Interview with Karen Facey

Transcription

My name is Karen Facey. I am a statistician by training. I've worked in drug development, medicines regulation and health technology assessment. Since being involved in health technology assessment for sixteen years, I've developed a passion for involving patients in the difficult decisions we have to make about health technologies. By health technologies, I mean medicines, medical devices, rehabilitation, really any kind of health intervention.

Health technology assessment is a systematic process of reviewing evidence about whether a health system should introduce a new health technology, that is a medicine or a device. It takes evidence from clinical studies, but it also may look for other forms of evidence about patients' experiences of living with a condition or of using a technology and from all this scientific evidence, it's trying to understand the implications of using that technology. Does it add value? Should we invest money in this new medicine? Is it really value for money? This systematic process takes evidence from international clinical trials, from research studies and hopefully from patients.

HTA is trying to help health services make these difficult decisions about what health technologies, medicines or devices to invest in. When it looks for scientific evidence to understand the implications of using the new technology, the evidence might not be perfect. We might have quite limited clinical trials over a short period, looking at outcomes which perhaps aren't the most important to patients. Patients can help us fill the gaps in the scientific evidence. They can help us understand what really makes a difference for

patients, what are the outcomes that matters to patients. They can help us understand when something is reported, what that benefit actually means to them … Can they return to school or work? Does it mean they can interact better with their family. And really help us understand the value of a new medicine?

WHAT IS YOUR MOTIVATION TO BE ENGAGED IN PATIENT INVOLVEMENT?

I was trained in health technology assessment in Denmark. In Denmark, we looked at health technology assessment in terms of how well the product works, what its value for money was, but also what difference it makes to patients. I established that process of HTA in Scotland that included patients' perspectives and sought to gain their opinions about how we shape the assessments itself and to understand the value, but what I've recognized over the past sixteen years is that not everybody does health technology assessment in that way. Some people focus very much on the clinical or the economic evidence and that evidence is imperfect. I think that patients can really give us unique insight into the value of a product. They can add to that scientific evidence their own unique knowledge. I think everybody should be trying to involve patients and so that's why I work with all stakeholders to encourage HTA agencies to involve patients and to encourage patients to be involved in HTA.

WHAT DIFFERENCE HAS THE EUPATI PROJECT MADE?

The EUPATI project has been really important because it has worked with all stakeholders, industry, regulators, HTA bodies and with patients themselves, to develop a really comprehensive training course to develop patient experts who can be involved in medicines development, regulation and in HTA. I've helped to develop the HTA training with other international colleagues in HTA so that we know it's of very

high quality, the training material, and that’s been used to train the one hundred expert EUPATI fellows, but it’s also been used for the wider audience of patients. I’ve seen great videos and leaflets which clearly explain the quite complex process of HTA to anybody who has really got an interest. That building the knowledge and understanding of patients about these very complex processes is important so that patients can get effectively involved and really make a difference to these processes.