PARTICIPANT INFORMATION SHEET

Talking about your experience having a small baby.

Project team: Associate Professor Jo James (lead investigator), Associate Professor Judith McCool, Associate Professor Alyx Clark, Dr Charlotte Oyston, Dr Wendy Burgess, Juliet Ngauamo, Caitlin Baard.

We would like to talk to groups of wāhine (women) who have had a small pēpi (baby). We want to find out about your experiences so that we can find some new ways to help whānau better understand what is happening and why.

To help you decide if you want to take part in the study, please read this information sheet. If you agree to take part, you will be asked to sign a Consent Form. This copy of the Participant Information Sheet is yours to keep.

What is the aim of the study?
The aim of this project is to find ways to better support women and their whānau with pregnancies where the baby’s growth is less than expected, by developing new ways of giving clear, accurate information about what is happening during their pregnancy and why.

Who can participate?
To take part you need to:

- Have been told you have, or were suspected of having, a baby that is smaller than expected or has growth problems (small for gestational age or growth restricted baby).
- Be able to attend to a focus group discussion within 18 months of giving birth.
- Be able to talk in, and understand, English.
- Be able to provide consent to participate.

What will my participation in the study involve?

- Attend one focus group of up to 8 women, with 1-2 researchers.
- 1-2 hours.
- Recorded
- Private venues (e.g. church hall or community venue), or via zoom.
- Female facilitators
- There may be male support people present.

Examples of types of questions

- How did you feel when you were told you had a small baby?
- Did you understand what was happening?
- How did you get information?
- What would have helped you?
We are interested in talking to women from all cultures, but are very interested in hearing from Māori, Pasifika and Indian women, who are most likely to have babies with growth problems. There will be special sessions for each of these groups.

Taking part in the focus groups is entirely your choice. You can leave at any time, or request an individual conversation with the researchers instead. You do not have to answer any question you don’t want to. Please note that once the focus group has occurred, we will not be able to remove the comments made by individual participants. This information will not be able to identify you in any material stored in writing or in audio/zoom recordings.

You will be given a $50 voucher to thank you for your time participating in the focus group. Parking and petrol/transport costs will be paid up to $20 if required.

You are welcome to bring a friend or whānau member with you. Pēpi (babies) and tamariki (children) are also welcome. There will be space for them to play and for you to feed and change your baby if needed.

Will the information about me be kept confidential?
Each focus group will be facilitated by a research assistant, who is a trained member of our research team and has signed a confidentiality agreement. Audio will be electronically recorded and securely stored on a University of Auckland approved electronic storage system protected by passwords. Recordings will be typed out by research team members. No information that could personally identify you will be used in any reports on this study. The information will be kept securely at the University of Auckland for six years. All computer records will be password protected. No-one other than the researchers and those running the focus groups will be involved. All future use of the information collected will be strictly controlled in accordance with the Privacy Act, 1994.

What are the risks and benefits of this study?
As focus groups consist of a number of people, your participation and contributions are not anonymous or confidential to others in the same group. However, all people taking part will be asked to “agree to respect and treat as confidential the contribution of other focus group participants” when they sign their consent form.

It is possible that some things we talk about could touch on culturally or personally sensitive matters. If you feel uncomfortable at any time during the focus group, you will be completely free to leave, with no questions asked.

If the discussions trigger uncomfortable feelings (such as being worried), you can talk to or email any of the researchers, who will be happy to listen to your concerns and/or refer you to specialist services that could help. If you would like to talk to someone not involved in the study, a list of services is provided at the end of this information sheet.
What happens if I change my mind?

You can leave at any time. You do not have to answer any question you don’t want to. Please note that once the focus group has occurred, we will not be able to remove the comments made by individual participants. This information will not be able to identify you in any material stored in writing or in audio.

What happens after the focus group?

The study will take a year in total to conduct, so results will be available in 2022. We can send you a copy of the final report.

You will also be asked at the end of the focus group if you would be willing to be contacted further to provide feedback on the communication tool as it is developed. Your decision to continue to take part with the research team about this is entirely voluntary.

Has the study received ethical approval?

The study has received ethics approval from the Auckland Health Research Ethics Committee on 24/05/2021 for three years, Reference Number 22050.

Who do I contact if I have more questions, concerns and/or would like to participate?

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Lead Investigator
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School of Medicine
Faculty of Medical and Health Sciences
Phone: 09 923 2549
Email: jjames@auckland.ac.nz

For any queries regarding ethical concerns you may contact:

The Chair, The University of Auckland Human Participants Ethics Committee
Office of the Vice Chancellor
Private Bag 92019, Auckland 1142.
Phone: +64 9 373 7599 ext. 83711
Email: humanethics@auckland.ac.nz

If you want to talk to someone who is not involved with the study, you can contact any of the following support services:

Support from a trained counsellor
Pregnancy Help Inc.
Healthline (available 24 hours 7 days a week)
Health & Disability Commission
Free call or text 1737 any time
09 373 2599
0800 611 116
0800 555 050