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Fetal Alcohol Spectrum Disorder Priority Setting Partnership Project

Survey Participant Information Sheet

You are invited to work with project investigators at the Telethon Kids Institute and the WA Health Translation Network's (WAHTN) 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 use during pregnancy and the potential impact on children and families), diagnosis, treatment or support for people who are affected by FASD.

The Priority Setting Partnership Project is part of the *Fetal Alcohol Spectrum Disorder Research Australia Centre for Research Excellence*. This Centre is a collaboration between the Telethon Kids Institute and the University of Sydney, and aims to reduce alcohol use during pregnancy; decrease the incidence of FASD; and improve diagnosis and management of FASD.

The research team conducting the Priority Setting Partnership Project comprises of: community members - Neil Reynolds, Helen Donnelly, Paula Sargent, Bridgette Birda and Diane Mayers; Consumer and from Community Health Research Network members - Anne McKenzie and Rebecca Nguyen; and *Fetal Alcohol Spectrum Disorder Research Australia Centre for Research Excellence* members - Carol Bower, Elizabeth Elliot, Amy Finlay-Jones and Narelle Mullan.

What is the Priority Setting Partnership Project about?

The aims of this project are to:

1. Conduct an on-line survey to find out from members of the community what they think are important questions and issues about alcohol use in pregnancy and FASD diagnosis and treatment.
2. Conduct the Ranking Survey - a follow-up online survey to put themes from the questions and issues raised in the first survey in order of importance.
3. Hold a one-day consensus workshop to develop ten community priorities from the results of the surveys. These priorities will be used to guide future research of the *FASD 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 on your questions and issues about 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 themes 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 be involved, you are free to withdraw at



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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.

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.