



Consumer and Community
Involvement Program



WAHTN

Western Australian Health Translation Network

ADHD MEDICATION IN PREGNANCY

COMMUNITY CONVERSATION SUMMARY REPORT



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ACKNOWLEDGEMENTS

Acknowledgement of Country

The WAHTN CCIP Program acknowledges the Aboriginal people of the many traditional lands and language groups of Western Australia. We acknowledge the wisdom of Aboriginal Elders, both past and present, and pay respect to Aboriginal communities of today.

Acknowledgement of Lived Experience

We acknowledge the importance and expertise of the lived experience voice of health consumers and carers. We recognise their involvement in making a difference in supporting health research and impacting the health and wellbeing of our communities.

We extend our heartfelt gratitude to the consumers and community members who shared their lived experiences of tinnitus.

Other Acknowledgements

We would like to acknowledge the research team from the School of Population and Global Health at the University of Western Australia, for their commitment to involving consumers in shaping the future of ADHD research.



BACKGROUND

Early career researcher Dani Russell actively partnered with the Consumer and Community Involvement Program to facilitate a Community Conversation event to bring together those with a lived experience of having an ADHD diagnosis, to discuss and capture feedback around living with ADHD and gaining insights into their ideas about medication during pregnancy. The information obtained during the event will be used to inform research priorities, grants and study design.

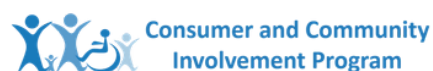


THE CONSUMER AND COMMUNITY INVOLVEMENT PROGRAM

The Consumer and Community Involvement Program (CCIPProgram) is dedicated to embedding the voices of consumers and community members in health research. Established as part of the Western Australian Health Translation Network (WAHTN), the program works to ensure that research is shaped by lived experience and addresses real-world health challenges.

At the heart of the CCIPProgram is a team committed to building connections between researchers, consumers, and organisations. This team provides tailored support, guidance, and resources to ensure consumer involvement is an integral part of research design, implementation, and translation.

By championing consumer and community involvement at local, state, and national levels, the CCIPProgram continues to evolve, ensuring that health research is informed, shaped and guided by those with lived experience.



WHAT IS A COMMUNITY CONVERSATION?

A Community Conversation is an event using an abridged version of the Word Café Method[1] and allows for the facilitation of informal, open conversations around a specific topic of importance. This method allows researchers to informally obtain a range of communal ideas from a group of people with lived experience around a particular topic specified prior to the event.[2],[3] Additionally, a Community Conversation provides an opportunity for attendees to reflect upon their own relevant experiences and contribute in meaningful discussions within a safe and comfortable space.



[1] Brown, J., & Isaacs, D. (2005). The World Café : Shaping our futures through conversations that matter. Barrett-Koehler

[2] Chieh-Ling Yang, Delphine Labbé, Brodie M. Sakakibara, Janneke Vissers & Marie-Louise Bird (2022) World Café- a community conversation: a Canadian perspective on stroke survivors needs for community integration, Topics in Stroke Rehabilitation, 29:5, 392- 400.

[3] Carter, E. W., Schutz, M. A., Gajjar, S. A., Maves, E. A., Bumble, J. L., & McMillan, E. D. (2021). Using Community Conversations to Inform Transition Education in Rural Communities. The Journal of Special Education, 55(3), 131–142.

ABOUT THE COMMUNITY CONVERSATION

This Community Conversation explored the lived experience of Perth women with a diagnosis of ADHD and medication use during pregnancy, to ensure future research explores and produces outputs of relevance to them.

The Community Conversation was held on 23rd August 2023, at the University of Western Australia (UWA). It involved Dani Russell PhD student, Caitlin Wyrwoll, Amina Rhaman, Erin Kelty, Wendy Feng, CCIP Program Coordinators Jillian Northwood, Ingrid Lange and Kerry Mace, and 8 women living with ADHD. Dani presented an overview of her background and the research project. Caitlin, Erin, Wendy and Amina acted as scribes for the subsequent discussion.



PROMOTION

The Research Team worked closely with the CCIP Program to recruit members of the Australian community who had lived experience of ADHD to hear their thoughts on ADHD medication during pregnancy. We shared promotional communications across multiple channels.

Flyers and social media posts (Twitter, Facebook, Instagram and LinkedIn) were posted and circulated around relevant networks, including consumer and/or related health service provider networks and community groups.

COMMUNITY CONVERSATION



**ARE YOU A WOMAN WHO HAS BEEN
DIAGNOSED WITH ADHD?**

Researchers want to know what are or have been women's concerns regarding their ADHD diagnosis and pregnancy. In particular, they would like to understand how they feel or have felt about the use of ADHD medications during pregnancy.

If you are a woman diagnosed with ADHD and would like to have input to this conversation, we encourage you to submit an expression of interest to attend. All attendees will be offered a \$70 honorarium and refreshments will be provided on the night.

WHEN: Wednesday 23rd August 2023
TIME: 6pm - 8pm
WHERE: Margaret Fairweather Education Space
University of Western Australia, Crawley.

Register your interest



<http://bit.ly/45ilNaR>

STRUCTURE AND PROCESS

Attendees were split between two tables. Each table had a facilitator from the CCIP Program to help guide the discussion and two scribes from the research team to collect attendee feedback.



Each table had a facilitator from the CCIP Program to assist attendees and guide them through the questions and discussions. Each table also had two scribes from the research team to record the feedback provided by the attendees.

Facilitators presented [3] questions to the Consumers at each table:

- What are your concerns regarding your ADHD diagnosis and pregnancy?
- How do you feel about the use of ADHD medications during pregnancy?
- What information do you think should be provided to women about the use of ADHD medications during pregnancy?

Each question was allocated time for discussion. The comments, feedback and suggestions were all captured by each scribe and are presented in the following pages of this report.

KEY INSIGHTS OF THE MICRO COMMUNITY CONVERSATION



Concerns about medication use:

- Concern about managing as a parent.
- Efficacy of medication during pregnancy.
- Lack of information about ADHD and its associated medication regarding pregnancy.
- Prenatal requirements for women with ADHD.



Feelings about medication use:

- Stigma associated with taking medication during pregnancy.
- Concerned about coping while unmedicated during pregnancy.
- Lack of information about ADHD and its associated medication regarding pregnancy.
- Is it safe and effective to continue, discontinue, decrease the dose or have a medication holiday during pregnancy or pregnancy planning?



Information required:

- Understandable statistics required for health risks and benefits associated with medication use during pregnancy for both the mother and the child.
- Is there a safe dose, a high-risk period or other options?
- Women feel that their birthing options are restricted and that maternity wards have poor training when it comes to neurodiverse people.

COMMUNITY CONVERSATION QUESTIONS AND RESPONSES

ATTENDEE INSIGHTS

The following pages contain the responses and thoughts shared by attendees at the Community Conversation.

QUESTION 1

WHAT ARE YOUR CONCERNS REGARDING YOUR ADHD DIAGNOSIS AND PREGNANCY?

PROMPTS:

- Physically
- Mentally
- The child
- The mother
- Stigma
- Community expectations

Our experiences with Diagnosis of ADHD

- Some were not concerned about the ADHD diagnosis and pregnancy.
- Found getting diagnosed as an adult quite difficult.
- Some more concerned about after pregnancy (post-natal depression, burnout, imposter syndrome, managing a household, managing being a mother etc).
- Worried about how ADHD will affect the care given to the baby as well as how it will affect the relationship with the partner.
- Concerns mentioned regarding medication use during pregnancy, as well as having to stop during pregnancy. What are the risks and benefits of staying on or going off medications?
- Stigma for taking medication during pregnancy. Dexamphetamine is different to street speed and other recreational drugs. However, they still feel criminalised.
- Hormonal fluctuations during pregnancy affecting medication effectiveness. Concerned about the interaction between medications and hormones.
- Difficulties with gaining information about ADHD and medication during pregnancy.
- Lack of research. Some of which are not clear and are difficult to interpret.
- Do babies process medication differently from adults?
- The healthcare system is not designed for neurodivergent people.
- Do women with ADHD have different prenatal medication requirements (e.g. folate and other vitamins and minerals)?
- Guilty for having own children, as ADHD is highly hereditary. Some people were concerned about passing down their ADHD to their children.

QUESTION 2

HOW DO YOU FEEL ABOUT THE USE OF ADHD MEDICATIONS DURING PREGNANCY?

PROMPTS:

- Concerns/fears
- Benefits
- Experiences
- Access to information

Options available to me

- Concerned about being judged for taking medication during pregnancy.
- Found clinicians reluctant to give advice regarding medication during pregnancy. If they were given advice, it was often conflicting.
- Had to perform own research. Lack of evidence. Evidence that is out there is unclear. Results are difficult to comprehend.
- Is the medication safe? Is it damaging to come off the medication?
- Should the dose be reduced? Is there a critical time to avoid the medication during pregnancy?
- Concerns regarding not being medicated whilst pregnant.
- Just having a diagnosis of ADHD has restricted birthing options.
- Can medication be taken during breastfeeding?
- Efficacy of the medication during pregnancy. Metabolism changes during pregnancy which could then affect the medication.
- Can medication affect fertility?

QUESTION 3

WHAT INFORMATION DO YOU THINK SHOULD BE PROVIDED TO WOMEN ABOUT THE USE OF ADHD MEDICATIONS DURING PREGNANCY?

PROMPTS:

- Safety
- Dose
- Impacts on mother/child
- Research conducted in this area

More Information required

- Will taking medication during pregnancy affect your birth options?
- Need for neurodivergent specialist staff in maternity wards.
- Is there a safe dose to take during pregnancy?
- Is there a vital period to go off the medication? (e.g. Rather than stopping medication for the whole pregnancy, could it be stopped during high-risk periods?)
- Does medication affect fertility?
- How effective is medication during pregnancy?
- Do women with ADHD need different supplementations, sleep, nutrition, exercise etc?
- What are the side effects for both mum and baby?
- Need for statistics on specific health risks.
- Does risk increase with each pregnancy?
- If medication is not safe, what are the other options?

EVENT SUMMARY

The Community Conversation provided a rich and focused discussion, allowing researchers to explore specific lived experiences of an ADHD diagnosis and pregnancy in depth.

Participants found the session valuable, with many expressing appreciation for the opportunity to contribute directly to research, hear from others with the same experiences and expressed a willingness to continue their involvement in the future.

This event fostered a deeper understanding of the real-world challenges people face when it comes to pregnancy while having a diagnosis of ADHD medications.



WHAT'S NEXT FOR THIS PROJECT?

We will use the information from the Community Conversation to:

- Identify research priorities from the discussion
- Refine our study design
- Build a research buddy network
- Invite participation in future studies

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