

# Shaping the future of childhood stammering research

A James Lind Alliance Priority Setting Partnership



James  
Lind  
Alliance  
Priority Setting Partnerships



Woodroffe Benton  
FOUNDATION



Action for Stammering Children is a registered charity in England and Wales, and a limited company (no. 02328627) with its registered offices:

Action for Stammering Children  
13 – 15 Pine Street  
London  
EC1R 0JG

Charity no. 801171

[www.actionforstammeringchildren.org](http://www.actionforstammeringchildren.org)

# Introduction

## A note on terminology

Stammering and stuttering are used interchangeably and refer to the same condition. Stammering is more often used in the UK, whereas stuttering is commonly used in the United States and Australia.

There is a distinction between developmental stammering, which is characterised by onset during early childhood, and acquired stammering, which typically begins in adulthood<sup>1</sup>. This Priority Setting Partnership focused on developmental childhood stammering.

## What is developmental stammering?

Developmental stammering is a neurodevelopmental condition that affects approximately 8% of children and 1% of adults<sup>2</sup>. Typically, children will begin to stammer between the ages of two and five as they begin to develop spoken language, although for some children onset can occur later<sup>1,3</sup>. Although relatively equal at onset, boys are more likely to stammer than girls by the time they reach adolescence<sup>2</sup>.

Childhood stammering is characterised by speech behaviours that may be observed by the listener, as well as covert features that may not be identifiable. Core speech characteristics include (i) repetition of sounds and syllables, (ii) prolongation of sounds, and (iii) blocks in airflow that can be silent or audible. These speech characteristics may be accompanied by secondary behaviours, such as head nods and jaw tension, in some children and young people. Stammering may also include features which are often invisible to the listener. The covert features associated with stammering, which often go unobserved, may include negative feelings and attitudes, and avoidance of particular words or some situations.

Just as the frequency and duration of stammering moments varies considerably from day to day and from person to person, the experience and impact of stammering will differ from one child to the next. Recognising the individuality of children who stammer is vital when considering how best we can support children and young people, and when thinking about the objectives of research. Nevertheless, for many children who stammer, teasing and bullying, and negative reactions from

their peers are common occurrences<sup>4,5</sup>. Many children will experience social isolation, anxiety and low self-esteem<sup>6,7</sup>. Consequently, stammering can have a detrimental impact on a child's social and emotional development, and mental health and well-being<sup>8</sup>. The experience of stammering can also affect the extent to which these children realise their potential educationally and economically<sup>9,10,11</sup>.

Despite the fact that stammering can have a substantial impact on children during the early years of development and those all important transitions into adolescence and early adulthood, this neurodevelopmental condition is still not well understood. The need to enhance our understanding of childhood stammering underpinned our decision to lead the very first Priority Setting Partnership in this area.

## What were we trying to achieve through the Priority Setting Partnership?

In 2019, Action for Stammering Children held a research event to celebrate the charity's 30th anniversary, and to reflect on the research advances in the area of childhood stammering since the establishment of the charity. The event was aimed at families, speech and language therapists and researchers in the field. The two key outcomes from that event underscored the charity's decision to explore the possibility of establishing the Priority Setting Partnership. These outcomes were as follows:

- 1 while progress had been made, there was still much further to go in terms of enhancing our understanding of stammering in children;
- 2 there was a very clear appetite within the stammering community – from academics, families and clinicians alike – to deepen our understanding of childhood stammering and address the questions that remained unanswered.



Photo credit: Michael Powell

At Action for Stammering Children, we champion robust research into childhood stammering, in order to inform the evidence base and influence public policy. We believe that research needs to have a meaningful impact on the lives of children who stammer and their families. With that in mind, we are committed to facilitating opportunities for the stammering community to engage in current and future research; fostering a mutually beneficial relationship between those undertaking research and those set to benefit from the research outcomes. We recognise that there needs to be a mechanism for those with lived experience of stammering to inform the research agenda, thereby ensuring that future research addresses the questions that are important, relevant and meaningful to those who stammer.

A Priority Setting Partnership (PSP) offers a unique opportunity to bring together young people who stammer, their families and the professionals who work with them, and jointly agree the priorities for future research. Using the systematic James Lind Alliance (JLA) methodology, we have done our utmost to engage the stammering community in the identification of the Top 10 priorities for future research into childhood stammering.

This report provides an overview of the process and outcomes of our PSP into Developmental Childhood Stammering. However, the release of the Top 10 Priorities has only been made possible by all those who participated in the process, the PSP steering group and all of our partners. We would like to put on record our sincere thanks to everyone who has given their time and shared their views with us over the course of this PSP. In particular, Woodroffe Benton who funded this project, giving us the opportunity to put the voices of young people who stammer and their families at the forefront of the research agenda.

## Acknowledgements

### Steering Group

**Phoebe Avbulimen**

*Action for Stammering Children Youth Panel*

**Dr Naheem Bashir**

*Researcher and person who stammers*

**Dr Tricia Ellis**

*JLA Chair*

**Thomas Grattoni-May**

*Action for Stammering Children Youth Panel*

**Dr Milly Heelan**

*Research & Outcomes Officer, Royal College of Speech & Language Therapists (RCSLT)*

**Charlotte James**

*Parent*

**Jessica Lane**

*Research & Outcomes Officer, Royal College of Speech & Language Therapists (RCSLT)*

**Dr Sharon Millard**

*Research Lead and speech & language therapist, Michael Palin Centre*

**Corinne Moffatt**

*Specialist speech and language therapist*

**Chris Nelson**

*Teacher*

**Dr Kristina Staley**

*Research Analyst*

**Rachel Stevens**

*Specialist speech and language therapist*

**Professor Kate Watkins**

*Professor of Cognitive Neuroscience, University of Oxford*

**Catherine Woolley**

*Children & Families Programme Lead, STAMMA*

### Partners



**STAMMA**



# How did we get to the Top 10?



## Who took part?

The scope of this PSP, agreed by the Steering Group, was concerned with developmental stammering in children and young people aged up to 25 years<sup>12</sup>. This included children who had experienced stammering earlier in their childhood and children who continued to stammer into early adulthood.

We invited the following groups to share their questions about stammering with us:

- Children & young people who stammer
- Parents/guardians of children and young people who stammer
- Education professionals who work with children who stammer
- Speech & Language Therapists
- Health professionals working with children who stammer
- Friends/colleagues of young people who stammer

<sup>12</sup>When we were asking family members, friends and professionals to contribute to the process, we aimed our marketing materials at those groups who supported young people aged 25 years or younger.

## Overview of the process

### October 2021 kick-off:

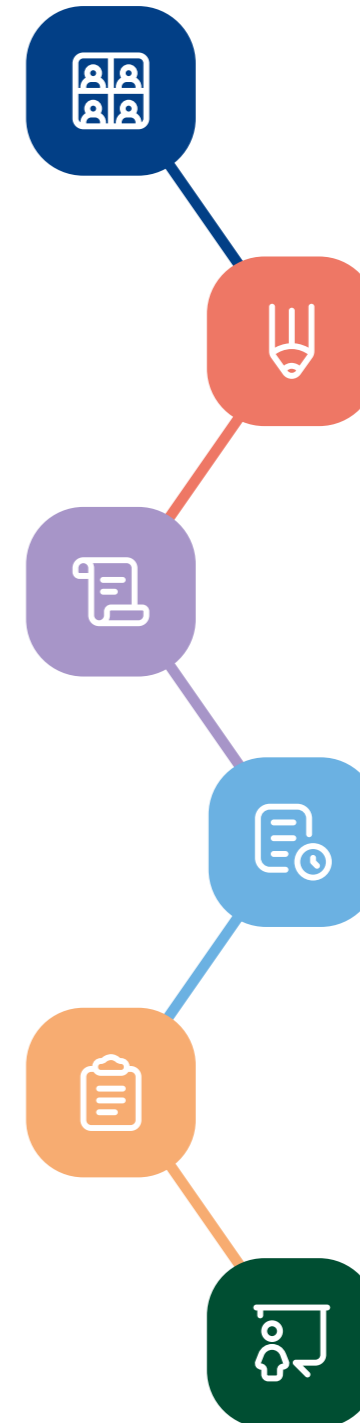
we convened a steering group comprising young people who stammer, parents/carers, speech and language therapists, teachers and partner organisations.

### October 2022 - January 2023 Long-listing:

these questions were grouped to form 50 summary questions, which we needed to check against the existing evidence.

### March - September 2023 Short-listing:

we invited the stammering community to choose 10 questions from the long list and rank them in order of importance. The rankings were analysed and the top 25 questions identified.



### February - September 2022 Gathering questions:

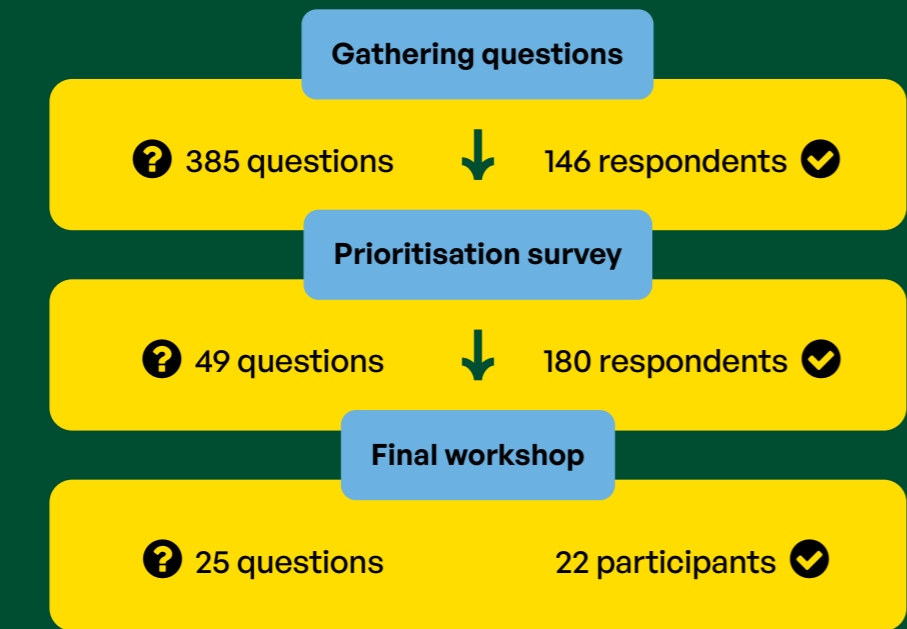
members of the stammering community shared three questions they had about stammering through an online questionnaire and in-person events.

### February 2023 - March 2023 Evidence Check:

the steering group checked whether any of these 50 questions had already been robustly answered by existing research.

### November 2023 Final Workshop:

we held a one-day in-person workshop with members of the stammering community to identify the Top 10 questions from the short-list of 25 questions.



# Gathering unanswered questions

The first job of the PSP was to identify evidence uncertainties in childhood stammering, which informed our understanding of questions that remain unanswered. This would help us identify the gaps in the research, so that our final Top 10 would contribute further to the evidence base.

We gathered these unanswered questions by engaging the stammering community and searching the existing research literature. The main way we did this was by sharing an online survey with members of the stammering community, alongside activities to raise the profile of the PSP within our community.

## The Survey

We designed a survey inviting respondents to share three questions they had about stammering. The survey was distributed by ASC and partner organisations via social media and supporter mailing lists. Printed leaflets were made available for display in clinic waiting rooms.

We received 385 questions in total from 146 respondents. After reviewing all the questions submitted, the steering group concluded that 247 questions were within scope for the PSP, which would be used to generate the long-list of summary questions.

**Children & young people**  
22%

**Parents / family / friends**  
34%

**Healthcare professionals**  
32%

**Other**  
12%

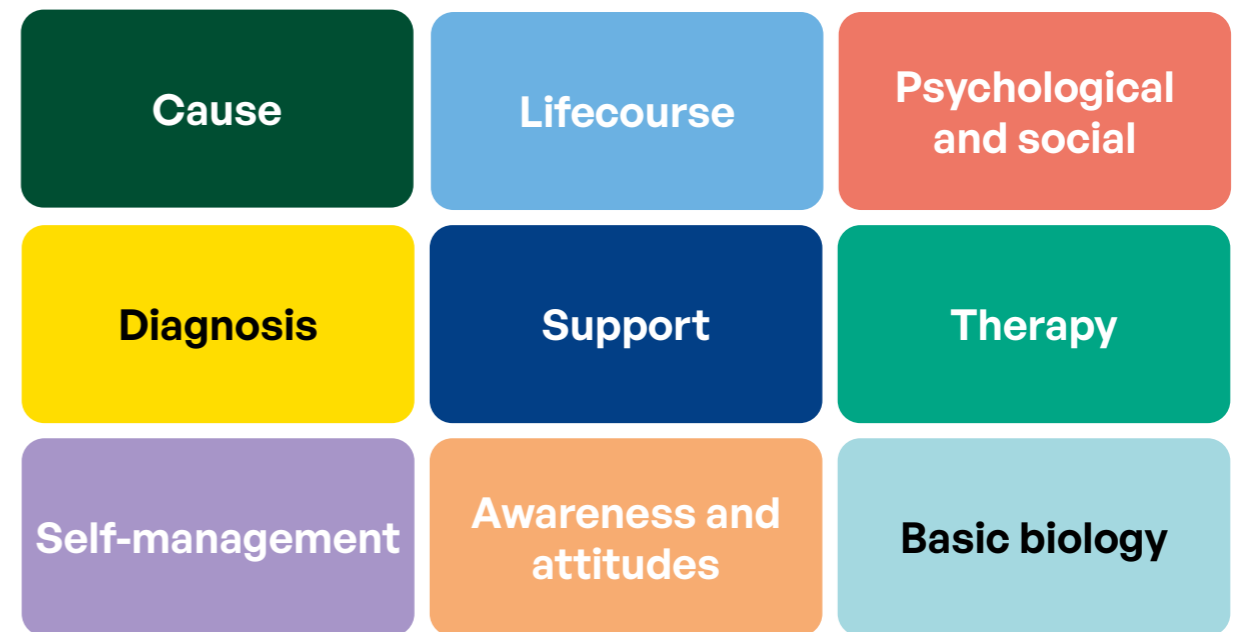
# What were the stammering community asking about?

Once we had determined the questions that fell within the scope of the PSP, we were able to generate summary questions that were informed by the original 247 questions gathered from the community.



Photo credit: Michael Powell

The questions that were being asked could be grouped into the following broad categories:



To make sure that these questions had not already been answered by existing research, three members of the steering group performed a search of published studies. After comprehensively searching academic journals for studies that addressed these questions, the steering group agreed that none of the 50 questions had been robustly answered<sup>13</sup>. This meant that all 50 questions were included on the long-list of questions taken forward to the next survey.

<sup>13</sup>The evidence checking process is detailed in the JLA Question Verification Form, which defines the standard of research agreed to be 'robust' evidence by the steering group

# Interim Priority Setting



Now that we had our long-list of summary questions, we needed to reduce this down to a short list of questions for discussion at the Final Workshop. We created a new “prioritisation survey”, which we shared with the community.

In this survey, respondents were asked to choose ten questions from the long list and then rank these ten questions from most to least important. Although the long list contained 50 questions, an administrative error meant that 49 were included in the Prioritisation Survey (see Appendix A for details).

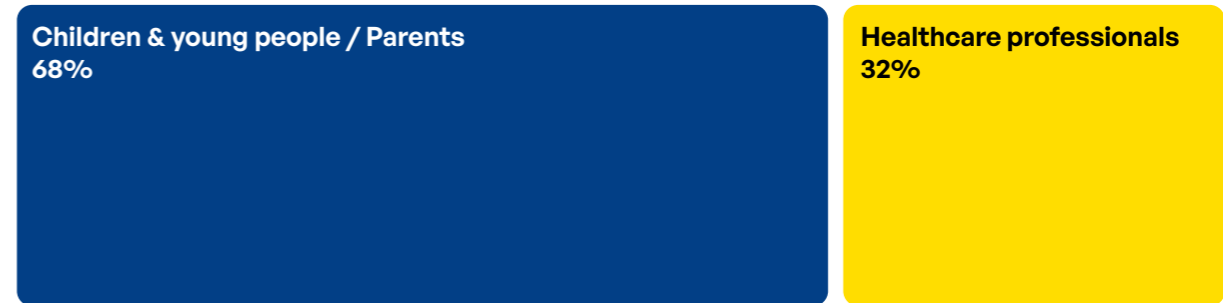
A total of 180 young people, families, friends and professionals completed the survey and ranked the questions they had selected from 1 – 10.



We looked at the questions that had been most highly ranked by respondents to the survey. This resulted in a short list of 25 questions that were taken to the Final workshop.

# The Final Workshop

We held a one day in-person workshop at the end of 2023. Twenty two young people, parents/guardians and professionals were split into four smaller groups to discuss and rank the 25 questions short-listed. At the end of the day, all of the rankings from the different group discussions were analysed, resulting in the list of Top 10 questions for future research to answer.



In the next section, we reveal the final Top 10, as well as the other 15 priorities that made it to the short list.





# The Top 10



**1** What are the most effective forms of speech therapy for children and young people who stammer to give the best long term outcomes?

**2** How can parents and family members best support children and young people who stammer? How can parents and family members best be trained and supported to do this?

**3** How can teachers in schools best support children and young people who stammer? How can teachers best be trained and supported to do this?

**4** What are the emotional and psychological impacts of stammering on children and young people who stammer (e.g. low self-esteem and depression)? How are these best treated and supported?

**5** What causes children to develop a stammer in early childhood?

**6** Are other brain-related conditions (for example autism and ADHD) linked to stammering? What impact do these have on stammering?

**7** What impact does stammering have on children's and young people's performance at school? How does this affect their prospects for further training, education and employment? What forms of support would be of most help?

**8** What is the most effective therapy and support for very young children who stammer (pre-school)?

**9** What triggers stammering to increase in children and young people in different situations e.g. anxiety or excitement? How is this best managed?

**10** How does a child's emotions and personality affect the impact of a stammer? Does helping a child to manage their emotions reduce the stammer and its impact?



# Priorities that made the short-list

- 11 What are the long-term outcomes for children and young people who stammer, either with therapy or without therapy?
- 12 What helps children and young people who stammer and their families to be more accepting of their stammer? Does this make a difference to the long term outcomes from therapy?
- 13 How can young people who stammer best be supported after leaving school?
- 14 Is there a way to identify which children will grow out of a stammer and which children might need extra support and therapy?
- 15 How do the attitudes of other people, especially parents, affect children and young people who stammer? Do these attitudes need to be improved and if so, how?



- 16 Why is stammering more common amongst boys than girls, particularly when they are teenagers/young adults?
- 17 Why does singing and performing reduce stammering and how can this be part of the support for children and young people who stammer?
- 18 What do children and young people who stammer and their parents think are the most important outcomes from therapy?
- 19 What are the environmental factors that cause a child to develop a stammer?
- 20 Why does a child's stammering vary from day to day, and come and go over the years?
- 21 Would combining speech therapy and support for mental well-being help children and young people who stammer?
- 22 Do drugs used to treat ADHD help children and young people who stammer?
- 23 Does anxiety cause children to develop a stammer?
- 24 Why do some children grow out of their stammer, but others don't?
- 25 What is the best way to prevent bullying of children who stammer in school?

# What's next?

The publication of the Top 10 is just the beginning! We need your help getting these priorities out there to inform the future research agenda.

## Call to Action...

### Researchers

Use the Top 10 to guide your future research projects and priorities – and tell us about your findings!

### Research funders

Facilitate more robust and meaningful research by making resources available to address the questions identified by the stammering community

### Young people, families and professionals

Raise the profile of the Top 10 by sharing your insights and engaging with research and policy processes

### Policymakers

Rely on the evidence-base generated by these questions to develop meaningful and practical policy recommendations that benefit young people who stammer and their families

## Our promise

We aim to facilitate greater engagement between researchers and the stammering community and we commit to the following to help us achieve this:

- We will actively seek out opportunities to promote and collaborate with partners on research projects that address these questions
- Working with the ASC Youth Panel, we will continue to facilitate public and patient involvement (PPI) in research development
- We will actively communicate new research findings in a more accessible and meaningful way to promote greater engagement of young people in stammering research
- Researchers will have the opportunity to share their research projects with us and engage the ASC community from initial concept through to participation in projects that address the Top 10
- We will share updates about the impact of the Top 10 with our supporters and the wider stammering community



# Get involved

## If you're someone with experience of stammering...

We want to hear from you! Tell us what you think about the Top 10 and the impact research has on YOU. Here are some of the ways you can share your views:

- Write for our blog – we love to share articles from guest contributors on the Action for Stammering Children blog
- Record a 10-second video that we can share on our socials
- Take to social media to share your thoughts

## If you're a researcher...

You can help us raise the profile around the Top 10 with your colleagues and academic networks. Here are some of the ways you might like to do this:

- Tweet about the Top 10, tagging fellow researchers, funders and networks
- Reference the PSP in your grant applications
- Give a presentation to your lab
- Write an editorial for a peer-reviewed journal
- Contribute to the Action for Stammering blog
- Consider submitting an article to your professional body, institution and other partner organisations

## Get in touch

Keep up to date about the impact of the Top 10 via the PSP website page.



If you would be interested in collaborating with us, take a look at our Project Partnership opportunities or drop us an email to learn more about the ways we could work together.



# Appendix A – a note on methodology

## Question omission

Although there was insufficient evidence to remove any of the 50 summary questions obtained from the first survey, the prioritisation survey included 49 questions. This was due to an administrative error, which resulted in 49 rather than the full 50 questions appearing in the survey. The question that was unintentionally omitted from the prioritisation survey was:

*Can working on executive function skills (for example flexible thinking, planning ahead, organising and problem solving skills) help children who stammer?*

This question was based on one submission from a health care professional. We have shared it both for transparency and to inform researchers of the interest in this area of research.

## Respondent numbers

A total of 201 respondents started the survey, however 180 participated in the second step (ranking the top ten questions they had selected). This is the reason that we have recorded the total respondents as 180.

It is also worth noting that not all respondents who began the process of ranking the questions, ranked all 10 questions (i.e. from 1 through to 10) but instead partially ranked them. In the analysis, we included data from all respondents who had either fully or partially ranked the ten questions.

## Final workshop

Due to an error during the analysis, four questions that had been ranked sufficiently highly to go forward to the Final Workshop were omitted. This error was uncovered after the Workshop had taken place and disclosed to the Steering Group. It was agreed by the Steering Group that these four questions had been satisfactorily represented by questions that were included in the list of 25 questions considered by workshop participants. There is no reason to believe that inclusion of these four questions in the long list would have affected the final Top 10. Nevertheless, in the interests of transparency, we have listed these four questions and provided an explanation as to how these questions were covered by other questions on the short list, all of which appear in the Top 10.

The questions are:

### **What is happening in the brain to make children stammer?**

This question is covered by a question that did go to the Workshop: *What causes children to develop a stammer in early childhood? (Question 5 in the Top 10)*

### **What is the most effective therapy and support for teenagers who stammer?**

This question is covered by a question that did go to the Workshop: *What are the most effective forms of speech therapy for children and young people who stammer to give the best long-term outcomes? (Question 1 in the Top 10)*

### **Do employers view or treat young people differently?**

This question is covered to some extent by a question that did go to the Workshop: *What impact does stammering have on children's and young people's performance at school? How does this affect their prospects for further training, education and employment? What forms of support would be of most help? (Question 7 in the Top 10)*

### **What genes are involved in stammering?**

This question is covered to some extent by a question that did go to the Workshop: *What causes children to develop a stammer in early childhood? (Question 5 in the Top 10)*

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## About Action for Stammering Children

Action for Stammering Children is the UK charity for children and young people who stammer, their families, and the communities who support them.

We're here to make sure that every child who stammers has the support, respect and confidence to live the life they want to lead.

We support and empower parents, caregivers and professionals; facilitate and champion research; and campaign for changes in policy and societal attitudes.

## Find out more

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