

Where Do We Go from Here? Autism Community Priorities for Future Suicide Research. Results from the International Research Priority Setting Exercise 2021

<https://drive.google.com/file/d/1OtR37WsQN4oANCywwVSwB1i8DHwsCbXJ/view>

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?

Recent research has shown that suicide is a leading cause of early death in autistic people. However, there is little research into why this is the case, or how suicide in autistic people could be prevented. It is crucial that the autism community set the agenda for future research. Traditionally, the priorities for autism research have been determined by funders and researchers, rather than autistic people or those who support them. Therefore, autism research does not necessarily address the issues that are important to the autism community. We must work in partnership with autistic people and those who support them in order to identify their priorities for future research. This will help ensure that future research is useful to the daily lives of the autism community.

What was the objective?

to work in partnership with autistic people and those who support them in order to identify their priorities for future research

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

January 2016 - April 2019

Which methods were used to identify research priorities?

focus group; group discussion; survey; workshop

How were the priorities for research identified exactly?

Step 1: two public engagement events: focus groups 1: discussion what was need to prevent suicide in autistic people, participants identified broad topics areas for future research and policy to focus on. Step 2: discussion groups: to develop more focused topics. Step 3: focus groups 2: developing focused topic areas into a long list of 48 priorities. Step 4: survey: participants ranked the 48 priorities and described the main issues for policy and practice. Step 5: workshop: participants ranked the top 20 from the online survey to identify the top 10, funders of research, policy makers, charities and service providers joined the discussions to recommend how the priorities could be implemented in policy and practice

Which stakeholders took part?

Focus groups 1: 60 researchers, clinicians, autistic people and their families. Discussion groups; autistic people, their families, researchers, clinicians and charities. Focus groups 2: 40 autistic people, researchers, charities and service providers. Survey: 88 participants.

How were stakeholders recruited?

No information provided.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.