

Autism: Top 10 Research Priorities

We are asking you to complete a short survey (5 mins approximately) that will ultimately lead to a Top Ten list of research questions on autism to improve health and wellbeing. The process aims to promote research that will lead to the outcomes people on the autism spectrum, family members, and professionals are interested in. Our goal is to provide a clear direction for future autism research so that it benefits the lives of individuals and families, and increases the amount of funding for the most important autism research. We want to see research made even better with your input.

IDENTIFYING IMPORTANT RESEARCH QUESTIONS

The James Lind Alliance is an independent initiative hosted by the government funded National Institute of Health Research (NIHR). Over the last 10 years it has helped identify the priorities of people affected by various health conditions such as dementia, diabetes and sight loss. Our plan is to run this process for autism.

The process is overseen by a Steering Committee, which is chaired by an independent James Lind Alliance consultant.

AUTISM

It is a priority for us to include the opinions of, and set priorities for, individuals from across the autism spectrum and from different age groups. We are interested to hear from:

- People who have a diagnosis of autism, Asperger's syndrome, Pervasive Developmental Disorder not otherwise specified, Atypical Autism and Autism Spectrum Disorder/Condition.
- People who strongly suspect that they are on the autism spectrum or are self-diagnosed.
- Parents, carers and siblings of individuals on the autism spectrum.
- Carers, siblings, partners and children of adults on the autism spectrum.
- Individuals and families who are currently going through the autism diagnostic process.
- Individuals and families who may have a diagnosis of a different condition – such as Fragile X syndrome or learning disability – but who also have an autism diagnosis.
- Professionals and volunteers who work with people on the autism spectrum and their families.

We are only asking for responses from people who are living in the UK.

We recognise that some people will need help from others to respond so please indicate that in question 10 of the survey.

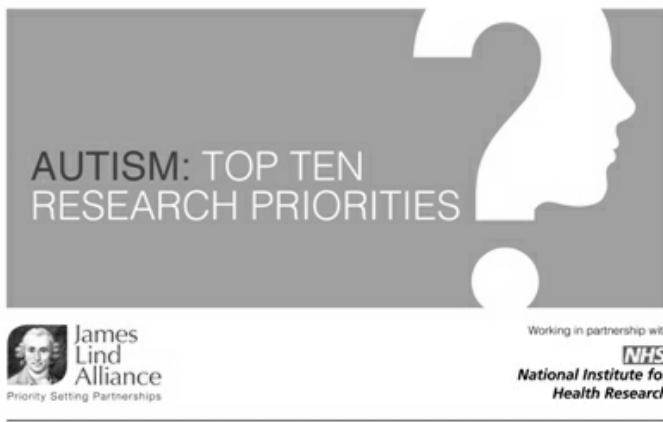
WHAT HAPPENS TO THE DATA COLLECTED?

In the survey we ask you for the 3 questions you think are most important for research to answer, your age, gender, ethnicity etc. and, if you are a professional, what your occupation is. You can respond anonymously to this survey – you do not have to give your name or contact details.

The agreed Top Ten list will be published on our project [website](#) and shared via email or post. We will then work together with researchers and research funders to promote the research you would like done.

AGREEING TO TAKE PART

By completing this survey you are agreeing to your opinions being included in the decision making process about future autism research. You can keep up to date with progress by registering an interest through our project website once you've completed this survey.



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The Survey

What questions would you like answered to improve your or your family member's health and wellbeing? Similarly, for professionals what would be the most important research questions to answer to improve the lives of the individuals you work with?

This may include questions about:

- Interventions, therapies and support to manage difficulties a person on the autism spectrum may have.
- How research can change the way society understands and interacts with people on the autism spectrum to help them achieve better health and wellbeing.
- The ways that research could improve service delivery (in health, education and social care).

Here are example questions that have been asked for other conditions:

What treatments help reduce balance problems and falls in people with Parkinsons?

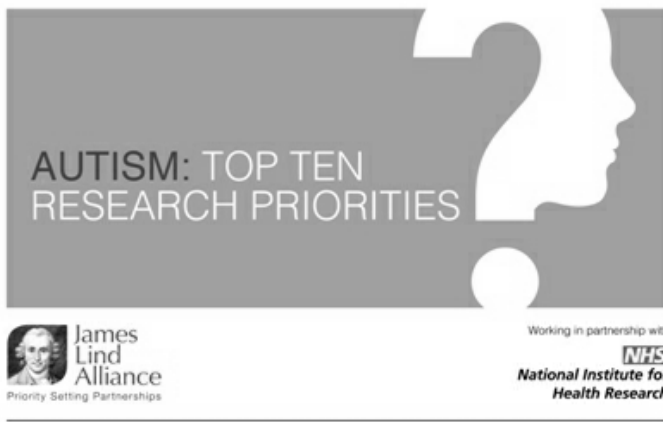
Would regularly monitoring my physical health improve my schizophrenia?

If my child did daily breathing exercises would it help control their asthma?

* 1. Now, please provide the top 3 questions that you would like research to answer (in any order). If you can't think of 3, please enter as many as you can.

Question	<input type="text"/>
Question	<input type="text"/>
Question	<input type="text"/>

The remainder of the survey contains questions about you.



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About you.

We would like to ask a few questions about you, to help us understand which groups of people have responded to the survey.

* 2. Where do you live?

- England
- Scotland
- Wales
- Northern Ireland
- Other (please specify)

3. Which of the below best describes your ethnicity?

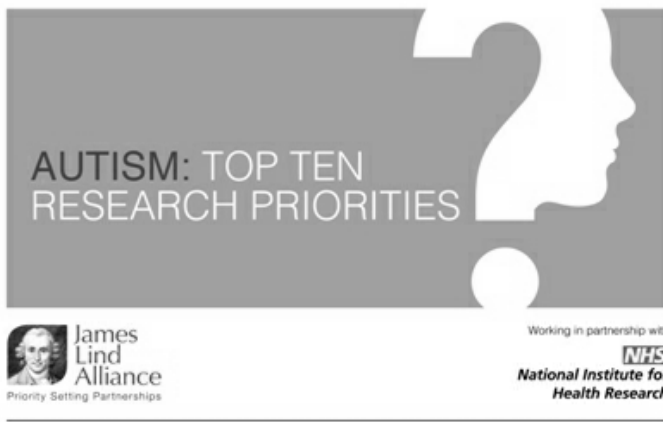
- White
- Black/African/Caribbean/Black British
- Mixed/Multiple ethnic groups
- Asian/Asian British
- Prefer not to answer
- Other (please specify)

4. What is your gender?

- Female
- Male
- Transgender Male/Female
- Transgender Female/Male
- Prefer not to answer
- Other (please specify)

5. How did you find out about this survey?

- Autistica
- The National Autistic Society
- Autism Alliance
- Autism Research Trust
- Other (please specify)

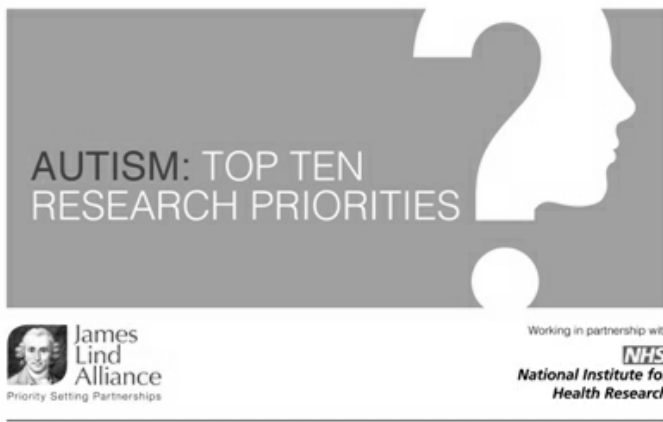


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Your connection to autism.

6. Which best describes you? (if more than 1 applies, you can complete the survey multiple times)

- A person formally diagnosed as being on the autism spectrum
- I strongly suspect that I'm on the autism spectrum or I'm self-diagnosed
- A parent, relative, spouse, child or carer of someone on the autism spectrum
- A professional or I work/volunteer for an organisation supporting people on the autism spectrum.



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For people diagnosed or suspected as being on the autism spectrum

7. My age is

8. I have a diagnosis of (please enter up to three if you have more than one diagnosis):

Diagnosis:

Diagnosis:

Diagnosis:

9. I strongly suspect I have a diagnosis of (please enter up to three if you suspect you have more than one diagnosis):

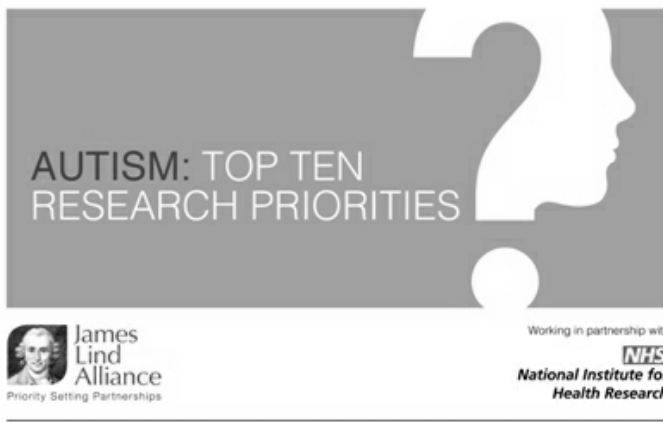
Diagnosis:

Diagnosis:

Diagnosis:

10. I had help completing this survey from someone else

11. If there is anything else you would like to add, please do so here



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For parents, relatives, spouses, children or carers of someone on the autism spectrum.

12. I am

- A parent of a person on the autism spectrum
- A sibling of a person on the autism spectrum
- A grandparent of a person on the autism spectrum
- A spouse/partner of a person on the autism spectrum
- A child of a person on the autism spectrum
- A carer of a person on the autism spectrum
- Other (please specify)

13. My age is

14. The person I am responding about is aged

15. The person I am responding about has a diagnosis of (please enter up to three if they have more than one diagnosis):

Diagnosis:

Diagnosis:

Diagnosis:

16. I strongly suspect the person I am responding about has a diagnosis of (please enter up to three if you suspect they have more than one diagnosis):

Diagnosis:

Diagnosis:

Diagnosis:

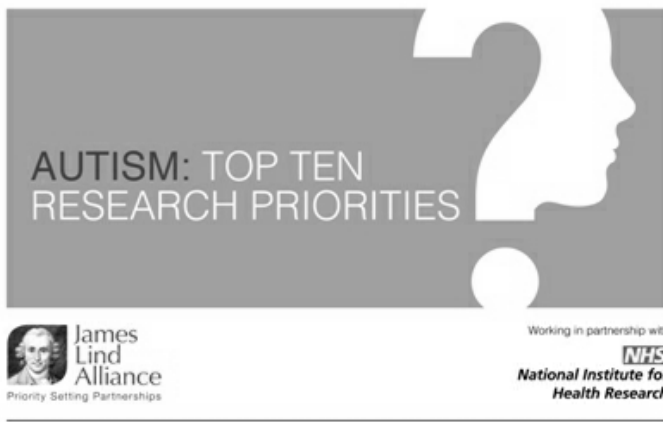
17. What type of education setting does the person you are responding about currently attend or what setting did they last attend?

- Preschool or nursery
- Mainstream School
- Class/unit attached to a mainstream school
- Special school
- Class/unit attached to a special school
- Special school (residential)
- Home schooled
- Further education
- Higher education
- I don't know
- Other (please specify)

18. How would you describe the current language abilities of the person you are responding about?

- Uses full sentences with good grammar
- Uses mostly simple phrases (2 words or more with a verb/doing word)
- Uses mostly single words
- Uses no speech but tries to communicate using gestures or pictures
- Uses no speech but tries to communicate with us physically
- I don't know
- Other (please specify)

19. If there is anything else you would like to add, please do so here



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For professionals or for those working for an organisation supporting people with autism.

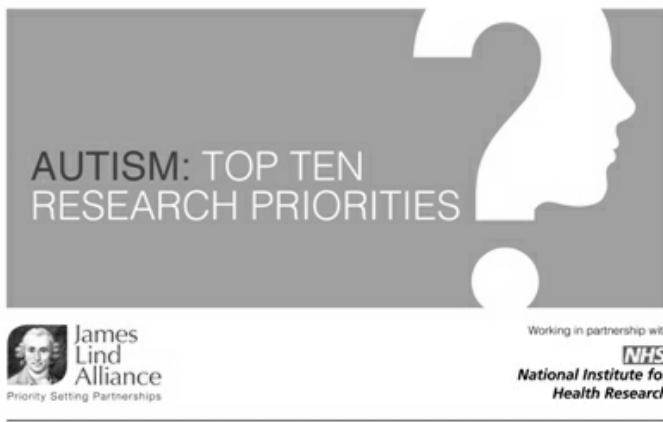
20. Please tell us your occupation (tick more than one if they apply).

- | | |
|--|--|
| <input type="checkbox"/> Paediatrician | <input type="checkbox"/> Care home support |
| <input type="checkbox"/> Psychologist | <input type="checkbox"/> Accommodation support |
| <input type="checkbox"/> Psychiatrist | <input type="checkbox"/> Community support worker |
| <input type="checkbox"/> Speech and Language Therapist | <input type="checkbox"/> Charity administration |
| <input type="checkbox"/> Occupational Therapist | <input type="checkbox"/> Counsellor/therapist |
| <input type="checkbox"/> Health Administrator or Manager | <input type="checkbox"/> Teaching professional |
| <input type="checkbox"/> GP | <input type="checkbox"/> Advocate of someone with autism |
| <input type="checkbox"/> Nurse | <input type="checkbox"/> Volunteer |
| <input type="checkbox"/> Other (please specify) | |

21. Which age group do you work with? (tick all that apply)

- Children (up to 12 yrs)
- Teenage (13-17 yrs)
- Adults (18+ yrs)

22. If there is anything else you would like to add, please do so here



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Thank you

Thank you for taking part in this survey.

If you would like to register for Top Ten updates, please provide your details [here](#).

If you would like more information about any issues raised by the survey, visit our Top Ten [website](#).

Please help us by forwarding this survey on to anyone who you think might be interested.