

Interview with Victoria Thomas

Transcription

Hello, my name is Victoria Thomas and I'm the head of public involvement at organisation called the National Institute for Health and Care Excellence, also known as NICE, based in the UK.

NICE is a national organisation in the UK charged with producing guidance on the use of individual drugs and devices and pathways of care for the patients of UK health service.

I run a small team of people whose sole purpose it is to ensure that the voice of patients, care givers, and the public is represented in everything that NICE does. When NICE was established in 1999 it set out to ensure that that voice was always heard. This isn't something we've had to add on at a later date, it's something that's always been part of the way we've worked. As NICE has expanded over the years and the team to support this work has expanded, we have increased the number of people we work with over to the stage where we are supporting about 250-300 people at any one time. We have a combination of involvement strategies whereby we work with organisation that speak on behalf of patients and service users. We also work with individual patients, and carers, and service users. They form part of our decision making committees.

The fact that this has always been a part of NICE's work I think has been really important for us. Many other organisations I see trying to add on patient involvement to their work and finding it very difficult. I think we have

always had support from our senior management team and from our board which has really helped. What we've noticed over the years is that the outcomes of our work, the products that we are producing, the guidance that we're writing is better as a consequence of having patients and carers in the room and supplying us with the evidence that's important to them, so that we can make decisions that are as relevant for the population that they're intended for as possible.

HOW DOES NICE INVOLVE PATIENT EXPERTS IN ITS WORK PROCESSES?

We work at a consultative level with patient organisations. Anything we produce we put out in draft form so that they can comment on and give us a benefit of their views. We ask them to submit evidence that they may have that we're not aware of that we wouldn't pick up in a normal literature review. Alongside that, and very importantly, and probably the bulk of the work that me and the team do is the direct involvement of patients and carers on our committees. We would recruit people at the start of a committee being developed. We would put out an ad on our website and ask people to apply to join very much like they would apply to join for work application. We have a job description, we have a person specification, and we ask people to apply if they're interested in a particular topic or in working in a particular field. We have a combination of people who are general patients who've got a general interest in the health service and health services and we also have people who are very interested in a particular topic. We might have someone who wants to work with us who has an interest in eating disorders or schizophrenia or epilepsy or any number of different topics. We would recruit those people to work alongside health care professionals and social care practitioners, academics, researchers, to work in a multi disciplinary way so that we ensure we have a patient focus in everything that we do.

WHAT ARE THE CHALLENGES IN THIS KIND OF WORK?

Sometimes we have a challenge that as a national organisation we have to make decisions at a population level. We're having to make decisions about what the best care might be for an overall population of patients say with a particular condition. But individual patients might well have very different views about their care, they might have a very particular experience of care that's very different from that population average. Sometimes there's a potential tension between what the individual patient wants to achieve from their care and what might be best practice according to the evidence and might be best practice for an overall population. And so we started working in a field that's called shared decision making as well. We bring ... we're trying to bring the conversation between the patient and the clinician together so they can work together to come up with the best possible solution for that individual patient.

HOW HAS YOUR WORK CHANGED OVER TIME, AND WHAT OTHER CHANGES WOULD YOU LIKE TO SEE IN THE FUTURE?

When I first started working in this field, which is very many years ago now, we came across quite a lot of people who didn't think this was a valuable exercise, who didn't think this was worthwhile. I've seen that change over the last 15 years. We get far fewer of the people who think that we're being politically correct to have a patient in the room. People are starting to see the value much more. Nobody questions it in the way they did 15 years ago.

If I could change anything I think I would have more patients in our groups. I think I would balance those committees more so that we have a stronger patient voice. We have at least 2

patients in the room in any one of our committee meetings but sometimes that's not enough. You need a far greater range of views and experience.

There's something that happens when you bring someone into a room and they can interact as an equal with health care professionals and academics and professors and ... the fact that everyone is in the room as an equal partner in an endeavor does something really magical to a patient sometimes. It allows them to feel self confidence and enhance self-esteem.

There's something really fantastic about this work that not only helps us as policy makers make really good decisions with and for patients, but actually really gives something back to the patients themselves. They really get something out of it as an individual too.