# Considering Patient & Public Involvement in preparation for the HRCI HRB Joint Funding Scheme 2024

Appropriately conducted Patient and Public Involvement (PPI) is integral to the Health Research Charities Ireland (HRCI) Health Research Board (HRB) Joint Funding Scheme. PPI reviewers form part of the review panel and there are specific questions in the application form which will inform the PPI rating awarded to each project (see below). It is therefore important to think about PPI in the earliest stages of planning a research project for submission to the Scheme. The following is a brief overview of PPI, summarised from the HRCI and Trinity College Dublin (2020) Making a Start - A toolkit for research charities to begin a PPI Relationship, Dublin: HRCI.

### What is PPI

Involvement of patients and public in research is a collaborative process that takes place throughout the research life cycle resulting in the co-creation and co-production of research.

PPI is defined as research carried out 'with' or 'by patients/members of the public rather than 'to', 'about' or 'for' them. (INVOLVE UK)

The Irish Health Research Forum describes 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.

The Health Research Board defines patients and public as follows:

By 'public' we mean everyone in Ireland who has an interest in health and social care as a public service including potential users of services. By 'patient' we mean people who use services such as patients, service users, clients or their carers.

#### What PPI is not

PPI is distinct from other forms of patient interaction with the research process such as:

Participation - when patients are recruited to a research study and they, or part of them, are the subject of the study and contribute to the data for that study.

Engagement – raising awareness amongst the public of research through media and outreach activities. Although this does not constitute involvement it is often needed to pave the way for both involvement and participation.

#### **Benefits of PPI**

Researchers are increasingly recognising the advantages of properly conducted PPI to all aspects of the research process. While it may require investment it is increasingly regarded as a gateway to introducing skills, contacts, and perspectives that may not exist within the research team and less as merely another hurdle to be jumped in the research process.

In addition, public funding agencies see increased citizen involvement in research as a way of promoting greater transparency, accountability and therefore trust in both research investment and scientific output generally.

Project level benefits cited by research charities include the following:

- Bringing in the lived experience involving contributors who are experts in their own lives and experiences provides a holistic view that can clarify relevance and importance of research and aid in identifying and overcoming potential barriers with practical insights.
- Keeping it real PPI contributors can challenge stereotypes and unspoken biases.
  Their presence can help crystallise the importance of achieving success in research and lead to a research environment that is more empathetic to patient needs.
- Keeping it going PPI contributors provide a gateway to the needs and perspectives of other patients and carers. They can help with recruitment, dissemination of results and can act as a powerful advocate for the project.
- Practical skills and contacts contributors may have other skills such as media experience, contacts within the public and private sector and access to a funder.

## PPI Question in the HRCI HRB JFS Application Form

The Joint Funding Scheme application requires a clear description of the role and influence of PPI in the identification, prioritisation, and design of the research project and the anticipated role of PPI in its conduct, analysis, oversight and dissemination. The PPI question is worded as follows:

#### 2.5.6 Public and Patient and Carer Involvement in the Research Project (maximum 600 words).

Important: The PPI section needs to be written as a plain English summary such that it is clear, easy to understand, and is easily accessible to a lay audience.

Are you including PPI in your application?

If Yes: please describe all PPI at each stage of the research cycle:

- Identifying and prioritising the research question
- Design
- Conduct
- Analysis
- Oversight
- Dissemination

*If No:* please explain why PPI is not relevant to your project.

## **Other Resources:**

Health Research Charities Ireland have developed three **Case Studies of PPI Excellence** in Joint Funding Scheme Applications – these can be accessed <u>here</u>.

An **updated video presentation** for researchers interested in the scheme is available on the HRCI YouTube channel available <a href="https://example.com/here/">here</a>.

**PPI Ignite University Contacts** can be found <u>here</u>

# **References:**

HRCI and Trinity College Dublin (2020) Making a Start - A toolkit for research charities to begin a PPI Relationship, Dublin: HRCI.

HRCI website - www.hrci.ie