How can regulators strengthen the patient voice in HTA?

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Transcript

[What practical steps should regulators take to strengthen the patient voice in HTA?]

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

Well, I think there’s a very practical suggestion in the sense of ‘Try it.’ Because quite often we’re looking for the big system to have the all-encompassing answer to everything. But I think, what we can see, for example, in EMA, I mean, it’s been a long process since 2005, since patient groups were involved all across the board in EMA committees.

And there’s always a big discussion around patient involvement, could it be more, is it adequate, and so on. But I think by, let’s say, taking courageous decisions, and involving patients, the feedback that we get today, that the contribution is essential, is very valuable. Patients are educated, patients are training themselves, patients are willing to bringing their voice on a confident sway. And I think that has been one of the crucial success factors also on our end. Because we, as a community, as a whole, invested a lot into educating our community to be a valuable partner for these kind of processes.

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

We’ve been watching, in terms of orphan drugs, and what happened in England, where they developed AGNSS, and which was specifically for ultra-rare conditions. Where, you know, the assessment wasn’t about a QALY, or life-years gained. The criteria was different.

As part of that criteria, patient involvement featured heavily. And that’s a system that we thought was good. Scotland is another system that we’ve looked at, and we’ve done actually a lot of work with Karen Facey, who is a health technology assessment expert in Glasgow, and who is actually doing a piece of work for HTAi at the moment. And I think, as a result of knowing here, we’ve been involved in that piece of work, where she’s developing a form which could be used by patient organisations and HTA agencies, as a tool to submit on HTA. So this form would be a template that could be used right across the board.