

Scoliosis Priority Setting Partnership. Final Report

JLA PSP final report (2017)

<https://www.jla.nihr.ac.uk/priority-setting-partnerships/scoliosis/downloads/Scoliosis-PSP-final-report-including-all-54-verified-unanswered-questions.pdf>

For which topic were research priorities identified?

scoliosis

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

To date, there has been very little active research on scoliosis in the UK.

What was the objective?

to stimulate research in this area by finding out what people with scoliosis, their carers and health professionals believe to be the most important areas for future research

What was the outcome?

a ranking list of 12 research questions

How long did the research prioritization take?

June 2016 - November 2017

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: stakeholders identified, steering group formed. Step 2: collecting uncertainties: survey asking participants to identify the questions they would like answered by research, 1961 questions submitted. Step 3: data processing: out-of-scope removed, similar questions grouped together, summary questions formulated and checked against evidence, resulting in 54 unanswered questions. Step 4: interim ranking: survey with list of 54 questions, participants were asked to choose their top ten questions and then put them in rank order, each stakeholder group's scores looked at to ensure equal balance between stakeholder groups, shortlist of 27 questions moved forward. Step 5: final prioritization: workshop: participants were asked to look at the 27 questions before workshop and to think about how they would rank them in order of importance, series of small group discussions

Which stakeholders took part?

People with scoliosis, their carers and health professionals. Survey: 697 participants: 53% people with scoliosis, 25% carers, relatives or friends, 16% health professionals or staff in other organizations. Interim ranking: 750 participants: 59% people with scoliosis, 30% carers, relatives or friends, and 11% health professionals or staff in other organizations. Workshop: people with different types of scoliosis, carers and health professionals.

How were stakeholders recruited?

The partners and Steering Group members sent the survey out to their networks, via email, newsletters, social media, websites and blogs. The second survey went out to everyone from the first survey who wanted to stay involved, and to all the same networks. As to the workshop, participants were recruited through the Steering Group's networks, via patient and clinician groups and through social media.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group. The steering group consisted of 14 members: patient representatives and partner organizations. The members advised on project and participated in the workshop.