

Summary of Outcomes– First 1000 days Focus Group

Women's Health Matters (WHM) conducted a focus group to understand and report on lived experiences of mothers, caregivers, and families with children on accessing health services and health information during the first 1000 days of life.

This document summarises key quotes from the focus group for the purposes of informing ACT Health in the development the First 1000 Days strategy.

Focus Group	Information access during the First 1000 days in the ACT
Objective	<p>The objective of this focus group was to understand:</p> <ul style="list-style-type: none"> • Who is most influential and trusted in sharing information about the First 1000 Days? • How easy or difficult is it to find the relevant and valuable information in this time? • What would make information more accessible, relevant and helpful in this time? • What information is most useful or would be most useful during this time?
Date and location	<p>18:00 – 20:00, 21st March 2022 Online (Microsoft Teams)</p>
Attendees	<ul style="list-style-type: none"> • 5 Participants from ACT • 2 Health Promotion Officers from WHM <p>Note: A sixth participant was registered but did not attend the focus group.</p>
Participant Criteria	<ul style="list-style-type: none"> • Women who live in the ACT and are pregnant or raising a child under three years living in the ACT (including primary carers and those who have conceived through Assisted Reproductive Technology) • WHM also encouraged the participation of women with lived experience who identify as Aboriginal and/or Torres Strait Islander women, women with disability, migrant and refugee background women and lesbian, bisexual and trans women

<p>Participant Recruitment</p>	<ul style="list-style-type: none"> • WHM recruited participants using social media, including LinkedIn and Facebook (through boosted advertising). • Participants registered through Eventbrite • Participants were called a week prior to the event to confirm their attendance and address • Participants were then sent an email with the focus group details along with the Participant Information Sheet and Consent Forms ahead of the focus group • All Participant Consent Forms were obtained returned prior to the focus group • Participants were reimbursed for their time with a \$50 gift voucher <p>Following the recruitment strategy, participants self-selected to be involved in the focus group. This indicates participants had a particular concern or interest about the topic and should be taken into account when considering the data. Several participants indicated their interest came from a background in health-related work and study as well as their personal experiences.</p> <ul style="list-style-type: none"> • All participants were recent mothers with infants between 4-11 months of age.
<p>Structure of discussion</p>	<p>The focus group was split into two main sections, with the first set of questions about information access from conception to birth, and a second set about information access post-birth and during infancy. The summary of quotes provided below is organised following this structure.</p>
<p>Methodology and limitations</p>	<p>As a qualitative method, data collected from this focus group provides rich insight and narrative into the ways in which women are negotiating complex health systems and health information.</p> <p>By its nature, the data collected from this focus group does not provide quantitative or statistically representative findings on the issues faced by women.</p> <p>Due to time constraints, WHM was only able to conduct a single focus group meaning data saturation may not have been reached.</p>

Overall comments

- It was evident from the discussion that all mothers actively sought information to give their baby the best start in life throughout their pregnancy and after birth.
- However, women experienced challenges with accessing health information. These experiences and difficulties influenced their future expectations and approaches to seeking information.
- In particular, women's distressing or difficult experiences during labour, birth and breastfeeding influenced their confidence in health professionals as sources of information.
- Women expressed a desire for choice and agency over their health and that of their baby and to be supported to make their own choices. In practice, many of the women experienced circumstances in which they felt they were not presented with a full range of information or supported to make informed choices. These experiences made their engagements with health information fraught.
- Women described difficult experiences with traditionally 'trusted' sources of health information, such as their GPs, obstetricians and nurses.
- It was clear that there were structural factors which constrained the ability of health professionals to provide women with adequate information, including short appointment times and hospital stays, lack of continuity of care, or inadequate specialist knowledge.
- In the absence of a full range of information, women found that at times they were presented with what appeared to be conflicting opinions or information, or information that didn't work for their circumstances, which made discerning evidence-based information more difficult and was compounded by simultaneous caring for an infant.
- It was also clear that these challenges contributed to distress and stress for women, which should be considered given the known impact of stress during the First 1000 Days
- Information sources women found useful because they did facilitate agency included:
 - Canberra Health Services Continuity of Midwifery Care program
 - Private midwives – because private services meant the mothers were able to ask any number of questions anytime during their pregnancy and after
 - Lactation consultants such as IBCLC (International Board-Certified Lactation Consultants)
 - Australian Breastfeeding Association
 - Educational workshops such as Baby makes 3 and CalmBirth
 - Facebook groups, podcasts, and peers
- When unable to find the information they needed from health professionals, women sought and found information from other sources, including podcasts, Facebook groups and their peers. This occurred within the focus group itself, with the women who participated asking each other questions and sharing information and experiences about breastfeeding support and tongue-tie. It was also clear there was a benefit to peer support and information, which countered women's feelings of navigating information and advocating for themselves on their own.
- Most women weren't familiar with the first 1000 days, including some with a health background. The women who were aware of the first 1000 days, were not able to identify

particular information sources where they heard about it. Women described the information they sought and received as primarily around individual-level factors such as birthing, sleep and nutrition, rather than social or family/community level factors which also influence the first 1000 days. While this may reflect the demographics of participants, it may also indicate a need to raise awareness among mothers and families about social, stress and community-level factors which shape the first 1000 days.

Information access post-conception and during pregnancy

1. Who is most influential and trusted in sharing information about this time?

“The first kind of tangible thing that I did in pregnancy care was to call my regular GP to confirm that with a blood test. And then it was, you know, a mad Google of weird and wacky questions for a couple of days between when I believed that I was pregnant.... And I tend to gravitate towards websites that end in.gov.au, but generally Australian websites, and I also managed to steer away from websites that were more, I guess, blog-style....”

“I just couldn't be bothered going to my GP, who's not, who is quite far from my house, and he was so useless he said like...Uhm, stop eating fish. Stop eating this, stop eating that which was all like absolute rubbish. Because I was like, oh, I haven't heard of the fish thing before... And I knew it was rubbish. And I guess I didn't care because, like, I had other care providers”

“I didn't do any googling, like when I found out I was pregnant; I knew I had to go to the GP. Well, I didn't have to, but I wanted to go to the GP to get all like blood and everything like that. And then I kind of stopped myself from Googling because I didn't want to get too excited. And then I guess where I found my information was more on podcasts and things like that... I learned a lot from other people rather than yeah, like on government websites and stuff.... I didn't get any information from my families or family or friends. I was the first of. Like I was the 1st in my family to get pregnant and 1st in my friends to get pregnant. So, they knew nothing. But I got to know a lot from the Australian Birth Stories podcast. I just had been listening to that for ages. And so I sort of knew, like, what sort of steps to take because of those personal stories about their birth and their pregnancies and what sort of steps they took...”

“I ended up being accepted for the continuity of care program in Canberra. And then, because of that, I decided that I would stick with the midwives... I was actually still? Doing appointments with both because although I do believe that the continuum of care program is amazing, I also very much appreciate that it is a public service, where they don't have endless amounts of time to talk to you about the benefits of vitamin K or, benefits of this or not. You know they don't. They've got half an hour for their appointment, and you know, you still do get a really good level of care, but you don't have a, you know, it's not like the same as if you're paying for that time and you've got, you know, longer. So, I was actually double-dipping on both and still kind of running through my work birth choices with my private midwife.”

2. How easy or difficult is it for women to find relevant and valuable information to support them in this time?

"What I did find challenging was the weeks of nothing between knowing that I was pregnant and then my first appointment with the midwife, which I think probably wasn't until maybe 13 or 14 weeks pregnant. So basically, the whole of the 1st trimester...I just navigated on my own"

"I did private birthing classes, which I believe that everybody in their right mind should do. And once again, I feel like the hospital classes; don't go into like a lot more than potentially what the hospital policy is. It's not like a big focus on relaxation or breathing or XYZ. It's like, OK, so this is when you call the hospital. And this is when you turn up and come. And I think women need a lot more than that..."

"I was actually in hospital for five days with my first, largely because of my anxiety of not knowing much about breastfeeding, being so stressful, so they actually kept me. So, well, yeah, I feel for women who are as lost as I was, but I kind of turfed out because it's very hard."

"I struggled to be present and kind of advocate for myself and ask questions and get the right information so that I could make informed decisions. And there was no more important time to be present so that I could ask those questions, get those answers, and make those decisions. And so, in hindsight, a doula or private midwife, or even just the continuity of care of an unknown midwife. It would have made a world of difference because it's on the day I needed it. You know medical professionals give me information to decide how to proceed, and I didn't have a relationship with anyone there to support me except for my husband..."

"When my baby measured quite large, I was getting quite a lot of pushback from the hospital, like, Oh, you need to have a scan, and you need to. And then I'm like, OK, well, what's going to happen if you have a scan? Oh well, it's quite inaccurate. So, you have to have two. OK, what happens if I have two?..."

"..one of the challenges was that I guess an obstetrician, but I'm not sure, the doctor came into the room and told me that I had been pushing for too long. And so now his recommendation was to go down to theatre so that I was prepped for an emergency caesarean. But we'll try and do a forceps delivery first and that is wildly different from the hopes and dreams that I had for my birth, but I also. Most you know, prepared for changes in how the day unfolded. But I had questions like, how long is too long for me to continue trying to push? Or are there other positions that I can put my body into? You know the pushing will be more effective..."

"The obstetrician I'd seen in my first, she tests my blood pressure, and then quickly be done with the appointment. And that continued after the baby was here to the point where I had a really bad experience. Well, I had a tear I and I healed badly, and so I had all this granulation tissue that was extremely painful. And I was just devastated because I was in so much pain with it. And she was just like, oh, just Google granulation tissue and then wrote it down and gave it to me and OK

appointment over. So that was kind of like a contrast to how caring my midwives have been. I've been blessed with my midwives in the public system."

3. What would make information more accessible, relevant and helpful in this time

"I went public. Uhm, and I didn't get into the continuity of care model, unfortunately, even though I asked multiple times to try and squeeze in, I think having a relationship with a midwife that knew me, knew my story, and you may want to send my wishes, et cetera, et cetera. I think that would have helped in gaining more information..."

"You know as much as I felt prepared. It's still the first time that I'm never getting something that is monumental and life-changing, and it's such a vulnerable thing to go through. In hindsight, it's just bonkers that I didn't do that with trusted people around me, and that's not from lack of trying like I also did my best to get into the continuity of care program..."

"finding different specific Facebook groups so valuable and so yeah, within I think a week of my pregnancy concluding I had left that pregnancy group, but I had entered at least two other Facebook kind of support groups that I feel so grateful for"

4. What information is most useful, or would be most useful, during this time

"The one thing I did find so helpful, which I didn't expect, was joining a Facebook group...something called Pregnancy Information for Australia. It had quite a number of people in the group, and I really liked that; I guess the way that the admins were.... a lot of the information could be linked back to reputable sites, so I found that helpful. And, without ever having to post a question myself or ask for feedback or advice, I saw my experiences in other people's posts. So, there was like this amazing level of anonymity and at the same time, this reassurance that my experience was similar to other peoples'..."

"I went to a birth skills course. I did so much research on birth. And read so many books...I did a course; I think it was an ACT course, "Baby makes 3" or something like that... And that was amazing because they went into the first year of your baby's life and what to expect. And like everything from The Wonder Weeks, daily care and crying and everything. So that was good..... I went through the Birth Centre for my second, third and fourth, which was quite a different experience. And I actually really liked the ACT public health, the public maternity system."

"I think for me it was it was my Calmbirth class and the Baby makes 3 class. I think those two things that I did outside of the hospital were most beneficial for me, read lots of books...the classes covered a lot of relationship things. So like, how a baby will impact your relationship? Uhm, I think that was the kind of stuff...."

"I'm so grateful that I learned during pregnancy that there's a difference between a lactation consultant and an IBCLC. Because when I was trying to navigate some of those challenges. When I wasn't getting the support that I needed, then I knew to pivot and employed the services of an IBCLC and we like, without a doubt, saved our breastfeeding relationship, and it's essentially been smooth sailing since then...."

"I did join the Australian Breastfeeding Association before, I joined before I had my baby and also did their online course, you can do it, I guess before COVID it was in person, but that was great beforehand. And just to know that you could like call up at any hour of the day and speak to someone, which I did..."

Information access after birth and during infancy

1. Who is most influential and trusted in sharing information about this time?

"I got a lot of the information from the NICU because he had some medical issues...."

"for me, it was the Australian Breastfeeding Association Facebook page. Yeah. And I found it a little bit later, like maybe around three or four weeks after delivering the baby, But it was perfect. And then they have this gentle sleep training they encourage."

"Through the private midwife, through the Australian Breastfeeding Association, through the Maternal and Child Health nurse, and then onto the Mothers group program. The ACT also offers a session run by a speech path and a dietitian for like starting solids jumped on that. And then I had a few issues with baby and her tongue tie was picked up by a chiropractor who specialises in Pediatrics..."

"Yeah, I am the same. I looked at Facebook. I've read a couple of books because I used to read in those days...."

"finding different specific Facebook groups so valuable and so yeah, within I think a week of my pregnancy concluding I had left that pregnancy group, but I had entered at least two other Facebook kind of support groups that I feel so grateful for"

2. How easy or difficult is it to find relevant and valuable information to support them in this time?

"Like, what do you do with it? Uhm, I was just sort of saying I didn't really know what to do with it when it was here. He was here.... but he was in NICU for 2 1/2 weeks and I feel like if it wasn't for that NICU, period, I would have no idea what to do with him like. Yeah, you just focus so much on the

birth, and there's not a lot even like the hospital classes that I went to were all about the birth, never about what do you do with the kid when you bring them home? Do they just sit there like, you know, like, what do you do? Come. But yeah, I just. I only learned what to do with him. Because we're in the hospital for like nearly 2 1/2 weeks."

"Into early parenthood, with already a pretty good idea about what was biologically normal for infants, sleep and so, my expectations were so realistic. And it was still so hard, and I can't help but have some feelings for friends and family who have unrealistic expectations and how hard they must find that. I you know, choose to parent my child responsively, no matter the time of day or night. And that has always been really important to me and it's really hard. And I probably can't say that enough. This is important and it's hard and I know what I believe to be true about normal baby sleep, and I didn't learn anything about that in any meaningful or specifically helpful way from medical professionals along the way.,"

"Uhm, with my first just if the Maternal and Child Health nurses had looked at her mouth...I think the midwives were all like you've been breastfeeding for ten years, so you don't need any help.... It's so hard because you only have that contact for five days and there's no follow up... perhaps if the midwives say, you know, if you get these problems to come, you know, this is what you need to look into.... It's still breastfeeding it's just I think it's the biggest challenge for everyone who chooses to breastfeed. The conflicting information is complicated to navigate when you're going through it, and you're sleep-deprived and all the rest of it, yeah..."

"But I guess from ACT health, I don't recall being provided with any information which has been tangibly helpful for me to navigate sleep for my baby and our family. And I think it's a thing that impacts every newborn family so..."

3. What would make information more accessible, relevant, and helpful in this time

"I remember in those first couple of weeks of being postpartum; I had this plastic folder that had all of these different pamphlets that we've been given in, you know the final weeks of pregnancy. And then at the hospital and from home, visiting midwives in postpartum. And I remember thinking is probably the answer for, you know, whatever I'm interested in right now somewhere in that folder. But it is just like too hard right now... And also, all of that information surely exists on various websites, but I guess having some kind of centralised electronic database of what we would have been given anyway, but you know, an online format surely would have been helpful."

"Things like, you know that you should be doing or whatever. And it would be great to have a resource like that come with trusted professionals potentially like talking about those kinds of things. So you could tap into when you want, and to do what you like when baby doesn't like tummy time, like how to help my baby do tummy time if they don't like it or why it's so important. And I mean the thing that I spoke about with the dietitian that you could like log into..."

'I must say that it's a little bit difficult. The whole breastfeeding thing, it's tough to find correct information with issues. The first had a really substantial tongue tie that I only just found out recently because I'm investigating it with my fourth, but no one kind of worked it out. No one said anything, I saw the Maternal and Child Health nurse, I was really annoying the Maternal and Child Health nurses and I think, I kept showing up and going. She's still like making these clicking noises, causing a Ridge. It's really painful, and no one could give me an answer as to what was going on, and I just pushed through, and I just kept feeding, and you know as she grew, she got better at it...'

"And I think, similar to what the other participant said earlier, you might not even need to post anything just like reading other people's stuff on is enough to fix your own issues, even for the simplest things. Like we have cloth nappies at home and like getting the beginning of a really good wash routine and stuff. It's all Facebook and it's all really good admins donating their time to help you find stuff out that actually has been the real wealth of knowledge..."

4. What information is most useful, or would be most useful, during this time?

"Information on breastfeeding and tongue-tie..."

"You know, kind of what my postpartum journey with my newborn looks like was normal or that it wasn't normal. But you know, this is kind of the avenues I should look down to get some extra support ..."

"And I will also say I found Instagram a really useful resource, particularly for normalising the fourth trimester experience in that very early parenthood."

"But I guess from ACT health, I don't recall being provided with any information which has been tangibly helpful for me to navigate sleep for my baby and our family. And I think it's a thing that impacts every newborn family so..."

"For me, it was, uh, the information about Co-sleeping. Because I wanted to co-sleep and then there was not much given from the nurses. So I googled it and then I did some research myself..."