

Document on: Public and Patient Involvement (PPI) in Research

April 2015

Introduction

A formalised and widespread approach to PPI is a relatively new concept in Ireland and yet one which has gathered considerable momentum in a short space of time.

The Irish Health Research Forum (IHRF), a collaboration of key stakeholders aiming to influence health research in Ireland, chose the topic of PPI for its first forum meeting in November, 2014. The meeting focused on best practice examples in Ireland and internationally, the need for a culture change in how the research community engage with patients and the public and highlighted the value of doing so.

The Health Research Board (HRB) has recently taken steps to actively involve the public in the research they fund. Researchers seeking funding are now asked to provide details in their applications of any public involvement in the design, conduct or outcome dissemination of their study. This provides a first step in the formalised engagement in PPI by a State funding agency in Ireland and is likely to result in increased awareness and participation in PPI by the health research community.

The aim of this document is to assist researchers, policy makers, institutions, the public and patient's to gain a better understanding of what PPI is and how to go about it.

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



About PPI

Public and patient involvement (PPI) occurs 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 INVOLVE (UK) definition of PPI is widely used and defines public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.

The goal of PPI is to achieve a true partnership between public/patients and researchers, leading to improved research quality, relevance and outcomes.

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

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

It is important to realise that there are a range of PPI activities (which can overlap). All approaches are valid and the level of PPI should be tailored to a particular project or initiative.

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.

One of the best examples of PPI is from the Canadian Institutes of Health Research, where the goal of the Strategy for Patient-Oriented Research (SPOR) is for patients, researchers, health care providers and decision-makers to actively collaborate, in order to build a sustainable, accessible and equitable health care system and bring about positive changes in the health of people living in Canada. Engaging patients is thus an integral component in the development and implementation of all elements of SPOR. SPOR has developed a Value Model for Patient Engagement which reflects how researchers, health care professionals and policy-makers work together with patients to ensure a patient-oriented approach that improves both practice and treatment. Patients provide input on identifying health research priorities and participate in the design and undertaking of research projects. As a result, research is conducted in areas that patients value; researchers understand the value of patient involvement and patients understand the value of research. Ultimately, patients influence and accelerate decision making, translation and uptake of new practices, leading to improvements in patient experience with the health system and health outcomes.

The key points on PPI that emerged from the IHRF meeting

It is acknowledged that implementing PPI in Ireland will require a culture change and that different groups have different aspirations around PPI.

A. Implementation

1. Spectrum of PPI
 - There is a spectrum of health research types, each requiring different levels of engagement.
 - There is a spectrum of participation, ranging from information to partnership.
 - There is a spectrum within the process. PPI can impact on the nature of the research question through to the conduct of the study and helping to implement outcomes.
2. PPI should not be forced upon people, a step by step, incremental approach should be considered.
3. Resourcing of PPI is important and can involve the following broad costs:
 - The cost of researchers' time.
 - People engagement costs.
 - Education and awareness costs.
4. Education and training around the processes of PPI is vital both for researchers and public/patients.
5. Organisations should ideally provide assistance with involving patients/public

(There is a role for patient organisations within PPI. However, there is also a role for individual participants.)

B. Outcomes of successful PPI

1. Case studies have indicated potential benefits in terms of improvements in research, but this requires further study.
2. Patients involved in PPI feel more empowered.
3. Dissemination of research information
 - Tailored to appropriate audiences.
 - Articulated in lay terms.
 - Feedback loops, "virtuous circle".
4. PPI has the potential to inform research funding policy and allocation.

C. Making PPI work

1. It is important to recognise that there are different levels of PPI and there are some particular challenges to overcome, including
 - Deciphering how to undertake PPI in basic biomedical research.
 - How to bring resistant people on board.

- Avoiding castigating researchers and understanding their research perspectives.
2. Patients should be valued for their experiential knowledge, however, they should not be treated as 'amateur researchers'.
 3. It is important to be aware of, and avoid tokenism in trying to implement PPI.

D. Way Forward

1. It is important to articulate the benefit and value of PPI to all stakeholders.
2. Studies that assess the value and benefit of PPI are required.
3. Assistance for stakeholders, to facilitate them incorporating PPI into their research/institutions/strategies is needed.

For a more detailed overview of the meeting discussions and outcomes, Click here for the meeting report or go to our website www.ihrf.ie

The role of Patient Organisations

Patient organisations have long played a role in acting as a lynchpin between the patients they represent and the research community and, by their very nature, they represent a very tangible form of PPI. In Ireland, the role of patient organisations in the broad sphere of health research is evolving and growing in importance. These organisations play a role in educating and involving patients in research, in tackling the many barriers between the 'bench and the bedside' and in ensuring that the outcomes of research are effectively translated into patient benefit. Below are a number of brief examples of the myriad of ways in which patient organisations practice PPI:

- The Irish Cancer Society funds a large percentage of the cancer research undertaken in Ireland.
- Fighting Blindness is instrumental in the development of a patient registry to underpin research into blindness.
- Cystic Fibrosis Ireland has been a key player in ensuring patient access to the outcomes of research, i.e. innovative, therapeutic drugs.
- DEBRA Ireland is instrumental in ensuring that the outcomes of research are translated into clinical care, through the development of evidence-based clinical practice guidelines.

The further development of PPI in respect of broader areas of health policy

Increasingly the public/patients and, in particular, patient groups in Ireland are involved in helping to shape areas of health policy and management in Ireland that is broader than a specific focus on research. Recent positive examples include: national policy on rare disease; participation in disease specific national clinical programmes; participation in the design of clinical trials and participation in the approval processes of new and innovative therapies. While some of this participation is at an early stage, the principles identified in this paper can be usefully adapted for other areas of health policy and administration.

Useful links

INVOLVE www.invo.org.uk
PCORI www.pcori.org
SPOR www.cihhr.ca under 'Strategies'
www.sph.uwa.edu.au
www.twocanassociates.co.uk/routemap

For examples of Researcher Testimonies please go to our website www.ihrf.ie

*This document was prepared by a Sub-group of IHRF Steering Group.
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