



## Patient reported outcomes

**Date of Discussion:** June 20<sup>th</sup>, 2016

**Location:** Patient and Public Involvement Summer School, University of Limerick, Ireland

Patient reported outcomes (PROs) are increasingly acknowledged to be a key part of good clinical research. In producing new medicines, we must not only measure the clinical effectiveness of a treatment, but also the acceptability and desirability of a treatment's outcomes for patients – and we must acknowledge that these two measures do not always tally. For example, researchers may be more focused in looking for the 'cure' or a ten-year improvement in mortality, while patients may be more interested in immediate relief from for example, pain, fatigue, nausea.

While participants agree these two measures do not necessarily need to align, they emphasized that value and resources need to be attributed to both. PROs (as a qualitative measure) are perceived by many researchers as a less reliable, a less scientific measure. Therefore a move towards recognising the benefits of more patient-centered research needs to happen. Undertaking to measure PROs requires the re-allocation of precious human and financial resources, but it is hoped that researchers and patients will soon come to a mutual appreciation of the added value of measuring the patient experience.

Participants underlined that PROs should be embedded in research from the very beginning; and they prefer that only when patients are routinely included in priority setting, trial design and other important aspects can *quality* PROs be incorporated into the research management and review process.

As patient involvement in early research and PRO development is new to both patients and researchers, identifying PRO concepts and setting the methodology for measuring these concepts are precise and important steps. Joint training is therefore recommended to ensure that PROs are robust and capture information which is genuinely important to patients rather than information which others think may be important to patients. Education of patients will help foster the confidence they need to say *what they want* measured and to understand *how* measurements are compiled, assessed and presented as evidence.

*This discussion paper was produced from an IPPOSI-facilitated workshop that took place at the PPI Summer School in the University of Limerick, organised by the University's Health Research Institute in June 2016. The workshop was facilitated by Laura Kavanagh and Derick Mitchell of IPPOSI, with three EUPATI fellows: Damien Peelo, COPD Support Ireland; Caitriona Dunne, Fighting Blindness; Rachel Lynch, Fibrolreland. Participants included patient and community organisations, health researchers, public research funders and postgraduate students.*



### Useful resources:

- All outputs from the 2016 workshop are available at the link below:  
<http://www.ipposi.ie/patient-experts-action>
  - The Irish Platform for Patient Organisations, Science and Industry (IPPOSI)  
<http://ipposi.ie/>
  - The European Patients' Academy on Therapeutic Innovation (EUPATI)  
<https://eupati.eu>
- 

*This discussion paper was produced from an IPPOSI-facilitated workshop that took place at the PPI Summer School in the University of Limerick, organised by the University's Health Research Institute in June 2016. The workshop was facilitated by Laura Kavanagh and Derick Mitchell of IPPOSI, with three [EUPATI fellows](#): Damien Peelo, COPD Support Ireland; Caitriona Dunne, Fighting Blindness; Rachel Lynch, Fibrolreland. Participants included patient and community organisations, health researchers, public research funders and postgraduate students.*