

Patient organisation involvement in HTA processes

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Transcript

[Are you aware of other organisations who have been involved in HTA processes?]

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

The cancer associations, and I certainly know that Jean Mossman was involved when she was the Chief Executive of BACUP, cancer BACUP.

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

There's a very different experience between countries and the UK. HTA has had a long history already, if we can talk about long history, of patient involvement in the HTA, and I think over the years NICE and the patient community and the regulators have discussed a thorough process and have described that very transparently, at which stages of the HTA process patients can be involved.

In Germany, as a comparison, I think we are pretty much in an infancy on that. At the moment, there are certain points where patients can be involved, and accredited patient organisations can send representatives to the hearings and they're also involved in some kind of committees during the floor of HTA assessment. But I would say at the moment it is not 100% transparent who can participate, when they can participate,

and especially how they can contribute.

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

The Irish government don't look at medicines for rare conditions through a different lens.

They assess them in exactly the same way as they would assess a treatment for diabetes or a treatment for asthma. And I suppose there's a certain – a lot of the assessment processes used by our HTA authority are good, and they do look at the efficacy.

They look at other areas, they look at cost effectiveness. But what we would suggest that we need patient involvement there more than ever, because high-cost treatment is never going to be cost-effective, particularly an orphan drug. And so we need to look at the ethics around access for patients. And I think that again, is another example where patient involvement is really important.

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