

Autistica. Building Brighter Futures Through Autism Research.

JLA PSP final report (2016)

<https://www.jla.nihr.ac.uk/priority-setting-partnerships/autism/downloads/Autism-PSP-final-report.pdf>

For which topic were research priorities identified?

autism

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

Autism is one of the most poorly funded areas of research (we spend less than £6 per person with autism per year), yet autistic people and their families face outcomes which would be totally unacceptable to other groups.

What was the objective?

to define a list of research priorities with the autism community

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

January 2015 - April 2016

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: establishing steering group. Step 2: collecting questions: survey asking people for their top three questions for autism research to answer, 3331 raw questions submitted. Step 3: data processing: sorting, grouping, removing duplicates, check against evidence, 89 questions remained, steering group decided that the 40 most frequently submitted questions of the 89 would go forward to the ranking stage. Step 4: interim ranking: survey asking participants to choose top ten questions, resulting in top 25 questions. Step 5: final prioritization: workshop: small group discussions and small group rankings followed by plenary discussion

Which stakeholders took part?

Patients, family members and caregivers, clinicians, and professionals. Survey: 1213 participants: 23% individuals on the autism spectrum or strongly suspect they are on the spectrum, 52% family members and caregivers, 25% clinicians and professionals. Interim ranking: 1266 participants. Workshop: equal numbers of autistic adults and young people, parents and professionals.

How were stakeholders recruited?

Participants were recruited via partner organizations.

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 charity and health organization representatives with experience of autism and autistic individuals. The members guided the entire process to keep it as independent and inclusive as possible.