

Children and young people to get more say in their health care

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The University of the West of England (UWE Bristol) has been chosen as one of seven new sites to develop Patient Centred Outcome Measures (POCMs) by NHS England. The new centres will mean that children and young people will play a more active role in deciding which outcomes are important to them.

UWE Bristol will be working with a range of services involved in providing health care for children and young people with life-limiting conditions across the South West. The project team will collate interactive electronic communications between patient, family and professionals via a new and innovative tool.

Dr Antonia Beringer explains, "The online tool is called My Quality and it has been devised to enable anyone to measure the things that they feel affect their quality of life. They simply log in to the website, (www.my-quality.net/) which is free to use, and select the measures that they would like to record; it might be appetite or how they are feeling or some aspect which relates to their illness; really anything that is relevant to them. The key is that this is a patient centred outcome measure which means that the patient is making an assessment and measuring their own quality of life.

The tool was set up by Dr Nicky Harris, a Palliative Care Paediatrician and Visiting Fellow at UWE Bristol. Dr Harris said, "It is really encouraging to see that My Quality, which was developed in 2011, is making a difference to people's lives. It enables professionals and

families to work in collaboration, to address the issues of most importance to their child's quality of life. Families of children with life-limiting illnesses have remarked that they find this approach empowering in their health care journey. The next stage is for us to make an assessment of how useful My Quality might be as an outcome measure for services caring for people, so that we can use the information to improve service delivery."

Tim Kelsey, National Director for Patients and Information at NHS England, explained, "This is all about asking young patients what is most important to them. The NHS wants to pioneer new approaches to measuring quality in [health care](#), and putting patient and carer voice at the centre of this is key.

"The NHS works best when it listens hardest to what is important to patients. I am delighted we are able to support seven organisations across England to work with patients to understand the most important outcomes for children and young people living with such a wide range of conditions and symptoms."

He explained that as childhood and adolescence is a formative period in any person's life, it is important to have outcomes centred on their needs so as to maximise their health and support their developing mind and body.

The work of the Children and Young People Health Outcomes Forum has championed the need to focus on [children](#) and young people's outcomes.

"Getting this right for the youngest members of the population means we build a firm foundation for a healthier adulthood," added Mr Kelsey.

Provided by University of the West of England

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