The extent of patient involvement in HTA processes

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Transcript

[To what extent have you or your organisation been involved in HTA processes?]

Jan Geisler – Patient advocate and Project Director for European Patients’ Academy on Therapeutic Innovation (EUPATI)

I have been involved in HTA on multiple levels.

First of all, I’m acting as a patient advocate, both on the European and the country level. And, some years ago, when the discussion started about patient involvement in HTA, I tried to engage on the European level to make sure that there’s a European framework that stakeholders like patients can actually contribute to the process.

In terms of my involvement as a patient advocate on the national level, I’ve contributed by taking part in appraisals in a sense that I was providing statements on the specific drug that was up for assessment in Germany.

The impact of participation in HTA in Germany is pretty much unknown at the moment because it’s a pretty new process. We haven’t had the new medicines law which actually requires value assessments only for a quite short period of time.

I myself have been involved in two appraisals while I was writing statements on behalf of my organisation on our perspective on the value assessment of these two drugs.

Mary Baker – Immediate Past President European Brain Council; Patron of the European Parkinson's Disease.

So the first thing I did when I was the Chief Executive of the Parkinson's Disease Association in the United Kingdom: I went to meet Sir Michael Rawlins.

I wanted to understand from him what exactly was involved, so that I may see him as not a barrier, but part of the journey of trying to get the patient voice involved with this new regulatory procedure.

Eibhlin Mulroe – CEO, Irish Platform for Patients Organisations (IPPOSI)

The national Centre for Pharmacoeconomics in Ireland perform most of the HTAs and assessments on drugs and on pharmaceutical products. And in the last year, they've started to reach out to IPPOSI in particular, to link them in with patient representatives in cases where pharmaceutical products are not reaching the – they're not passing – and where they need further information from patient groups.

We'd like to take that a step further in Ireland and make it a process whereby as a matter of form, when an HTA is being performed by the NCPE, the patient involvement is there from the beginning. And that's a challenge, that's new. But it's a challenge right across the board. This is something that patient groups all across Ireland, Europe, the world are trying to get involved in.

And there's a group called HTAi – which is the Health Technology Assessment International – that have a particular unit that looks at patient involvement in HTAs. And we've been doing some work with that group to look at other countries in the world and what they do in terms of bringing patients into the mix.

And I suppose the big thing within the States and the change –

there’s a change happening in terms of where patients get involved in medicines development. It’s not just within HTAs or even protocol stage of clinical trials. The FDA are actual reaching out to patient organisations and asking them to think about patient outcomes before the process even begins – before a medicine’s development even begins. And I think for that to happen in Europe and across the US, we’re going to need to train patient representatives on what that actually means.

And I think there’s a lot of people out there that are ready for that, and there’s a lot of people out there that need to learn. And that’s where EUPATI will really come in.

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