The contribution of patient involvement to policy

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Transcript

[Has patient involvement in your view contributed to the development of healthcare policy?]

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

I think patient advocacy has had a great impact over years on health policy and increasingly we’re getting heard more and more. When I started patient advocacy back about 12 years ago, I think patients didn’t really have much a voice in the European healthcare debate and healthcare policy. And also, on the national level, I think patient involvement was pretty much a new concept.

Today we sit in committees, we’re being heard by the European Commission, by the Parliament, by the European Council. We are a part of the EMA (European Medicines Agency) committees because people appreciate that we have a certain perspective what is most important to patients.

I think over the past years we’ve had numerous opportunities to bring our perspective in, and I think really it has had an impact on legislation.

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

Well, I like to think that the patient organisations, I think depending on their age and experience, are realising every day that they must be involved, with all the challenges that are in the system. After all, it takes I think it’s 13 and a half years to get a medicine from the bench to the bedside. And that involves, of course, the eight years in development, which I think patients also should be involved in.

Then, the regulatory process, the clinical trials. And then, of course, the HTA, which demonstrates the societal benefit. And I think that has been quite difficult for patient advocates to get their heads around.

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

I think a really good example, from IPPOSI’s perspective, is rare diseases because we’ve done a lot of work over the years. I’ve been in this job seven years. From the day I started, Rare Disease Day was a big part of what we do, and getting patients involved in policy around developing national plans for rare diseases.

And in Ireland, what is a really good example of patient involvement is this, because patients are actually sitting at the table in the Department of Health, in the ministry, writing the plan for rare diseases. And I know that in other countries patients have been consulted, consultations have been organised by ministries, but I think we’re quite unique in that we’re actually sitting – and I’m one of those patient representatives, there are four – who are sitting around the table with our department of health, with our health technology agency and with members of staff from the minister’s office and we’re actually writing the plan.

And I myself chair the subgroup which is developing a strategy for access to treatments for people with rare conditions. And I think that’s a really good example of where patients can really not just influence policy, but be involved in crafting it.

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