

Participant Information Statement



Research Study: Motherhood Narratives of Women with Cystic Fibrosis

Professor Lynette MacKenzie (Responsible Researcher)

Department of Occupational Therapy, School of Health Sciences, Faculty of Medicine and Health, University of Sydney

Phone: +61 2 9351 9832 | Email: lynette.mackenzie@sydney.edu.au

Mrs. Alena Haines (PhD student) | Email: alena.haines@sydney.edu.au

1. What is this study about?

We are conducting a research study about the experiences of women with cystic fibrosis (CF) who have recently had a baby. This study aims to: *a) Develop an understanding of how women with CF experience pregnancy and motherhood and b) Gain an understanding of how mothers with CF prioritise their time and energy compared to mothers who don't have CF.* Understanding pregnancy and motherhood from the perspective of women with CF will enable healthcare providers and others to better support mothers and women with CF and assist in developing and updating guidelines and evidence-based practice for optimal patient management and better clinical care.

Taking part in this study is voluntary.

Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

2. Who is running the study?

The study is being carried out by the following researchers:

Alena Haines (PhD candidate, Discipline of Occupational Therapy)

Professor Lynette MacKenzie (Professor, Discipline of Occupational Therapy)

Dr Anne Honey (Senior Lecturer, Discipline of Occupational Therapy)

Professor Peter Middleton (CF Service, Westmead Hospital, Westmead, NSW, Australia)

Alena Haines is conducting this study as the basis for the degree of Doctor of Philosophy at The University of Sydney.

Alena Haines has a diagnosis of cystic fibrosis and attends Westmead Hospital, Sydney for her CF care.

Professor Peter Middleton is a specialist doctor and treats patients with cystic fibrosis at Westmead Hospital, Sydney.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

3. Who can take part in the study?

You can take part in this study if you speak English, live in Australia and are the biological mother of a child between one and five years of age. We wish to interview women both with and without cystic fibrosis.

4. What will the study involve for me?

If you decide to take part in this study, you will be asked to:

- Complete a questionnaire online (10-15 minutes)
- Participate in two online video interviews over 'Zoom', which will be audio and video recorded. The interviews may vary in length depending on how much you want to tell us, but are expected to take around one hour each. You will be able to complete the interview with audio only if you would prefer to remain anonymous.

The timing of the interviews will be flexible and negotiated between yourself and the interviewer once you have consented to the project. It is hoped that your interviews will take place within a month of your consenting to participate in the study.

In the interviews you will be asked a series of questions about your pregnancy, birth and motherhood experiences.

The interviews will be transcribed into writing for us to analyse.

After the study is complete, some of the interviews may be used to create a resource for women with CF about pregnancy and motherhood. If your story is selected, we will ask you separately for your consent to this and you be given the opportunity to review and revise your story.

5. Can I withdraw once I've started?

Being in this study is completely voluntary and you do not have to take part.

Your decision will not affect your current or future relationship with the researchers, The University of Sydney or any healthcare provider or association.

If you decide to take part in the study and then change your mind at any time you can withdraw by contacting any member of the research team. You can ask for your information and/or interview to be removed before it is deidentified.

If you take part in an interview you may refuse to answer any questions that you do not wish to answer.

If you choose to withdraw, we will not collect any more information from you. Please let us know at the time you withdraw what you would like us to do with information we have collected about you up to that point.

6. Are there any risks or costs?

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study, however recounting your personal stories can sometimes be distressing, especially when recalling stressful events. Please contact a member of the research team if you experience distress at any time in relation to your participation in this project. Alternately you can contact the following confidential services for support:

- Lifeline:** Provides 24-hour crisis counselling, support groups and suicide prevention services. Call **13 11 14**, text on **0477 13 11 14** (12pm to midnight AEST).
- Beyond Blue:** Aims to increase awareness of depression and anxiety and reduce stigma. Call **1300 22 4636**, 24 hours/7 days a week.
- FriendLine:** Supports anyone who's feeling lonely, needs to reconnect or just wants a chat. You can call them 7 days a week on **1800 424 287**. All conversations with FriendLine are anonymous.
- PANDA:** (Perinatal Anxiety & Depression Australia) supports women, men and families across Australia affected by anxiety and depression during pregnancy and in the first year of parenthood. Call **1300 726 306**, 9am – 7:30pm AEST (Mon-Fri).

7. Are there any benefits?

You will not receive any direct benefits from being in the study. However, we hope that the study will result in better healthcare for mothers with CF in the future.

8. What will happen to information that is collected?

By providing your consent, you are agreeing to us collecting information about you for the purposes of this study.

Any information you provide us will be stored securely and we will only disclose it with your permission, unless we are required by law to release information. We are planning for the study findings to be published.

Video recordings will be deleted immediately following transcription into writing, audio recordings will be retained until after the results of the study have been written.

All information collected in the study will be stored in secured digital files under the University of Sydney licences both during and after the study. These will only be accessible to the research team. Because some participants may be his patients, Prof. Peter Middleton will not be able to access any identifiable data and will not know who participated in the study.

All data will be deleted by the researchers following a period of 5 years.

9. Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. This feedback will be in the form of a brief lay summary. If you wish to receive feedback please check the relevant box in the consent form below.

10. What if I would like further information?

When you have read this information, the following researcher/s will be available to discuss it with you further and answer any questions you may have:

| | |
|-----------|----------------------------|
| Name | Alena Haines |
| Position | PhD Candidate |
| Telephone | 0418 501 079 |
| Email | alena.haines@sydney.edu.au |

| | |
|-----------|---|
| Name | Lynette MacKenzie |
| Position | Professor Occupational Therapy, University of Sydney |
| Telephone | (02) 9351 9832 |
| Email | lynette.mackenzie@sydney.edu.au |

11. What if I have a complaint or any concerns?

The ethical aspects of this study have been approved by the Human Research Ethics Committee (HREC) of The University of Sydney [2023/014] according to the *National Statement on Ethical Conduct in Human Research (2007)*.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the University:

Human Ethics Manager
human.ethics@sydney.edu.au
+61 2 8627 8176

This information sheet is for you to keep