

Ms Fiona Murphy Joint Sessional Committee on Gender and Equality Parliament of Tasmania genderandequality@parliament.tas.gov.au

Dear Ms Murphy,

Thank you for inviting the Victorian Women's Trust to prepare a submission to the Joint Sessional Committee on Gender and Equality.

We appreciate this opportunity as women's health and wellbeing has been a consistent interest and focus of our work over many years.

Please find attached the Victorian Women's Trust's submission to the Joint Sessional Committee on Gender and Equality's inquiry into gender bias in healthcare.

Sincerely,

Mary Crooks AO Executive Director

Eleanor Lee Intern University of Melbourne



The Victorian Women's Trust

Established in 1985, the Victorian Women's Trust (VWT) promotes gender equality through grants to grassroot projects, conducting research, creating social change projects and campaigns, and policy submissions. Our work centres on three key focus areas: health and safety, economic security, and equal representation, as change in these areas is necessary to achieving gender equality. VWT is entirely sustained by donations and individual benefactors.

We welcome this opportunity to make a submission on gender bias in healthcare to the Joint Sessional Committee on Gender and Equality.

Our starting proposition:

Gender bias in the Australian healthcare system is evident and a problem. Women, transgender, and gender diverse people face prejudice, exclusion, and medical ignorance from researchers and healthcare practitioners. Major systemic issues include the exclusion and underrepresentation of females from studies, biases in medical training, and a gendered wage gap for nurses. Women can present differently when seeking medical help, which can result in misdiagnosis, mistreatment, and even death.

Women's health and wellbeing has been one of our three key focus areas for decades. We have given grants on many areas of women's health, including but not limited to, endometriosis support, public education campaigns on women's health issues, supporting women with chronic pain and illness, assisting vulnerable women through childbirth, and providing education programs to emergency responders to better recognise women's symptoms.

We have researched and published on menstruation and menopause, with a special interest in naming and dismantling the menstrual taboo. We have run campaigns around violence and abuse, and the insufficient response of medical practitioners in understanding and treating symptoms which arise from the hidden nature of violence. We have more recently collaborated with journalist and researcher Isabelle Oderberg, who has raised the issue of miscarriage care and the lack of support women receive following pregnancy loss.

Through these connections with women across the community, we have seen and understand the prevalence of gender bias in healthcare and the need for urgent change.

This submission addresses the following Terms of Reference:

- 1. Areas of healthcare in which gender bias is particularly prevalent;
- 2. The impacts of gender bias in healthcare on overall health outcomes;
- 3. Systemic behaviours that cause gender bias in healthcare; and
- 4. Gender bias in research grant allocation and health related research.



Gender bias in medical research

Medical research bias against female inclusion has occurred due to concerns of studies negatively impacting the female reproductive system, and that female hormonal changes may impact the reliability of results. This exclusion of women was enforced by the United States Food and Drug Administration (FDA), which prohibited researchers from including women of childbearing age in drug trails. This effectively blocked all women internationally from participating in clinical trials, reinforcing within the medical profession that the male body is the norm, and the female body is a variation of the male body which data can be generalised to.

Although recent studies of Australian research shows that there is now equal sex representation in studies, only 8.9% of research analysed data by sex, preventing identification of differences in results between females and males, which may impact diagnosis and treatmentⁱ. There are known sex differences in the ways drugs are processed by the body, and in the ways the body reacts to a drug once it is in the bloodstream, therefore research which does not analyse data by sex, will not be able to analyse or observe these differences.

This can result in negative outcomes for female patients, including adverse reactions to drugs, lower effectiveness of interventions, and delayed or misdiagnosis. With women twice as likely to experience adverse drug reactions than men, partially due to dosing recommendations being based on the average male body. Further, despite general sex parity in research, some areas of research still lack female representation in studies, due to incorrect assumptions that women are less affected by a disease, such as in cardiovascular research.

Against this broad background, we can look more specifically at how gender bias occurs in various areas of medical research, including cardiovascular health, chronic pain, and endometriosis.

Specific illustration 1: Cardiovascular health

Cardiovascular disease (CVD) is the leading cause of death for Australian women and is one of the clearest examples of gender bias in medical research. CVD has traditionally been seen as a disease which primarily affects men, resulting in gender bias at the research, policy, and clinical levels.

Clinical trials have primarily recruited male patients, which has resulted in drugs being less effective for women who have CVD. Even despite recent gains in understanding of sex differences in CVD, research shows that since 2008, women account for only 40% of participants of cardiovascular clinical trials, with only 36% of these studies reporting results by sexⁱⁱ.

Female patients often present differently to male patients when experiencing a heart attack, with 40% of women not experiencing what has been considered to be the 'typical' (male) symptoms. Women are therefore more likely to have their heart attack symptoms missed by



doctors, with a UK study finding women were up to 37% more likely to be misdiagnosed when experiencing a heart attackⁱⁱⁱ. Women are less likely to be assessed, tested, and prescribed medications for CVD.

A study conducted by the University of Sydney found that women admitted to Australian hospitals with serious heart attacks, are half as likely as men to get correct treatment and are twice as likely to die six months after discharge^{iv}.

Another study conducted in Australia, found that women were 12% less likely to be screened for CVD risk than men^v. This gap is even larger for Indigenous women, who are twice as likely to be diagnosed with, and die from CVD.

Disparities in medical research create a clear flow on effect in the treatment, diagnosis, and outcomes for female patients.

Specific illustration 2: Chronic pain

Women report more chronic pain in Australia than men, with women's pain often being normalised by healthcare professionals, and less likely to be taken seriously. Approximately 80% of all patients diagnosed with an autoimmune condition are women, many of whom present with chronic pain. Importantly, a number of chronic pain conditions can only occur in women, such as endometriosis, but this does not explain the sex disparity.

There are many proposed causes for the sex disparity in prevalence of chronic pain, some of these include: gender roles resulting in men presenting a higher threshold for pain, likely due to it being less socially acceptable for men to show pain, psychological differences in the experience and reception of pain, and genetic differences. The causes are highly debated, but what is certain, is that there is a large sex bias in the research of pain.

Even with reduced sex disparities in recent research, the majority of pain research was prior to these improvements, and undertaken in male humans and male rodents. Pain is also an area of research where sex disparities are continuing, as seen in a recent study of research articles published in the journal, Pain, which found that only 12% of articles contained studies which tested on only females, or both sexes^{vi}.

Recent research that is being conducted on pain continues to have sex disparities, with conditions that have a disproportionate effect on women, such as migraines and endometriosis, receiving far less funding than conditions which predominately affect men, even when they are less prevalent population wide.

Pain in women is more likely to be considered normal, and not taken as seriously. Healthcare professionals are more likely to underestimate women's chronic pain, and report that women would benefit from psychotherapy, when this is not recommended in male patients. This causes delays in diagnosis, as seen in a recent study of Australian women, which found there was an average wait of four years for diagnosis, and almost half of these women were re-diagnosed at least once^{vii}.



Women's pain is often ignored, dismissed, and attributed to being from a psychological cause, delaying and preventing diagnosis and treatment. This delay is especially prevalent in the diagnosis of endometriosis.

Specific illustration 3: Endometriosis

Endometriosis, a disease in which tissue similar to the lining of the uterus grows in other parts of the body, affects 1 in 9 women, girls, and people with uteruses in Australia. It takes an average of 6.5 years for a diagnosis, which can only be achieved through surgical intervention. This delay is attributed to patients having to see an average of three different health practitioner specialities, normalisation of menstrual pain, misdiagnosis, and lack of knowledge of endometriosis by healthcare practitioners.

Across Australia, there are currently over 830,000 people with endometriosis, of which almost 16,000 reside in Tasmania. It can be a debilitating disease with common symptoms including pain, bloating, fatigue, nausea, and heavy bleeding, leading to reduced participation in school, work, and other commitments, and can impact fertility.

Endometriosis is estimated to cost the Australian economy almost \$10 billion annually, at a cost of \$30,000 per patient, mostly due to productivity loss. Despite affecting the same number of women as diabetes, it receives only 5% of the funding. Current treatments include prescription painkillers, hormonal treatments, removal of lesions via surgery, and hysterectomy, all of which are either invasive, have major side effects, or both. There is no cure.

Endometriosis faces more difficulties than other conditions in receiving funding, sitting at the intersection of chronic pain, and being a condition which only affects people with female anatomy. This results in less funding, research, and awareness from medical professionals.

There have been recent breakthroughs in endometriosis research, including in Australia, with growing understanding of possible causes and cures. Increased funding is needed to ensure that this continues.

Gender bias in healthcare systems

Given that women make up over half of the Australian population, one might expect that the issue of gender bias in healthcare would not be a systemic issue. The reality, however, is that gender bias and prejudice are structural and institutional, and are embedded through healthcare practice, false assumptions, and the 'othering' of women in a patriarchal world.

Women are experiencing high rates of trauma and violence in childbirth, resulting in negative outcomes for both the mother and child; healthcare practitioners lack skills and confidence in treating menopause, a transition in which almost all women will experience; and following a miscarriage, women's psychological pain is often dismissed or ignored, despite miscarriage being the most common pregnancy complication.



These are not uncommon issues for women. Yet these issues are shrouded in silence and stigmatised.

This bias begins in the education of healthcare practitioners. A study examining the gender bias in anatomy textbooks used at Australian medical schools, found that the representation of sex in images from these textbooks remain predominantly male, except within sexspecific sections^{viii}.

Further, menopause is excluded from Australian undergraduate and post-graduate medical and allied health training, likely a major factor in practitioners reporting lacking skills and confidence in treating menopause.

There are no federal clinical guidelines for healthcare practitioners to provide psychological support following miscarriage, with Queensland Health being the only jurisdiction to provide guidelines. This positions women's bodies and conditions as abnormal and influences potential biases of healthcare practitioners.

Specific illustration 1: Childbirth

Childbirth and postnatal bonding are some of the most significant, and hopefully safest, times in a woman's life. Sadly, this is not the case for women who experience obstetric violence. Obstetric violence (OV) is violence which occurs in the context of childbirth and is considered by the United Nations to be a form of gendered violence. Although called obstetric violence, it can be perpetrated by any healthcare professional involved in pregnancy and birth, not just obstetricians.

A study published in 2022, which surveyed Australian women's experiences of obstetric violence, found that one in ten reported experiencing OV^{ix}. Women in the study reported bullying, coercion, non-empathetic care, and physical and sexual assault, resulting in feelings of helplessness, fear, and powerlessness.

Notably, systemic issues such as lack of education, understaffing, and limited continuity of care impact these outcomes. Higher rates of OV were found in women who were younger, Indigenous, lower income, had no tertiary education, or did not have a partner.

Linked to OV is birth trauma, in which women report traumatic birth events that result in ongoing psychological distress, including OV. Research has found that almost half of Australian women report traumatic birth events, which can trigger PTSD, anxiety, phobia of childbirth, and bonding and relationship issues^x.

A majority of women give birth in their lifetime, the rates of OV and birth trauma during what should be an important and safe life event, are concerning and need to be addressed.

Specific illustration 2: Menopause

Menopause affects almost all women and people with uteruses in their lifetime, with common symptoms including hot flushes and night sweats, anxiety, depression, and



disturbed sleep. Despite safe treatments through menopausal hormone therapy (MHT), as well as nonhormonal treatments, over 85% of Australian women with moderate to severe symptoms, are not receiving treatment.

A study published in 2021 reported that many Australian GPs and specialists lack skills and confidence in managing menopause, recommending unproven treatments, and avoiding MHT due to widespread misunderstanding of it^{xi}. MHT also benefits women at high risk of postmenopausal bone loss, a risk that is not being treated and may have long lasting health impacts.

Concerns about MHT are also held by women seeking treatment, with a study published in 2020 reporting that Australian women viewed MHT negatively, due to concerns of cancer risks and over prescription^{xii}. Further, whilst Australian women understand the immediate effects and symptoms of menopause, they lacked knowledge of the long term post-menopausal changes, including vulvovaginal atrophy, increased risks of cardiovascular disease, diabetes, osteoporosis, and some cancers.

Women require more information from reliable sources in order to be able to advocate for themselves, and to ensure they are receiving appropriate treatment in their transition to menopause.

Specific illustration 3: Miscarriage

Miscarriage is defined in Australia as the loss of a pregnancy up to 20 weeks gestation, and occurs in approximately every one in four pregnancies, although as Australia does not collect miscarriage data, this is likely an underestimate.

Miscarriage can result in significant psychological impacts, with international research reporting 50% of women experience some form of negative mental health impact, although there is little research which has explored psychological impacts in Australia. A study conducted in the UK found that 29% of women met the criteria for PTSD one month following miscarriage^{xiii}. Common feelings associated with miscarriage are anger, distress, self-blame, isolation, sadness, guilt, and shock, as well as clinical levels of anxiety and depression.

A pilot study conducted in Australia in 2019, exploring women's access to healthcare services and support at the time of miscarriage, found that 59% of women were not offered information about miscarriage support organisations, nor were they referred to counselling services^{xiv}. Instead, less than a quarter received information about support organisations, and fewer received referrals, almost all women reported they would have liked some form of support.

Women are further traumatised by the healthcare system due to practitioners focusing on physical health not psychological wellbeing, lack of sensitivity and empathy from practitioners, and the expectation that recovery from grief should occur quickly. Healthcare practitioners can reduce the likelihood of negative mental health impacts through providing adequate care, as well as acknowledgement and validation of grief.



Case Study 1:

Menstrual and menopause wellbeing policy

In 2019, we published *About Bloody Time: The Menstrual Revolution We Have to Have*, which highlights the impacts of menstrual taboo on those who menstruate, and the difficulties and trauma experienced by women through menarche, menstruation, and menopause.

In our research for *About Bloody Time*, we surveyed 3,460 women and girls, and had 22 discussion groups with all age groups around Victoria.

Our research found that:

- 58% believed that time to rest would make their period a better experience.
- 34% were uncertain or had no idea what was happening when they had their first period.
- 77% received information about menstruation from their mother, 56% from school, and 38% from friends, increasing the chances of misinformation.
- For menopause, the key sources of information were from friends (51%) then doctors and the internet (both 42%).
- 36% of respondents believed reliable information would make the transition to menopause a better experience, as well as ability to take time off when needed (26%).
- Being able to speak openly, and not needing to make excuses were major responses in making both periods and menopause a better experience.

We also conducted research with Circle In, which found 83% of those surveyed said that their work was negatively affected by menopause. With almost half of respondents saying they considered retiring or taking a break from work, struggled with reduced confidence at work, and felt stressed by hiding their experience.

Menstruation and menopause are not illnesses, but they impact all aspects of life, including paid work. Women should not be penalised by workplaces by having to deplete sick or personal leave. We found that a key measure to address concerns found through our research was to develop and implement a menstrual and menopause leave policy, becoming one of the first organisations in Australia to do so.

Over five years, VWT staff took 37 days of menstrual or menopause leave, averaging 7.5 days across all staff members per year. This has had significant benefits to our organisation, resulting in more open and responsive discussion about reproductive health, staff feeling supported, respect for and greater trust in management, and staff practicing greater self-care by looking after themselves.

We have since published our leave template on our website (see appendix 1), to encourage and help other organisations to also implement a menstrual leave policy and have provided support to other businesses and organisations in developing their menstrual and menopausal workplace policies.



Conclusion:

This submission has demonstrated the pervasiveness of gender bias in healthcare, with a particular focus on gender bias in medical research and in healthcare systems. Through examples such as cardiovascular disease, and menopause, this submission has addressed the terms of reference provided by the committee, highlighting the importance of this issue, and the urgent need for change.

Whilst the issue of gender bias in healthcare is evident, change is possible. The first step has already been taken by the Tasmanian parliament in undertaking this inquiry. Our proposals are ambitious, but they are also logical and achievable.

Government should encourage and legislate change in collaboration with the community, to address these issues of gender bias in healthcare. Addressing gender bias within research, policy, and clinical practice will improve health outcomes for women, transgender, and gender diverse people, which in turn benefits all of society.

Recommendations

Research:

- 1. Encourage research institutions that receive state funding to ensure equal sex representation in studies and analysis of data by sex.
- 2. Prioritise sex specific research for conditions such as cardiovascular disease and chronic pain, to better understand these conditions in women and improve outcomes.
- 3. Increase funding for research which reflects the prevalence of conditions that disproportionately impact women such as endometriosis, migraines, and autoimmune conditions.

Education:

- 1. Actively support educational programs for healthcare practitioners on conditions that impact women such as endometriosis and chronic pain, to improve confidence and skill in treating patients, and reduce wait times and misdiagnosis.
 - Actively support improvements in education on the ways in which women may present differently to men such as with cardiovascular disease and heart attacks.
- 2. Encourage a greater educational focus for healthcare practitioners, especially obstetricians and midwives, to understand obstetric violence and birth trauma, and how to provide trauma informed care.
- 3. Encourage a greater educational focus for all healthcare practitioners on effective treatments for menopause, with a focus on menopause during medical training, especially to address misunderstanding and fear of menopausal hormone therapy.
- 4. Support and fund public information campaigns about the long-term effects of menopause and treatment options, so women do not have to suffer in silence.



Legislation and wider systems improvement:

- 1. Recognise obstetric violence as a form of gendered violence in Tasmania, with the implementation of legislation to protect women from obstetric violence, in line with UN recommendations.
- 2. Implement evidence based clinical guidelines for healthcare practitioners to provide psychological support following miscarriage, as Queensland Health has done.
- 3. Encourage workplace menstrual and menopause leave at the state level and provide workplaces and community organisations with an incentive-based grants program to undertake workplace audits to consult and install a menstrual action plan.

Data collection:

1. Tasmania should collect state-wide miscarriage data and encourage national collection to have a true understanding of the socioeconomic cost of miscarriage, to ensure policy is well informed, and that research and support is correctly funded.



Appendix 1: Victorian Women's Trust - Menstrual Policy Template^{xv}

Your logo here

Menstrual Policy Template

Rationale

Insert organisation name has introduced a menstrual and menopause policy. Experiences of menstruation and menopause can be very debilitating, yet we have been enculturated to mask their existence in the workplace, at schools and at home. This policy supports employees in their ability to adequately self-care during their period and menopause, while not being penalised by having to deplete their sick leave. Periods and menopause are not a sickness after all. This policy also seeks to remove the stigma and taboo surrounding menstruation and menopause.

Policy

This policy is designed to provide opportunities for restful working circumstances and self-care for employees experiencing symptoms of menstruation and menopause. The policy is designed to be flexible depending on the employee's needs, providing for the following options:

- 1. The possibility of working from home*;
- 2. The opportunity to stay in the workplace under circumstances which encourage the comfort of the employee eg. resting in a quiet area; or
- 3. The possibility of taking a day's paid leave.

In the case of paid leave, employees are entitled to a maximum of 12 paid days per calendar year (pro-rata, non-cumulative) in the event of inability to perform work duties because of menstruation and menopause, and their associated symptoms. A medical certificate is not required.

*This provision should be incorporated into your organisation's working from home policy.



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