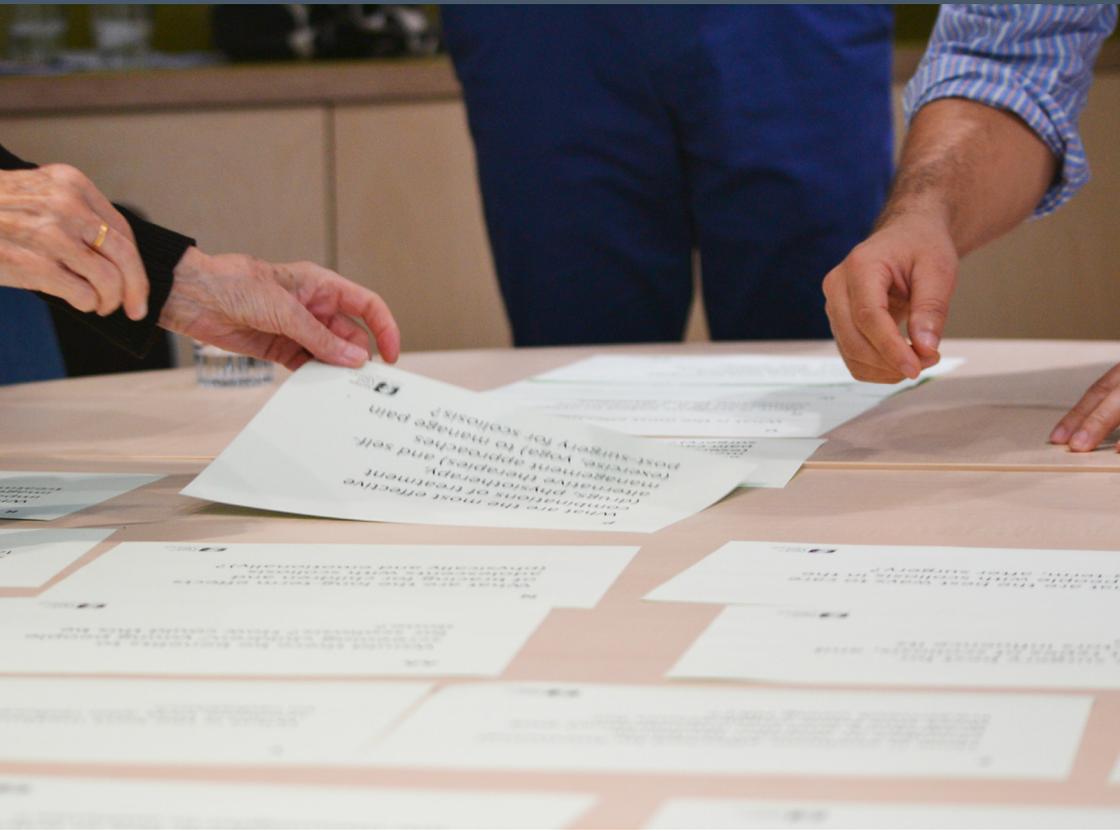


# Scoliosis Priority Setting Partnership

Final Report



**James  
Lind  
Alliance**  
Priority Setting Partnerships



**SCOLIOSIS  
ASSOCIATION (UK)**



**BRITISH  
SCOLIOSIS  
RESEARCH FOUNDATION**

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# Acknowledgments

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## Members of the Steering Group:

Pierre Bernard, Young person Carer representative

Stephanie Clark, Scoliosis Association UK

Katherine Cowan, JLA Adviser, Steering Group Chair

Claire Curley, Scoliosis Association UK

Jeremy Fairbank, Consultant Orthopaedic Spine Surgeon, Oxford

Lizzie Holloway, Student observer/ Social media & website

Linnemore Jantjes-Robertson and Judith Rogers, PSP Coordinators

Rosalind Jefferson, former Consultant Neurodisability Paediatrician

Fraser Old, Adult Carer

Chris Morris, Child Health Group, University of Exeter Medical School

Anne Richards, Paediatric Physiotherapist, Oxford University Hospitals NHS Foundation Trust

Dominique Rothenfluh, Consultant Spine Surgeon, Oxford University Hospitals NHS Foundation Trust

Camilla Seckin, Patient representative

Kristina Staley, Information Specialist

Peter Virley, British Scoliosis Research Foundation



# Top 12 Priorities for scoliosis research

1. What are the best strategies for reducing or preventing the curve from getting worse, combining treatment and self-management approaches to avoid the need for surgery?
2. How is quality of life affected by scoliosis and its treatment? How can we measure this in ways that are meaningful to patients?
3. Could surgical procedures be improved to become less invasive, reduce scarring and increase flexibility?
4. What are the long-term outcomes and side-effects of surgery?
5. How likely is scoliosis to get worse over time, either with or without treatment? Should people be monitored?
6. What is the best method of imaging scoliosis that also reduces exposure to radiation?
7. Which type of brace (e.g. rigid or dynamic) is most effective in the treatment of (a) early onset scoliosis and (b) adolescent idiopathic scoliosis?
8. What forms of postural care are most effective (standing frames, seats, sleep suits & wheelchairs) for managing early onset, neuromuscular and syndromic scoliosis?
9. If scoliosis is diagnosed earlier, does this change the choice of treatment and/or lead to better outcomes?
10. How are the psychological impacts (including on body image) of diagnosis and treatment best managed?
11. Can the instrumentation (rods/ implants etc) cause harm in the short or long term?
12. How is scoliosis affected by hormonal changes in women (puberty, pregnancy and the menopause) and does this have implications for treatment using HRT?

# Why set priorities for scoliosis research?

Scoliosis (a curve of the spine) most often occurs in children and teenagers, but adults of all ages can also be affected. Recent research suggests that by the time their skeleton has fully matured, about 6% of young women will have a curve in their spine. Young people with a spinal curve are more likely to have back pain than young people without a curve. This may cause them to take time off school, which may in turn affect their educational achievements and future employment.

Scoliosis is associated with a wide range of other conditions, such as cerebral palsy, muscular dystrophy and some genetic conditions - but in the majority of cases (85%) it has no known cause (idiopathic). In about 2% of cases, a spinal curve will develop before the age of two. Some curves progress rapidly and can cause life threatening heart or breathing problems, while others will disappear without the need for treatment. In children, the curve often gets worse as the child grows, and in adults the curve can get larger over time.

Diagnosing scoliosis involves imaging the spine, either using x-rays or other types of scan. These alternative techniques may have fewer health risks than x-rays, but do not always provide as much detail. Current treatments, such as bracing, do not always correct the curve, leaving people feeling self-conscious and concerned about their body image. 40% of people that do not respond to treatment, may require surgery. Approximately 2000 scoliosis operations are done each year in England. Surgery has



complications, including infection and implant failure leading to repeat surgery. The most serious, though rare, complication is spinal cord damage and paralysis. Therefore there is much more work to be done to improve the diagnosis and treatment of this condition.

To date, there has been very little active research on scoliosis in the UK. This Priority Setting Partnership aimed 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.

## Setting the limits of this priority setting exercise

The Steering Group debated which areas of research and which types of scoliosis should be included in this priority-setting exercise. They agreed that the research areas should include:

- Diagnosis of scoliosis, including screening and assessing the risk of a curve getting worse over time
- Management of scoliosis, including treatment and care, and managing the psychological impacts
- All types of scoliosis affecting people of all ages

They decided that research into the cause of scoliosis would not be included, but if people sent in questions about causes, then these would be passed on to the British Scoliosis Research Foundation and Scoliosis Association UK and made available on the JLA website ([www.jla.nihr.ac.uk/priority-setting-partnerships/scoliosis/](http://www.jla.nihr.ac.uk/priority-setting-partnerships/scoliosis/)).



# How were the priorities identified

## Getting started

Key organisations, clinicians, and people affected by scoliosis were identified and invited to become partners in the project, and a steering group was formed to oversee the work. The partnership was officially launched in early 2016.

## The first survey

A wide range of people with scoliosis, their friends and family members, and the health and social care professionals who support them, were asked to identify the questions they would like answered by research. They submitted their questions via an online survey between June and October 2016. A paper version of the survey was also made available.

The partners and Steering Group members sent the survey out to their networks, via email, newsletters, social media, websites and blogs. 697 people responded. 53% of them were people with scoliosis, 25% were carers, relatives or friends, and 16% were health professionals or staff in other organisations. Altogether, they asked 1,961 questions.

## Processing the survey results

Some of the questions they asked were not relevant to this project. Any questions about the cause of scoliosis were sent elsewhere (see above). Some people were asking for information or advice, questions that do not need to be answered through research. Other questions were about access to services or the quality of health professionals' training. These might need to be addressed through changing policy rather than research, and again these questions were removed. The full list of removed questions is available on the JLA website ([www.jla.nihr.ac.uk/priority-setting-partnerships/scoliosis/](http://www.jla.nihr.ac.uk/priority-setting-partnerships/scoliosis/)).

1,231 questions remained. Some of these questions were asked lots of times by many people, in slightly different ways. Similar questions were grouped together and an overarching question was written which summarised all the questions in the group. A small number of questions were only asked once. These were added to a long list with all the summary questions. We then checked the published evidence from research that has been carried out in the past, and removed two questions that previous research had already answered, and altered two questions that had been partly answered. At the end of this stage, we had 54 unanswered questions (see Appendix).

## The second survey

The list of 54 questions went into a second survey, where we asked people to choose their top ten questions and then put them in order of importance. The second survey went out to everyone from the first survey who wanted to stay involved, and to all the same networks. This time 750 people responded (between April and May 2017). 59% were people with scoliosis, 30% were carers, relatives or friends, and 11% were health professionals or staff in other organisations. We scored people's top ten questions (giving ten points to question number 1, nine points to question number 2, all the way down so that question 10, got one point) and then added up the total scores. We looked at each group's scores, so that everyone could have an equal influence on the final outcome. A shortlist of 27 questions was agreed by the Steering Group, to include each of the groups' top priorities.

## The priority setting workshop

The 27 shortlisted questions were discussed at a workshop in London in November 2017. People with different types of scoliosis, carers and health professionals came to the workshop – some Steering Group members, some people who had taken part in the surveys, and some people who were new to the project. They were recruited through the Steering Group's networks, via patient and clinician groups and through social media. The Steering Group aimed to select a diverse group covering a wide range of types of scoliosis and the different professional groups involved with the treatment and care of people with scoliosis.

The participants were asked to look at the 27 questions before they came, and to think about how they would rank them in order of importance. Their priorities were obviously informed by their own experience. By coming to the workshop and taking part in a number of small group discussions, everyone got to hear other people's views on which



questions were most and least important. This helped the group as a whole to reach an agreement on which questions should be a priority. Although a question in the final list might not have been important to one of the people there, they were willing to accept it being prioritised because they could understand its significance to other people. In fact the group finally decided on a Top 12 rather than a Top 10, because they wanted to make sure that the list included at least one priority question for people with every type of scoliosis – even for people with adult scoliosis, who weren't able to come on the actual day. This is the aim of the JLA to build consensus and shared understanding between lots of very different groups with an interest in research.

The 15 questions (from the original 27 discussed at the workshop) that did not make the final Top 12 are listed below. They are listed in order of importance as agreed by the people at the workshop:

13. What are the most effective combinations of treatment (drugs, physiotherapy, alternative therapies) and self-management approaches (exercise, yoga) to manage pain post-surgery for scoliosis?
14. What are the long-term effects of bracing for children and adolescents with scoliosis (physically and emotionally)?
15. What are the most effective combinations of treatment (drugs, physiotherapy, alternative therapies) and self-management approaches (exercise, yoga) to manage the pain caused by scoliosis (pre-surgery)?
16. What are the psychological impacts (including on body image) of scoliosis and its treatment?
17. Would there be benefits to screening children/ young people for scoliosis? How could this be done?
18. When and how does scoliosis affect other parts of the body to cause additional symptoms?
19. How is scoliosis linked to other conditions (e.g. osteoporosis, connective tissue disorders, arthritis)? What impact do those conditions have on progression and vice versa? What are the implications for treatment and screening?
20. When is surgery best for different types of scoliosis, and what factors influence its success?
21. Is physiotherapy cost effective in the treatment of scoliosis, in terms of reducing other NHS service use/ future complications?
22. What are the best ways to care for people with scoliosis in the long-term, after surgery?
23. What triggers relatively mild scoliosis to worsen rapidly?
24. When and how often is repeat surgery for scoliosis required in later life?
25. What are the best strategies for preventing scoliosis (combining physiotherapy, orthotics, alternative therapies, diet, and/or exercise)?
26. Does scoliosis affect life expectancy in adults?
27. What is the most effective type of exercise (e.g. Yoga, Pilates, Schroth Method, Alexander Technique) for people with scoliosis?

# Next steps

The JLA Scoliosis Priority Setting Partnership hopes that by identifying these priority questions for research, we will ensure the future research is focused on the issues that matter most to people with scoliosis, their carers, relatives and friends and the health and social care professionals who support them.

## A call to arms

Many people took the time and effort to submit their questions and to work through the JLA process to identify the final top 12 questions for future. We want to ensure that these efforts are respected and recognised and therefore:

- We encourage research funders to include these priorities in their research strategy and to target these topics for future research funding.
- We encourage researchers to focus their efforts on answering the highest priority questions and to mention the JLA Scoliosis PSP in their applications for funding. If a researcher receives funding to address any of the listed priorities, we ask that they please inform the JLA.
- We encourage funders, researchers and all interested parties to share this report with others and to raise awareness of the need for more scoliosis research in the UK.

If you have any queries or comments about this work, please contact Jeremy Fairbank ([jeremy.fairbank@ndorms.ox.ac.uk](mailto:jeremy.fairbank@ndorms.ox.ac.uk))

Further information about the project can be found at [www.jla.nihr.ac.uk/priority-setting-partnerships/scoliosis/](http://www.jla.nihr.ac.uk/priority-setting-partnerships/scoliosis/)

If you would like more information and advice about scoliosis, please contact the [Scoliosis Association \(UK\)](#).





## Appendix: The long list of research questions

These are the 54 unanswered questions sent in by people with scoliosis, their carers, relatives and friends and the health and social care professionals who support them. People sent in their questions via a survey. The questions that were asked many times have been grouped and summarised in a single question. A full list of all questions asked, and the questions belonging to each group can be found on the JLA website ([www.jla.nihr.ac.uk/priority-setting-partnerships/scoliosis/](http://www.jla.nihr.ac.uk/priority-setting-partnerships/scoliosis/)).

- After scoliosis corrective surgery, will hip replacement(s) be necessary later in life?
- Are there any activities that people with scoliosis should avoid?
- Are there options other than surgery for reducing a rib hump?
- Are wasted erectae spinae muscles in early adulthood a sign of increased risk of adult onset scoliosis?
- Can degeneration of the facet joints be prevented?
- Can the instrumentation (rods/ implants etc) cause harm in the short or long term?
- Could seating clinics after spinal cord injury prevent scoliosis?
- Could surgical procedures be improved to become less invasive, reduce scarring and increase flexibility?
- Does diet have an impact on scoliosis?
- Does scoliosis affect life expectancy in adults?
- Do older people living with significant untreated scoliosis receive appropriate health and social care in the UK?

- Do people with scoliosis have muscles that are different from other people?
- How are the psychological impacts (including on body image) of diagnosis and treatment best managed?
- How can schools and sports-settings be made aware of scoliosis, to adapt and provide care appropriately?
- How can stress fractures be prevented post-surgery in people with Ehlers-Danlos syndrome?
- How can we prevent scoliosis after spinal cord injury?
- How cost effective is surgery in the management of scoliosis?
- How is osteoporosis best monitored in a person with scoliosis?
- How is quality of life affected by scoliosis and its treatment? How can we measure this in ways that are meaningful to patients?
- How is scoliosis affected by hormonal changes in women (puberty, pregnancy and the menopause) and does this have implications for treatment using HRT?
- How is scoliosis linked to other conditions (e.g. osteoporosis, connective tissue disorders, arthritis)? What impact do those conditions have on progression and vice versa? What are the implications for treatment and screening?
- How likely is scoliosis to get worse over time, either with or without treatment? Should people be monitored?
- If scoliosis is diagnosed earlier, does this change the choice of treatment and/or lead to better outcomes?
- Is there a correlation between differences in leg length and idiopathic scoliosis?
- Is there a difference between girls and boys in adolescent scoliosis?
- Is there a link between being overweight and increased back pain in scoliosis in adults?
- Is there any correlation between the outcomes of surgery seen in an x-ray, and the patient's body image perception?
- Is physiotherapy cost effective in the treatment of scoliosis, in terms of reducing other NHS service use/ future complications?
- What are the best indicators for children with cerebral palsy needing non-invasive ventilation in the immediate post op period?
- What are the best strategies for preventing scoliosis (combining physiotherapy, orthotics, alternative therapies, diet, and/or exercise)?
- What are the best strategies for reducing or preventing the curve from getting worse, combining treatment and self-management approaches to avoid the need for surgery?
- What are the best ways to care for people with scoliosis in the long-term, after surgery?
- What are the chances of someone having scoliosis?
- What are the long-term effects of bracing for children and adolescents (physically and emotionally)?
- What are the long-term outcomes and side-effects of surgery?
- What are the most effective combinations of treatment (drugs, physiotherapy,

alternative therapies) and self-management approaches (exercise, yoga) to manage the pain caused by scoliosis (pre-surgery)?

- What are the most effective combinations of treatment (drugs, physiotherapy, alternative therapies) and self-management approaches (exercise, yoga) to manage pain post-surgery?
- What are the most effective strategies for managing breathing problems?
- What are the psychological impacts (including on body image) of scoliosis and its treatment?
- What can be done to reverse paralysis when surgery goes wrong?
- What forms of postural care are most effective (standing frames, seats, sleep suits & wheelchairs) for managing early onset, neuromuscular and syndromic scoliosis?
- What impact does an intrathecal baclofen pump have on the progression scoliosis in adolescents and young adults?
- What is the best method of imaging scoliosis that also reduces exposure to radiation?
- What is the most effective type of exercise (e.g. Yoga, Pilates, Schroth Method, Alexander Technique) for people with scoliosis?
- What relationship is there between a scoliosis and falling in older people?
- What strategies can people with scoliosis adopt to prevent their walking getting worse?
- What strategies improve safe eating and drinking for people with severe scoliosis?
- What triggers relatively mild scoliosis to worsen rapidly?
- When and how does scoliosis affect other parts of the body to cause additional symptoms?
- When and how often is repeat surgery required in later life?
- When is surgery best for different types of scoliosis, and what factors influence its success?
- Which type of brace (e.g. rigid or dynamic) is most effective in the treatment of (a) early onset scoliosis and (b) adolescent idiopathic scoliosis?
- Would there be benefits to screening children/ young people for scoliosis? How could this be done?
- Why do muscles become weaker in patients with scoliosis? Could this lead to new treatments?





British Scoliosis Research Foundation  
c/o SAUK  
Unit 4 Ivebury Court  
325 Latimer Road  
London  
W10 6RA  
Tel: +44 (0)20 8960 5343  
<http://www.bsrf.co.uk>  
 /BritishScoliosisResearchFoundation  
 @ScoliResearch

Scoliosis Association (UK)  
c/o SAUK  
Unit 4 Ivebury Court  
325 Latimer Road  
London  
W10 6RA  
Tel: +44 (0)20 8960 5343  
<http://www.sauk.org.uk>  
 /ScoliosisAssociationUK  
 @ScoliosisUK

The James Lind Alliance  
National Institute for Health Research Evaluation,  
Trials and Studies Coordinating Centre  
University of Southampton  
Alpha House, Enterprise Road  
Southampton SO16 7NS  
Tel: +44 (0) 23 8059 5489  
<http://www.jla.nihr.ac.uk>  
 @LindAlliance

Scoliosis PSP  
NIHR Oxford Biomedical Research Centre  
Churchill Hospital, Joint Research Office, Block 60  
Headington  
Oxford OX3 7LE  
Voicemail: 01865 223298  
<http://www.scoliosispartnership.uk>  
 @scoliosis-psp