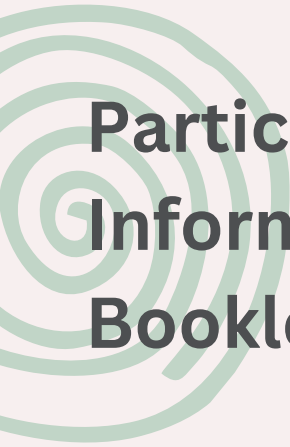




pause**matters** ^{STUDY}

*Exploring natural pauses
during labour and birth*



Participant Information Booklet



Invitation to participate in the PAUSEMATTERS study

Thank you for your interest in the PAUSEMATTERS Study. To help you decide if you would like to take part, this booklet contains important information about this study. Please take the time to read this information carefully. If you have any questions, do not hesitate to ask us - you will find contact details to the research team at the end of this booklet.

What is this study about?

The PAUSEMATTERS Study **explores natural pauses** during labour and birth, so-called '**physiological plateaus**'. Physiological plateaus are moments when labour slows down or stop entirely, but resumes naturally after some time.

Physiological plateaus are common during labour, but they can be easily mistaken for a birth complication, called 'labour dystocia'. **Labour dystocia is rare** and usually requires medical treatment.



When plateaus are mistaken for dystocia, this means that women are advised to have a medical treatment, despite not needing it. This is a problem, because unnecessary medical treatment carries risks for mother and baby.

The PAUSEMATTERS Study is designed to find out more about physiological **plateaus and how they differ from dystocia.**

In future, this information will make it easier for health professionals to differentiate plateaus from dystocia. Thereby, this new knowledge can **help protect women from unnecessary medical treatment during healthy labour and birth.**

“Our vision is to help more women achieve a healthy birth and a positive birth experience.”

We would love your help to achieve this aim!



Do I have to take part in this study?

No. Participation in this study is completely **voluntary**. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you can withdraw again (see page 7). **The care that you receive throughout your pregnancy and birth, and your relationship with your midwife, will not be affected by your decision about this study.**

Who can participate in this study?

You may have heard about this study through your midwife who collaborates on this research project. Or you might have seen this study advertised online. There are **specific requirements** for who can participate in this study.

You can participate if you

- **are currently in Western Australia**
- **are at least 18 years old**
- **are pregnant**
- **are planning to birth at home (even if plans change later)**
- **have a midwife who will support you during labour and birth.**

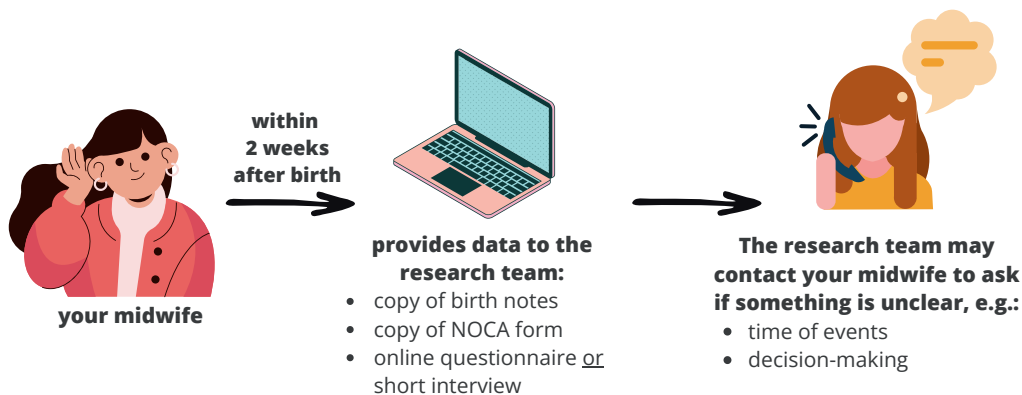
What does participation in this study involve?

If you decide to participate, we will work with you and your midwife to collect the information we need for this study.

Your midwife / midwives will need your written consent to share information with us. If you consent, we will ask your midwife to:

- **provide a copy of the birth notes**
- **provide a copy of the 'NOCA form'** (a two-page document with key details about your pregnancy and birth)
- **complete a questionnaire about your birth pattern** (including if there were any plateaus) or take part in a short interview to provide this information.

Your midwife will be asked to provide this information within two weeks after you gave birth. **Your midwife will not change anything in the care that she will provide to you.**



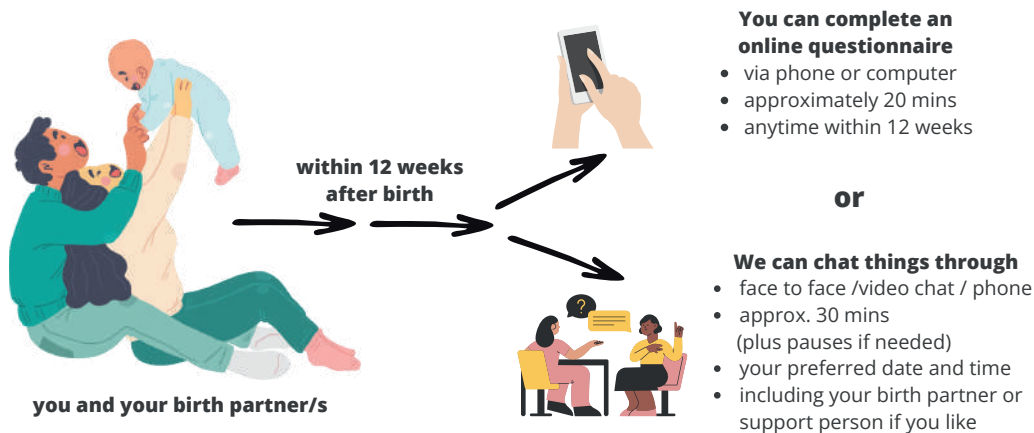
Additionally, we would like to collect information from you about your birth. For this information, an **online questionnaire** can be completed, or a **short interview** can be scheduled. The choice yours. We would like you to complete the questionnaire or interview within **12 weeks after you gave birth**.

Option 1: If you choose to complete a questionnaire,

you will receive an online link after your birth. We understand that having a new baby is a very intense time for the whole family, so the questionnaire is short (**up to 20 minutes**) and can be completed in multiple sessions, if needed. You may receive weekly reminders between 6 to 12 weeks after birth. Questions include details **about your birth** (e.g., where and how your baby was born), **about plateaus during labour** (if any, e.g., at what time of the day your labour slowed down), and **about your overall birth experience** (e.g., if there is anything you would have liked to be different). You can decide which questions you answer, and which ones you skip. The questionnaire can be completed on your phone or computer at any time you like within 12 weeks. If you would like your birth partner/s to answer questions as well, this is possible by joining in with you, or receiving their own questionnaire (p.13).

Option 2: If you prefer to talk things through in an interview,

a member of our research team will contact you to arrange a meeting. The interview can be **face to face** (e.g., at your home, in a nearby park), online via **video chat**, or **on the phone**. You decide what works best for you, but if you live outside of Perth Metro area, the interview will likely have to be online or via phone. During the interview, we will ask you questions **about your birth, about plateaus during labour** (if any), and **about your overall birth experience** - the questions are the same as in the questionnaire, but you have more opportunity to tell us 'the bigger picture'. You decide which questions you answer, and which ones you skip. The interview should be scheduled **within 12 weeks after your birth**. If you wish, you can have your birth partner/s or another support person present during the interview, and of course, your baby/children can be there as well. The research team member who will be interviewing you is also a midwife, so they will understand the situation when having a new baby at home.



You can choose either questionnaire or interview - it's completely up to you, and you can change your mind later again.

Are there possible benefits if I participate?

This research **may not provide benefit to you personally** but may provide benefits to women in the future by improving the understanding of physiological plateaus. This **may lead to improved care and health outcomes for mothers and babies**. This study does not involve any payments to you for participating.

Are there possible risks if I participate?

The risk of participating in this study is minimal but may include that we unintentionally ask questions that are triggering negative emotions for you. To reduce this risk, all questions were tested by women with birthing experience. If you **feel uncomfortable or distressed**, you can skip questions or stop the entire questionnaire or interview with immediate effect. If you wish to speak to someone because of participating in this research, please consider contacting your trusted health professional (e.g., GP, midwife, counsellor) or consider accessing the following cost-free and anonymous support/counselling services.

Beyond Blue (Mental Health Support)

Tel: 1300 22 4636 (24hrs/7days)
www.beyondblue.org.au



Lifeline Australia (Crisis Support)

Tel: 13 11 14 (24hrs/7days)
www.lifeline.org.au



As a research participant **you are covered by Edith Cowan University's insurance** in the event that you are injured or become unwell during the course of participation in research activities. For details about this insurance coverage, please contact us.

Has this research been approved?

Yes. This research project has been reviewed and has received approval from Edith Cowan University's Human Research Ethics Committee (approval number 2023-04863-WECKEND).

Can I decide to participate and later change my mind?

Yes. It is absolutely fine if you decide to participate and later change your mind. This is called withdrawing.

Option 1: Complete withdrawal

You can withdraw completely from this study and request that all information that you or your midwife already provided is deleted. Once we receive your withdrawal request, we will remove your information from our dataset within 2 weeks.

Option 2: Withdrawal from further participation

You can withdraw partly from this study, meaning that the information that you or your midwife already provided can be used in this study, but that you will not provide further information (for example, if you do not want to complete a questionnaire/ interview). This withdrawal will be effective immediately.

Your decision to participate or withdraw will not affect your relationship with your midwife, the research team, or affiliated organisations (ECU). The last chance to withdraw is 12 weeks after your birth, because thereafter, your data will be anonymised and included in the analysis. **To withdraw, simply scan the QR code** or follow this link:

<https://forms.office.com/r/SmH4Zf5h9f>



How is my privacy protected?

Your **privacy and confidentiality** are of utmost importance to us. All data collected during this study will be **handled securely** and will **not be disclosed to anyone** without your explicit consent. The information you provide to us will also **not be disclosed to your midwife**. Only authorised members of the research team will have access to the data. Strict measures will be taken in alignment with national data protection regulations to ensure the protection of your data and confidential information. This includes, for example:

- **storing digital data** on devices that are password protected and only accessed by members of the research team
- **sending digital data** through pathways that ensure encryption at rest and in transit (e.g., certified software for the online questionnaire, and cybersecurity monitored email accounts)
- **storing paper documents** with confidential data in a locked filing cabinet, where only authorised research team members have access to (e.g., printed and signed consent forms).

Once we have collected all data from you and your midwife (usually, within 12 weeks after birth), we will anonymise this data. This means that we will replace your name and other identifiable information with a code. You can see on the last page of this booklet, which members of the research team have access to identifiable information (including your name), and which team members can only access anonymised data (they will not know who you are).

All data will be stored for 7 years, then permanently destroyed. Only if you agree for anonymised data to be retained, anonymous data will be stored permanently in a data repository (see page 9).

What happens after this study is completed?

When this research is completed, findings from this study will be **communicated to the public in various formats**. It will **not** be possible to identify you in any publications. The findings will be published internationally. For example, we plan to:

- publish findings in journals
- present findings at conferences
- create videos that are shared via social media
- publish findings through media outlets (e.g., TV, radio).

We would also like to **make the anonymous dataset of this study permanently available to other researchers** by placing it in a data library (ECU Repository ‘Research Online’). Through this, other researchers may access this data in future to conduct other studies, and data will not be destroyed after 7 years. You can choose if you agree to this or not, and you can participate in this study even if you prefer not to make your anonymous data permanently available to other researchers.

Who is funding this study?

This study receives partial funding from Edith Cowan University (ECU). This funding covers honorariums for collaborating midwives (covering loss of time for billable work) and community engagement (meetings with research advisers), among other things. Researchers on this project receive no other funding for this study and have no conflicts of interest.



Who are the people behind the PAUSEMATTERS Study?

We are a team of midwife researchers in Australia, UK and Germany. You can see below who will have access to identifiable data (**) and who will only be able to access anonymous research data (*).



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Independent Midwife &
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Prof Sara Bayes
Associate Investigator*
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Prof Nicky Leap
Associate Investigator*
University of Technology Sydney
New South Wales & UK



Prof Julia Leinweber
Associate Investigator*
Charité Universitätsmedizin
Berlin, Germany



Prof Sally Tracy
Associate Investigator*
University of Technology Sydney
New South Wales



Research Adviser Team
A small group of women
with birth experience
collaborates in this study as
research advisers.

Questions? Concerns? Contact us!

For any questions, please contact Marina Weckend

(m.weckend@ecu.edu.au) or Ciara O'Brien (c.obrien@ecu.edu.au)

If you have any concerns or complaints regarding this research and wish to talk to an independent person on a confidential basis, please contact a Research Ethics Support Officer at ECU (research.ethics@ecu.edu.au, Phone: (08) 6304 2170).

I want to participate! What should I do?

That's wonderful news! Just scan the QR code or follow this link to register your interest: <https://bit.ly/PAUSEMATTERS>



After registering your interest to participate, a member of our research team will give you a call to

- check if you have any questions
- confirm that we can include you in this study.

You will then be asked to sign a consent form, either on paper or electronically. **We are excited to welcome you in this study!**

Your PAUSEMATTERS Team



Welcome on board!

Room for your questions



Welcome, birth partners!

Birth partners are welcome to co-participate in this study. Birth partners can be the baby's **parent**, a **family member**, a **relative**, a **friend**, or a **doula**... anyone who was invited by the baby's mother to be with her during labour.



Information for birth partners

Dear birth partner,

It can be a great way to show support if the baby's mother asks you to join in this study. Please know that your co-participation is **voluntary**. There are specific requirements for co-participation as a birth partner, including that you:

- are at least 18 years old
- were present during some or all of the labour and birth
- were asked by the baby's mother to participate.

Co-participating can happen in two different ways. If the baby's mother chooses to complete a questionnaire after birth, you can sit together and complete the **questionnaire** together, or we can send you a link to an own questionnaire. If the baby's mother chooses to participate in an **interview** instead, you are welcome to join in the interview as well and contribute your thoughts and views. We greatly appreciate your involvement. We also thank you for your understanding that if the baby's mother prefers you not to co-participate in this study, you will not be able to join in.

If you wish to co-participate, please tell the baby's mother (we will ask her about this) **or contact us via email or phone.** If you co-participate, the information provided in this booklet is also relevant for you - for example, information about why we do this study, how data is protected, and what risks and benefits participating may have. Please read this information carefully before deciding whether you wish to co-participate or not.

Thank you for your interest in this study!

Want to learn more about natural pauses in childbirth?

Visit www.childbirthresearch.com

Want to participate?

That's wonderful news! Just scan the QR code or follow this link to register your interest:
<https://bit.ly/PAUSEMATTERS>

