

Participant Information Form



Project title: Empowering neurodivergent voices: a participatory action research approach to co-develop neurodiversity-affirming perinatal care services

Approval Number: [2025-06183-BAYES]

Research Team:

- PhD Candidate Investigator: Jata Elliott RM
 - Chief Investigator: Prof. Sara Bayes
 - Associate Investigator: Dr. Kate Buchanon

Institution:

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You are invited to take part in a **unique** research project titled:

Empowering Neurodivergent Voices: A Participatory Action Research Approach to Co-develop Neurodiversity-Affirming Perinatal Care Services.

You are being invited because **you**:

- **Identify as an 'ADHDeR'** (a person with Attention Deficit/ Hyperactivity Disorder) **and**
- Have **had a perinatal lived experience within the last 5 years in Australia.**
- Are **over 18yrs** old now.
- Your insights will help shape **neuro-inclusive and neurodiversity-affirming perinatal care services.**

Before deciding whether to take part, please read this information carefully. You may also wish to discuss it with a trusted person or use read-aloud technology to assist.

If you have any questions, **feel free to ask.**



What is a Perinatal experience?

◆ For this project within the last 5 years

- Your role in the pregnancy was as **the pregnant / birthing person**

**A Perinatal experience (from conception to 2 yrs postnatal)
can include:**

- **Live births, stillbirths or newborn losses**
- **Miscarriages (including ectopic pregnancies)**



Invitation to Participate

This research is being undertaken as part of the requirements for Jata's **PhD research at Edith Cowan University.**

As an **Autistic and ADHD person and Midwife - researcher**, I prioritise the **autonomy, dignity, and perspectives** of neurodivergent individuals. This study recognises that **ADHD is not a deficit but a neurotype**, and participation is designed to be **accessible, affirming, and flexible.**

I acknowledge that **ADHDers may experience executive function challenges, sensory sensitivities, or fluctuating attention and energy**

If you choose to participate, you will be asked to sign a consent form.

By signing it, you confirm that you:

- ✓ **Understand** the research and your role in it.
- ✓ **Agree** to take part voluntarily (your own choice).
- ✓ **Consent** to the use of your responses as described.
- ✓ **Understand** that your personal details will remain confidential.



What is this research about?

This study explores **ADHDers' experiences of perinatal care** (pregnancy, birth, and postpartum) to **identify barriers and solutions** in maternity services. Our goal is to **develop practical recommendations** for more neurodiversity-affirming care.

This project is self-funded using my **Australian Government Research Training Program Scholarship**.

Your participation is valued **not just as a source of data, but as a key contributor** to creating **positive change** for neurodivergent parents.

Do I have to take part?

No, **participation is voluntary**. You can say **no** now or withdraw **at any time** without any impact on your healthcare, employment, or relationships.

If you withdraw, you can decide that the **unpublished** data you have provided will be deleted. However, **once the data is analysed and published, withdrawal may not be possible**.

If you decide to take part, you will be given a **copy of this Information Letter and your signed Consent Form** for your records.

Your Privacy

By **signing the consent form**, you agree to the research team collecting and using de-identified data for this study.

- Your personal information will **remain confidential**.
- Data will be stored **securely on ECU's Microsoft SharePoint system**, with access restricted to only the research team.
- **No identifiable details** will appear in publications or presentations without your consent.
- Data may be **used in future research if you agree**, but only after ethical approval.

The findings from this research will be shared through publications and presentations to raise awareness and help improve perinatal care for ADHDers. Your privacy is a top priority - **all information will be de-identified**, ensuring that you cannot be recognised. If there is ever a reason to include identifiable information, **we will seek your explicit written consent first**.

How long will my data be kept?

Your data will be retained for 3 years and securely destroyed thereafter.

Possible Benefits

While there is **no direct benefit** to you, your insights may **help improve perinatal care** for other neurodivergent parents. The findings may also contribute to **policy recommendations** for healthcare providers or generate new ideas.

Possible Risks & Support Options

This study has been designed to be **low-risk**, but some topics may feel emotional or dysregulating.

- If you feel uncomfortable at any point, you can **pause, skip questions, or withdraw**.
- If you need extra support, consider contacting:
 - ◆ **Beyond Blue:** 1300 22 4636 (24/7 support)
 - ◆ **PANDA (Perinatal Anxiety & Depression Australia):** 1300 726 306
 - ◆ **Lifeline:** 13 11 14 (24/7 crisis support)

If you require **medical support** due to participation, please contact your GP or a trusted healthcare professional. We can provide a contact list to neurodiversity-affirming psychologists &/or perinatal psychologists for further counselling or support.

For **insurance-related queries**, visit ECU's research participant insurance page:

🔗 <https://intranet.ecu.edu.au/staff/centres/strategic-and-governance-services/our-services/risk-and-assurance/insurance/practicum-work-experience-or-volunteer-activities>



What happens after the research ends?

After the study, you will be offered a **summary of key findings** via **email, social media, or other platforms**. The research may be published in journals or presented at conferences, but **your identity will never be revealed**.

Has this research been approved?

Yes. This project has been **approved by the Edith Cowan University Human Research Ethics Committee** in accordance with the **NHMRC National Statement on Ethical Conduct in Human Research (2023)**.

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PhD Candidate Investigator	Chief Investigator	Associate Investigator
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Ethics & Complaints Contact

If you have concerns about the research, you may contact:

◆ **Research Ethics Advisor**

Edith Cowan University

P: 6304 2423

E: research.ethics@ecu.edu.au



If you choose to take part, please **sign the Consent Form document** and return it to **Katherine.elliott@ecu.edu.au**

Your contributions are invaluable to advancing our understanding of **ADHD in the perinatal period**. We appreciate your time and contributions to this important research.

