

INNOVATIONS CONFERENCE -- UK INITIATIVE: JAMES LIND ALLIANCE

SPEAKER: ELA PATHAK-SEN,
DIRECTOR,
COMMOTION

PATHAK-SEN: Very quickly moving onto the James Lind Alliance, and here's a different approach to patient involvement. This is about patients' involvement in -- in the research that underpins some of the decision-making.

The James Lind Alliance was established in 2004. And what it does is it brings patients, carers and clinicians to identify and prioritize uncertainties about the effects of treatments that they believe are the most important.

It's funded by the National Institute for Health Research, and it's a really small initiative. There are four part-timers, who run the James Lind Alliance, and actually, if you looked at the time they spent, they probably make-up one whole-time equivalent in terms of -- in terms of workforce.

What does the JLA do? Well, actually as we said before the JLA is about creating partnerships. About -- it's about bringing patients and carers and patients together to say what are the uncertainties about a particular disease or condition. What -- is there an uncertainty in the research which means that we as patients are perhaps not getting the best treatments that we deserve.

And here are some examples of the partnerships. The things that I want to point out to you are that there is no -- there's no pattern to what's being -- what's being developed. It's not that the partnerships are being focused around lifesaving treatments, but they are focused around what's important to patients and where patients actually feel more research needs to be done.

This is just to give you an idea of how the partnership is developed. The thing that I do want to point out to you is this whole area -- idea of working with DUETs. DUETs is a database which has been set up to list all the uncertainties that exist in the evidence looking at particular -- when looking at particular diseases.

So anybody who wants to set up a priority setting partnership has to make sure that they're registering with the DUETs database. And the DUETs database allows them to understand whether or not there is uncertainty in the area, and therefore whether or not to proceed.

But more importantly, it's this database that now is informing research within in the United Kingdom in terms of where one should be looking and how one should prioritize.

Here are just some examples of the difference and the impact, very difficult to say -- to evaluate and say here's the impact. I guess the impact goes back to the DUETs database and the partnerships that you saw that have been -- that have been established and those that are being established now.

In your slide pack, you will have the details of these particular articles. And if you want to find out more about the JLA, there -- there's the website address.