

Moving beyond patient to public involvement in HTA

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Transcription

[Should stakeholder involvement in the HTA process extend beyond patients to include the wider public?]

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

Quite often, we are mixing different stakeholder groups and thinking that consumer groups and patient organisations are the same. And they're not, because they have different objectives and they have different opinions, also on priorities. I think all of them need to be involved because, of course, payers have an interest in the budgets. Patients have an interest in survival and in quality of life, and in well-being of citizens. But only, probably, they are representing, mostly, those that have the problem of not being healthy. So they might have a different perspective than the general population.

So yes, I think all citizens need to be involved, and all different stakeholder groups need to be involved.

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

I think the societal impact is, honestly, so important in the United Kingdom. We are an aging population. We are an infertile population. We have the worst sexual health across Europe because of teenage pregnancies. We're still smoking,

still taking drugs. Now we've added alcohol and obesity. And as Michael Rawlins would tell me, that's 60% of the NHS budget gone, and that's before you've got a disease on the table.

So you have to understand the perspective of where your patient association is coming from. Because when you're working with the people living with these illnesses, you do think that that's the most important, the most central thing. But actually, it's all part of society and we have got to pay a certain attention to our own lifestyle.

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

This is something that IPPOSI have been talking about for five years, in every single event and report and consultation we've been involved in with the HTA agencies here. We've asked them to start to consider the cost to the state of not treating someone. And that includes if there's a carer in the home who is looking after a patient, who will no longer need to look after the patient if they have access to the right treatment. That carer can go back into the workforce and pay tax. That's money back into the system.

And I certainly learned that hasn't really been factored in. And from our perspective – from the patient perspective – we don't really see that that's really factored in in the process.

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