Waipapa Taumata Rau University of Auckland

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Participant Information Sheet

Online Survey Participants

Project title: Costs Associated with Raising a Child with Fetal Alcohol Spectrum Disorder (FASD)
Research Team:

Dr. Joanna Chu, University of Auckland
Professor Anita Gibbs, University of Otago
Josie Tait, Research assistant, University of Auckland
Dr. Jessica McCormack, University of Otago
Holly Wilson, University of Auckland

We want to understand the cost of caring for someone with Fetal Alcohol Spectrum Disorder (FASD) and the burdens caregivers experience. Please take the time to read this information in full, before you decide to participate. If you would like support to take part please ask a friend or whānau member to help you.

What does the study involve?

You will be asked to complete a 30-40 minute questionnaire, which asks questions about you and the person with FASD's experience of health and wellbeing. We include questions about costs you have had, your experiences accessing healthcare, barriers you have faced, and how caregiving for a child with FASD has impacted on you as a caregiver.

The survey will be completed on a web-based survey platform called Qualtrics. This tool is approved by the University of Auckland for research surveys that are sensitive in nature. This is a university-managed software, hosted overseas. Alternatively, you can choose to complete this survey on paper by contacting a member of the research team. Paper surveys will be distributed in person or by post, by a member of the research team and returned either directly to the researcher in a sealed envelope or via a secure collection box.

The only costs to you in taking part in this survey, are your time and internet connection. No identifiable information will be collected. Please refrain from sharing information that could potentially identify the person being discussed.

Inclusion Criteria

We, the research team, aim to identify the costs of caring for someone with Fetal Alcohol Spectrum Disorder (FASD). We are seeking the views of caregivers of people with FASD. To participate in this study, you must be at least 18 years old. You may be a parent, guardian, sibling, caregiver, whānau member or other relative who cares for someone with FASD. The person with FASD may have a diagnosis of FASD or they may have a similar diagnosis, such as Fetal Alcohol Syndrome, Neurodevelopmental Pre-natal Alcohol Exposure, Alcohol-Related Neurodevelopmental Disorder, Partial FAS, Fetal Alcohol Effect, or you may suspect they have FASD, but they have not got a formal diagnosis as yet.

Persons with FASD are not sought to take part in the survey; if this is you, please ask a support person or caregiver to fill in the questionnaire.

Benefits and risks

There is minimal risk to participation. You will complete the questionnaire anonymously online or on paper; therefore, your identity and the identity of the person you care for will remain hidden. There is a small risk that the questions may lead you to reflect on your own experiences, which may be distressing. If this occurs, we encourage you to **seek support from a trained counsellor by free calling or texting 1737** at any time.

All those that complete the questionnaire will be invited to enter into the draw to win one of ten, $100 gift cards. To enter the draw, you will be asked to add your contact details at the end of the questionnaire. This information will be stored separately to the responses to the questionnaire.

Rights of Participants

Taking part is voluntary and anonymous. It will not result in any bias or disadvantage to you. You may withdraw from the study at any time, until you complete the questionnaire, by closing the browser. As this survey is anonymous, you will not be able to withdraw your data from the study once you have completed the questionnaire.

What will happen after you complete the survey?

The data you provide will be analysed by members of the research team, or additional students/research assistants brought into the team. Tools that utilise artificial intelligence in an offline (protected) capacity may be used to analyse the data. The findings will be used to inform research publications and may be presented to wide audiences, including at conferences or in policy briefs. The information you provide will be kept confidential. Any potentially identifiable comments will be deidentified before being quoted in publications, and you will not be identified as the source.

Storage and retention of data

The University of Auckland will hold these data for 6 years. It will then be destroyed in accordance with the University of Auckland procedures.

If you require Māori cultural support, talk to your whānau in the first instance. You may also contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 Ext.2324, or contact the Auckland and Waitematā District Health Boards Māori Research Committee or Māori Research Advisor by phoning 09 4868920 Ext.3204 to discuss any questions or complaints about the study.

If you have any questions or concerns about the study at any time, you may contact one of the research team:

Dr. Joanna Chu	jt.chu@auckland.ac.nz or by phone 093737599 Ext.86390.
Josie Tait	josie.tait@auckland.ac.nz
Prof. Anita Gibbs	anita.gibbs@otago.ac.nz
Dr. Jessica McCormack	jessica.mccormack@otago.ac.nz
Holly Wilson	holly.wilson@auckland.ac.nz

Or the Head of Department overseeing this research project:

Prof. Janine Wiles	j.wiles@auckland.ac.nz

Approved by the University of Auckland Human Participants Ethics Committee on 06/10/2025 for three years. Reference number: UAHPEC30056.