COMMISSIONING RESEARCH ON IMPORTANT TOPICS

It has long been recognised that questions addressed by health researchers are not always those that are important to patients or the public. One study published in 2000 compared the research priorities of patients with osteoarthritis of the knee with funded research and found that most research focused on drug treatments whilst patients were interested in other interventions including knee replacement, education and advice.\(^1\)

A similar study published in 2015 concluded that little had changed, with a continuing mismatch between patient priorities and funded research.\(^2\) Where funding for research is limited, it is important to reduce waste by ensuring that researchers address the right questions – those that are important to patients and clinicians who face practical decisions about health issues every day, in areas where evidence may be lacking.
ACHIEVEMENTS IN PRIORITY SETTING: THE CHILDHOOD DISABILITY PSP

The Childhood Disability PSP is one of many examples of how these partnerships have successfully identified and prioritised uncertainties. The Childhood Disability PSP was established by the British Academy of Childhood Disability Strategic Research Group. The PSP involved young people, carers and health professionals identifying and prioritising unanswered questions about the effectiveness of interventions for children and young people with neurodisability. The project was led by a team at Peninsula Cerebra Research Unit (PenCRU), a childhood disability research unit at the University of Exeter Medical School, and supported by a motivated Steering Group.

In response to an open survey, 369 people (40% of whom were not health professionals) submitted one or more suggestions for areas of future research. In January 2015, following prioritisation, the PSP published its Top 10 and Top 25 research areas, thus highlighting to researchers and research funders what children and young people, families and the health professionals who work with them every day consider to be the right research questions.

Mary Busk was part of the Steering Group that managed the PSP, representing the National Network of Parent Carer Forums:

“I am a mum with 3 children, one with neurodisabilities, and the JLA process was a whole new experience for me. It was empowering to feel that families like mine could influence research priorities for children with neurodisabilities. We worked hard to make the case to parent carers to be involved because our time is precious and we need to know what we do is going to make a difference. The final prioritisation genuinely reflected what families wanted and would make a difference to our children’s lives.”

The James Lind Alliance (JLA) addresses this issue by bringing patients, carers and health professionals together in Priority Setting Partnerships (PSPs). PSPs use an established, transparent method to identify and prioritise uncertainties, or ‘unanswered questions’ in a particular area of healthcare, including the views of patient and clinician stakeholders who have not traditionally had a say in what research should be done. The method highlights research questions of direct relevance and potential benefit to patients and the clinicians who treat them, with the aim of influencing the way research funds are granted.

The JLA is a non-profit making initiative, established in 2004 by Iain Chalmers, John Scadding and Nick Partridge, and is now hosted by the National Institute for Health Research. Since its initial ground-breaking PSP in Asthma, it has gone from strength to strength, facilitating PSPs in areas as diverse as Acne, Childhood Disability, Multiple Sclerosis, Palliative and end of life care, and Mild to Moderate Hearing Loss. By March 2016, 37 PSPs have published their results. More information about the James Lind Alliance can be found on their website: www.jla.nihr.ac.uk
Since the PSP published its results, members of the steering group have worked hard with staff at the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) to identify research questions within the priority areas. This has resulted in the HTA Programme commissioning a systematic review of interventions for sleep disturbances, and a Technology Assessment Report around the cost-effectiveness of wheelchair interventions for very young children.

A scoping study of therapy interventions for children with neurodisability has been funded by the HTA Programme and jointly commissioned with the HS&DR Programme. In addition, three HTA primary research commissioning briefs have been advertised covering sensory integration for children with Autism Spectrum Disorder, interventions to improve eating ability in children with neurodisability, and behavioural interventions in managing symptoms of Autism Spectrum Disorder. The HS&DR programme has commissioned a researcher-led project to identify appropriate symbol communication aids for children who are non-speaking, which cited the JLA priority 2 in its application to highlight the importance of the issue.

The questions gathered by the PSP are verified as uncertainties by checking existing evidence, and are then voted on by patients, carers and health professionals to put them in order of priority. The final step in the prioritisation process is a face-to-face workshop, which allows for discussion and consensus building, so that agreement on the Top 10 most important questions for researchers to address can be reached. It’s a tried and tested process that results in a balanced inclusion of patient, carer and clinician interests and perspectives. The results of the process are then disseminated by the PSPs so that identified important unanswered questions can be taken up by the research community.


HOW DOES THE PRIORITY SETTING PARTNERSHIP WORK?

PSPs are organised by a steering group, which represents a balance of viewpoints of patients and carers, and the clinicians working in a particular health area. Patients, carers and those who treat and support them are first asked to take part in a survey in which they identify unanswered questions or “uncertainties” that they think are important for researchers to address. The uncertainties submitted to a PSP can be numerous. For example, in the Mild to Moderate Hearing Loss PSP, 461 people submitted 1,147 questions. For the PSP in Acne, 4,363 people with experience of acne submitted 6,255 relevant questions.
ABOUT THE JLA

The James Lind Alliance (JLA) is a non-profit making initiative which was established in 2004. It brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs) to identify and prioritise the Top 10 uncertainties, or ‘unanswered questions’, about the effects of treatments that they agree are most important.

The aim of this is to help ensure that those who fund health research are aware of what matters to both patients and clinicians.

GET IN TOUCH

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