



## Ethics Review Process within Medicines R&D:

**Date of Discussion:** June 22<sup>nd</sup>, 2017

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

Within the discussion on the ethics review process, positive aspects to the process were noted, including the protection of patients, who are a diverse group of people. However, many also noted that the process is seen as an administrative burden and people can interpret ethics in a different way because of different agendas and backgrounds. Additionally, it was acknowledged that patients have a different perspective on medicines that include their lived experiences, and this viewpoint is regularly not accounted for by research ethics committees.

One recommendation to address this was that the ethics review committees should have a specific patient representative and not just a lay representative. Second, there needs to be increased transparency around the selection of committee members and the publication of the decisions of the committee. There are multiple reporting lines and it should be clear how the members of the review committees are picked as well as how the committee makes decisions about medicines R&D.

An additional recommendation was the establishment of a larger independent body to oversee and review all the research ethics decisions in Ireland, and this could potentially be run by HIQA. This would create a standardised ethics review process and guarantee that individual research centers are not making different ethical-based decisions. The establishment of this body and the way ethics reviews are conducted could benefit from observing practices abroad, like in the United Kingdom. In other countries, patients are more involved and there are systems of national oversight and standardisation, and by looking to those countries, Ireland can take advantage of the opportunity to bring researchers and patients together to improve ethics review processing.

*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 2017. The workshop was facilitated by Laura Kavanagh and Gemma Killeen of IPPOSI, with two [EUPATI fellows](#): Joan Jordan, MS Ireland; Julie Power, Vasculitis Ireland Awareness. Participants included patient and community organisations, health researchers, public research funders and postgraduate students.*



### Useful resources:

- All outputs from the 2017 workshops 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>
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