

## **PARTICIPANT INFORMATION SHEET**

Project title: Whānau of children with feeding challenges in Aotearoa/ New Zealand

Name of Principal Investigator/Supervisor (PI): Dr Clare McCann

Name of Co-investigator(s): Dr Bianca Jackson and Dr Sarah Leadley

Name of Student Researcher(s): Stacey-Louise Corney

### **Researcher introduction**

Ko Maungarei tōku maunga  
Ko Oratia Stream tōku awa.  
Ko Stacey tōku ingoa.

Kia ora! My name is Stacey-Louise Corney (Masters of Speech and Language Therapy student). I am training to become a speech-language therapist and want to learn about how feeding difficulties affect families and whānau. I have a special interest in this project as I have worked as a support worker for teenagers/young adults with cerebral palsy for many years before beginning this program. I am interested in how swallowing challenges affect people's lives, and how policy can be adapted to improve support systems for children and whānau affected by these challenges.

My research supervisors are Bianca Jackson, speech-language therapist and clinical educator, and Sarah Leadley, applied behavioural analysis psychologist. We are in the School of Psychology and are working together to change the supports that are available for whānau of children with feeding difficulties. Bianca and Sarah have worked with many whānau over the years to help them understand feeding difficulties and have worked with children to develop their eating and drinking skills so they can enjoy food and drink safely.

### **Project description and invitation**

We invite parents and whānau of children with feeding difficulties in Aotearoa to participate in this study. Participation in this project is entirely voluntary.

Our study aims to understand the financial and psychological impact, experiences, and implications of raising a child with feeding difficulties. You and your whānau's responses to the survey will help us develop an understanding of the impact of feeding difficulties from the caregivers perspective.

### **Project Procedures**

If you choose to take part in this research you will be asked to complete a one-off anonymous online survey through the Qualtrics application. This will take between 20-30 minutes to complete.

The content of this survey may cause psychological distress, or discomfort. If you experience any distress, we advise you to reach out to your support system (friends and whanau) and/or family GP. You can also contact the members of the research team directly. Otherwise, you may like to reach out to the following organisations:

- 1737-Need to Talk?: Free call or text for anonymous support from a trained counsellor
- Lifeline: Free call 0800 543354 or free text 4357 for anonymous support
- ParentHelp: Free call 0800 568856 for anonymous parent and whanau support

There is no direct compensation offered individually to participants, however, you may enter a prize draw to win one of ten \$50 grocery vouchers. You will be invited to enter this draw upon completion of the survey.

### **Data storage/retention/destruction/future use**

During data collection information will be stored on the Qualtrics platform. Information stored on the platform will be password protected and access is limited to members of the research team. After data collection information will be stored securely on a University of Auckland database provided by the research team (a shared folder in the cloud) and will only be accessible to members of the research team via VPN. Data will be accessed on student laptops, which are password protected, for the duration of study and then deleted.

Data will be kept for six years, after which point it will be destroyed in line with University of Auckland guidelines and protocols.

No audio or video recordings will be collected during this research study.

### **Right to Withdraw from Participation**

You have the right to withdraw at any time before you submit your data, without giving a reason. After you submit, we cannot withdraw your data because it is anonymous.

### **Anonymity and Confidentiality**

The survey will be anonymous and the research team will not know names or addresses of who has answered the questions. However, your responses may contain information that might identify you or your child to the research team. Any such information will not be mentioned or discussed beyond the research team, or passed onto anyone else.

The Qualtrics application automatically encrypts data to ensure it remains anonymous to the researchers.

Any published data will not include potentially identifying details (location, identity of medical professionals involved, details of a diagnosis that may be identifiable).

### **Contact Details**

If you require more information about the study you may contact any member of the research team.

**Student researcher:**

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**Supervisors:**

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**UAHPEC Chair contact details:**

For any queries regarding ethical concerns you may contact the Chair, The University of Auckland Human Participants Ethics Committee, Office of Research Strategy and Integrity, The University of Auckland, Private Bag 92019, Auckland 1142. Telephone 09 373-7599 ext. 83711. Email: humanethics@auckland.ac.nz

Approved by the University of Auckland Human Participants Ethics Committee on 20/08/2021 for three years. Reference Number 22188