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Fetal Alcohol Spectrum Disorder Priority Setting Partnership Project

Survey Participant Information Sheet

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You are invited to work with project investigators at the Telethon Kids Institute and the WA Health Translation Network Consumer and Community Health Research Network to identify the issues and questions that you feel are important to Fetal Alcohol Spectrum Disorder (FASD). This may be concerns relating to prevention (alcohol consumption during pregnancy and the potential impact on children and families), diagnosis, treatment or support for people who are affected by FASD.

The research team conducting this research project include the following investigators: from Telethon Kids Institute - Carol Bower, Elizabeth Elliot, Amy Finlay-Jones and Narelle Mullan; community members – Neil Reynolds, Helen Donnelly, Paula Sargent, Bridgette Birda and Diane Mayers; and Consumer and from Community Health Research Network - Anne McKenzie and Rebecca Nguyen.

What is this project about?

The Fetal Alcohol Spectrum Disorder Research Australia Centre for Research Excellence is a national research program that aims to reduce the effects of alcohol use during pregnancy by: supporting families to reduce or stop alcohol use in pregnancy, increasing awareness of Fetal Alcohol Spectrum Disorder (FASD), finding effective treatment and improving access to services for children with Fetal Alcohol Spectrum Disorder and their families.

The aims of this project are to address this by:

1. Conducting an online survey to identify themes and topics of interest for future research considered important by community members who are/have been affected by FASD and service providers, specifically around two streams: a) Prevention of FASD and b) Diagnosis and treatment of FASD.
2. Conducting a follow-up online survey to rank the order of importance of the themes and topics identified from the survey results
3. Holding a one-day consensus workshop, informed by the above-mentioned list to develop ten community priorities for the Prevention and Diagnosis and Treatment streams that will be used to inform future research of the Fetal Alcohol Spectrum Disorder Research Australia Centre for Research Excellence.

What does participation involve?

If you agree to participate you will be asked to:

1. Complete a 10-minute online survey about your thoughts and feelings about is most important for you for the prevention, diagnosis and treatment of FASD.
2. (Optional) Complete a second, short 5-minute online survey that will ask you to rank the order of importance of identified themes/topics from the first survey.
3. (Optional) Register your interest to attend the FASD Priority Setting Partnership Project Consensus Workshop

Voluntary Participation and Withdrawal from the Study

Participation in this study is entirely voluntary. Should you no longer wish to

Discover. Prevent. Cure.



be involved, you are free to withdraw at any time without explanation or justification by contacting the Project Coordinator Ms Rebecca Nguyen on (08) 6488 8176 or email Rebecca.nguyen@uwa.edu.au. Following this, any data of yours that has already been collected will be destroyed appropriately and not used in the study.

Your privacy

All project-related information including participant information will be treated in a confidential manner and be stored securely at the Telethon Kids Institute's password-protected electronic database or locked in the project manager's office and will only be accessed by the research team.

We are required to store the data for a minimum of 7 years after publication or project completion, after that time it will be destroyed. The information and data gathered from this study may be published, however the identity of participants will not be disclosed at any time. Participant privacy and the confidentiality of information provided by participants, is assured at all other times. The data will be used only for this project, and will not be used in any extended or future research.

What are the possible benefits of this research project?

It is vital that any further research into this area is informed by questions that are important to people who people who has or supports someone with FASD either personally or professionally, as well as people who are interested and/or concerned with the affects of alcohol consumption during pregnancy and the potential impact on children and families. Working together with the community to inform the development of a list of priorities to inform research within the Fetal Alcohol Spectrum Disorder Research Australia Centre for Research Excellence will have a much greater impact to the community. It will also allow the Priority Setting Partnership Project to direct research funding agencies to FASD research that is likely to have the most impact and importance to the community.

Are there any risks in participating in this research project?

You may find it difficult to describe or express your ideas - there is no 'right way' to do this and the project team members will work with whatever you manage to tell us about. You may also feel potential distress when confronted with memories or stories. If you feel you need to speak with someone please contact:

Beyond Blue

Website: <https://www.beyondblue.org.au/>

Phone: 1300 22 4636

Chat: <https://online.beyondblue.org.au/WebModules/General/OutOfHours.aspx>

NOFASD AUSTRALIA

Website: <http://www.nofasd.org.au/>

Phone: 1300 306 238

Who do I contact if I wish to talk about the project further?

If you would like to discuss any aspect of this study with a member of the research team, please contact me on 9489 7751 or email Carol.Bower@telethonkids.org.au or Rebecca Nguyen on (08) 6488 8176 or email Rebecca.Nguyen@uwa.edu.au.

How do I get involved?

If you are interested in participating in this project, please continue onto the next page to sign the electronic consent form. If you would like a copy of your Participant Consent Form, please email

Rebecca.Nguyen@uwa.edu.au

Approval to conduct this research has been provided by the University of Western Australia with reference number RA/4/1/9240, in accordance with its ethics review and approval procedures. Any person considering participation in this research project, or agreeing to

participate, may raise any questions or issues with the researchers at any time. In addition, any person not satisfied with the response of researchers may raise ethics issues or concerns, and may make any complaints about this research project by contacting the Human Ethics office at UWA on (08) 6488 4703 or by emailing to humanethics@uwa.edu.au. All research participants are entitled to retain a copy of any Participant Information Form and/or Participant Consent Form relating to this research project.