Participant Information EC 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:

Edith Cowan University

270 Joondalup Drive, JOONDALUP WA 6027

Phone: 6304 2967

Email: Katherine.elliott@ecu.edu.au or s.bayes@ecu.edu.au

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:

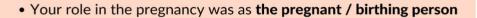
- Identify as an 'ADHDer' (a person with Attention Deficit/ Hyperactivity Disorder) and
- Have had a perinatal lived experience within the last 5 years in Australia.
- Are **over 18yrs** old now.
- Your insights will help shape neuro-inclusive and neurodiversity-affirming perinatal care services.

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



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 <u>low-risk</u>, but some topics may feel emotional or dysregulating.

- If you feel uncomfortable at any point, you can pause, skip questions,
 or withdraw.
- o 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).

Approval Number: [2025-06183-BAYES]

PhD Candidate Investigator	Chief Investigator	Associate Investigator
Jata Elliott RM	Prof. Sara Bayes	Dr. Kate Buchanon
Edith Cowan University	Edith Cowan University	Edith Cowan University
P: 6304 2967	P: 6304 2967	P: 6304 2967
E: Katherine.elliott@ecu.edu.au	E: s.bayes@ecu.edu.au	E: k.buchanan@ecu.edu.au

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.

