UNIVERSITY of TASMANIA

Select Committee on reproductive, maternal, and paediatric health services in Tasmania.

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Acknowledgment of Country

The University of Tasmania pays its respects to elders past and present and to the many Aboriginal people that did not make elder status and to the Tasmanian Aboriginal community that continues to care for Country.

We acknowledge the profound effect of climate change on this Country and seek to work alongside Tasmanian Aboriginal communities, with their deep wisdom and knowledge, to address climate change and its impacts.

The Palawa people belong to one of the world's oldest living cultures, continually resident on this Country for over 65,000 years. They have survived and adapted to significant climate changes over this time, such as sea-level rise and extreme rainfall variability, and as such embody thousands of generations of intimate place-based knowledge.

We acknowledge with deep respect that this knowledge represents a range of cultural practices, wisdom, traditions, and ways of knowing the world that provide accurate and useful climate change information, observations, and solutions.

The University of Tasmania likewise recognises a history of truth that acknowledges the impacts of invasion and colonisation upon Aboriginal people, resulting in forcible removal from their lands. Our island is deeply unique, with cities and towns surrounded by spectacular landscapes of bushland, waterways, mountain ranges, and beaches.

The University of Tasmania stands for a future that profoundly respects and acknowledges Aboriginal perspectives, culture, language, and history, and a continued effort to fight for Aboriginal justice and rights paving the way for a strong future.

Acknowledgments

The submission wishes to acknowledge the women and people who have participated to date in this research and thank them for their valuable contributions. We acknowledge the individual and collective contributions of those with a lived and living experience of stigma, discrimination, trauma, mental ill-health, and suicide, and those who love, have loved and care for them.

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Disclaimer

The views expressed herein are those of the primary author, Dr Ayton. The document does not necessarily represent the views of the Tasmanian School of Medicine, The University of Tasmanian, or the Tasmanian Government Department of Health. These organisations do not accept responsibility for any information or advice contained within the document.

This submission includes some preliminary findings from a rapid descriptive analysis of the Tasmanian data only (not interview data) and does not represent the final analysis at completion of the research.

Suggested citation.

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Background

The care women receive during pregnancy, birth and the postnatal period has a significant impact on their maternity experiences, with potentially profound implications for their ongoing health and wellbeing. Respectful maternity care, in addition to high quality clinical care, is now recognised as essential to optimise health outcomes. (1, 2) Documenting women's recent experiences of maternity care provides evidence for women-centred respectful maternity care policy frameworks and enables service providers to respond to the changing needs of populations. (3) There is a significant evidence gap around understanding how childbearing women from diverse sex and gender, social, geographical, and cultural contexts experience maternity care in Australia. Increasingly, in Australia and internationally, attention is being given to the phenomenon of 'mistreatment' within the context of respectful maternity care. (3, 4) Thus, new research evidence that provides understanding into women's experiences of 'mistreatment' is vital.

In September 2023, the 'Giving Voice to Women' (GVtW) project received an initial $20,000 of the $90,000+ funding committed by Department of Health, Tasmania for the purpose of documenting women's experiences of receiving and accessing maternity health care and developing a *Respectful Maternity Care Framework*. The GVtW study was given human research ethical approval October 10th, 2023 (# 29211), employed a research assistant, commenced collecting survey and qualitative interview data first in Northwest Tasmania and then other areas.

This submission uses preliminary data from the GVtW project as evidence to address the Terms of Reference including, assessing the adequacy, accessibility and safety of maternal health services, experiences of birth trauma, midwifery, medical, Child and Family Health Services (CHAPs) workforce. It also describes the projects progress to date, and recommendations.

The release of the remainder of the funding committed will enable continued data collection to diversify the sample, and the analysis of the data to evidence the key outcome, the development of a *Respectful Maternity Care Framework.*

Study Design

The GVtW study is a mixed methods research study collecting both quantitative (survey) and qualitative (interview and free text) data from women/people who have had a live or still birth or miscarriage between 2020-2024. It uses an intersectionality lens to consider people's differences and offers a new way of thinking about how ethnicity, disability, sexuality, gender, and social and geographical contexts shape experience. This approach is essential to informing the *Respectful Maternity Care Framework* and improving the responsiveness of services to the social and cultural needs of their communities. (4) Importantly, this approach centres on doing 'with' rather than 'to', and working together with the participants to generate knowledge. (5)

Sample

The aim is to collect a range of experiences from a large and diverse sample of childbearing women/people. This is essential to adequately capture the distinct issues that arise for childbearing women/people who live in rural/remote and socially disadvantaged areas, people who identify as culturally and linguistically diverse, live with a disability, and are lesbian, gay, or bisexual. In 2024 we will undertake targeted recruitment of the above communities to achieve an ~20% of the total sample. The following research questions will be addressed once the sample is complete:

1. How do Tasmanian childbearing women/people experience care during pre-pregnancy, pregnancy, birthing and the postnatal period and are there differences between key groups of women/people?
2. What forms of mistreatment do Tasmanian childbearing women/people experience during pre-pregnancy, pregnancy, birthing, and postnatal care and are there differences between key groups of women/people?
3. What strategies do childbearing women/people use to manage and negotiate their care?

Selection of Preliminary draft findings

For the purposes of this submission, we present a descriptive summary of the data collected to the 01 December 2023. We have not undertaken a comprehensive analysis because the Tasmanian sample currently lacks sufficient diversity. Any preliminary findings presented will not represent the results from the research at completion.

Participants

- As of 1st December 2023, 153 participants had enrolled via the online Redcap survey. Of those 63% (98) accessed and received maternity care in Tasmania through a private (n=8), public health service (n=85) or private midwifery care (i.e., home birth) (n=5). Figure 1 shows the percentage of participants by location to date.
- To date, the Tasmanian sample is made up women/people who identify as straight, female, married, and born within Australia. Mean age was 33.3 years (Std 4.6). Half of the sample (52%) reported a high education attainment (University Degree) and 79% were employed. Just over half (55%) of the women/people in this study were first time mothers and one third (30%) of the women reported birthing via a caesarean section.

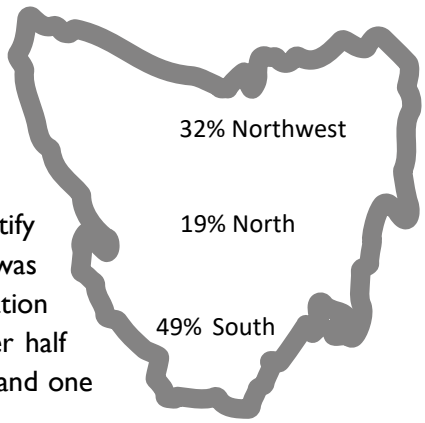

Figure 1. Distribution of the Tasmanian sample by location

Women's experiences of maternity care

Of the 98 Tasmanian women/people currently enrolled, 58 have participated in a ~one-hour audio recorded phone or in person interview (n=29 Northwest, n=20 South, n=9 North). **This data set is incomplete at this stage of the project and has not been analysed or reported here.**

For this submission, preliminary data has been taken from the Redcap online survey free text question; 'Briefly describe your experiences of maternity care.' Eighty one percent (n=79) of the Tasmanian sample provided a response. The written experiences described below include participants who experienced any or all the following, In Vitro Fertilization (IVF), miscarriage, stillbirth, antenatal care, birthing, and postnatal care to 12 months after birth. The experiences were powerful, honest, and direct. In depth analysis of the qualitative data set is needed to explore the type and forms of respectful care received. However, we can report that the forms of 'mistreatment' experienced by women vary from those documented in previous studies in other contexts. (3, 4) This will be important to inform a more context and place based *Respectful Maternity Care Framework*.

- **Positive** maternity care experiences were reported across the state. Women often noted that it was care from one midwife or one doctor that changed how they felt about their overall experience. Participants described how they had 'an **amazing experience'**, had received '**exceptional care'** and 'couldn't fault them (doctors and midwives) as it was one of those

emergency situations.' These 'good' experiences where often described by women who received care from Midwifery Group Practice (MGP), had engaged a doula, a private independent midwife for a home birth or a private obstetrician. As one participant wrote,

> All it takes is one person to make the difference so there were good and bad parts but if I hadn't had a prenatal private support (doula) it would have been negative. (Participant, 150)

- Being pregnant, birthing and receiving postnatal care during the **COVID-19 pandemic** was a difficult experience and challenging. Participants reported experiences of confusion, misinformation, and a deep sense of loneliness. This appeared to be exacerbated for women/people living 45 minutes or more outside of the hospital radius and during the postnatal period. The exception was the Northwest MGP, and some Child Health and Parenting services (CHAPs) where women described feeling supported and able to contact someone they knew at a time when 'everything was so confusing'. Routine antenatal classes where women and their partners receive information to prepare for birth and the postnatal experience were lacking during COVID-19 and in some areas have not returned or are inadequate and lack attention to gender inclusivity.

- **Fragmentation** of and the range of models of obstetric and maternity care across the state was challenging for all women and their families to navigate. This manifested in a deep lack of confidence and trust in the maternity health system. The presence of student midwives and to a lesser extent student doctors appeared to mitigate this because they were felt to be an 'advocate'. Many women sought out and engaged private doulas, midwives, and obstetricians at great personal financial cost to increase their control over who provided care.

- In our current sample an estimated 1 in 3 women experienced a **traumatic event** such as an unwanted **clinical intervention**, being spoken to in a **dismissive manner** or **feeling ignored**. For example, women cited feeling pressured, 'coerced' into an induction of labour early in their pregnancy and the 'unnecessary cascade' of interventions including emergency caesarean sections and breastfeeding failure that followed. For most of these women they received little or no information about the process or what to expect. Told that they were putting their babies at risk – they felt they had not choice but to 'go along with the experts'.
- Overall, women described **poor coordination** and **communication** between the obstetric and at times midwifery care providers and themselves. Women referred to limited and inconsistent models of continuity of care. Partners, wives, and husbands were ignored and often told to leave the hospital. Mental health support and care was absent. Some women described feeling unable to ask questions or seek help when needed, as one participant wrote about their postnatal care, 'it was awful I just shut down I was so raw and vulnerable'.

- There is a lack **health equity** for childbearing women and their families in rural and remote areas. We noted that living outside the **45-minute radius** (the Golden circle) of a tertiary referral hospital health service exacerbated the inequity. Women described the frustration of not having sufficient access to all aspects of maternity health care. A lack of breastfeeding support, little or no postnatal care, travelling long distances, fear of birthing enroute, significant out of pocket expense due to relocating to 'town' temporarily and the lack of choice and continuity were common experiences. These experiences appear to be intensified for first time mothers but were

also encountered for multiparous (second and subsequent pregnancies) women. A larger sample, and more detailed analysis of social and geographical context is needed.

- An **estimated 38%** of the women in this study to date reported having a **miscarriage or stillbirth**. Women described their care during these times as either 'beautiful and amazing care' or 'atrocious' and 'deeply traumatic'. The quality of experience was dependent on location. Such as the trauma of 'loosing a baby' was exacerbated for women living in the north and northwest of the state. The use of 'sensitive language' were cited as most helpful. General Practitioners (GPs) or the private obstetricians were often the first point of contact. Mental health support was absent. Women wrote of the lack of acknowledgement of the loss, of the miscarriage and stillbirth. They were rarely referred for counselling, cited poorly trained and dismissive staff who at times lacked sensitivity such as telling the mother that 'it… was only 8 weeks.' As one mother said, 'no one checks on you when you don't bring a baby home'.

Reflections from the research team

The GVtW research team is made up of trauma informed, highly experienced maternal health and public health researchers, a sociologist and two PhD students who are undertaking projects within the theme of the GVtW project. The team meets weekly to debrief and ensure compliance to the approved research protocol.

Overall, the team has been surprised by the continued momentum of interest and response to the study. This suggests unmet deep social and health care needs within the Tasmanian childbearing community. Indeed, there is a clear sense from the initial data that women/people have welcomed this opportunity to share their stories. Many wrote to thank us for allowing them to tell their story citing that 'I am doing this to make sure it doesn't happen to anyone else'. Others chose to share because they have had exceptional care, 'I had an amazing experience so I wanted you to hear what it could and should be like for others.' (Participant 58)

Importantly, the experiences shared were not a reflection of individual care providers. Women were highly sensitive to perceived workforce pressure and shortages and appreciative of any 'care'. They often reflected on how 'overworked' the staff appeared and prefaced their experiences with 'I know the staff are busy but that is not the issue here'. (Participant 120) This appeared to impact how and when they accessed care and their confidence in the health system.

Our overall impression to date is that Tasmanian women have an overwhelming desire to use their voices to improve care for women everywhere. As health consumers who seek to be partners in their care during a vulnerable time in their lives it is imperative that their voices are heard and used to lead and drive change. We have now begun collecting data in other Australian states and territories to allow data comparisons.

Next phase

GVtW data collection and analysis

As previously noted, we have not yet achieved a diverse research sample which is necessary to inform the *Respectful Maternity Care Framework.* To achieve this,

- We will continue recruiting and interviewing childbearing women/people in Tasmania and across Australia and attempt to cover the identified sex and gender and socio-cultural gaps in the data. This includes increasing the North and Northwest Tasmania sample sizes. (Figure 1)

- Complete the outstanding interviews (n= ~50-60) of the women who are currently enrolled and responded to the survey.
- Undertake a comprehensive analysis of the quantitative and qualitative data.
- Use this data to develop and inform the *Respectful Maternity Care Framework, for Tasmania.*

Respectful Maternity Care Framework

Evidencing and developing the Tasmanian *Respectful Maternity Care Framework* is the primary objective of the GVtW project. It is essential that we include practice, policy, and consumers in the building and drafting of the framework. To achieve this the following are required:

- Present the draft of the *Respectful Maternity Care Framework* in a GVtW 'Knowledge Exchange' event to gain feedback, expected April 2024. We will work with the Tasmanian Institute Collaboration for Health Improvement to organise and host this event.
- We have identified fathers, partners, wives, as important maternity health care consumers and supports for women. It is essential that their views are included. additional funding is required to gather this data.
- The GVtW project requires the **remainder of the funding** (~$80,000) to be released to meet the above actions, and objectives and complete the project by the end of 2024.

Recommendations

Though the data collection and analysis are not yet complete the following recommendations are proposed.

- **Respectful care**: the evidence from the GVtW project will inform and produce a *Respectful Maternity Care Framework*. This is crucial to benchmarking Tasmanian maternity and reproductive standards of care, policy, and services delivery against national and international standards. Further funding of this research is recommended.
- **Maternity care bereavement training** be developed and integrated into all medical, nursing and midwifery undergraduate and postgraduate education and training. This must include evidence-based context appropriate **pathways of care** with multidisciplinary community-based services for women and their families who experience loss (miscarriage, stillbirth) and trauma.
- Frame maternity care as a **normal life process** rather than a 'risk' disease or illness.
- Avoid one size fits all approaches and investigate, expand and trial **rural Midwifery Group Practice (MGP) type models of care** within the community context to meet the needs of families who live in rural and remote areas.
- Develop dedicated maternity health **bereavement** team and services statewide.
- Develop dedicated maternity health service **mental health** support services.
- Establish and support state based maternal, reproductive, and sexual health **research funding**.
- Include **health consumer** and **multidisciplinary research** approaches to gather the diverse range of evidence necessary to inform safe, respectful, and effective care for maternity and reproductive health services for all women and their families.
- Establish and fund **Tasmanian midwifery led research programs** and opportunities to support midwives to lead and produce the evidence needed to inform midwifery practice.

Other relevant work underway

In addition to the GVtW project, there are several related research projects currently being undertaken that will contribute Tasmanian maternal healthcare evidence and inform future policy and practice. Further information on these important projects is available on request.

- Ms Sally Hargreaves, UTAS PhD project is currently underway and investigating young mothers' experiences of maternity care in Tasmania. Supervisory team: Dr Jennifer Ayton, Dr Sarah Young, Dr Emily Hansen.
- Dr Odunayo Sobowale, UTAS PhD project, investigating COVID-19 Pandemic impacts on maternal and reproductive health. Supervisory team: Dr Jennifer Ayton and Dr Emily Hansen.
- Currently advertised UTAS PhD project, investigating Birth Trauma in Tasmania. Supervisory team: Dr Jennifer Ayton and Dr Louise Clarke.
- Mr Albert Nyaaba, UTAS PhD project, Investigating fathers/partners and breastfeeding in Tasmania. Supervisory team: Dr Emily Hansen and Dr Jennifer Ayton.
- Ms Grace Bennett-Daly, UTAS PhD project, antenatal sexually transmitted infection and blood borne virus testing in Tasmania. Supervisory team: Associate Professor Nicola Stephens and Dr Jennifer Ayton.

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