

HRB Definitive Intervention and Feasibility Awards 2020:

Tips for writing the PPI section

The HRB is highly committed to patient and public involvement (PPI) in health research. This is demonstrated by the HRB's recent commitment to invest a further €3.3 million over the next five years to establish a National PPI Network in Ireland.

HRB strongly promotes public and patient involvement (PPI) in the research that they fund. They use the definition of PPI in Research proposed by INVOLVE: "Research carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them" (www.invo.org.uk).

The HRB also use the INVOLVE definition of the term 'public' which includes patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services.

Note:

- PPI does **not** include the recruitment of study participants. This is participation of the public rather than involvement ¹.
- PPI does **not** include work aimed at raising awareness of the public around research, such as media publications of research findings, and outreach activities such as open days in research facilities. This is engagement ¹.

Will PPI form part of the assessment of the DIFA?

Yes! The HRB are currently planning a public review in DIFA 2020 of Full Applications (HRB DIFA Guidance pg: 12)

Tips on writing the PPI section

Firstly, you should decide on what involvement approach you are going to take. There are three approaches to involvement: consultation, collaboration and user led.¹

- **Consultation** is when you ask members of the public for their views and use these views to inform your decision making. Consultation can be about any aspect of the research process:
 - Agenda setting - identifying topics for research;
 - Study design/procedures - comment on research projects/research design;
 - Analysis –providing a patient perspective on research outcomes or findings.
- **Collaboration** involves an ongoing partnership between Investigators and the members of the public they are working with. In this context, decisions about the research are shared. For example, members of the public:
 - collaborate on developing the research grant application;
 - members of the study advisory group, informing decisions about study recruitment strategies, etc.
 - collaborate with researchers to disseminate the results of a research project.
- **User controlled** is when the research is actively controlled, directed, and managed by service users and their service user organisation.

You can pick one approach and stick with it throughout the research project or you can use different approaches at different stages of the research project. For example, you may **consult** with patients on issues around research design during the grant application stage. You might then **collaborate** with patients by involving them as members of the research team, who inform decisions on specific issues, such a recruitment strategy, etc.².

PPI section of the DIFA 2020 Pre-application

In the full application, you are asked if you are including public involvement in your application? YES/NO

If Yes, you are asked to please describe:

- i. the purpose of the involvement,
- ii. public and patient involvement to date and how that has influenced/changed what work has been planned,
- iii. public and patient involvement planned for the duration of the award (e.g. oversight, conduct, analysis and/or dissemination)

We will discuss these overleaf

(i) If Yes, please describe the purpose of the involvement,

Here the reviewers are asking applicants to give an overview of where PPI will add value to your project and what you would like to get out of it³. You might consider the following:

- **Why are you involving public/patients?** What do you think they will add/ help with? What are you hoping to achieve?
- **Who are you involving?** List the patient organisations/representatives, patients/public involved. Do they have lived experience of the research topic? How will you identify or recruit these people? (Note: The applicant team may be re-configured at Full Application to add a PPI co-applicant/collaborator)
- **When are you going to do the involvement?** Identify the key stages of the research project that you would like to get PPI contributors involved (e.g. application, design, recruitment, analysis dissemination).

(ii) Describe, public and patient involvement to date and how that has influenced/changed what work has been planned

Here the reviewers are trying to establish if you have consulted or collaborated with patient/public on the development of the research proposal and DIFA application to date. Beware if you have not involved public and patient in the application as this will be highlighted as weakness. It is important to **consult and/or collaborate** with patients/public who have a lived experience of the research topic in the development of the application. You will also need to give credible examples of how this involvement has influenced/changed the DIFA application. At a minimum, you will need to obtain a PPI review and comment on your application (or relevant sections) from a named patient and/or public and/or organisation.

(iii) Describe public and patient involvement planned for the duration of the award (e.g. oversight, conduct, analysis and/or dissemination)

Here, the reviewers will want to see a clear PPI plan for the duration of the award. If you are new to PPI, keep things simple and achievable. If you want to write a realistic plan, it can be useful to think about the 5 W's of meaningful PPI. These are:

1. **Why are you involving people?** What do you think they will add/ help with? What are you hoping to achieve?
2. **Who are you involving?** List the patient organisations/representatives, patients/public involved. Do they have lived experience of the research topic? How will you identify or recruit these people? How many people will you involve? Quality not quantity is key here. Identify (name) the individuals /organisations involved in the application. (Note: The applicant team may be re-configured at Full Application to add a PPI co-applicant/collaborator)
3. **Where are you going to do the involvement?** If you are planning on having face-to-face meetings, think about patient accessibility. Is the location easy to find? Is there parking available? Is it a comfortable room? If you are going to run meetings virtually or ask them to review documents remotely, will this suit the PPI contributors?
4. **When are you going to do the involvement?** Identify the stages of the research project that you would like to get PPI contributors involved (e.g. design, recruitment, analysis, dissemination). This will link back to your 'why'.
5. **What will PPI contributors do in your study?** Once you know your 'why' and you have identified your key stages, you then need to decide what you are going to ask the patient/public contributor to do. For example:
 - Participation on Steering Group for study
 - Advise on the development of study instruments, material, literature, etc.;
 - Advice on recruitment/retention strategy;
 - Involvement in analysis, e.g. add patient perspective to the synthesis and interpretation of findings;
 - Involvement in dissemination e.g. critically reviewing articles/reports, delivering presentations, etc.

Other important things to consider:

Cost:

Always budget your PPI appropriately. Think about all the costs that may arise including:

- room hire;
- catering;
- parking;
- travel expenses for PPI contributors;
- payment of PPI contributors etc.

For further information and advice on costing PPI see the INVOLVE website: (<https://www.invo.org.uk/posttypepublication/budgeting-for-involvement/>).

If you allocate enough budget to these costs from the outset, it will show the reviewers that you are serious about doing meaningful PPI. The HRB's view is that if you have not budgeted for PPI, then it will not happen! In other words, if you do not budget appropriately, your PPI plan will be seen as tokenism.

PPI oversight/governance

It is important that clear PPI oversight and governance structures are in place^{1,2}. Clear work instructions around patient public remuneration should be in place. Similarly, work instructions around the organisation of project meetings involving patients/public should be in place.

Coordination of the public patient involvement activity is important. Does the research team have PPI experience? Do they have experience in facilitating groups? How will the power dynamic here between patients and research/medical professional be managed?² It is crucial that the patient/public contributors have clearly defined roles². It is also important that the patients/public contributors receive training or mentorship on their role. Researchers should also receive training on involving patients/public².

Examples of PPI in Research projects

There are many examples of how patients/public contributors can be involved in a research project. The following are examples provided by the HRB.³

- Co applicant/collaborator on DIFA application
- Co researcher
- Participation on Steering Group for study
- Group/individuals collaborating with the research team to provide support or input on specific project tasks
- PPI advisory group/panel providing support or input on specific project tasks
- Focus groups for specific topics

Pitfalls:

- An adequate **budget** for PPI activity is key. The HRB insist that if members of the public/patients are involved, they must be compensated for their time and contributions.
- Beware of **tokenism**. If your PPI plan is not substantial, public reviewers will spot it immediately!!!

For a full list of **PPI challenges and enablers**, see S. Marjonovic, et al. 2019 (pg 7)²

Support available:

The HRB CRF-C can advise you on the content of the PPI section in the DIFA full application and on your PPI Budget.

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<https://crfc.ucc.ie/>

References:

1. INVOLVE (2012) Briefing notes for researchers: involving the public in NHS, public health and social care research. INVOLVE, Eastleigh https://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf
2. S. Marjonovic, et al. (2019). Involving patients and the public in research. The Healthcare Improvement Studies Institute <https://www.thisinstitute.cam.ac.uk/research-articles/involving-patients-public-research/>
3. Cody, A. (2020) HRB: *PPI considerations for studies*. HRB DIFA Webinar 6th May 2020

Further information:

- Online repository of relevant PPI documents has been launched on the IPPOSI website at the link below: <https://bit.ly/ppiclinicalresearch>
- INVOLVE (2012) Public involvement in clinical trials: Supplement to the briefing notes for researchers (<http://www.invo.org.uk/wp-content/uploads/2012/04/INVOLVEpublicinvolvementinclinicaltrialsBriefingnotes2012.pdf>)
- <https://www.cancerresearchuk.org/funding-for-researchers/patient-involvement-toolkit-for-researchers>
- European Patient Forum Value + Handbook: For Project Co-ordinators, Leaders and Promoters On Meaningful Patient Involvement. http://www.eu-patient.eu/globalassets/projects/valueplus/doc_epf_handbook.pdf