

Community Priority Setting for Fetal Alcohol Spectrum Disorder Research in Australia

Finlay et al. (2020)

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For which topic were research priorities identified?

fetal alcohol spectrum disorder (FASD)

In which location was the research priority setting conducted?

Australia - Australia

Why was it conducted at all?

Fetal Alcohol Spectrum Disorder (FASD) is a neurodevelopmental disorder caused by prenatal alcohol exposure (PAE). FASD research is a rapidly growing field that crosses multiple disciplines. To ensure research is relevant and meaningful for people living with FASD, their families, and the broader public there is a need to engage community members in setting priorities for research.

What was the objective?

to formally identify the views of people living with fetal alcohol spectrum disorder (FASD), their parents/caregivers, service providers, and the general community on the research priorities for FASD and alcohol use in pregnancy in Australia

What was the outcome?

a list of 10 research topics

How long did the research prioritization take?

No information provided.

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: identifying uncertainties: survey: to elicit questions that community members (including families living with FASD, FASD service providers, and members of the general public) would like addressed through research, four open-ended questions: What questions or concerns do you have about the consumption of alcohol during pregnancy? What questions do you have about the diagnosis of FASD? What questions do you have about the treatment for FASD? Do you have any other comments (about anything else regarding FASD)?, 128 responses about PAE, 123 about diagnosis and treatment, and 103 other comments. Step 3: data processing: submissions reviewed, checked and verified as true uncertainties, resulting in list of 29 topics. Step 4: interim ranking: participants asked to rank topics, 22 highest ranking topics moved forward. Step 5: workshop: final prioritization: discussions resulted in combination of some themes and introduction of some new themes, small group rankings, agreement on final top 10 established. Step 6: rapid literature review: conceptually similar topics were grouped into areas, rapid literature review undertaken to identify relevant studies

Which stakeholders took part?

People living with FASD, their parents/caregivers, service providers. Survey: 146 participants. Interim ranking: 45 participants. Workshop: 21 participants.

How were stakeholders recruited?

A snowball sampling strategy was used to distribute the survey to community and professional networks, including the CCHRN's Involvement Network, FASD Research Australia Community Reference Group's community networks and FASD service providers. The survey was also promoted through the CCHRN and Telethon Kids Institute social media channels.

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 4 researchers, 2 members of the Consumer and Community Health Research Network and 5 community members.