

With the publication in December 2018 of the **IPPOSI (IRISH PLATFORM FOR PATIENT ORGANISATIONS, SCIENCE & INDUSTRY) CHARTER FOR PATIENT INVOLVEMENT**, we discuss the value of patient involvement in the medicines reimbursement process, the key proposals of the charter, and the next frontier for patient involvement in Ireland.

## Patient Involvement in Medicines Reimbursement

In recent years it is increasingly accepted that there are important equity and scientific reasons for incorporating patient involvement into the medicine assessment and reimbursement processes. Firstly, as key stakeholders, patients have a right to a seat at the table. Secondly, only patients can truly reflect the day-to-day experience of living with a specific condition, and how they would expect a different treatment to impact quality of life. This information is crucial to weighing up the costs and benefits of new interventions.

Commitment to meaningful patient involvement in medicines reimbursement in Ireland is steadily growing. In 2016, the National Centre for Pharmacoeconomics (NCE) launched their Patient Organisation Submissions Process, allowing patients to give evidence during Health Technology Assessments (HTA). The process was refined via public consultation in 2018. Additionally, in collaboration with IPPOSI, the NCE deliver a patient education module on the HTA process. However, there is no patient engagement as of yet at a decision-making level within the HSE.

## IPPOSI Charter Overview

In December 2018 IPPOSI published their **Charter for Patient Involvement**, aiming to radically expand the patient involvement remit. The charter was developed with the input of IPPOSI's patient membership, to address their concerns about lack of transparency and accountability in the Irish HTA and decision-making process.

The Charter was divided into six broad themes, calling for;

- 1) commitment from the HSE to increase patient involvement
- 2) earlier engagement in the proceedings
- 3) better education and training programmes
- 4) more emphasis placed on patient and clinician evidence
- 5) more transparency and more timely communication
- 6) the right to appeal

## Reading Round-up: Patient Involvement in R&D

1. *Increasing Patient Involvement in Drug Development - Lowe, Maria M. et al., Value in Health, Volume 19, Issue 6, 869-878.*
2. *Partnering with Patients in the Development and Lifecycle of Medicines: A Call for Action - Hoos, Anton et al., Therapeutic Innovation & Regulatory Science, Volume 49, Issue 6, 929-939.*
3. *EUPATI Guidance for Patient Involvement in Industry-led Medicines R&D*

## IPPOSI Charter Policy Proposals

IPPOSI detailed some specific, actionable policy proposals which includes the establishment of a Patient Advisory Panel to guide the HSE in this area, advising

- the nomination of patient representatives to HSE assessment committees and decision-making groups
- the introduction of a payment to compensate patients who actively participate on such committees and groups
- sharing of relevant HSE meeting agendas, minutes and supporting documents with patient communities and interested members of the public.

Similar initiatives are already practiced in countries such as England, Scotland, and Canada. The IPPOSI charter has drawn from international best practice, as well as guidelines for patient involvement in HTA written by **the European Patients' Academy on Therapeutic Innovation (EUPATI)**, **the European Patients Forum (EPF)**, and **Health Technology Assessment International (HTAi)**. There is an acknowledgement of the need to bring Irish policy in line with these standards. IPPOSI plan to convene a working group consisting of the patient organisation signatories of the charter in early 2019 to ensure the recommendations are actioned quickly and effectively.

## Patient Involvement in R&D

IPPOSI's policy proposals have the potential to change the Irish reimbursement landscape, improving both the quality and equity of decision-making in the reimbursement landscape. The pharmaceutical industry now has an opportunity to take inspiration from the Charter and invest in developing their own patient involvement standards, as patient involvement is as important in the development of new treatments as it is in the reimbursement process. Listening to patients leads to the creation of more valuable products, by ensuring that research that addresses unmet needs is prioritised. Patient input can also help design trials that avoid potential barriers to patient participation, and therefore improve recruitment and retention.

## \*\*\* KEY TAKEAWAYS \*\*\*

- ◆ Early engagement with patients and/or patient groups is essential for equitable, high quality and comprehensive Health Technology Assessments.
- ◆ Patient involvement needs to be a key priority for decision-makers, HTA assessors, and the pharmaceutical industry to ensure an in-depth understanding of the impact on patient's quality of life from various diseases, and to thereafter ensure innovative, effective treatments are made available to those with significant unmet need.
- ◆ Patient involvement is growing and the impact it will have on the reimbursement landscape will be significant. It is vital for industry to work with groups such as IPPOSI to ensure the patient voice is represented at every step.
- ◆ Additional resources may be required to enable early and effective patient involvement with HTA.