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. This Giving Voice to Women (GVtW) project received seed funding from the Tasmanian Government, Department of Health.

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 Tasmania, 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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PLAIN LANGUAGE SUMMARY

Essential elements of high-quality maternity care are dignity, privacy, confidentiality and freedom from experiencing any form of mistreatment. In 2023, Tasmanian women began to speak in public about the lack of respectful maternity care and describing practices that are recognised internationally as mistreatment. In response, UTAS researchers, in collaboration with maternity health care professionals, representatives from government and non-government organisations commenced documenting evidence to design and implement respectful maternity care interventions tailored to our unique Tasmanian context. Preventing mistreatment occurring and supporting the maternity care services workforce is critical to improve maternal health outcomes.

WHAT WE DID

Commencing in October 2023, with seed funding from the Department of Health, the Giving Voice to Women Project has captured the stories of 170 women who have used maternity services in the Tasmania since 2020. The stories of good and bad maternity health care span the continuum of pregnancy, birthing, and postnatal care up to the first 12 months after birth. It also includes 90 women who have experienced a still birth or miscarriage. The aim of the research is to estimate the prevalence of mistreatment using World Health Organizations criteria, and develop an evidence based Respectful Maternity Care (RMC) framework and workforce education tool for the Tasmanian Health Service.

KEY FINDINGS FROM THE STUDY

- Across the Tasmanian maternal health service women experience one or more forms of mistreatment. This occurs within both positive and negative experiences. For example, over half of the Tasmanian sample experienced a form of abuse (physical, sexual, verbal).
- The most reported type of mistreatment by women in both in the interview and written data was verbal; being verbally scolded, yelled at, talked down to and spoken to in a harsh and dismissive way.
- One in three women experienced coercion; behaviour that pressured them to undergo a procedure or treatment they did not want such as being weighed, an induction of labour, caesarean section, or care pathway i.e., high-risk care. Just under half of the sample cited that health professionals ‘always sought consent’ and that ‘benefits and risks’ were both discussed and easy to understand.
- Overall women cited communication between health care providers as a ‘real problem.’ A quarter of the sample reported feeling involved in decision making.
- Almost half the sample talked of being aware of workforce shortages, describing the health professionals as ‘clearly under strain’. In the hospital environment women rarely saw the same person twice and noted the substantial number of agency staff and overseas trained doctors.
- The ‘lack of redress’ was a frequent form of mistreatment followed by support persons (husband/partner) asked to or made to leave.
- An estimated quarter of women described living with a long-term health problem (depression, anxiety, sexual health, perineal damage) because of their maternity care experience.

RECOMMENDATIONS

- Fund the implementation, monitoring and evaluation of the respectful maternity care framework being developed from this research.
- Develop multidisciplinary care pathways for women who experience pregnancy loss and birth trauma.
- Develop pathways to improve access to postnatal care from birth through to the first 12 months.
- Expand workforce capacity and diversity including rural generalist obstetricians to work with midwives, obstetricians and GPs.
- Audit the care pathways available to Tasmanian women and develop /provide accessible information.
- Co-design with women a dedicated family bereavement and debriefing primary health service statewide.
- Enable and support midwives and rural generalist obstetricians to work to their full scope of practice.
- Create funding pathways for women’s health research in Tasmania.
- Provide more peer-to-peer support programs within the community.

WHAT WE KNOW

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 are significant evidence gaps 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, our research set out to provide a deeper understanding into women's experiences of reproductive and maternity care with the purpose of informing the Tasmanian maternal health care services to prevent mistreatment and optimise respectful maternity care.

This submission uses data from the Giving Voice to Women (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 key findings from the current research project, and recommendations.

WHAT WE DID

The Tasmanian Giving Voice to Women study commenced in October 2023 and provides high quality current empirical evidence about how Tasmanian women experience maternity health care across the continuum of pregnancy, birthing, and postnatal care and up to the first 12 months after birth. This research study responds directly to the growing concerns about the impact of 'poor workforce culture' and fragmented services in generating a culture of disrespect, that now threatens the sustainability and viability of maternity care in Tasmania. (5, 6)
There are several limitations to this research. We need to capture more stories, particularly from those who may feel their experience is currently underrepresented, such as migrant and refugee women. Fathers or birth partners have not yet had the opportunity to contribute. Ongoing funding is urgently required.

Consumer and stakeholder engagement

A multi-stakeholder research steering committee was convened to guide the study process. The GVtW steering committee meets quarterly and is composed of community members, clinicians (independent and Tasmanian Health Service midwives, rural generalist obstetrician, social workers), a range of women's health consumer representatives and community leaders.

A mixed methods approach was used to collect both quantitative (survey) and qualitative (interview) data from women/people who have had a live or still birth or miscarriage between 2020-2024. An intersectionality lens guided the study design to ensure that people's social and cultural differences were included. (7) Tasmanian women enrolled via the online Redcap survey, providing written responses (~150-1000 words) and consented to participate in one-to-one phone interviews. We sought to achieve a study sample of 100+ women per geographical site which include the northwest, north, and south of Tasmania. The research process uses the World Health Organisations typology of mistreatment to assess quality of care. (3)

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Selection of key findings

For this submission, we have used aggregated qualitative and quantitative data collected between 01 October 2023 through to 01 August 2024. This includes 79 responses to the Redcap online survey free text question: 'Briefly describe your experiences of maternity care' and 170 one to one in-depth phone interviews.
Any summarised findings presented may not represent the results from the research at completion of the project.

WHO PROVIDES MATERNITY CARE?

We estimate that women may see from 2 to 45 different care providers through their maternity care journey. These may include, private and public midwives, doulas, nurses, child health nurses, emergency department nurses, special care, neonatal intensive care nurses. Medical staff; general practitioners, obstetricians, gynaecologist, anaesthetists, surgeons, psychiatrists, paediatricians, plastic surgeons, endocrinologist, foetal medicine specialist. Axillary and Allied health care; pathologist, ambulance/paramedics, dietitian, ultra-sonographer, radiologist, physiotherapist, psychologist, social worker, counsellor. Professional staff' receptionist, cleaner, food services. These are health service points of contact; opportunities where women and their families receive maternity care and information.

HOW DO WOMEN EXPERIENCE CARE?

Women shared both positive and negative experiences. Many of these were confronting and were provided by the participants with the desire to help other women and improve women's health care. The women's experiences included accessing and receiving care in the context of In Vitro Fertilization (IVF), miscarriage, stillbirth, antenatal care, birthing, and postnatal care to 12 months after birth. A summary of positive respectful and negative experiences including types of mistreatment are provided below.

Respectful care

Respectful positive experiences were when the women felt supported in their choices and felt heard; being treated with dignity and listened to and spoken to in a calm and gentle manner. This empowered the women's sense of self, personhood and bodily autonomy. Many of these experiences were closely related to the model of care. For example, women who chose to have a home birth, private obstetrician, or were eligible for the Midwifery Group Practice (MGP) commonly reported feeling in control of their experience and safe to ask questions. A positive interaction at any point within their maternity care journey with a health care provider (midwife, doctor) reinforced their sense of enablement.

> *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)*

When continuity was lacking, the mothers birth plan deviated, or an obstetric emergency occurred, women highly valued sensitive communication and individual or team-based care. This enabled a positive rapport between mother and provider[s] and a sense of safety and trust.

> *They all advocated for us the doctor as well, like in in a subtle way that, you know, like, she was agreeable to our conversation, and that, you know, she wasn't imposing her beliefs on us, and that we could find the middle ground. So I guess she did, kind of advocate for us, but she was flexible and understanding in our desire and our goals, you know, to try and avoid the caesarean and an induction. So, yeah.(Participant, 98)*

Mistreatment

Mistreatment is quantified using the World Health Organizations (WHO) seven domains. Types/forms of mistreatment may occur at any stage across the continuum of maternity care. We estimate that 1 in 3 Tasmanian women experienced a form of mistreatment such as being spoken to in a verbally abusive-harsh or dismissive manner, their choices and requests ignored, and/or stigma and discrimination. Mistreatment commonly occurs within a health care setting. This includes hospital emergency departments, maternity services, community-based child health services, hospital or community pathology and ultrasound and general practice settings. Women who had home births or 'free births' reported a 'bad experience' only when they interacted with the hospital care setting or at times with their GP and Child Health Nurse. Rarely did mistreatment occur in the mother's home during the postnatal period. Women themselves were the major receiver of the mistreatment. At times, the baby and father /partner either witnessed the abuse and/or in the case of the baby were a victim. Within the women's stories different forms of mistreatment often occurred together. For example,

> *The baby wasn't latching I couldn't get her to latch my husband said [to the health care professional], 'Oh, sorry, my wife's having a bit of trouble,' and she turns around and goes, 'Oh, I can't be here to help you feed all the time,' and she grabs my bruised forceps baby's head so hard and slammed her into my chest and was like, 'Just put her on the boob,'(Participant 62)*

The above quote provides an example of where the family unit experienced four forms of mistreatment: verbal and physical mistreatment, a failure to meet professional standards and poor rapport between the mother and providers.

- The most reported type of mistreatment by women in both in the interview and written data was verbal; being verbally scolded, yelled at, talked down to and spoken to in a harsh and dismissive way.
- The most common examples of stigma and discrimination were about the women's body size. For example, amongst women who referred to themselves as being in a 'bigger body.' Ageism (younger <24 years and older mothers, >35 years) and birth choices i.e. home birth. Women often acknowledged that they were 'white, educated and privileged' and that this may have positively influenced how they received care.
- An estimated one in three women experienced coercion; behaviour that pressured them to undergo a procedure or treatment they did not want and with no or little explanation, such as being weighed, an induction of labour, caesarean section, or care pathway i.e., high-risk care.
- Women frequently talked of health professionals only presenting the risks and feeling forced to agree to procedures or treatment for themselves or their baby. Scare tactics, such as accusing the mother of putting the baby at risk or misquoting statistics, were frequently cited.
- Overall women cited communication between health care providers as a 'real problem.' Roughly a third of women reported feeling involved in decision making, listened to and that 'options of care' were discussed within the antenatal, birth or postnatal period. This included choices around care pathways, birthing positions, pain relief, and infant feeding. Almost half of the sample felt afraid or unsafe during their maternity care journey.
- Most participants felt that the built environment was safe, clean, and well ventilated. Almost half the sample talked of being aware of workforce shortages, describing the health professionals as 'clearly under strain'. In the hospital environment women rarely saw the same person twice and noted the substantial number of agency or locum staff including overseas trained doctors.
- A quarter cited health service constraints, such as lack of care choices; access to water birth facilities, MGP, homebirth and GPs. Traveling up to and or over an hour to access care impacted a third of the women in the sample. Under the domain of health services and conditions, the 'lack of redress,' was the most frequent form of mistreatment, followed by support persons (husband/partner) asked to or made to leave.

OTHER RELEVANT FINDINGS

- Our data includes women's experiences through the **COVID-19 pandemic** 2020-2023. 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 (rural areas) have not returned or are inadequate and lack attention to gender inclusivity.
- **Fear of the system** was a palpable finding throughout the study. Women across the age demographic and care pathways (home birth compared to hospital) talked of uncertainty and of hearing 'terrible stories'. Some women addressed the fear of the maternity system by engaging private obstetric or midwifery care, citing an out-of-pocket expense of > $6,000 per birth. For these women this experience was felt to be "wonderful and empowering".
- **Fragmentation** of and the range of models of obstetric and maternity care across the state were 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.
- There is a **lack of 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. These included 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 more detailed analysis of social and geographical context is needed.
- **Postnatal care** was inconsistent and lacking for all women except for those who received care from the MGP. Women spoke of feeling alone, isolated, and ignored. Citing that they did not know who to seek help from when discharged from the hospital. Most women who were in the MGP program talked of feeling supported for the first 2-4 weeks post birth. Infant feeding issues and the lack of breastfeeding support were viewed as the most impactful on the women's ability to successfully recover from childbirth. This sense of failure when breastfeeding did not continue as planned was heightened for women who experienced a traumatic birth. Lactation consultants when accessible were helpful.
- **Perinatal and 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'. Few women reported receiving any mental health care at any stage within their journey. Women commonly reported doing a 'survey' but felt this was a tick a box exercise and unhelpful.

PREGNANCY LOSS

- Over one half of women reported having an experience of 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 'losing my baby girl' was exacerbated for women living in the north and northwest of the state. The use of 'sensitive language' was cited as most helpful.

General Practitioners (GPs) or private obstetricians were often the first point of contact for many women. However, women felt disoriented by the lack of clear pathways of care.

- Women cited the lack of acknowledgement of the loss of the miscarriage and stillbirth. They talked of poorly trained health and allied health professionals 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'.
- Women also described being ignored, spoken down to or in a harsh manner, feeling stigmatised, and dismissed. Many described being cared for in maternity wards where they could hear crying babies or see other pregnant women. No mothers reported receiving follow up care, mental health support, grief counselling, pregnancy loss, or bereavement care. This compounded their sense of loss and fear for future pregnancy.

REFLECTIONS FROM THE RESEARCH TEAM

The team has been surprised by the continued momentum of interest and response to the study. This suggests that there are significant unmet needs within the Tasmanian childbearing community. Indeed, women have welcomed this opportunity to share their real experiences. 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) Our overall impression to date is that Tasmanian women have an overwhelming desire to use their voices to improve care for women everywhere.

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. However, this did appear to place an added burden on the women and negatively impact efforts to seek redress and debriefing.

The lack of trust in the maternity health care system directly impacts women's choices. 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.

RECOMMENDATIONS FOR NEXT STEPS?

Based on the findings from our research the following recommendations are presented for consideration. These align with the five strategic priorities in the Tasmanian Women's Health Strategy (8) and Woman-centred care: Strategic directions for Australian maternity services. (9)

Our research is informing the development of a Respectful Care Framework as a solution to the issues we have identified through the research. A conceptual draft of this framework has been developed. To operationalise and enable implementation into practice and the local contexts, the following are required.

- Support, advocate and invest in this critical research to build evidence and monitor the occurrence of forms of mistreatment that occur in our Tasmanian maternity services; this will fill in the gaps in the data, for example migrant and refugee women, fathers/partners, First Nations women and women living in most remote areas such as Flinders and King Island.
- Fund the co-design, implementation and evaluation of the respectful maternity care framework being developed from this research. An estimated budget is available on request.

Workforce and Services:

- Expand and develop rural obstetric and midwifery training programs/courses in Tasmania to grow our own workforce capacity and diversity.

- Expand and fund opportunities for rural generalist obstetricians to work with hospital-based midwives, and Midwifery Group Practice (MGP) midwives.
- Enable and support midwives and rural generalist obstetricians to work to their full scope of practice.
- Expand and trial the effectiveness of primary health care MGP models of care in rural and remote areas.
- Increase provider access to hospitals for home birth midwives/services to support continuity of care.
- Audit UTAS undergraduate and post graduate women's health curriculums and courses. Identify gaps and develop women's and reproductive health curriculums in medicine, public health, nursing, psychology, midwifery, social work and other allied health programs.
- Implement Trauma Informed maternity care bereavement training for all medical, nursing, midwifery allied health undergraduate and postgraduate education and training.
- Enable and support midwives and rural generalist obstetricians to work to their full scoop of practice.
- Increase research training opportunities for midwives.

Mental health and wellbeing:

- Promote cultural change; create socially and culturally safe primary health care-based pathways of care and use terms and language that normalise pregnancy, birthing and postnatal care as a normal life process rather than a 'risk', disease, or illness.
- Co-design with women a dedicated family bereavement primary health services statewide.
- Co-design with women a dedicated perinatal, maternity and reproductive mental health support service, including telehealth access.

Women's health needs:

- Investigate the determinants of mistreatment and birth trauma to develop prevention strategies.
- Investigate the impact and effectiveness of debriefing after birth trauma.
- Create dedicated funding pathways for women's health research in Tasmania.
- Co-design with women and relevant academics, clinicians and community organisations a multidisciplinary dedicated Tasmanian Women's Health Research centre.
- Co-design with women and health consumers a research agenda and what outcome measures are needed to measure and monitor women's reproductive, maternal and sexual health over the short and long term.
- Develop pathways of care for perinatal mental health including community-based counselling and mother and baby units across the state.
- Develop and implement context specific multidisciplinary care pathways for women and their families who experience pregnancy loss (miscarriage, stillbirth) and birth trauma.
- Enable the development of more peer-to-peer support programs within the community.
- Develop pathways to improve access to postnatal care from birth though to the first 12 months, including access to telehealth services with midwives, Child Health Nurses, psychologists, GPs, counselling services.
- Investigate culturally safe respectful maternity care through co-designed initiatives with multicultural services.
- Audit the range of care pathways available to Tasmanian women and develop and provide accessible information about the maternity care options and how to access them for Tasmanian women and their families.

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