

Best practices for patient involvement in HTA processes

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Transcript

[Do you know of any best practice in HTA patient involvement?]

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

I think in terms of patient involvement, looking at the UK at least, we can tell exactly where patients are involved. There's quite a nice brochure from NICE which outlines patient and patient involvement in this appraisal process. And where it actually tells where patients are involved, where advocacy organisations are being involved, and which decisions are being made without any patients present.

I think that transparency helps quite a lot to understand how can I bring myself in. Am I being asked as an individual patient with my own personal experience? Or am I being asked as a representative of a larger group of patients?

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

I think patients start all of this negotiation on the back foot. It's really very similar to somebody trying to conduct their own case in the legal system. There is a language of negotiation.

And this is what we found by going to the London School of Economics and asking if they would work with us to develop a

course at the LSE, a three-day course that would explain to the patients exactly what HTA was about. How they could best learn the language of negotiation. How they could best draw upon evidence, and to feel confident and not concerned at how they would negotiate with professors, medical doctors, and all the rest of it.

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

Well, I know the Health Innovation and Quality Authority have patient involvement on the advisory board of the particular HTA that they're doing. And that's a good example of patient involvement right the way through. Our arguments around that is – and they take this on board – is that those patient representatives need to be fully informed, and trained, and really feel that they can be part of the process.

And those that interact with them on the advisory board also need to be trained. That they're, you know, this is a patient representative from the public. And how to engage at that level as well is really important.

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