



Health Technology Assessment

Date of Discussion: June 20th, 2016

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

Patient involvement in health technology assessments (HTA) gives a voice to patients at a critical stage in the medicines research and development process, namely the review which determines whether access to this medicines will be granted or denied by the national health service. HTA is enhanced by input from patients based on experiential or lived evidence; input which offers the opportunity to make recommendations that are not solely based on budget restrictions, cost effectiveness or quality of life assessments. Patient involvement is perceived as particularly important in HTAs considering medicines for rare diseases where the cost per patient may be high due to the low number of potential users.

While patient involvement in HTA has merit in itself, it was suggested that patient involvement at earlier stages of the medicines research and development process leads to a wide range of benefits, including in this instance an improved dossier presented for HTA. For example, involving patients in developing robust patient reported outcomes can ensure that HTA officials automatically have the quality evidence they need.

Transparency is an important consideration when discussing HTA. Firstly, there should be transparency around who is involved in HTA, and this applies equally to patients as to other stakeholders. Care needs to be taken to determine whether patients are being asked to comment as individuals with their own personal experience or as representatives of a larger group of patients. There are some concerns that smaller organisations or individual patients may be less equipped, and therefore less likely, to engage in HTA. Participants spoke about the 'missing voices' which may have no representation, and about the 'dissenting voices' which are needed to ask the difficult questions and raise the unpopular views.

Other discussions on transparency centered around what is reviewed in HTA, and how patients are notified of upcoming reviews. The current mechanism of patient involvement is through a process of submissions, but participants questioned whether the burden of involvement fell to the patient to proactively involve themselves. Transparency concerns are also evident in relation to how the recommendation of the HTA informs the final decision –

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in the case of Ireland, the decision made by the HSE Drugs Committee. Currently participants are unaware of any patient involvement in this Committee, or of how patient input into HTA recommendations is considered (if at all) by Committee members.

Participants agreed that HTA is a very complicated process and that patients need some form of training to ensure that they understand the procedures, the language and the outcomes. While patients benefit from an enhanced understanding of the HTA process, it was also suggested that the process should adapt to become more patient-friendly. As an example, it was proposed that HTA agencies explore creative ways to capture patient information and capture a diversity of patient views. To facilitate this change, the HTA agency might invite patient advisors to review the HTA process in general, as well as respond to individual HTA reviews. It was deemed necessary to require each HTA review to incorporate the patient voice.



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>

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