The benefits of patient involvement in HTA processes

”Enhance your reading experience by turning on the subtitles of the accompanying video.”

Transcript

[What are the benefits of patient participation in an HTA process?]

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

I think it is crucial to have patient advocates and patients in that process, because patients and patient advocates are actually the experts for a lot of things that concern life of patients with a certain disease and the treatment.

They are the experts on quality of life. They know how it is to live with a disease. They can probably assess one against the other because we must be very, very clear that medical efficacy is one of many factors that affect patients’ lives.

So talking about endpoints, talking about comparators, talking about the importance of certain quality of life parameters is something that patients can quite well understand and probably help assess. And what we see as patient advocates is that there’s a very different perception on the impact of certain side effects, of disease symptoms and so on, on the life of a patient. So doctors have a very different perspective. Health economists have a very different perspective on the impact. And I think that you can’t be assessed without those that get the treatments.

Mary Baker – Immediate Past President European Brain Council;

Patron of the European Parkinson's Disease

I think it's really important for the patients that the association to which they belong becomes a real strong advocate of their voices and their experiences. Because unfortunately for them, they are the experts in living with these illnesses 24 hours a day.

And therefore, the expert patient – the living with – is really important to get into the process. I think it's important for them to understand what health technology is about. I think it's important to gather evidence to back up your views. You've really got to understand the process and follow it most carefully.

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

I suppose a really good story to explain what the benefits are about is this: In Ireland over a year ago there was a case where patients weren't involved in the process. They didn't know why there was a stall, why it was slow for the product to get to the market. And this product was for patients with serious, life-threatening conditions.

And so what the patients in that case did, they went to the Irish media. They went to the Minister for Health. And they created a huge campaign where this was discussed on talk shows and radio shows. And this is where sick people were forced to go that direction because no one in the agency would talk to them. And it's not that they said n. It's just they had never done that before.

And I think that's where the learning came in. The communication's really important.