

# Public and Patient Involvement (PPI) in HRB Grant Applications

The HRB has embedded public and patient involvement (PPI) across their grant applications. They also have a panel of public reviewers that review PPI in the proposal.

## What to expect from Public Reviewers

Public Reviewers have access to the full proposal.

The HRB recommend public reviewers focus on:

### 1. Lay summary

[Our Advice:](#) A good lay summary is not simply the technical abstract with the complex words changed. It should give the reader enough information on the “why”, “who”, “how”, and “what for” of the project in a clear (but not condescending) manner. See [Promote your research](#) for more.

### 2. Project description, specifically the section on public involvement

[Our Advice:](#) This section should not be all aspirational. It should be grounded in PPI to date “PPI has informed X in this grant and we will build on this via x means throughout the project”.

- > It should demonstrate co-design with the PPI contributors (avoid “us and them” language).
- > The PPI section should have a justification or reason for the PPI plans (rather than just to “do PPI”).
- > The stated PPI involvement should be backed up by evidence in other sections of the grant, such as budget.

### 3. Project description, dissemination and knowledge exchange plan

[Our Advice:](#) Look for evidence of collaboration with people with lived experience for knowledge exchange between academia and patient communities.

>Are there plans for dissemination to communities beyond academia and if so, will PPI contributors be involved with these.

>Is there mention of PPI collaborators as co-authors or co-presenters of research findings?

#### 4. Project description, project management section

Our Advice: Look for evidence of special considerations for interacting with PPI contributors.

For example: Are there plans for the frequency of meetings with PPI contributors?

**HRB also ask the public reviewers to consider certain technical sections but note that these will not be written for lay reviewers**

##### 1. Research design

Recommended where, for example, there is recruitment of study participants. Is there evidence of PPI informing the recruitment practices?

##### 2. Details of research team

Recommended to determine if there are PPI contributors included on the research team

##### 3. Project budget

Recommended to determine evidence of resourcing for PPI.

**In their reviews, Public reviewers are asked to comment and provide constructive feedback on:**

- Is the proposed research important to patients, service users, carers or the health of the general population?
- Is the proposed research looking for answers that are important to patients, service users, carers or the health of the general population?
- If the research involves patients, do you believe people would be willing to take part?
- Is the plain English summary of the funding application easy to understand?
- Could the plain English summary be improved?
- How appropriate are any plans for patient and public involvement (PPI) in the research application?
  - ***The HRB note: Some applications particularly those that are based in laboratories may not require much PPI. However applications that are looking at health (specific diseases, the prevention of ill health or promotion of good health) or health services (e.g. delivery of care and***

***treatment in hospital, primary care, General practice) should have patients or the public involved in the research team***

- What difference will it make?
- How could the researchers improve their plans for PPI in their research?
- How would you like to hear about the outcomes of this research– for example Media interview, public talks, through your health provider if relevant, etc.?

# Example of a good PPI incorporation into a grant proposal

This example is taken (with permission) from a real (successful) application to the HRB ILP grant scheme.

## **Public, Patient and Carer Involvement (PPI) in the Research Project Section**

**Identifying and prioritising the research question:** The voice of people with arthritis, families and carers have been at the heart of the UCD Centre for Arthritis Research since 2017. Peer to peer dialogue occurs between people living with Arthritis and researchers. People educate researchers on their lived experiences and what is important to them and also show researchers how to communicate science in a more people friendly accessible way.

**Design:** In 2020/2021 the centre worked with Arthritis Ireland and University of Limerick to undertake a National Research Prioritisation for Arthritis Research in Ireland. Three Patient Involvement Partners (PIPs) or 50% were part of the prioritisation project team. Over 400 people living with a rheumatic disease took part in the survey. Early diagnosis, preventing disease progression, and improving our understanding of disease biology were among the top ten priorities identified.

### **Conduct & Oversight:**

- The core project team including a PIP will be active in decision making at project team level.
- A patient Research Advisory Group (RAG) will be assembled. Members of the RAG will meet remotely quarterly, and annually in person as part of the larger project annual meeting.
- The responsibilities of the RAG is to ensure the project is patient-centric focused throughout.
- RAG will consist of four patient members living with rheumatoid arthritis.
- Member's input will be minuted, with discrete actions noted. Minutes and actions will be confirmed by the RAG.
- Implementation of these actions by the researcher(s) will be recorded as a measure of responsiveness to PPI input.

- The core PIP member of the project team (and co-applicant) will act as a contact point for the RAG should any issues arise that the RAG believes need to be addressed at a higher level.
- All associated expenses will be compensated as per the UCD PPI Ignite compensation guidance document and as outlined in the budget.

**Analysis:** PPI will not be directly involved in the analysis of the project. However, PIPs will be involved in the communication of the study results. This will include acting as PPI mentors for Plain English research communications, in which a PIP works with the researcher(s) to improve research communications for nonscientific audiences. This will be done in a formalised workshop setting which is to be offered by the PPI Ignite Office in UCD.

**Dissemination:** In addition, to mentors in plain English previously mentioned above, PPI partners will be involved in a range of dissemination methods for the project, including:

- Outreach, such as video pieces of PIPs in dialogue with the clinical and research members of the project.
- Updates in News Rheum, our patient-researcher co-produced newsletter
- Co-delivered presentations where appropriate.
- PIPs will also engage with researchers and project administrators to update project progress in a clear and understandable manner on the centre's website.
- When preparing scientific publications, PIPs will be involved in making the publications as accessible as possible, in terms of language used throughout the publication in addition to leading role in developing Plain English Summaries.

UCD Centre values and strive to foster PIPs' ideas for creative engagement, outreach and dissemination. There is a budget to support this, and facilitate PIPs to attend training courses they identify as beneficial to them and their remits within projects. For example, previously PIPs have been facilitated in attending UK ENGAGE Conference. Workshops we have specifically commissioned for the centre's PIPs previously include Patient Involvement in Clinical Research delivered by the Bettina Ryll, patient representative of the EU's Cancer Mission.

**Importantly, PPI was reinforced throughout the rest of the application**

**Dissemination and Knowledge Exchange Plan Section**

The PPI panel will outline their experience and learnings from this project in a twice-yearly fashion through a column in our patient/researcher co-produced newsletter, called News Rheum, and at our annual PPI conference (as detailed in 7.12). We have also budgeted for conference travel for the PPI panel so that they can network and disseminate at national or international level.

**Project management section**

To ensure continuous involvement with our Patient Insight Partners we will hold monthly Zoom discussions and annual face-to-face meetings.

**Research Design and Methodological approach Section**

It will use state-of-the-art technologies and bring together a collaborative team of leaders in relevant scientific disciplines with PPI involvement throughout.

**Impact Statement Section**

a) Human Capacity: The project will give a post-doctoral scientist training in molecular and cellular biology, proteomics, transcriptomics and computational analysis and PPI involvement in research. These skills will also be transferable to other members of the UCD rheumatology research team and the wider Irish research community

**Co-Applicant Section**

Type of co-applicant: PPI co-applicant

**Running costs section**

Running Costs 5 Item PPI

**Running Costs Justification Section**

PPI (€11,700): As outlined in Section 7.12 PPI has a major role throughout this study and includes a 4 member RAG:

- Remuneration (voucher per meeting to cover caring costs etc), typically about €40-50 per half-day meeting. (4 patient members x 4 meetings x 3 years =€2400)
- Travel (one annual meeting per annum) (approx 200 per person = 4\*3\*200= €2400)

- Virtual allowance (to cover stationary, phone bills, wifi associated with virtual meetings). Approx €75 per person per annum (€900)
- Training budget €1000 per annum. Budget for approx €3000
- Conference attendance, estimated at €750 per person. Budget €3000

## PPI checklist for Proposal Support

There is evidence of PPI collaboration before or during the grant application	Yes ▾
The plain english summary is easy to understand	Yes ▾
The lay summary clearly describes why this research may be important to patients/ service users or other publics (evidence of PPI in the research concept?)	Yes ▾
The lay summary clearly describes how the research team have come to the conclusion that <b>this specific research project's</b> findings may be important to patients/ service users or other publics	Yes ▾
The lay summary section (at minimum) appears to have been reviewed by a PPI contributor	Yes ▾
PPI contributors are part of the project team	Yes ▾
PPI plans appear grounded/specifically co-designed rather than solely aspirational	Yes ▾
PPI plans and collaborators have been explicitly described	Yes ▾
PPI plans are evidenced in other areas of the grant	Yes ▾
PPI has been appropriately costed	Yes ▾
PPI is explicitly evident in budget	Yes ▾
PPI is evident in project management	Yes ▾



## PPI checklist for researchers

Have you collaborated with PPI contributors before or during the grant application?	Yes ▾
Have you explicitly evidenced within the application how PPI has informed this grant?	Yes ▾
Is the plain english summary easy to understand?	Yes ▾
Was the lay summary reviewed or co-written with a PPI contributor?	Yes ▾
Does the lay summary clearly describe why your research may be important to patients/ service users or other publics (evidence of PPI in the research concept?)	Yes ▾
Does the lay summary clearly describes how PPI has informed <b>this specific research project</b> and why the research findings may be important to patients/ service users or other publics	Yes ▾
Have you outlined how PPI contributors will influence the research throughout the project lifecycle	Yes ▾
Have you outlined how you will support and manage PPI contributors throughout the project lifecycle	Yes ▾
Have you co-designed the PPI plans with PPI contributors?	Yes ▾
Are your PPI plans solely in the future? If so, have you justified why, and included an implementation plan.?	Yes ▾
Have PPI plans and PPI collaborators been explicitly outlined?	Yes ▾
Have you outlined your PPI implementation, monitoring and evaluation plan?	Yes ▾
Has PPI been appropriately costed?	Yes ▾
Is PPI evident in other areas of the grant (where appropriate: methodology, dissemination, budget, impact)?	Yes ▾
PPI is explicitly evident in budget	Yes ▾
PPI is evident in project management	Yes ▾

# Resources

**How to plan for PPI**

[PPI Planning Canvas](#)

[Video about the PPI Planning Canvas](#)

**How to appropriate cost for PPI**

[PPI Costing Tool](#)

[Video on how to use PPI Costing Tool](#)

**How to assess the PPI process**

[The PPI Assessment Survey](#)

[Other methods to Evaluate PPI](#)

**PPI Ignite Network @ UCD:** [www.ucd.ie/ppi/](http://www.ucd.ie/ppi/)

**National PPI Ignite Network:** [www.ppinetwork.ie](http://www.ppinetwork.ie)