

Development of Aotearoa New Zealand diagnostic guidelines for Fetal Alcohol Spectrum Disorder (FASD)

Community Consultation Participant Information Sheet

You are invited to take part in this project to share your thoughts and experiences on what you consider important in the development of Aotearoa New Zealand diagnostic guidelines for fetal alcohol spectrum disorder (FASD).

This Participant Information Sheet will help you decide if you would like to take part. Before you decide you may want to talk about the project with other people, such as whānau, family, friends, healthcare providers or other support workers.

What is the purpose of this project?

Hāpai te Hauora is leading this project for the Ministry of Health to develop FASD diagnostic guidelines for Aotearoa New Zealand. The project is co-led by Tangata Whenua (people of the land) and Tangata Tiriti (people of the treaty) so we can prioritise the needs of our people in Aotearoa New Zealand. Our process is grounded in Te Tiriti o Waitangi and utilising Kaupapa Māori methodology and practice.

Project Scope

Three important areas of care delivery have been identified to support individuals and families affected by FASD (Mukherjee, 2021), and the focus of this project is on the diagnosis area of care delivery.



The project aims to deliver guidelines that will enable clinicians to follow best practice in FASD assessment and diagnosis reflecting on both the latest international research and within the cultural and health context of Aotearoa New Zealand, encompassing Te Ao Māori (the Māori world) perspectives of health and wellbeing.

Who can take part?

It is important we speak to a wide range of people. This includes:

- People who have FASD (or who think they may have FASD).
- Families, caregivers, and support people of those who have FASD.
- Consumer Representatives.
- People involved in the assessment and diagnosis of FASD, such as psychologists, pediatricians, psychiatrists, social workers, speech and language therapists, occupational therapists, physiotherapists, FASD coordinators or navigators, other specialists.
- People working in FASD research.
- People providing screening and referral for FASD.
- People providing support to people with FASD and their whānau, caregivers and/or support community.

What will my participation in this project involve?

We are inviting people to take part in a zoom hui and/or complete a questionnaire to share your thoughts.

We want to know what you feel are the most important considerations in having an assessment and making a diagnosis for FASD. We will talk in smaller groups as well as altogether. You have the right to leave the zoom hui at any time, and if you are not feeling comfortable you do not have to speak.

All zoom hui will be audio-recorded to make sure we do not miss anything important. These will then be written down, word for word, from the recordings. Once the zoom hui is complete, we will send you a summary of the key themes. What are the benefits and risk of this project?

This project is a chance to have a say about how FASD is assessed and diagnosed in Aotearoa New Zealand in the future. Until now we only have guidelines and information from other countries to follow, and it is exciting to talk about what is important for our own people. We understand that talking about experiences with FASD assessment and diagnosis may bring up strong feelings for some people. If you do experience any difficulties or stress at any time during the project, please let someone in the Project Team know.

Will information about me be kept confidential?

We ask that all participants maintain confidentiality with respect to other participants and what is being discussed. However, due to the nature of the zoom hui, confidentiality of who said what cannot be guaranteed. Audio from the zoom hui will be transcribed by a third party. All transcribers will sign a confidentiality agreement and agree not to discuss or distribute information about the project.

All discussion from the zoom hui will have identifying information removed. The project files, audio files, and all personal information that you provide will be strictly confidential. No material that could identify you will be used in any reports on the guidelines, or within the guidelines, without your permission.

The Project Team recognises that the zoom hui participants have ownership of their story, which for Māori is intrinsic to tino rangatiratanga. The Project Team agree to be kaitiaki (guardians) of the information. They will be guided by strong ethics around gathering, and storing data, and acknowledge they do not own the information.

Voluntary participation and withdrawal

Your participation in this project is voluntary (your choice). You can withdraw from this project at any time, without giving a reason. You may choose not to answer a question and/or can leave the zoom hui at any time. If you withdraw from the project, any data you provided as part of the zoom hui cannot be withdrawn, as withdrawal may affect the remaining data.

Who is organising the project?

The Project Team are being hosted and supported by Hapai Te Hauora, the contract holder to the Ministry of Health. The Project Team consists of Tangata Whenua and Tangata Tiriti co-leads - Sarah Goldsbury and Andi Crawford, Project Coordinator – Maria Ngawati, and Research Associates – Tania Henderson and Joanne van Wyk.

If you have any questions or concerns about this project, please feel free to contact the Project Team on nz.fasd.guideline@gmail.com.