology hire	€ per Contributor per event	
Braille material	€ per Contributor per event	
Audio material	€ per Contributor per event	
RECRUITMENT COSTS		
Advertisements	€ per run of ad	

Ref: PPI Ignite at Trinity College Dublin

(<https://www.tcd.ie/tcaid/assets/pdf/ignite/TrinityPPIBudget.pdf>)

¹ Please see [Trinity Centre for Ageing and Intellectual Disability - Trinity College Dublin \(tcd.ie\)](https://www.tcd.ie/tcaid/assets/pdf/ignite/TrinityPPIBudget.pdf) on challenges of costing a contributors time and how it can be managed.

Additional resources

1. HRB PPI Guide: <https://www.hrb.ie/funding/funding-schemes/public-patient-and-carer-involvement-in-research/>.
2. Campus Engage: <https://www.campusengage.ie/wp-content/uploads/2021/04/WEB-IUA-Campus-Engage-Online-Engagement-Publication.pdf>.
3. TCD PPI Ignite Toolkit:
https://www.tcd.ie/tcaid/assets/pdf/MakingAStart_PPIToolkit.pdf.
4. HSE PPI Patient and Public Involvement in Research (PPI) - HSE | Research & Development ([hseresearch.ie](https://www.hseresearch.ie))
5. University of Oxford 'A researcher's guide to patient and public involvement' [A Researcher's Guide to Patient and Public Involvement \(nihr.ac.uk\)](https://www.nihr.ac.uk)
6. INVOLVE www.invo.org.uk
7. Patient-Centred Outcomes Research Institute (PCORI) www.pcori.org