

What is meaningful patient involvement in HTA?

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Transcript

[What does good and meaningful patient involvement look like?]

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

Well, I think on one hand it is important that patients are involved in all aspects of decision making. I mean, we can't be part of every vote, but we can be transparently in any committee that is taking decisions on behalf of patients. And secondly, I think what is very important is that there is transparency. Who's taking decisions, and to what level patients have been involved in decision making.

I think more transparency on the whole process will make our life much easier, will create better decisions on behalf of patients as well.

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

I remember to begin with, I saw that the payers and the regulatory system were barriers. And then the more I got to engage with them, I understood they were part of a very difficult and complex process. And one with which I should engage in. And the more I engaged in it, the more I understood why they were there and the challenges that they faced themselves.

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

I think it's a really good time to ask that question because we've just had the National Centre for Pharmacoeconomics partner with us for a EUPATI event actually in Ireland to train patient representatives and HTAs. And it's the first kind of event of this kind that targeted the patients directly.

And one of the outcomes from that is, it's great to talk to us. You know, when you're at that point where the HTA is nearly complete and a decision has to be made on access by the government to bring patients in. That's very positive.

But the other – there's another opinion. And that's where patients come in at the very start with their data. A lot of patient organisations have registries. They have information on their patient population. There are opportunities there for patient organisations to really get involved at a different, at a really kind of technical level in the HTA process.

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