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# Embedding consumer and community involvement in antenatal healthcare research: A methodological approach and perspectives of culturally and linguistically diverse women in Australia

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## Abstract

**Background** Consumer and Community Involvement (CCI) in healthcare research ensures that the needs of target populations are met through active collaboration between consumers, communities, and researchers. For culturally and linguistically diverse (CALD) women in Australia, disparities in antenatal healthcare are pronounced due to barriers such as language, cultural differences, and systemic inequities. Inclusive CCI can help identify healthcare gaps and improve care. This study aimed to describe the formation of a CCI reference group using the Health in Preconception, Pregnancy, and Postpartum Alliance CCI Co-Development Framework to explore antenatal healthcare experiences and identify opportunities for improvement.

**Methods** A CCI reference group of 18 CALD women was formed through purposive recruitment. Focus groups were conducted to capture their experiences with antenatal care, focusing on healthcare accessibility, cultural competency, and barriers encountered. Thematic analysis was performed using NVivo software to identify key themes related to antenatal care experiences.

**Results** Three key themes were identified from the analysis: (1) Navigating cultural beliefs and antenatal care: Women expressed challenges in reconciling traditional cultural practices with information received during antenatal care, particularly in relation to dietary modifications required for gestational diabetes management, which often conflicted with their cultural norms. (2) Social support: Many women highlighted the importance of familial and peer support during pregnancy, but some experienced isolation due to geographic separation from family. Peer networks and cultural community groups were noted as important alternative support systems. (3) Cultural competency of healthcare providers: Participants consistently reported that healthcare providers with cultural awareness and

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sensitivity improved their care experiences, increasing trust and satisfaction. The absence of such competency led to confusion and dissatisfaction, particularly when managing pregnancy complications.

**Conclusions** Embedding CCI in antenatal healthcare research is essential for creating culturally competent care for CALD women. Addressing healthcare provider cultural competency, adapting health information to reflect cultural nuances, and enhancing mental health support were identified as priority areas. The findings highlight the importance of ongoing consumer engagement to achieve equitable and responsive antenatal care for CALD women in Australia.

**Trial registration** Not applicable.

**Keywords** Pregnancy, Women's health, Healthcare access, Culturally and linguistically diverse, Consumer and community involvement, Cultural responsiveness, Maternity care, Stakeholder engagement, Qualitative

### Plain English summary

This study focuses on improving pregnancy and birth care for women from culturally and linguistically diverse (CALD) backgrounds in Australia. These women often face challenges when accessing healthcare due to language barriers, cultural differences, and lack of understanding from healthcare providers. We aimed to better understand these challenges and find ways to make care more culturally responsive and inclusive; meaning to better understand and respect different cultures so women feel safe and accepted. To do this, we formed a group of 18 women from different cultural backgrounds. These women shared their experiences with pregnancy care in Australia through group discussions. We found that many women struggled to balance their cultural practices with standard medical advice. This was especially true for women with gestational diabetes, where the recommended diet often did not match their traditional foods. Women also talked about the importance of family and peer support during pregnancy, but some felt isolated due to being far from their families. One of the main issues raised was that healthcare providers often lacked understanding of their cultural needs. Women felt more comfortable when their culture was respected and understood during care. The study shows that there is a need for better cultural training for healthcare professionals and more personalised health information for CALD women. This research highlights the importance of involving women from diverse backgrounds in the development of healthcare services. By doing so, we can create pregnancy care that is fair, respectful, and better suited to the needs of all women.

## Background

Consumer and Community Involvement (CCI; also known as patient or public engagement) in health research commonly involves consumers and communities working in active partnership with researchers or organisations, to shape decisions and deliverables that are made with, and are responsive to the needs of, the population impacted by the research and/or healthcare initiative [1, 2]. This is achieved through co-creation and shared decision making in shaping research questions, design, implementation and outcomes that consider the lived experiences, priorities and cultural and societal nuances of consumers [3, 4]. As such, countries including Australia, the United Kingdom, Canada, and the United States, incorporate CCI as a central policy directive, acknowledging that publicly funded health research should reflect public interest to ensure outcomes benefit the communities they are intended to serve [1, 3–5]. Therefore, CCI is now regarded as a mainstay across healthcare improvement initiatives, health research and policy development.

In this context, CCI is particularly vital for priority populations, including those who are culturally and linguistically diverse (CALD). The term CALD describes individuals or groups from diverse languages, ethnic backgrounds, nationalities, traditions, societal structures, and religions, that differs from the main ancestry of a given country or region [6]. CALD populations can face significant disparities in healthcare arising from a complexity of individual, environmental and systemic barriers [7, 8]. Individual barriers may include migration experience, language barriers, lower health literacy [9], and cultural differences in health and lifestyle practices [10]; while environmental factors can include inequitable access to, and difficulty navigating health systems [11, 12]. Systemic issues such as a lack of cultural competency, sensitivity and responsiveness further exacerbate inequities [13]. Australia is a culturally diverse country, with approximately one third of the total population non-Australian born [14]. For CALD women experiencing pregnancy in Australia, such disparities are pronounced, as pregnancy itself is associated with increased vulnerability

to adverse health outcomes, increased healthcare needs and more frequent interaction with healthcare providers and health systems [15, 16]. Annually, CALD women contribute to one third of births in Australia, yet face a higher risk of preterm birth, congenital abnormalities, neonatal care admission, stillbirth, and maternal and infant mortality compared with Australian born women [17].

Globally, evidence highlights that CCI improves engagement and outcomes in initiatives to improve health, particularly for CALD and lower socioeconomic populations [18]. Therefore, fostering meaningful CCI in antenatal healthcare is a crucial step towards addressing disparities in maternal health that are responsive to the diverse needs of CALD women. In tandem, persistent barriers that curtail meaningful CCI should be addressed, including inconsistent terminology, superficial engagement, limited capability and a lack of real-world evidence of effective methodologies, including application of guiding frameworks [1, 2, 14]. To address these gaps, we aim to describe the formation of a CALD CCI group to inform and co-develop a culturally tailored program to optimise antenatal health, guided by the Health in Preconception, Pregnancy and Postpartum (HiPPP) Alliance CCI Framework [19]. By embedding cultural responsiveness into antenatal health, we aim to foster trust, promote engagement, and enhance maternal health outcomes for CALD communities.

### Methodological overview

The HiPPP Alliance, formed in 2018, aims to optimise health outcomes before, during, and after pregnancy and comprises multidisciplinary international stakeholders across consumer, community, government, academic, private and public health services and primary care [19]. The HiPPP CCI framework aims to increase consumer involvement in research across preconception, pregnancy, and postpartum stages by promoting inclusive, flexible, and equitable participation, addressing barriers, and enhancing awareness [19], as detailed below in Phase One. The framework promotes pragmatic activities utilising diverse and meaningful consumer involvement throughout the research cycle, ultimately improving health outcomes for women, families, and future generations. In this context, Phase Two focused on forming a CCI group for CALD women, engaging relevant networks and stakeholders, while Phase Three explored antenatal healthcare experiences with the CCI group through focus groups to scope experiences, missed opportunities and barriers and identify key areas for improvement in, maternal healthcare.

### Phase 1: guiding framework, implementation strategy and application

Phase 1 is underpinned by the HiPPP CCI Co-Development Framework [19], tailored to meet the objectives of our CCI formation and research deliverables. The present study's interpretation of the framework includes five essential co-development principles, each designed to foster meaningful and impactful consumer engagement throughout the research process, comprising:

**1/Purposeful engagement** Shared understanding of the research objectives from the outset to ensure research activities and processes are conducted with specific goals in mind. Participants receive regular updates and opportunities to provide feedback to enable transparency of process.

**2/Inclusivity and adaptability** Ensuring engagement methods are accessible and representative of diverse perspectives. Participants are recruited from various backgrounds and research activities are adapted to meet the needs of women with enhanced accessibility including remote engagement.

**3/Respectful interaction** The lived experiences of participants is valued. Participants are regarded as experts in their own right, with perspectives and feedback encouraged to enable integration into research design. Participants are provided necessary support, including financial compensation and logistical assistance.

**4/Transparency** Clear communication of expectations and maintaining an open, two-way feedback loop fosters transparency. We ensure that all participants understand their roles and the progress of the research through detailed Terms of Reference and regular updates.

**5/Collaborative partnerships** Build and sustain long-term, meaningful relationships through ongoing activities and support. This involves organising workshops and regular meetings to keep participants actively involved and engaged.

Figure 1 illustrates our processes and implementation strategies aligned with each HiPPP value and CCI principle.

### Implementation strategy

We aimed to establish a CCI reference group of between 10 and 20 women, with a core quorum of four women. The CCI reference group size was purposively larger to account for the increased barriers experienced in engaging women of reproductive age, particularly those with young children (i.e. time, primary care giving, work commitments), as well as the transient nature of pregnancy.

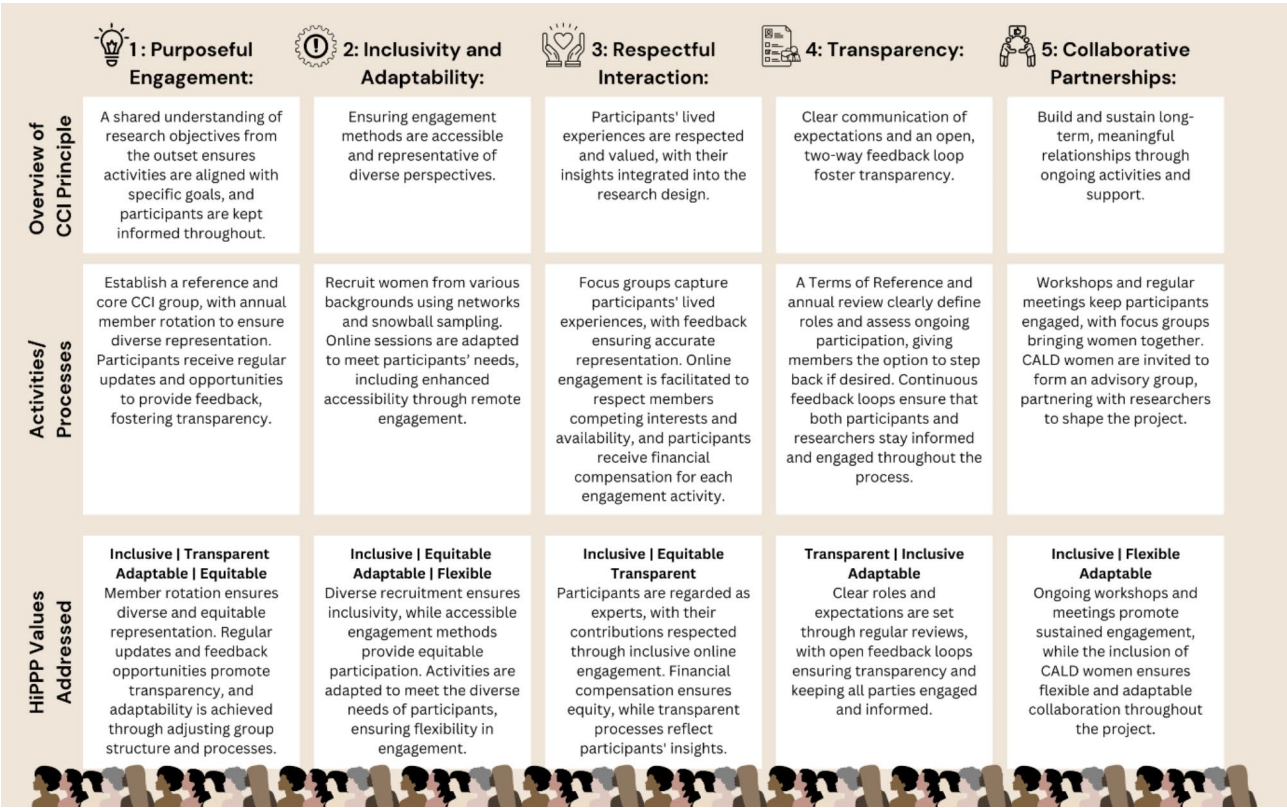


Fig. 1 Implementation process for CCI group formation and ongoing partnerships

The core quorum is reviewed annually, with existing members alleviated and supplemented with members from the wider reference group according to capacity, circumstance and individual preferences.

A Terms of Reference (TOR) was developed to guide the CCI reference group by outlining the research vision and the establishment and operation of the reference group. Key components of the TOR include participation expectations, meeting frequency, engagement, and remuneration. The group's contributions underpin the research project, fostering culturally sensitive, accessible, and relevant outcomes with an initial 12-month commitment, extendable for the project's duration. Supported by the TOR, our engagement approach is iterative, designed to engage members and adapt research design, components and outcomes based on ongoing feedback during key project milestones. This dynamic structure allows for the continuous integration of consumer insights into the research process, enhancing the relevance and effectiveness of our outcomes. The core quorum represents the wider CCI group in a project steering capacity when necessary.

By applying this comprehensive and responsive framework, we aimed to create a research process that is not only informed by the community but also genuinely responsive to their needs that emerges along time.

Ongoing engagement and adaptation ensures that our research is developed by CALD women, for CALD women, embodying principles that ensure cultural safety and relevance at every stage of the research.

**Phase 2: consumer and community involvement group formation**

**Consumer engagement and recruitment**

Established researcher contacts and collaborations were used to identify consumer networks, consumer-led organisations, community groups and organisations providing healthcare for women from CALD backgrounds based in the state of Victoria, per the research setting, as well as more broadly throughout Australia. These included, the Multicultural Centre for Women's Health [20], Centre for Culture Ethnicity and Health [21], Sisterworks [22], LAMAZE Australia [23], Women's Health in the North [24], Women's Health Research Translation and Impact Network [25], the Centre of Research Excellence Health in Preconception and Pregnancy (CRE HiPP) [26], Wellsprings for Women [27] and Perinatal Anxiety and Depression Australia (PANDA) [28]. Key consumer consultants, representatives and stakeholders from these networks and organisations were identified and iteratively engaged via email and with follow up phone calls to establish connections, rapport and



**Table 1** Participant characteristics

<b>Baseline characteristics</b>	
<b>Age (years): mean (SD)</b>	41 (4)
<b>Years living in Australia: mean (SD)</b>	8 (9)
<b>Country of Birth: n (%)</b>	
Australia	1 (5.6)
China	2 (11.1)
India	3 (16.7)
Indonesia	7 (38.9)
Iraq	1 (5.6)
Libya	1 (5.6)
Myanmar	1 (5.6)
Somalia	1 (5.6)
United Arab Emirates	1 (5.6)
<b>Work Status: n (%)</b>	
Not currently working	7 (38.9)
Casual	5 (27.8)
Part-time	4 (22.2)
Full-time	2 (11.1)
<b>Education Status: n (%)</b>	
Year 12 or equivalent (senior high)	0 (0.0)
Certificate/apprenticeship/trade/technical/vocational training	1 (5.6)
Diploma/advanced diploma	2 (11.1)
Bachelor degree or above (university/college)	12 (66.7)
Prefer not to say/did not answer	3 (16.7)
<b>Marital status: n (%)</b>	
Married	17 (94.4)
Living with long term partner	1 (5.6)
<b>Pregnancy Status: n (%)</b>	
Pregnant	3 (16.7)
Not currently pregnant	15 (83.3)
<b>Number of Children: n (%)</b>	
1 child	3 (16.7)
2 children	11 (61.1)
3 children	4 (22.2)

mutual interests. The project was then advertised via key contacts, who facilitated engagement and recruitment of consumers via convenience sampling following an expression of interest. Snowballing techniques were then used whereby engaged consumers were encouraged to identify interested peers, including family, friends and co-workers to further assist in diversification of participants.

Guided by Pham *et al.*'s (2021) definition of CALD [29, 30], we engaged women aged 18 to 50, who were pregnant or had given birth in Australia, and were born in a non-English-speaking country. While our initial aim was to engage women with recent childbirth experiences in Australia (within five years) and more recent migration (within ten years), we broadened the time restrictions of these criteria during recruitment to facilitate greater

participant numbers. This allowed for the inclusion of women who expressed a strong desire to engage in the reference group, reflecting the project's commitment to inclusivity and the value of diverse perspectives. For the purposes of participating in the working CCI group, proficiency in English was required. We included one woman who identified as CALD but was born in Australia, as she was a key contact for her consumer-led organisation. The Monash Health Research Ethics Committee provided research approval (RES-22-0000-380 A) and all engaged participants provided written and informed consent.

Demographic data including age (in years), country of birth, length of time living in Australia (years), current working status, education status, marital status, pregnancy status/reproductive stage and number of children were collected in survey format at the point of recruitment. Data analysis was performed using IBM SPSS Statistics version 27 (Armonk, New York, NY, USA).

### Reference Group Characteristics

In total 18 women were sequentially engaged following expression of interest to form the reference group. Table 1 provides an overview of participants demographic characteristics, with data presented as mean (SD), unless otherwise stated.

### Phase 3: antenatal care experiences, identified priorities, enablers and barriers

The CCI reference group attended an inaugural focus group to build rapport and co-develop guiding principles for the TOR with feedback captured and the TOR iteratively updated prior to mutual acceptance of a final working document. The group also shared their experiences with antenatal care, providing a foundation for setting research priorities aimed at implementing a healthy lifestyle program to improve maternal health in a Victorian antenatal care setting. A discussion guide was developed to explore (i) women's experiences of antenatal care in Australia, (ii) health and lifestyle information seeking behaviours during pregnancy, (iii) pregnancy and cultural considerations of significance and importance and (iv) identify opportunities for improved cultural responsiveness in antenatal healthcare (Additional file 1). Women attended one of two, three-hour focus groups in October 2022, according to individual preference. Focus groups were held on an online videoconferencing platform, facilitated by researchers (R.M, C.L.H and R.M.G). Per the guiding principles, a conversation style format was adopted, inviting women to discuss their lived experiences and experiences of other members of their community group or consumer-led organisation. The facilitators proactively invited all individuals to participate, aiming to foster an inclusive environment where every member had an equal opportunity to express their viewpoints

and be actively heard. All consumer participants were remunerated in accordance with TOR, consistent with the Monash Partners remuneration guidelines [31]. The focus group recordings were transcribed verbatim by an independent transcribing service.

### Thematic analysis

Qualitative transcripts were analysed using a reflexive thematic analysis, informed by Braun and Clarke's six phase framework [32]. In brief, this included two researchers reading transcripts until sufficiently familiar with content; generating initial codes independently which were thereafter arranged into potential themes (R.M and B.R.B) [32]. An independent researcher with no involvement in the delivery of focus groups assisted with initial coding and formation of the themes (B.R.B) to prevent the dual role of the researchers delivering and evaluating the results. In depth, iterative discussion of potential themes then took place ensuring reflection of the data before a final set of named themes was agreed upon between all researchers involved in data analysis (B.R.B, C.L.H, R.M and R.M.G). Quotes from interviews that best represented the key findings for each theme were highlighted for subsequent reporting purposes. Thematic coding was performed in the NVivo Software program (QSR International Pty Ltd, Version 11).

### Qualitative themes

#### Theme 1: lived experiences of antenatal care

##### **Sub-Theme: barriers following standardised health information**

When receiving health information during maternity care, women reported frequent requirement to reconcile differences in health and medical information with their cultural beliefs and practices, particularly those considered mainstay and passed down generationally:

*"You're getting information from all sorts of sources, the health services and the medical side of things... But also, I think from your own cultural background...maybe your mothers or your aunts or your sisters, and you have to try and somehow fit all of that in and make sense of all of that and still advocate for yourself. Which sounds very difficult, right." W2P8.*

Women perceived less accommodation of their cultural preferences within maternity care practices as medical intervention increased. This was typically experienced following diagnosis of a pregnancy complication and was reiterated by several participants who were diagnosed with gestational diabetes mellitus (GDM). GDM is defined as glucose intolerance with onset or first recognition during pregnancy and is typically diagnosed between

24 and 28 weeks gestation with first line management involving lifestyle modification (i.e. diet and physical activity optimisation), self-monitoring of blood glucose and intensive education, followed by pharmacotherapy if lifestyle modification is inadequate to control blood glucose targets [33]. In the context of modification to dietary intake as a core component of GDM management, women reported food preferences and/or usual dietary practices commonly misaligned with standardised Australian dietary recommendations and/or dietary prescription related to GDM management provided:

*"As far as diet is concerned, the diet options that were given, I did not go for it because that was not the diet that we eat. It is mostly Australian vegetables and boiled chicken and that kind of a diet, which is not what we eat... For gestational diabetes, information pamphlets [...] it's more like one size fits all, there is no tweaking in there." W2P2.*

This lack of culturally receptive care impacted significantly on women's health and wellbeing with associated feelings of distress and uncertainty due to limited individualised guidance:

*"...you have to take it into your own hands... because you're being told this is what you should do but in reality, it doesn't quite fit in with how you eat normally at home, how you feed the rest of your family.... you just have to figure it out yourself. Which is very stressful." W2P8.*

##### **Sub-Theme: cultural competency of healthcare providers and services**

Women often reported seeing multiple healthcare professionals over the course of their pregnancy and discussed that those who were from a similar background and/or acknowledged and considered cultural practices within care interactions significantly enhanced trust and comfort, fostering a more receptive and supportive environment:

*"In my case, my GP was from India...she [completed] gynaecology studies [in Australia]. So, it was luckily very helpful for me [...] because she already knew our culture in India, where we are coming from, and what the misconceptions [are, which] really helped me." W2P2.*

The importance of ensuring that health information is communicated in the community's native language and in a culturally appropriate manner was also emphasised. Using generic or automated translation platforms (e.g. Google Translate) may not reflect true meaning due to

nuances between languages. Therefore, translations need to be tailored by someone with a deep understanding of the community's language and cultural nuances to ensure that the information is not only linguistically accurate but also culturally acceptable.

*"to make sure all the information [is] in [the] community language, and most important thing it has to be community appropriate. So, the translation, if someone is not from the community or...say google translated, some of the words are not acceptable."* W2P5.

Additionally, some took the proactive step of bringing their own translators, often family members or a close trusted connection to antenatal appointments. This often provided comfort and a source of trust in the information they were receiving.

#### **Sub-Theme: navigating cultural norms and stigmas**

Women's experiences in antenatal care were significantly shaped by the intersection of cultural beliefs and practices and antenatal care received within the healthcare system. Common cultural norms and practices observed during and following pregnancy were discussed and varied widely by cultural background. Emphasis was particularly placed on traditional cultural practices that typically would not influence pregnancy outcome, but were nonetheless deeply valued by women and their families. Here, consideration and acknowledgement of beliefs was important if women chose to observe them:

*"Definitely...conflicts exist...we've got to be very careful that we're not saying one [is] better than the other. Is there evidence base for this in medicine versus the cultural practices that have been going on for generations... I think it's just all about allowing individuals to make their own decisions....rather than a myth busting exercise... you know."* W2P8.

Observing traditional beliefs and practices appeared to be determined on an individual level. For some women, new information and common practice or norms in Australia replaced or modified traditional norms from their native country:

*"It's just very difficult to unlearn things. It's difficult to let go of things...But personally what I did was, like one of the others had mentioned, I didn't share a lot of information with my parents or with my family back home with what was happening here. Because I just wanted to stick to one kind of health-care system... I let myself be open to these things, to whatever the midwives told me. I listened to them, I*

*tried to follow as much as I could without sticking to my cultural learnings..."* W2P7.

For example, one participant shared her relief and satisfaction at being able to take a shower after giving birth, a practice not permitted in her home country:

*"I was quite happy that after I gave birth, I can take a shower... in China we're not allowed to do that... You can't wash your hair. The only things you can do is lie down on your bed. So, I'm quite happy in Melbourne."* W2P9.

Furthermore, stigma associated with mental health in some cultures prevent open discussion or professional help seeking for common conditions including anxiety, depression, or general stress. The ability to discuss this within Australian settings was valued by women:

*"I just want to make sure that mental health is also covered... I just think about my own personal cultural background, I could never talk to my parents about mental health issues."* W2P8.  
*"Another thing is the post-pregnant depression. When you told your old parent I got that, they wouldn't understand...they will turn back to the culture and the religion instead of looking for medical, I know that's important too, but straight away they dismiss [it]..."* W2P3.

These narratives underscore the complex dynamics of navigating the antenatal care system and healthcare professional advice in Australia for women from CALD backgrounds. The healthcare system's ability to acknowledge and consider cultural practices and beliefs, particularly those that do not conflict with care, were valued. Similarly, empowerment and choice to adopt new practices positively impacted women's overall well-being and satisfaction with their pregnancy and childbirth experiences. This reiterates the significance of engaging with women during the antenatal care period, which offers an opportunity to address their cultural preferences to optimise care experience.

#### **Theme 2: social support**

Social support from family and friends was identified as a vital component of antenatal care experiences in Australia. Participants acknowledged the significance of connecting with female family members, such as mothers and sisters, to seek support and draw upon their experiences. This form of support was highly valued and considered a trusted source of information. Women relied on these close relationships to navigate their pregnancy

journey, benefiting from the wisdom, guidance, and empathy provided by their family, peers or support network.

*"The first point of contact is [my] mother and [a] friend, because they have lot of experience, [my] mother especially. They went through all of this. So, they have a whole bunch of experience to share." W1P6.*

Women also expressed a preference for connecting with peers from a similar cultural background to support them during their antenatal care experiences:

*"...I got a lot of health information from other mums... we have, [a] WeChat group." W1P4.*

Social support was not only fundamental but often essential for CALD women navigating antenatal care, as many experienced profound isolation due to being new to the country or separated from their families. This isolation placed greater reliance on healthcare providers or cultural connections, as reflected in the following experiences.

*"Here, we are just alone without our family. My husband sometimes goes to the office and leaves me here alone with the kids, struggling. My GP, who is very kind, comes to my house to help me with everything—information about pregnancy, what to do at home, or what to do in an emergency. She's from Sri Lanka and has been so helpful, especially when I'm on my own and need support." W1P2.*

*"...in my first pregnancy, I was, I feel very new in country and don't know anyone. I was driving or my husband was driving 40 minutes every time we wanted to visit the doctor because he was Arabic from our culture/background." W2P1.*

### **Theme 3: individual factors**

#### ***Formative experiences and prior pregnancy care***

Formative experiences and prior pregnancy in women's native countries shaped perspectives of antenatal care in Australia compared to their countries of origin. For some women, receiving care in Australia was more transparent, with clearer explanation of maternity care practices and procedures during pregnancy, facilitating enhanced knowledge and understanding. Others described how pregnancy was viewed differently in their native country, often perceived as an 'illness' or 'ailment' requiring restrictive care. In contrast, Australia offered a perspective that viewed pregnancy as a natural and healthy phase of life, fostering a greater sense of agency and empowerment among some women.

*"My birthing experience was better in Australia [...] basically in our culture and our countries when we are pregnant, we are told of all the things of what we can't do. But in Australia, I learned that I could do a lot of things during my pregnancy. So, that was a wonderful [...] I learnt that 'oh my god, you are pregnant, you're just a normal woman, you're not sick.' You can do everything you like to, generally speaking, [my] overall experience was a good one." W2P7.*

*"So, during pregnancy when I was pregnant back home, everyone around me they will act [like I am] someone sick, not a normal person. You can't walk too much, you can't dance, you can't carry heavy things. So, it's all about [what] you can't do... But here, no, the doctor straight away will say to you everything [is] alright. You can just enjoy your normal life and your routine. You can do exercise, you can go shopping, everything. But home, no. You have to just know by yourself or someone older, your mum or someone like that, just to teach you, which they don't have the right information maybe because they just got it from another person." W2P5.*

Women's formative experiences also influenced their attitudes toward birthing preferences and their engagement with antenatal care:

*"So, when I came to Australia, and I conceived I was just told that of course you can't have a vaginal delivery again....I wasn't very satisfied with the fact that everyone just told me that you will have an elective caesarean...I was just really scared of the caesarean. And that's also because of what happens in our culture. All the women, many women who have caesareans, they have post-operative issues like back pain and all of that." W2P7.*

#### **CCI consolidation of identified themes**

In line with best-practice principles of qualitative research, the CCI group were provided with the opportunity to review the focus group transcripts and/or a plain language summary of the main themes from the reflexive thematic analysis and invited to provide feedback to ensure accurate reflection of the data via email, phone or during an online videoconferencing session (facilitated by R.M and R.M.G).

In total, seven members provided feedback to the plain language summary via videoconferencing which passed the minimum quorum requirements per the TOR. Overall, the CCI group indicated that the thematic analyses were broadly congruent with the discussion and experiences shared during the focus groups. Interactions with the healthcare system and social support were collectively considered of highest importance in influencing



antenatal care experience. Participants expressed that the healthcare system broadly lacked responsiveness to provide culturally considered support and information, particularly related to dietary modification following GDM diagnosis but also more broadly, when a complication was experienced. In consideration of this feedback, themes were revisited to provide additional and/or more reflective quotations to strengthen qualitative interpretation and better represent the sentiment of the CCI group.

## Discussion

This study provides a foundational exploration of how to establish a CCI group to engage CALD women in antenatal healthcare research. In doing so, we identified barriers and enablers experienced by CALD women during antenatal care in Australia, providing valuable insights to inform future improvements in care delivery and the development of programs and interventions that optimise pregnancy outcomes. The structured yet iterative approach to engaging CALD women in CCI, guided by the HiPPP Alliance CCI Co-Development Framework [19], highlights the feasibility of forming a reference group of consumers [34].

We adopted an inclusive approach, leveraging existing community networks and lived experienced experts to accelerate rapport and facilitate broader reach with flexible engagement strategies to mitigate barriers to participation. Previous research has demonstrated that engaging individuals within their own communities enhances recruitment efforts, as community members are more likely to encourage their peers to participate [35]. This is particularly important in CALD populations, where mistrust and/or unfamiliarity with research institutions and/or health care organisations is a common barrier to research engagement [36]. Mistrust may be further compounded by communication issues, health literacy and research processes requiring a high level of reading comprehension, including obtaining participant informed consent [36]. Here, two thirds of women were tertiary educated and had resided in Australia for a mean of eight years overall, which likely facilitated engagement and formation of the CCI group alongside English proficiency. Yet, this does not necessarily translate to desaturated capturing of cultural beliefs, healthcare experiences and priorities for care in CALD populations. Previous research exploring consumer engagement and healthcare experience in non-English speaking CALD participants residing in Australia for as little as three months, reported similar issues to those reported here [37]. Results emphasised the importance of adequate translation and the influence of diverse healthcare professionals and culturally responsive systems on healthcare experience [37]. This is encouraging, indicating that despite engaging English speaking participants for pragmatic

purposes, we were still able to capture deeply held cultural practices and beliefs in our CCI group, relevant to the aims of our research.

Our thematic analysis identified several areas where antenatal health services could better meet the needs of CALD populations, including the accessibility of culturally tailored health information and the importance of cultural competency of healthcare providers. Participants emphasised the challenges in mediating standard healthcare practices that often conflicted with cultural beliefs and traditions. This was particularly evident in cases where women were diagnosed with GDM and standard dietary recommendations were poorly aligned with cultural food preferences [38]. A diagnosis of GDM is associated with significant and rapid modification to lifestyle behaviours, which in turn are often deeply tied to enjoyment, tradition, and identity [39]. Here, women emphasised that these challenges are compounded by a lack of adapted support relevant to cultural needs and practices, underscoring a significant gap in care. This result is not surprising, with similar findings on lack of adaption to diet and physical activity education following GDM diagnosis that meets the needs of CALD women extensively reported in previous research in Australia by our authors and elsewhere [39]. Instead, this indicates the persistently limited impact within Australian health systems to ensure meaningful, relevant and accessible adaptations that meet the needs of CALD women diagnosed with GDM. Ensuring cultural diversification of health professionals within health care systems offers one pathway in which to create more culturally responsive and competent health systems and care [40]. For example, bicultural workers, employed for their cultural, language, lived experience and community connections can facilitate relationship building between individuals and health systems [41] and during pregnancy have been shown to increase trust between women from CALD backgrounds and their healthcare provider [42]. Increased cultural diversification offers opportunity for women from CALD backgrounds to interact more meaningfully with healthcare professionals that are culturally knowledgeable given culturally competent healthcare provision and education cannot be achieved through language translation alone, as previously highlighted [39]. This is supported by participants in our study, who reported a more positive experience when cultural practices were acknowledged and understood within care interactions and/or incorporated into care plans; particularly when attended by a healthcare professional from the same cultural background as theirs. Further, healthcare information that is communicated in culturally appropriate ways, by individuals familiar with the cultural and linguistic nuances of the community, was also valued.

Navigating the integration of cultural norms and stigmas in the context of maternity care practices in Australia was often a significant source of confusion and stress for CALD women during pregnancy. Such norms ranged widely, including but not limited to, refraining from particular foods, limiting intake of cold water or exposure to cool air, bathing after childbirth or beliefs around mode of delivery. These tensions were often heightened during critical moments of care, particularly when women were faced with decisions that could impact their health or that of their baby. Additionally, stigma surrounding mental health within certain cultural communities prevented some women from seeking the necessary support for conditions such as postnatal depression. The ability to openly discuss mental health concerns within the Australian healthcare system was seen as a positive departure from the cultural norm for many participants. This highlights the need for healthcare systems to not only provide culturally tailored physical health care but also to offer mental health support that recognises and addresses the cultural stigmas that may prevent women from seeking help. Integrating mental health support with practitioners who are either from similar CALD backgrounds or are trained to understand the cultural nuances can help build trust and reduce the stigma associated with seeking mental health care. By addressing both physical and mental health in culturally sensitive ways, and by fostering a connection with capable healthcare practitioners within their communities, healthcare providers can help mitigate the barriers that prevent CALD women from receiving comprehensive antenatal care.

### Implications for practice and policy

The methodological approach detailed in this paper has implications for antenatal healthcare practice and policy. It underscores the importance of embedding CCI as a core component of healthcare research and when working with CALD populations to ensure deliverables are reflective of the needs and experiences of diverse communities. Insights gained emphasise a persistent lack of cultural responsiveness and competency within Australian healthcare systems during antenatal care, particularly related to lifestyle modification and education. Improved cultural diversity, training in culturally competent care beyond superficial interactions or acknowledgement offer potential to dismantle barriers and optimise patient-provider experience and trust [8].

Policy implications include the need for relevant antenatal care guidelines and national health strategies (e.g. Australian National Antenatal Guidelines and the Women's Health Strategy) to explicitly incorporate the needs of CALD populations [43]. The Woman-Centred Care Strategic Directions developed by the Council of Australian Governments (COAG) Health Council in 2019,

emphasises the implementation of culturally safe models of pregnancy care, supported by culturally competent staff and healthcare systems. Despite this, challenges in systems implementation clearly remain, curtailing progress, as reflected by our findings. Embedding CCI into policy development, healthcare planning and systems implementation is essential for ensuring that health services are equitable and accessible to all women, regardless of their cultural or linguistic background.

### Limitations and future directions

While the study successfully demonstrates a methodology for engaging CALD women in CCI, it is important to acknowledge its limitations. Our CCI group may not capture the full diversity of CALD experiences in Australia; however, we captured perspectives from nine different world regions, reflecting a meaningful cross-section of backgrounds. While not exhaustive, this approach represents a pragmatic effort within the constraints of the research environment. The requirement for English proficiency may limit generalisability to non-English-speaking women, who may experience increased vulnerability and marginalisation. Future work could address this limitation by engaging CALD facilitators to conduct focus groups within their own communities or by training facilitators from CALD backgrounds, alongside the use of translators, to ensure broader inclusivity and representation. Owing to the qualitative nature of the study design, it is possible that social desirability bias occurred, where participants adjust their answers in order to conform to a more socially acceptable response [44]. Researchers addressed the possibility of this bias during focus groups by ensuring participants understood the voluntary nature of the research, that responses were not required if questions induced distress or discomfort and guiding discussion points by use of open-ended prompts to facilitate conversation. All focus group attendees were respectful of the opinions and voices of others, per the principles of our co-developed TOR.

### Conclusion

This study provides a replicable methodological framework for engaging CALD women of diverse backgrounds in CCI. The findings highlight persistent barriers that prevent the achievement of culturally competent healthcare systems in Australia. In particular, culturally sensitive care in the context of modifiable health areas such as lifestyle change as well as mental health support were emphasised as important areas to optimise during the antenatal care journey for women from CALD backgrounds. We demonstrate the potential of CCI to shape antenatal healthcare that is culturally competent and responsive to ultimately achieve care that is equitable,

accessible, timely, relevant and that meets the diverse needs and cultural priorities of all women.

## Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s40900-025-00710-6>.

Supplementary Material 1

Supplementary Material 2

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## Author contributions

Conceptualisation and refining of research idea: CLH, RM, RMG; responsibility of funding to support the work: CLH; research design: CLH, RM, RMG; thematic analyses: BRB and RM, supported by CLH and RMG, and CCI group members; interpretation of analyses: CCI group members and all authors; preparation of manuscript: BRB and CLH; intellectual input into manuscript: all authors; review and approval of manuscript: all authors; supervision of work: CLH; overall responsibility for the work and corresponding author: CLH.

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## Data availability

No datasets were generated or analysed during the current study.

## Declarations

### Ethical approval and consent to participate

Ethics approval was obtained from Monash Health Human Research Ethics Committee (Project no. HREC RES-22-0000-380 A). All participants provided informed consent prior to participating.

### Consent for publication

All authors and participants provide consent for publication.

### Competing interests

The authors declare no competing interests.

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