

Overcoming obstacles to patient involvement in HTA

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Transcript

[What are the obstacles to patient involvement in HTA and what can policy makers and patients do to overcome these obstacles?]

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

I think one of the barriers that we experience is that patients are being seen as being biased or having interests. And that, of course, hinders the process because there's always an argument to claim that somebody is being influenced by anyone. But we need to rationalise that discussion because I think everybody has an interest.

What I think is most important is to declare the interests and then let patients and everyone actually participate in the process to bring their opinion in. That really helps a lot.

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

So, there are barriers, but once you start engaging, once you start rubbing shoulders with the payers, the regulatory bodies, you find one big lesson. They're very anxious to help you. They're very anxious to try to involve you. They're not dismissive. And I really found that encouraging.

Eibhlin Mulroe – CEO, Irish Platform for Patients

Organisations (IPPOSI)

The biggest barrier from where I'm sitting in Ireland is education. And that's not just for the patient organisations but it's for the regulator. And the agencies themselves, they need to be educated on why it's important to have patient involvement in HTAs.

And again, that's the brilliance of EUPAT coming at this time, for Ireland and for all of the countries in the EU, because we need some help in terms of how we communicate that message to the HTA agencies. So they reach out and bring the patients in a systematic way. We have to communicate the value of patients being involved in the process to those regulators, to the governments, and to the decision-makers.

And on the other side of that coin, we also have to communicate that to the patient leaders. Why they need to, why it's important for them to be involved in the HTA process. And I take that a step further, why it's important for them to be involved in the medicines development process from the very beginning. And because I think patient-related outcomes is where patient organisations need to be at.

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