



Developing a PPI Strategy: A Guide

Practical advice on developing a patient and public
involvement (PPI) strategy for research activities

medical
research
charities
group

Unity is our Strength

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Irish Organisations

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 Cystic Fibrosis Ireland
 DEBRA Ireland
 Fighting Blindness
 MS Ireland
 National Children's Research Centre

UK/International organisations

Alzheimer's Society
 Bowel Cancer UK
 Cystic Fibrosis Trust
 DEBRA International
 JDRF, the type 1 diabetes research charity
 Parkinson's UK
 Psoriasis Association
 Stroke Association



Introduction

It is an exciting time in health research. Barriers between the research community and the public are being eroded, we are taking a broader view of what constitutes expertise and research is now more likely than ever to result in impact for the people it is intended to help. Patient and public involvement in research is growing and is here to stay.

For groups looking to incorporate PPI into their practices for the first time or to develop their PPI practices further, there are many things to think about. This guide aims to lead you through the things you need to consider and to support you in putting a PPI strategy in place. **It is primarily targeted at charities and patient organisations with a focus on health research.** However, it could also be adapted for other groups.

If PPI is new to you, our advice is to start small (and simple) and revise and expand the strategy as your activities evolve and as you gain experience. It might form part of your overall strategy or stand alone. Very importantly, while this guide urges you to aim high, you should not be daunted if some of the guidance is not currently possible for you. The most important thing is the make a start – reaching out to those you are working on behalf of can only ever be a good thing.

A PPI Strategy: **Heading by Heading**

Below are the headings that we suggest you use in your strategy and a brief description of what should be included under each.



Outlining our vision for PPI

In this section (which is likely to be brief) you should outline why you want to embrace PPI within your organisation and what you hope to achieve from it e.g. how will it add value to the research process or to the people who get involved.

Things to consider here

- You should consult with members of the population you hope to involve, in order to get their views on this and all aspects of the strategy. It might also be useful to consult with the relevant research community.
- You should consider including a statement on the ethos of the organisation around inclusion, diversity and respect.
- Aim to set your PPI plans in context with the wider vision of the organisation as it is important to achieve buy-in across the entire organisation.

Examples of statements to include in your PPI vision



We believe that people with X condition and their carers should have a guiding voice in shaping our research work.



Effective involvement will ensure that the research we fund reflects the needs of people living with X condition, thereby helping to ensure that our work has impact.



We will foster a culture of inclusion and respect in all our activities, taking steps to include people from all relevant groups and communities in our research activities.



Defining what we mean by PPI

It's important to define what your organisation means by PPI. It is helpful to view the different ways of involving people in research as a spectrum. Your strategy should make it clear that while participation of patients in research studies and the engagement of patients/the public through the imparting of information are very useful, they are different from PPI. While early activities might usefully focus on engagement, the strategy should encourage your organisation to strive for true involvement.

The Irish Health Research Forum, a partnership of organisations and stakeholders that aims to influence health research in Ireland, has described PPI as:

occurring when individuals meaningfully and actively collaborate in the governance, priority setting, and conduct of research, as well as in summarizing, distributing, sharing, and applying its resulting knowledge.

You might also find it useful to borrow the INVOLVE definition of PPI at www.invo.org.uk:

PPI is research carried out 'with' or 'by' patients/members of the public rather than 'to', 'about' or 'for' them.



Who we will involve in our research activities and how we will reach them

In this section you need to define who you will involve. This might be patients, parents, other family members, carers, the general public or a mixture of the above. The decision on who to involve is likely to be particular to your organisation, depending on the demographics of the group you are working with and the particular challenges they face.







You should also outline how you will reach the people you want to involve. Possible avenues include through newsletters, social media, other digital platforms, patient meetings and public gatherings.

Things to consider here

- Many organisations establish a **research involvement network**, which allows them to share important information and opportunities for involvement, with a community of people who have expressed an interest.
 - Think about whether you require PPI contributors to represent only their own personal experience or also the broader experience of the community.
 - Consider the importance of diversity. Aim to ensure that you are involving people from diverse groups, and that your methods of involvement allow for this.
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The language of PPI

-  Language is important in conveying our meaning and is also an instrument of positive change. The language of PPI is therefore very important but it can be challenging to get right and needs to be continually adapted to the context.
-  The use of the term 'patients' can be appropriate in a broad medical or health research context. It is clearly understood and fits with the phrase 'patient and public involvement'. Referring to the involvement of members of the 'public' is often appropriate also but, in some instances, fails to convey the unique expertise held by people who live with a long-term health condition.
-  While such broad terms have their place, when dealing with a specific population affected by a health condition, the term 'patient' is best avoided where possible. It can imply that people are little more than their diagnosis and it can also exclude family members and other carers, often deeply affected also, albeit in a different way.
-  It is important to give the PPI-related language you use due consideration. Start from a place of respect and work with the population(s) you represent to define the terms that are most acceptable. Then make sure they are used consistently across your organisation's activities.
-  Preferred phrases are often along the lines of 'people with' or 'people affected by' a particular condition. Within charities and patient organisations, the following terms are also commonly used: members, service users, research volunteers, research contributors etc.
-  While not necessarily practical for use in all contexts, occasional use of terms such as 'experts by experience' can be powerful in emphasising that expertise doesn't always come with academic qualifications.



Activities that will include PPI

You should consider in which areas of your work PPI will be valuable and outline what they are, acknowledging that this may change over time. There are numerous research activities in which you might either directly involve people or facilitate their involvement, including:

- Exercises to identify and prioritise the types of research that will be supported by the organisation
- Co-designing research projects and proposals
- Reviewing research grant proposals
- Participating in research project steering groups
- Reviewing clinical trial protocols or study information for participants
- Collecting or interpreting data
- Disseminating or implementing research findings

Things to consider here

- You should consider developing role descriptions that clearly explain the specifics of the role(s) that PPI contributors will play.
- If you are facilitating PPI on behalf of other groups e.g. researchers or industry groups, you will need to consider your terms and conditions for providing this service.
- It might be important to outline what PPI does not include e.g. being a subject in a clinical trial or completing a survey.
- While this guide focuses on research, you could expand it to include PPI in other aspects of your organisation e.g. care activities.

**How we will support PPI**

Depending on the size of the organisation and your existing relationship with the people you work on behalf of, some new practices and initiatives might be required to support PPI. You should outline what will be required to support meaningful PPI. For patient organisations developing a PPI strategy, it is also important to consider how you will support researchers and industry groups to connect with PPI contributors and to facilitate them in undertaking meaningful PPI activities.

Things to consider here:

- Who will be the main PPI contact point(s) in the organisation?
- How will the additional communication and event management activities that PPI requires be managed?
- How will your PPI activities be undertaken e.g. face-to-face meetings, conference call, email?
- How will PPI contributors be supported in preparing for their role in research activities? Some degree of training is likely to be required.
- Training or guidance might also be required for staff, volunteers (e.g. members of research advisory committees), researchers, committee Chairs) on how to effectively support PPI.
- How will you manage requests from researchers and industry groups looking to you to support their PPI activities? An application form, to assess the value and practicality of what they are proposing and/or a PPI support agreement, can be useful.

Your strategy should also outline what policies relevant to PPI you already have and what policies you will need to develop. These might include:

- An expenses policy for PPI contributors
- An equality and diversity policy
- Codes of conduct e.g. for PPI contributors acting on behalf of the organisation
- Confidentiality agreements e.g. for PPI contributors being provided access to sensitive research material



Rewarding and respecting our PPI contributors

You need to outline how you will ensure PPI contributors feel valued for their experience, their time and their commitment. This should extend to research groups you are supporting with PPI and your expectations of these groups should be clearly communicated. Most (but not all) charities do not pay people for PPI activities, in keeping with practice for the various other volunteer roles with the charity. At the very least however, PPI contributors will need to be reimbursed for their out of pocket expenses. You might wish to either draw up a list of acceptable expenses or operate on a case-by-case basis.

Things to consider here:

- One of the most important ways to ensure PPI contributors feel valued, is to approach activities with a full commitment to ensure that their input has impact.
- Always take the time to provide feedback to PPI contributors, to inform them why their input mattered or made a difference, both in the short and long-term. If their input did not have influence, you need to respectfully explain why.
- If you are unable to pay PPI contributors for their time, you might consider giving tokens of appreciation. Think broadly about how you can demonstrate your appreciation e.g. free tickets to a fund-raising event, inclusion in a charity draw, a personal thank-you in a newsletter etc.



Measuring the impact of our PPI activities

Much of the impact from PPI is hard to measure. A patient that feels more empowered; a slow change in focus by a researcher; a shift in attitude towards the value of the lived experience; are all difficult to capture in metrics. None-the-less it can be useful to consider how you might mark your progress over time and both quantitative and qualitative measures of impact can be useful. Ultimately, you should strive for a situation where your PPI activities are being constantly developed and routinely evaluated by your PPI contributors. Resources permitting, you could consider some of the following:

- Simple measures of how many people have been involved over time, across how many activities.
- Evidence that PPI led to different outcomes (although it is important to acknowledge that this will not always be the case).
- Case studies of individual PPI contributors or researchers, demonstrating either how PPI led to a change in research direction (or provided reassurance about a direction) or had a personal impact on them (positive or negative).

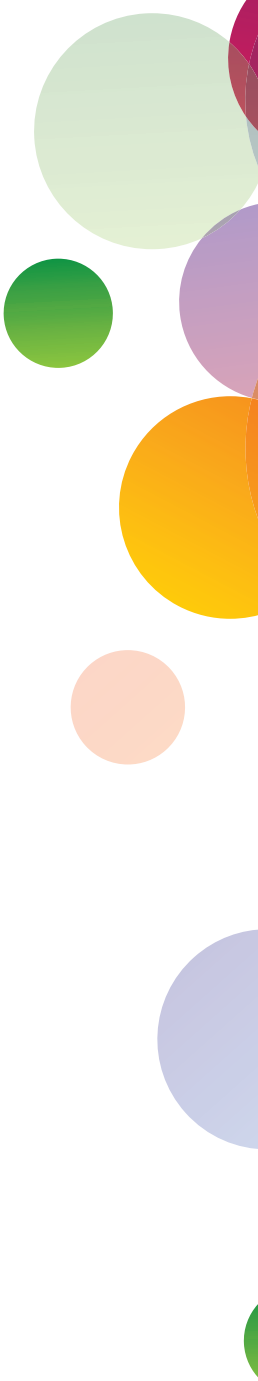


Budgeting for our PPI activities

While your strategy won't necessarily need to go into detail on the costs of PPI for your organisation, it should acknowledge that PPI activities and the reimbursement/payment of PPI contributors will need to be appropriately resourced and outline how this will be managed.

Further Information

For further information on the work of the MRCG on Patient and Public Involvement, please visit the Medical Research Charities Group website www.mrcg.ie and the Irish Health Research Forum website www.ihrf.ie.



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