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Developing a research agenda for maternal health in the Top End of the Northern Territory of Australia: a participatory approach

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Abstract

Background Evidence supports that engaging consumers in developing and co-designing research priorities and protocols with key stakeholders improves acceptability of and participation in research and leads to better health outcomes. This is particularly relevant when considering research with First Nations, migrant and refugee populations, adolescents, women living with disability and those in the LGBTQIA + community who face systemic disadvantage, shouldering a disproportionate burden of poor outcomes. This study aimed to identify priorities for maternal health research in the Top End of the NT from the perspective of consumers and key stakeholders.

Methods Using a participatory approach, focus groups and in-depth discussions with consumers, maternal health care providers and stakeholders were conducted over a three-month period (Part A), followed by a 1-day stakeholder forum in Darwin (Part B). Data was triangulated and a list of research priorities developed.

Results Five priorities emerged. First, there is a need to develop and test strategies removing barriers for engagement of consumers and clinicians in maternal health research. Second, research into specific clinical concerns raised by consumers, such as prevention of preterm birth, must be complemented by health systems research enabling better patient journeys. Third, there is a need to develop and test innovative tools to enable comprehensive counselling of women from diverse backgrounds regarding aspects of care, based on most recent evidence-based and consumer needs. Further, there is a demand for research into innovative approaches to recruitment and retention of maternity care providers in a sparsely populated region of Australia, with a focus on provider well-being and continuity of integrated care. Finally, a need for research collaboration across similar settings and relevant disciplines to enable enhanced maternal health was identified.

Conclusions Emerging research priorities, implementing evidence-based practices, and regularly updating these priorities through ongoing stakeholder engagement, can work towards a future where maternal health services are accessible and responsive to the diverse needs of women and families residing in the Top End of the NT.

Whilst consumers and stakeholders raised specific clinical priorities, health system research was identified as a key priority, focussing on patient journeys, co-design, and continuity of care through staff retention.

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Introduction

The impact of health research globally is undeniable, with empirical evidence demonstrating improvements in clinical outcomes and processes of care across a wide range of disciplines [1]. Despite great advances in maternal health research and reduction of adverse pregnancy outcomes in Australia and globally in recent years, maternal health research agendas have primarily been driven by clinician interest. There is evidence to support that including consumers and communities in developing and co-designing research priorities and studies improves acceptability, research participation, and health outcomes [2]. This is particularly relevant when considering research with Australian First Nations, migrant and refugee populations, adolescents, women living with a disability and those in the LGBTQIA + community who continue to face systemic disadvantage and shoulder a disproportionate burden of poor outcomes [3–5]. Elevating the relevance of research and thus reducing this research-practice gap requires a paradigm shift towards the identification and prioritization of consumer needs and priorities [6]. Authentic and rigorous stakeholder engagement and participation confers agency to consumers, the end-users of maternal health services, and is particularly important for those who experience high levels of systemic disadvantage [7]. Including frontline workers, many of whom themselves have lived experience of pregnancy, birth and parenting, and have the benefit of scientific understanding of critical clinical issues, adds further value to the process [8]. This philosophy is reflected in recent national and international guidance on consumer and community involvement (CCI) to align priorities of consumers, service providers and research organisations to shape future research [9]. CCI ensures applicability and relevance of research findings, improves patient safety, promotes ownership of results and addresses some of the power imbalance prevalent in healthcare and health research [6, 8].

In our setting of the Northern Territory (NT), Australia, the population is approximately 230,000 people [10] residing on 1.42 million square kilometres of land (equivalent to the size of France, Spain and Italy combined) [11], with the vast majority of people living in 'very remote' locations [12]. The population comprises 26.3% Aboriginal and/or Torres Strait Islander peoples (hereafter respectfully referred to as Australian First Nations peoples), 21.8% first generation migrants and 51.9% non-First Nations people [10]. While English is the most commonly spoken language at home (57.3%), over 100 Australian First Nations [13] and many other non-English languages are used daily with Kriol (2.2%), Djambarrpuyngu (1.7%), Greek (1.4%) and Nepali (1.3%) the next most commonly spoken [10].

Disproportionate exposure to adverse social determinants of health, such as inadequate access to safe housing, fewer educational and employment opportunities, and higher rates of violence and conflict [14], contribute to poorer health outcomes for Australian First Nations people compared to non-First Nations people across the Top End of the NT. This includes maternal health outcomes, with remote residence a significant contributing factor due to reduced access to many services [12, 15]. Migrants and refugees living in Australia also experience systemic disadvantage and have poorer health outcomes when compared to other non-First Nations people [16–18]. Women in particular face unique challenges when engaging in maternal health services in the NT. These challenges are evidenced by later commencement of pregnancy care and fewer than the recommended interactions with health care providers [15, 19]. Language and cultural differences, as well as a lack of culturally safe care, exacerbate the situation [16]. Consultation with these women and their service providers is key to effectively prioritising areas for future maternal health research.

In response to this research gap, we aimed to develop priorities for maternal health research in the Top End of the NT from the perspective of consumers and key stakeholders (health care and other service providers) using a participatory approach in the form of focus groups and in-depth discussions with consumers and maternal health care providers conducted over a three month period (Part A), followed by a 1-day stakeholder forum held in Darwin, Australia (Part B).

Methods

Study setting

The northernmost part of the NT is known locally as the 'Top End', generally accepted as extending from Katherine in the South to Melville and Bathurst Islands (also known as the Tiwi Islands) off the North coast, and from Groote Eylandt off the East coast, see Fig. 1. Most of the Top End population ($n = 140{,}000$) live in the capital city of Darwin and its surrounding suburbs, which sits to the north on the coast of the mainland [10]. The remainder of the population is spread across 31 very remote Aboriginal communities and approximately 600 homelands/family outstations with a combined population of between 6,000–8,000 [20].

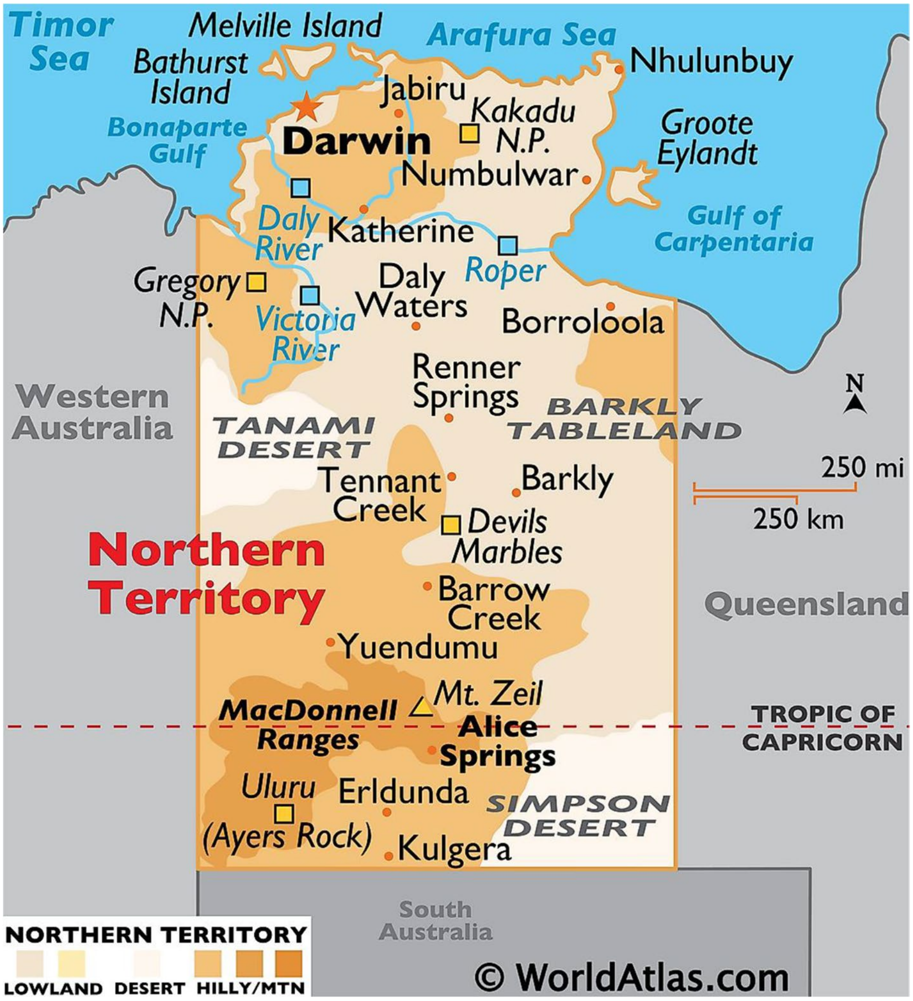

Fig. 1 Map of the Northern Territory of Australia [21].

Health services in the Top End are provided by NT Health, including four (4) publicly funded hospitals and twenty-four (24) Community Health Centres; one (1) private hospital; nine (9) Aboriginal Community Controlled Health Organisations (ACCHOs), with a range of visiting specialists supporting all these health services. Care in very remote communities, (considered to be > 200 km from specialist services) [22], including antenatal and postnatal maternity services, are provided by the Community Health Centres or ACCHOs (n = 19) [23].

Other supporting health services to people in the NT include community service organisations, some of whom address social determinants of health by providing essential ‘wrap around’ services. These services include assistance with securing safe housing, provision of food and clothing, support for victims of domestic and family violence, debt management, and many other social supports. In addition, there are several research organisations based in the NT which contribute to the development of evidence-based practice, the discovery of new treatments, and the improvement of health outcomes for individuals and families within the NT [24–26].

Study design and participants

To gain a comprehensive understanding of perspectives reflective of the diverse consumer and stakeholder demographics of the Top End of the NT, a mixed-methods qualitative study comprising: Part A) focus group discussions (FGDs) and in-depth discussions (IDDs); and Part B) a stakeholder forum, was conducted to inform priority-setting in maternal health research in our setting. Participants included consumers with lived experience of pregnancy/birthing, maternal health care providers, researchers, and workers providing social and emotional support to consumers.

Part A

Focus group and in-depth discussions

To provide a safe space to understand the perspectives and gain baseline knowledge on maternal health priorities, FGDs and IDDs were held with a range of consumers prior to the stakeholder forum. Similarly, FGDs were held with maternal health care providers. After gaining approval and support from the relevant ethics committee (HREC2023-4611), research governance office (EFILE 2023114645), and Australian First Nations reference group, recruitment for FGDs and IDDs was via purposive sampling through maternity services provided at Royal Darwin Hospital. Further, following an online review of services available to migrant, refugee, adolescent, LGBTQIA +, and disabled populations in the Top End, service providers were contacted via details provided on websites with a request to assist with recruitment. Assistance was rendered by various agencies by advertising the FGDs via posters in waiting rooms/offices, inclusion of advertising in regular mailouts, social media, and face-to-face discussions with beneficiaries. The FGDs and IDDs were conducted over a period of three months from 01 June to 31 August 2023 in various locations across the Top End of the NT, and continued until, despite extensive efforts, no more could be scheduled due to lack of further participants available in the allocated time frame.

A list of trigger questions was developed, for use with consumer FGDs and IDDs to ascertain participant experience with research, what they saw as the needs pertaining to maternal health care in the Top End, and what challenges they had encountered while utilising maternal health services themselves. A similar list was developed for use with health care providers (Table 1).

Table 1 Trigger questions

Consumers
What, if any, is your experience with research? Have you ever been approached to be involved in research? Have you participated? How did you feel?
Here are some examples of research conducted in maternity care for (insert cohort) women. What do you think about this? Can you see any gaps or opportunities for future research in maternity care?
From your experience in the maternity care system, were there any questions you felt couldn't be answered well by your health care provider?
Were there aspects of your care where the explanation could've been better or where knowledge seemed deficient?
Can you think of any examples from people you know where things/outcomes were not ideal and there could have been opportunities for improved care?
Health care providers
Can you think of an example from your recent clinical practice where the care you provided was not necessarily evidence-based and where you think improvement of knowledge could occur?
Are there other questions you've had from consumers or students that you couldn't answer from the literature/evidence?
Are there areas where we have seen little gain over the past 5-10 years that we could focus on?
Are there really great things happening in other places that you'd like to see happen here?
Do you have any suggestions for any opportunity for future research in the maternal health space in the Top End?

FGDs and IDDs were facilitated by members of the research team (JM, KB, MSC, ERB, HWU) from the Menzies School of Health Research Maternal Health Program and continued until saturation was reached within the FGD or IDD, with each running for approximately 1 h. To ensure cultural safety for participants, Australian First Nations researchers (KB, MSC) led FGDs with Australian First Nations women. Similarly, a case manager working for a community service organisation supporting adolescent women in pregnancy was present during that FGD. One woman from a migrant background was interviewed, however no interpreter was required, and despite extensive efforts, we were unable to interview women from a refugee background, or consumers from the LGBTQIA + community. Interviews were audio recorded with consent and transcribed verbatim. Further, copious notes were taken, capturing additional observations and insights.

Part B

Stakeholder forum

Following on from Part A, we conducted a one day stakeholder forum ("Lighting the Spark") at Menzies School of Health Research on 20 October 2023 in Darwin, NT, Australia, to hear stories of women with 'lived experience' from the Top End, learn about key outputs from latest 'NT Mothers and Babies' report [15], receive a summary of the principle themes identified in consumer and health care provider FGDs and IDDs conducted prior to the forum (Part A), and finally to consolidate that data through working groups and a panel discussion. The forum included FGD and IDD participants, and key members involved in maternal health care in the Top End of the NT. An outline of the day can be seen in Supplementary file Fig. 1 Agenda.

During presentations of the Mothers and Babies report, and summary data from Part A, forum participants were asked to document on sticky notes, provided to the participants by organisers, key words or phrases of particular interest or significance to them from the findings. After the presentations, forum participants placed these sticky notes on A3 pages, which were hung up in the foyer of the facility and were headed with 'working group titles' that had been developed from the FGDs and IDDs. Aiming to broadly categorise data collected during Part A into ideas (or 'sparks' as they were referred to on the day), 'working group titles' were *knowledge, fear, trust, staffing, support, power, conflict, time, options, other*. Following that exercise, participants were asked to allocate themselves to one of the working groups for further in-depth discussion.

Working groups spent approximately one hour following *Rolfe* et al.'s 'what,' 'so what,' and 'now what' critical thinking framework to identify what do we now know ('what?"), why is that important ('so what?'), and where do we go to from here ('now what?'). [27] Each group was asked to discuss and list key points relevant to their allocated 'spark' that included what they heard, noticed, or that stood out to them from the presentations, and the sticky notes (the 'what'). Participants were encouraged to discuss and document the significance of the 'what' (the 'so what'); and to construct two nuanced questions relevant to their chosen 'spark' to be discussed by the panel (to become the 'what now').

Panel discussion

The stakeholder forum closed with a panel discussion of experts that included an Australian First Nations obstetrician and researcher; a midwifery academic; a member of the NT hospital executive leadership involved in maternity services; a non-clinical program manager for an adolescent pregnancy support service; a project coordinator of women's services at a non-government organisation caring for refugees; a midwifery researcher; and a woman with lived experience of pregnancy complications. The panel moderator asked the panel members the questions developed by the working groups (Supplementary file, Table 1).

Data analysis

Worksheets produced by working groups were collated and written notes were taken by several team members during the panel discussion and cross-referenced with all team members immediately after the forum. Data from FGDs/IDDs were then triangulated with workshop outputs and panel discussion transcripts to develop a set of research priorities for maternal health in the Top End of the NT. FGD, IDD, workshop outputs, and the panel discussion were analysed using an inductive thematic analysis approach [28]. Data were further analysed in terms of number of mentions by consumers and health care providers during interviews and workshops, using transcripts. This secondary analysis was conducted using NVivo where we systematically coded phrases from the transcripts according to the sentiment expressed. These phrases were then assigned to nodes that corresponded to themes emerging from the primary analysis. If there was overlap, phrases were coded to more than one node, with the primary objective being to identify the most prominent themes by examining the frequency and distribution of these coded phrases across the various nodes. Two researchers independently followed this coding process.

Results

The results are presented in three parts: A) data collected from focus group and in-depth discussions with consumers and health care professionals; B) data collected from the working groups and panel discussion held at the stakeholder forum; and C) data synthesised across all components to capture overarching themes and priorities. These stages are illustrated in Fig. 2.

Part A

Focus group and in-depth discussions

A total of 38 participants comprising consumers ($n = 10$) and healthcare workers ($n = 28$) were engaged in six FGDs and two IDDs. These included Australian First Nations women from remote and very remote areas ($n = 4$), a migrant woman ($n = 1$), adolescent women ($n = 4$), a woman living with a disability ($n = 1$), and maternal health care workers, which included Aboriginal Health Workers, midwives, and obstetric doctors ($n = 28$).

Perspectives on research in practice

Overall, consumers reported limited experience with research. Those that had been involved in research in the past expressed difficulties differentiating between research and routine care, highlighting the need to improve consent processes and the conduct of research, particularly in the clinical setting.

> *"I just remember signing papers. It could've been for one of them?? Yeah, I don't know. I just probably remember signing them." (Australian First Nations woman)*

Some women expressed a guarded openness to participation in research. Other women were concerned over potential harms arising from research, which was associated most closely with clinical interventions. This highlights the need to find better ways to engage with potential participants and to co-design clinical studies in pregnancy to align with women's priorities.

> *"Yes, I want better outcomes for women, but I also know the reason why we don't have evidence is because we as women are hesitant to try things that haven't been tried before. So we don't actually know if I'm going to do this trial, is that putting me and my baby at risk for negative outcomes?" (Adolescent woman)*

Other women, however, had never considered the possibility of being involved in research, and some did not feel they were missing out by be not being involved. This highlights the need to increase the visibility of research,

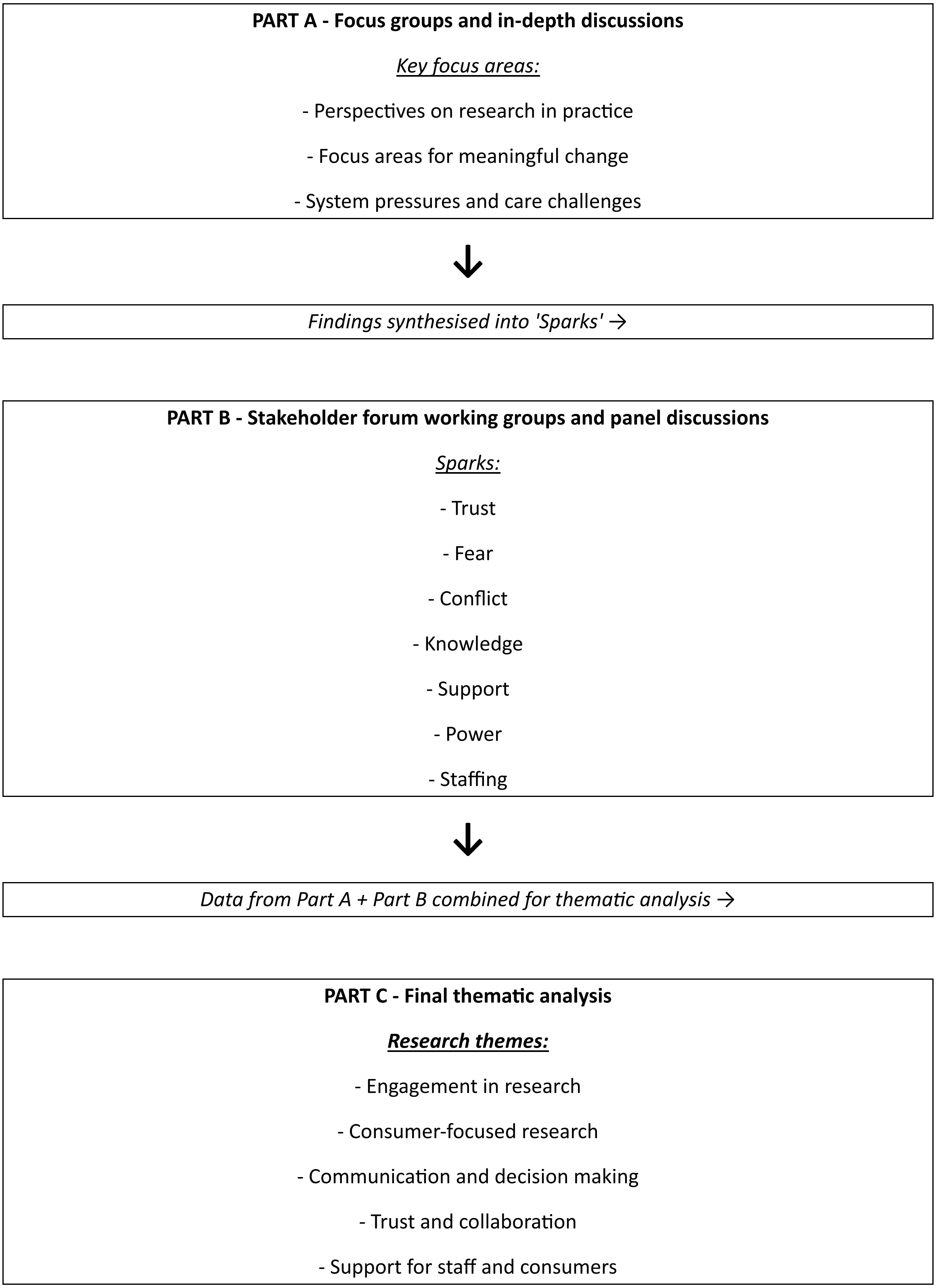

Fig. 2 Study flow chart

and to acknowledge that some women do not wish to be involved.

> *"I don't think that it's something that ever crossed my mind. To be honest. Like, it's not something that I would have thought about to be honest." (Migrant woman)*

Conversely, many health care providers had considerable experience with research in a variety of roles from being named as an investigator on a grant, to recruiting participants through their clinical role. The desire was for there to be genuine collaboration across the tropical North of Australia, including Western Australia and Far North Queensland, given the similarities in geography, climate, and populations, and shared workforce challenges.

> *"One of the challenges is that we are a large geographical area with a small population…if you study a very rare outcome that you're trying to prevent…it's hard because you need the numbers" (Doctor)*

Historically, studies were perceived as being poorly funded and time-consuming for time-poor clinicians.

> *"Who's going to recruit the patient? Not me, I don't have time" (Doctor)*

Multiple health care providers expressed that there was limited time to participate in research activities or appreciate new evidence due to high clinical loads, maintained by chronic understaffing. Embedding research into practice was thus perceived a challenge. Research was nevertheless valued as vital for informing evidenced-based practice but there were concerns about translation into practice, specifically, the lag between gaining evidence and guidelines being updated.

> *"We're just waiting for the guideline to reflect the research" (Midwife)*

This underscores the need for research to be pragmatic and relevant to the context of people in the NT, and for knowledge translation to be timely.

Focus areas for meaningful change

A variety of systems-related needs for future research were identified by consumers, commonly expressed in terms of their lived experience with a medical condition, an intervention, or a screening test. Issues raised identified a need for innovation, shared decision-making, and flexible approaches to care, including the way space is used in a health facility.

> *"Pregnant women do throw up doing it [respondent refers to the oral glucose tolerance test], and you're in that vulnerable state already having fasted for like 10 hours and then having to do this test, and then you're just sitting there nauseous, for three hours with nothing to do." (Adolescent woman)*

Other, more clinical concerns raised briefly by women centered around access to assisted reproductive technology, the high burden of preterm birth, risk factors for pre-eclampsia, the perceived overuse of antibiotic in newborns, and breastfeeding problems.

Further, psychosocial needs were identified as a high priority, highlighting social and emotional wellbeing support as a currently untapped area of research in this context.

> *"It's a lonely process when you don't have family… so yeah, pregnancy in that sense was a bit lonely." (Migrant woman).*
>
> *"Your partner can't even stay overnight, after you've just given birth to this weird ass baby. Like, what are you supposed to do with it? And your support system is not there" (Adolescent woman)*

In addition, consumers identified the common use of problem-focused rather than strengths-based language and a perceived lack of in-depth explanations limiting access to information tailored to individual needs.

> *"When I asked about it, [pre-eclampsia] they just told me like, the normal, like stuff like swelling feet, headache, but don't go away type of thing. But it's just like, I feel like that's just normal pregnancy stuff as well. And they didn't really explain well enough, like, how severe does the headache have to be because I always get frequent headaches when I was pregnant even with him. So like, I was always like, on edge like, oh, is this it?" (Adolescent woman)*

Aligning with consumer sentiments, a wide variety of clinical and psychosocial research priorities were identified by clinicians. The inclusion of consumers in decision-making processes bringing about major policy changes was identified as critical. An example of this centred around the topic of including 'ethnicity' as a standalone criterion for the induction of labour. Further, and also mirroring needs identified by consumers, was the requirement for non-judgemental, factual knowledge presented in an understandable way to consumers as they make major decisions.

> *"I wish they would actually say the statistics, like when they say, 'your risk of stillbirth doubles,' and*

> *actually it goes from like point zero 1 percent [0.01%], to point zero 2 percent [0.02%], and stuff like that." (Midwife)*

This further demonstrates the need for suitable frameworks for clinician conversations with consumers, ensuring that advice is evidence-based, location and population-specific, and consistent.

It was noted that most clinicians will at some point in their career experience an adverse outcome which may influence future decision-making and advice given to consumers. Discipline-based support and mandatory, regular 'supervision' by a mentor or peer, was highlighted as an area of need and potential research. This may be particularly valuable for clinicians caring for a consumer perceived to be '*not walking the usual path*'. The feelings of trauma and inadequacy experienced by clinicians from a past event may be magnified in these situations and requires support.

> *"I have some people that I know I can call anytime of the day or night, and they will pick up and they'll get me through whatever is going on…but if something is going on that causes distress you just get a pat answer from management." (Doctor)*

Further, barriers to effective communication were identified as a critical need and were, despite some recent improvement in services and availability, the result of insufficient numbers of interpreters and a lack of resources in required languages, both audio and visual.

> *"… and then you have a woman from community who speaks so many different languages, and you're just hoping they have an escort [accompanying family member or friend who can interpret]" (Midwife)*

Once again mirroring consumer concerns, the current lack of an evidence base for several clinical and non-clinical scenarios appropriate for the NT context were highlighted by clinicians. These included the management of preterm prelabour rupture of membranes, postpartum haemorrhage, management for women with rheumatic heart disease, care of women from remote communities with gestational diabetes, dosage of steroids for fetal lung maturation, postnatal depression in fathers, and supporting women with a history of trauma or domestic violence.

> *"So I do feel like I'm using a little bit of an evidence-free extrapolation" (Doctor)*

System pressures and care challenges

The sharing of lived experiences further highlighted challenges and potential areas for future research.

Consumers reported mixed experiences of journeying through the health system. Those who were engaged in a continuity model of care or had a midwifery student allocated to them reported having a great experience. For women with babies in the neonatal intensive care unit (NICU) or special care nursery (SCN), however, the experience was mixed. Unpredictable or changing schedules within the NICU or SCN sometimes caused distress to consumers.

> *"They used to feed him and stuff without me even being there. And I'd be like 'I'm 10 minutes away'. You know, like, it's a waste of my time coming all the way from home to up here, and then you're feeding my son before I could even think…it's not fair" (Australian First Nations woman)*

Women with risk factors or pregnancy complications that required attendance at a 'high risk' antenatal clinic to see an obstetrician sometimes struggled to understand the importance of this.

> *"it's like 'rush, rush, rush' when you get to see them. And when we finally got to see him, he was just like, well, everything's all good…and sped through the process. I was like, what was the point of even waiting" (Adolescent woman)*

Other challenges identified centred around rigid policies for pregnancy and birthing care, and under-staffing in the clinical setting. The limited pain relief options for woman having a publicly funded home birth were perceived by women as not being consistent with other high-income countries' expectations, leading to transfer to hospital during labour, thereby increasing pressure on an already taxed hospital system.

> *"I was planning a home birth, but I ultimately decided to transfer in for more pain relief. They don't do something as simple as gas and air at home births.' (Adolescent woman)*

Further, women accepted for a homebirth were at times unable to access this care modality due to staff shortages. Staff shortages were also stated as the reason for women's inability to receive intrapartum care in the midwife-led 'birth centre', forcing women to birth in the 'delivery suite' where support for and access to medical interventions are more common.

> *"And then also downstairs at the birth centre, it's not busy down there in terms of women birthing so they could have a greater capacity to have women down they just don't have the staff." (Adolescent woman)*

Echoing issues highlighted by consumers, health care providers identified several challenges around the patient journey and understaffing. A lack of support for women with a migrant or refugee background, or women recently arrived from interstate having a baby in the NT, being discharged from hospital too early postnatally, and services not being family friendly were highlighted as major challenges. It was felt that this potentially impacted outcomes for families physically and psychosocially.

Some health care providers perceived a progressively junior workforce, resulting in an increasingly interventionist mindset as a risk mitigation strategy. Clinician comfort was felt to be prioritised over evidence-based, woman-centred care, for example, an overuse of fetal scalp electrodes in labour without a specific clinical indication. Chronic staff shortages not only facilitate promulgation of a junior workforce, but they also place a high physical and emotional toll on other clinicians.

> *"We are constantly destroying our body clocks, which is no good for our longevity, or mental health, or general health in terms of eating and so forth. But it's stressful. There's quick decision making with often really high stakes, and then this added concern as a compassionate person that you might inadvertently cause harm" (Doctor)*

These challenges are interconnected and inseparable, highlighting the need for innovative and imaginative change.

Part B

Stakeholder forum

Attendees of the stakeholder forum ($n = 47$) included FGD and IDD participants; representatives from ACCHOs and research organisations based in the NT; staff from Royal Darwin Hospital maternity services; other NT Health staff; social service organisation staff involved in the support of pregnant women; and maternal health service consumers.

Data from the workshop and panel discussion were synthesised and a summary of the key points ("sparks") is presented below. While the data is presented under the headings of the 'sparks', it embodies nuanced concepts with considerable overlap and should not be interpreted in a strictly didactic manner.

Trust

Trust in healthcare providers and systems is crucial, particularly for women navigating their pregnancy journey. It involves being made to feel welcome, having time and space to process information, and building trusting relationships with providers. The journey to birth should be participative, and choice driven in order to facilitate women's autonomy. Interdisciplinary trust is also vital for better outcomes, requiring collaboration and communication between different disciplines. Multidisciplinary meetings and regular reviews can help foster trust and improve consumer experience and outcomes.

Fear

Fear was a recurring theme in workshop and panel discussions. Consumers often fear the unknown, sometimes exacerbated by the 'deficit-based' language used by providers. Terms like 'high risk'and 'failure to progress' should be replaced with more 'strengths-based' language such as 'medically complex' and 'slow labour'. Building trust helps care providers understand individual women's fears and tailor care accordingly. Providers also experience fear, such as fear of causing harm, making mistakes, or speaking out against others with whom they disagree. Creating a supportive work environment where fear can be openly addressed without blame is crucial. Naming and addressing fear was deemed essential for effective healthcare delivery.

Conflict

Conflict between health care providers, particularly those from different disciplines, is not uncommon in the acute clinical setting. Attendees agreed that conflict does not necessarily have to be disadvantageous, as it may bring to light a critical issue to be addressed or be a catalyst for change. Where conflict about clinical care arises between health care providers, bringing the consumer into the conversation and being open about the difference of opinion, if done in a safe way with boundaries in place, may have the effect of empowering consumers. At other times policy drives conflict, and it is on these occasions that individually tailored packages of care need to come to the forefront.

Knowledge

Healthcare providers face the challenge of presenting vast amounts of research and clinical data to consumers in a meaningfully relevant way. In maternal health care, differing disciplinary perspectives may lead to conflict. While retrospective data often focuses on negative outcomes, understanding individual stories behind the numbers is crucial. Collective impact groups involving various healthcare providers and consumers are key to sustainable change. Regular forums for sharing positive consumer stories are vital, yet currently underutilised. Learning from successful outcomes requires collaboration and ongoing relationships among health care providers and support services. This approach offers valuable insights into achieving desired outcomes and addressing longstanding challenges like static smoking rates amongst Australian First Nations women, and a rising incidence of diabetes in pregnancy.

Support

Support for both healthcare providers and consumers are crucial. Staff need to feel valued and part of a team to enhance job satisfaction and improve consumer outcomes. Dedicated time for clinical supervision can address trauma and can also foster professional growth. Cross-sectoral partnerships and regular service mapping are essential for healthcare providers to understand available external support with whom they can collaborate. All consumers, but especially those from culturally and linguistically diverse backgrounds, require holistic, individually tailored support throughout their pregnancy journey. Holistic care involves linking women to appropriate support services. The provision of culturally safe care should be considered business as usual and include patient advocates and flexible engagement options.

Power

Discussion over power dynamics in healthcare were largely focused on consumers, highlighting a significant imbalance with providers, systems, and policies on one side, and consumers on the other. Shifting this balance in favour of consumers involves amplifying consumer voices through community consultations and individual discussions. Understanding women's expectations and empowering them to make decisions is crucial, especially for women living with systemic disadvantage. Designing spacious, family-friendly facilities and providing consumer-friendly tools aid in this empowerment. Engaging consumers in discussions about their needs and preferences, and creating spaces for decision-making, are key steps toward rebalancing power dynamics in the healthcare system.

Table 2 Principal evidence gaps and research questions for maternal health research identified by consumers and healthcare workers

Research themes	Recommendation/suggestions
Engagement in health research	• Knowledge, attitude, practice (KAP) surveys • Qualitative research
Consumer-focused research	• Research into improving the patient journey • Clinical studies focusing on consumer priority areas
Communication and decision-making	• Co-design, and evaluation of innovative tools and resources, including use of different technologies • Translation of evidence-based research into clinical practice (implementation research)
Trust and collaboration	• Co-design and evaluate models of care • Develop and evaluate innovative ways to foster interdisciplinary collaboration • Collaboration across similar settings in Australia and beyond
Support for staff and consumers	• Innovatively address workforce challenges (recruitment and retention) • Co-design and evaluate services to align with consumer priorities

Staffing

The panel agreed that the workforce is in crisis, emphasising the need for a broader perspective on who can contribute to maternal health services. Innovative pathways and models must be developed to accommodate diverse career aspirations and life stages. Flexibility, such as job-sharing and part-time options, is essential for workforce retention. Adopting a life course approach to recruitment, considering different generational preferences, is also crucial. Furthermore, measuring the psychosocial benefits of various models of care can ensure resource allocation is more closely aligned with women's priorities. Developing novel strategies to attract and retain a strong and compassionate workforce is essential for addressing the challenges in maternal healthcare.

Part C

Synthesis of data

Data obtained from FGDs and IDDs (Part A) and stakeholder workshops and panel discussions (Part B) were triangulated and synthesised to develop a list of emerging research themes to be considered in a consumer and healthcare worker informed research agenda, detailed below and summarised in Table 2.

Engagement in research

There needs to be a stronger focus on engagement in research for both consumers and clinicians. Evaluating knowledge, attitudes, and practices (KAP) relating to clinical research amongst pregnant women and health care providers through KAP surveys would provide insight into this. Further, there is a need for innovative and novel processes to be developed and evaluated if more women are to be engaged in maternal health research. The development of audiovisual resources, and the use of other technologies could be useful for this.

Consumer-focused research

Research needs to be consumer-centric, focusing on the needs of and priorities for end-users. Identifying ways to improve the patient journey, including collaborative care planning which places equal value on clinician expertise and patient-identified needs and priorities could be an innovative approach requiring evaluation. Acknowledging that reference groups already exist, the expansion of and collaboration between well-funded and diverse consumer and community reference groups are required to ensure that the voices of all consumers are heard. Further, designing clinical studies that are of particular importance to consumers is crucial. Examples of this, as identified through this study, include:

- Enhancing access to fertility treatments in remote and rural Australia
- Prevention and management of preterm birth
- Prevention and management pre-eclampsia
- Antibiotic regimens in newborns
- Addressing complex breastfeeding problems
- Evaluating psychosocial support needs during pregnancy and postpartum and the impact on maternal and child well-being
- Patient-centred screening for gestational diabetes

Communication and decision-making

Communication between healthcare providers and consumers must be improved to improve consumers experience of care. Co-design of resources and tools for improving communication, shared decision making, and accessing information on clinical interventions, using a range of technologies would be one approach. Further, developing and evaluating systems for rapid translation of evidence-based research into clinical practice is essential.

Trust and collaboration

Trust between different disciplines within maternal healthcare is lacking, and this impacts development of trust between consumers and healthcare providers. There is a need for co-design and evaluation of models of care that promote trusting relationships between consumers and healthcare providers. Models that foster adequate time, attention, and relevant detail, with packages of care tailored to individual consumers are required. In addition, development and evaluation of innovative ways to foster interdisciplinary collaboration has the potential to improve consumers experience of care and should be prioritised. Further, collaboration across similar settings may increase the viability, robustness and applicability of research.

Support for staff and consumers

The provision of multi-faceted support for maternal health care providers may increase staff longevity. Innovatively addressing workforce challenges, including high turnover rates and chronic understaffing through research on staff wellbeing and career development, development of a local workforce (including a remote workforce), and the viability of various flexible workplace arrangements are required. Further, holistic support for consumers can improve consumer experiences and health outcomes through the co-design and evaluation of comprehensive, culturally safe support systems for consumers, including referral to services that meet individual needs and preferences.

A secondary analysis of the data was conducted, defined as the number of mentions of themes, based on inferred meaning of phrases rather than specific words, by consumers (Fig. 3) and health care providers (Fig. 4) during interviews, and are represented by the hierarchy charts below. Health care providers placed greater emphasis on the need to develop and test approaches to overcome provider-provider conflicts within maternal health, whilst consumers frequently mentioned challenges with establishing a trusting relationship with health care providers. Both consumers and health care providers highlighted challenges with knowledge generation, staffing, and support, whilst healthcare providers more frequent expressed concerns over risks associated with roles in maternity care provision.

Discussion

Themes that emerged from our research provide an outline of research topics, enabling a set of first recommendations on what research in the maternal health space should be conducted in the Top End of the NT. Future research in maternal health in the Top End of the NT must prioritize innovative solutions to staffing issues, culturally safe practices, and interdisciplinary cooperation.

While specific clinical research areas were highlighted by some consumers and stakeholders (e.g., better tests for diabetes screening in pregnancy), most identified gaps or challenges related to communication, research engagement and co-design, well-being, and staff-retention. This study highlighted the need for research that involves innovative approaches to the recruitment and retention of maternity care staff, with a focus on well-being and to enable continuity of integrated care. This is critical during an ongoing health workforce crisis in the NT and rural and remote Australia [29], and highlights the importance of training programs such as delivered by the Menzies Ramaciotti Regional and Remote Health Science Training Centre, developing a local, and First Nations Health workforce in the NT by providing multiple entry and exit points to training, study, and employment for young people [30].

Another prominent theme was the need of research to further investigate and overcome power imbalances within healthcare settings, e.g., through the provision of culturally safe care. These include evaluations of education interventions and enhanced provision of interpreters for Aboriginal and other languages for a diverse patient population.

Investigating drivers of conflict between different healthcare disciplines may be key to reduce adverse impacts on consumers' experiences and patient journeys, and research into integrated approaches to

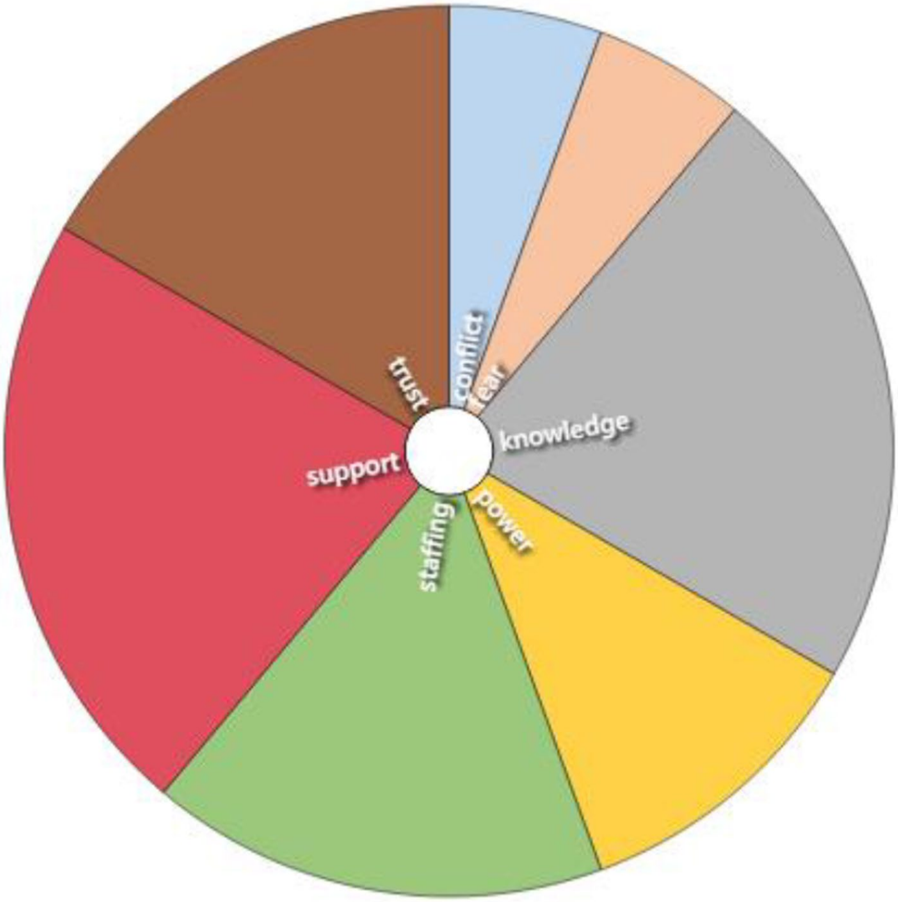

Fig. 3 Hierarchy chart consumers

consensus-driven, evidence-based, consumer-informed maternity care is needed. These factors are integral to improving the quality of care and addressing the comprehensive needs of the population served by these health facilities.

We strongly recommend that regular forums, at least annually, be established to provide ongoing opportunities for consumers and health care providers to discuss and prioritise areas for future maternal health research. It is crucial that future research be grounded in consumer preferences to ensure relevance and participation. To this end, the strengthening, development and utilisation of existing or new consumer reference groups, whose aim is to provide advice and guidance to researchers from initial stages, should be standard practice.

Strengths and limitations

This study has a number of strengths that include i) the diversity of consumers represented by the FGDs, ii) the large number of health care workers who participated in FGDs and the stakeholder forum from urban and remote communities in the Top End of the NT; ii) requests from a local university to collaborate in future maternal health research; and iv) an invitation to partner with an ACCHO for a maternity services re-design project are direct results of this study. Limitations included i) the underrepresentation of women from a migrant or refugee background, ii) people living with a disability; iii) the lack of representation of LGBTQIA + people in the FGDs; and iv) being unable to provide a post-forum opportunity for participants to review and agree upon the emerging themes. Many of these limitations could be significantly mitigated by holding annual forums where research agendas are reviewed and refined.

Conclusions

In this study, we found increasing engagement in research requires a greater emphasis on consumer-focused approaches and designs; consumers value strong communication and shared decision making; intentional efforts to foster trust and collaboration between healthcare providers and consumers are essential; and providing individualised support for both staff and consumers can lead to improved job retention and a more positive experience for women. Thus, it is essential to address the complexities of maternal health through a multifaceted approach that prioritizes

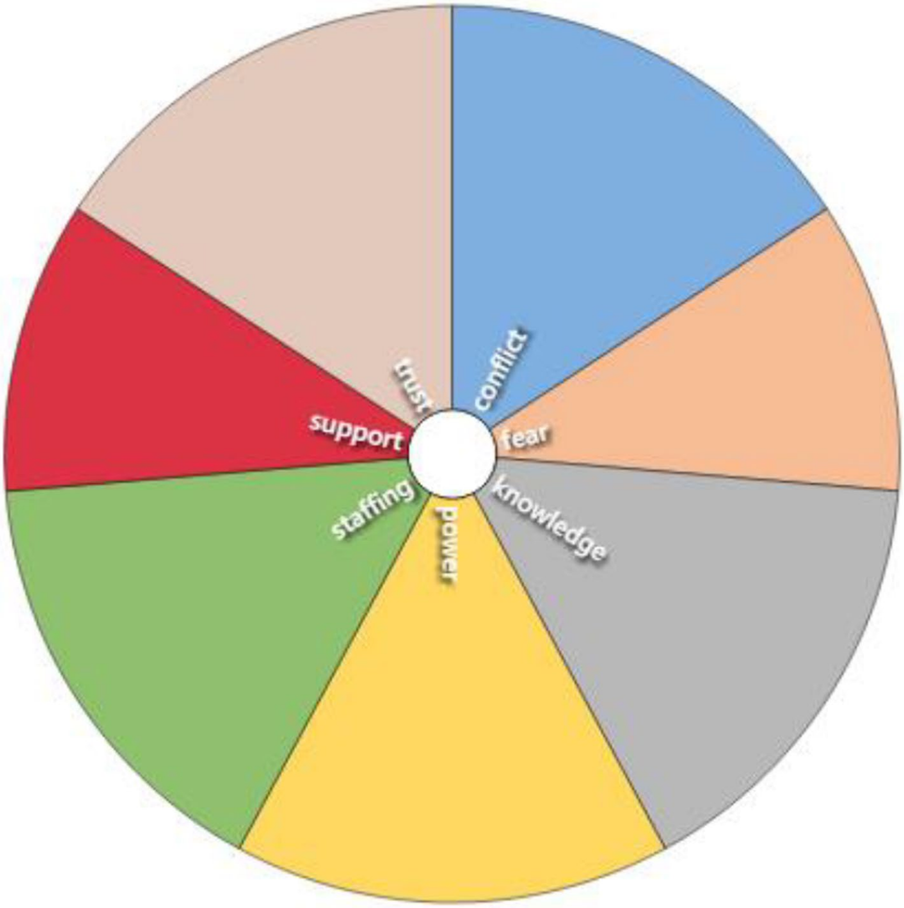

Fig. 4 Hierarchy chart health care providers

consumer engagement and building trust through collaborative research efforts. Addressing workforce challenges and providing comprehensive support for both staff and consumers are crucial further steps toward improving maternal health outcomes and experiences in the NT. By focusing on these research priorities, implementing evidence-based practices, and regularly updating these priorities through ongoing stakeholder engagement, we can work towards a future where maternal health services are accessible and responsive to the diverse needs of women and families residing in the Top End of the NT.

Abbreviations

ACCHO	Aboriginal community-controlled health organization
CCI	Consumer and community involvement
FGD	Focus group discussion
GBS	Group B Streptococcus
GDM	Gestational diabetes mellitus
HREC	Health Research Ethics Committee
IDD	In-depth discussion
KAP	Knowledge, attitude, practice
LGBTQIA +	Lesbian, gay, bisexual, transgender, queer, intersex, asexual or ally, other expressions not represented by initial letters
NICU	Neonatal intensive care unit
NT	Northern Territory
SCN	Special care nursery

Supplementary Information

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Supplementary Material 1.

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Authors' contributions

ERB, HWU, and KB conceived and designed the study. ERB, KB, MSC, JM, HWU and MK collected the FGD and IDD data and conducted the stakeholder form. ERB, HWU, and GBM verified, analysed and interpreted the data. ERB drafted the original version of the manuscript, with substantial revisions by HWU, and GBM, and minor revisions by KB. All authors read and approved the final manuscript.

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Data availability

Data used for this study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

This study is aligned with the National Health and Medical Research Council (NHMRC) guidelines on the ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities. Ethics approval was received from the Menzies School of Health Research and Northern Territory Government Health Research Ethics Committee (HREC) for this study (HREC 2023–4611). The study was also discussed with, and approved by, the Menzies School of Health Research Australian First Nations Reference Group for Child Health. Informed written consent was obtained from all participants who took part in a FGD or IDD.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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