Women's Health East's submission to the Department of Health

Inquiry into Women's Pain

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Acknowledgement of Country

Women's Health East acknowledges the Wurundjeri Woi-wurrung people, the Traditional Owners of the land on which we work. We pay our respects to Elders past, present and future. We affirm that sovereignty was never ceded and that colonialism and racism continue to impact the lives of Aboriginal and Torres Strait Islander women. We recognise the strength, resilience and leadership of Aboriginal and Torres Strait Islander women and express our organisational commitment to reconciliation, truth-telling and Treaty.

Inquiry into Women's Pain 2024

Women's Health East is an independent, regional women's health promotion organisation that works to build an equitable and inclusive society, so that women experience their best health and wellbeing. We work collaboratively with local governments, healthcare providers, organisations and communities, equipping them to make the institutional changes needed to create fairer, healthier and safer communities. Women's Health East delivers evidence-based health promotion and prevention programs to women who experience marginalisation and disadvantage to advance their health, safety and wellbeing.

Women's Health East's vision is equality, empowerment, health and wellbeing for all women. Our strategic priorities are gender equality, the prevention of violence against women, and improving women's sexual and reproductive health. We drive change towards these goals by equipping others with the expertise, information and guidance they need to make the systemic changes needed within their organisations and within the wider community.

Introduction

Women's Health East welcomes the Victorian Government's Inquiry into Women's Pain. Our organisation brings a wealth of knowledge and experience to this inquiry, informed by over 35 years of work in Melbourne's east. This includes leading partnerships, regional strategies, and intersectional primary prevention projects that address the underlying drivers of women's health inequities in areas such as gender inequality, mental health, sexual and reproductive health, and violence against women.

Women's Health East's submission draws on consultations with women in Melbourne's east with whom we have strong relationships and who experience intersecting discrimination and inequality. In addition to these consultations, Women's Health East offers a unique perspective shaped by our long-standing relationships with diverse communities in the region. This includes close collaboration with grassroots organisations and communities serving women with disabilities; women from migrant and refugee backgrounds; and those facing social, cultural and economic barriers to accessing pain management, models of care and the provision of culturally appropriate, accessible healthcare services.

Women's Health East is one of 12 women's health services funded through the state government's Victorian Women's Health Program, operating under the title 'Victorian Women's Health Services Network.' This enables our sector to function as a coordinated, mutually reinforcing statewide network comprising both place-based and specialist services. The network has been a driving force in progressing and shaping Victorian women's health and equality for four decades.

Women's Health East is a partner and contributor to the joint Women's Health Services Network submission into the Victorian Government's Inquiry into Women's Pain (see **Appendix One**). Women's

Health East's submission and our recommendations are to be read in conjunction with our sector submission. We propose that our recommendations, along with those detailed in our sector submission, be implemented in full by the Victorian Government. This will ensure that women's and girls' pain is effectively prevented and treated through best-practice models of care and primary prevention programs.

Women's Health East's submission includes four sections:

- Section one: The importance of applying an intersectional gender lens to women's pain
- Section two: The evidence relating to women's pain
- Section three: The findings from Women's Health East's three roundtable consultations with community women from priority populations
- Section four: Women's Health East's recommendations.

Section one: The importance of applying an intersectional gender lens to women's pain

Intersectionality involves understanding how individuals experience multiple, overlapping systemic inequalities. An intersectional gender lens examines how gender discrimination interacts with discrimination based on attributes such as disability, race, sexuality, or age. Applying this lens to the healthcare system provides a nuanced understanding of how gender inequality and other forms of oppression result in more girls and women experiencing chronic pain and being less likely to receive treatment than men.[1]

An intersectional gender perspective is crucial for identifying and challenging medical biases within the healthcare system and the assumptions held by practitioners about different population groups of women, particularly regarding why they experience pain, and the treatment and services for pain conditions. Women and girls' disproportionate experiences of chronic pain stem from systemic and structural issues rather than individual attributes or behaviours. By taking a systems approach, an intersectional gender lens ensures that strategies to address barriers to equality are effective in transforming norms and stereotypes, and in preventing discrimination.

There is a crucial need for all parts of the health system to understand gender as a key social determinant of health and to centre women's voices and experiences in their care, treatment, and services for pain conditions. This includes collaborating with women from diverse backgrounds to address gender bias and mistrust in the healthcare system, stemming from women's experiences of discrimination, disempowerment, and systemic violence in health systems and the broader community.

Research shows that intersectional gender inequalities are deeply embedded within societies and healthcare systems, impacting access to care through the distribution of power within the medical field.[2] These inequalities intersect with other forms of inequality experienced by specific groups of women, leading to higher levels of pain and affecting the quality and effectiveness of prevention and treatment of

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[1] Hankivsky O, Grace D, Hunting G, Giesbrecht M, Fridkin A, Rudrum S, Ferlatte O & Clark N 2014, 'An intersectionality-based policy analysis framework: critical reflections on a methodology for advancing equity,' *International Journal for Equity in Health,* available here

[2] Merone L, Tsey K, Russell D, & Nagle C 2021, 'Sex and gender gaps in medicine and the androcentric history of medical research,' *Australian and New Zealand Journal of Public Health,* available here

pain.[3] Our practice evidence shows that centring the voices of women, especially those facing intersectional inequalities, is critical to addressing the social determinants of health, including those within the healthcare system and broader society.

Section two: The evidence relating to women's pain

Women's Health East has drawn on its broad practice knowledge and evidence base to inform our submission to this inquiry.

Intersectional gender bias within the health system

Research has shown well-documented gender bias in pain assessment and management. Women are more likely to experience pain than men, yet they are less likely to receive adequate pain treatment.[4] Women facing additional inequalities, including Aboriginal and Torres Strait Islander women, women with disabilities and migrant and refugee women, frequently encounter significant barriers and discriminatory practices when accessing healthcare services.[5] Language barriers, cultural insensitivity, racism, ableism, sexism, and systemic biases often undermine their ability to seek and receive adequate care.[6] These challenges are compounded by intersectional discrimination based on gender, race and ability, exacerbating health disparities in treatment and access to resources.[7] In addition to gender discrimination, Aboriginal and Torres Strait Islander women, and women from refugee and immigrant communities face additional racial discrimination.[8]

In 2024, Women's Health East published a research report exploring Chinese women's experiences of racism in Melbourne's eastern region. The *Taking Action to Combat Racism Research Report,* shows "some Chinese women experienced unfair treatment when accessing social or health services, facing assumptions and judgements from practitioners unwilling to understand their situations."[9] Research shows that Aboriginal communities experience interpersonal racism in health settings, which is associated with increased psychological distress over and above what would be expected in other settings.[10] There is an urgent need to address interpersonal and institutional racism and promote cultural safety, respect and responsiveness to Aboriginal women and women from immigrant and refugee communities who access treatment and services for pain and other related conditions.

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[3] Samulowitz A, Gremyr I, Eriksson E & Hensing G 2018, '"Brave Men" and "Emotional Women": A Theory-Guided Literature Review on Gender Bias in Health Care and Gendered Norms towards Patients with Chronic Pain', *Pain research & management*, vol. 2018, issue 1, 58624

[4] Samulowitz A, Gremyr I, Eriksson E & Hensing G 2018 '"Brave Men" and "Emotional Women": A Theory-Guided Literature Review on Gender Bias in Health Care and Gendered Norms towards Patients with Chronic Pain,' *Pain research & management*, vol. 2018, issue 1, 6358624. https://doi.org/10.1155/2018/6358624

[5] Fitts M, Cullen J & Barney J 2023, 'Barriers Preventing Indigenous Women with Violence-related Head Injuries from Accessing Services in Australia. Australian Social Work,' vol. 76, issue 3, pp. 406–419, available here

[6] Women with Disabilities Victoria 2022, 'Fact sheet 3: Take an Active Approach to Understanding Gender,' Health and Disability, available here

[7] Women with Disabilities Victoria 2023, 'Experts in our health project,' available here.

[8] Sullivan C, Vaughan C & Wright J 2020, 'Migrant and refugee women's mental health in Australia: a literature review,' University of Melbourne & Multicultural Centre for Women's Health, available here; Carangio V, Farquharson K, Bertone S, Rajendran D 2021, 'Racism and White privilege: highly skilled immigrant women workers in Australia,' *Ethnic and Racial Studies*, vol. 44, issue 1, pp. 77–96, available here

[9] Women's Health East 2024, 'Taking Action to Combat Racism Research Report,' Melbourne, Australia, p. 11.

[10] Kelaher M, Ferdinand A & Paradies Y, 2014, 'Experiencing racism in health care: the mental health impacts for Victorian Aboriginal communities,' *The Medical Journal of Australia*, vol. 201, issue 1, available here

Women with disabilities frequently encounter significant discrimination and barriers when accessing the health system. Many health services continue to be influenced by the outdated medical model of disability "which focuses on the person's impairment and views disability as an individual problem that needs to be fixed or treated by medical professionals."[11] In contrast, the social model of disability "recognises that people with disabilities have the same human rights and fundamental freedoms as all other people and are capable of claiming their rights and making their own informed decisions."[12]

Women with disabilities frequently experience ableism, which is the "system of beliefs, processes and practices that privilege people without disabilities, and disadvantage and exclude people with disabilities."[13] Ableism leads to harmful or discriminatory behaviour toward women with disabilities and is "more than just negative and prejudiced attitudes about people with disability. It occurs when prejudice is accompanied by the power to discriminate against, repress or limit the rights of others."[14]

Women's Health East developed a practice asset for health professionals entitled the *Sexual and reproductive health and women with disabilities*. The resource was co-created with women with disabilities in Melbourne's eastern region. Women with disabilities accessing sexual and reproductive healthcare, many of whom experience pain, reported various service access barriers, including ableist attitudes and practices among staff and organisations. These barriers impact the quality and effectiveness of services and contribute to health inequities. Women commonly experienced negative assumptions, judgments, and biases from health professionals in Melbourne's eastern suburbs and throughout Victoria's healthcare system, with the women participating in the report noting that they have far more negative and ableist experiences than positive and accessible ones when it came to accessing healthcare.[15] Ensuring that health services and health professionals shift towards the social model of disability, with strategies to prevent ableism and promote disability accessibility, is essential in responding to women's pain conditions and management.

The importance of healthcare systems that recognise violence and trauma as relevant to women's pain

An understanding of the interconnected nature of trauma, violence and pain is critical to the effective treatment of women's pain and must be embedded within prevention and intervention programs and models of women's care. One in three women in Victoria experience violence,[16] and women experiencing violence are highly represented among those experiencing pain. While violence itself is a direct cause of pain, research has shown complex links between trauma and some pain conditions, suggesting that trauma itself contributes to the experience of pain[17].

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[11] Our Watch and Women with Disabilities 2022, 'Changing the landscape: a national resource to prevent violence against women with disabilities,' Melbourne, Australia, available here

[12] Our Watch and Women with Disabilities 2022, 'Changing the landscape: a national resource to prevent violence against women with disabilities,' Melbourne, Australia, available here

[13] Our Watch and Women with Disabilities 2022, 'Changing the landscape: a national resource to prevent violence against women with disabilities,' Melbourne, Australia, available here

[14] Commonwealth of Australia 2023, 'Royal Commission into violence, abuse, neglect and exploitation of people with disability: Executive summary, our vision for an inclusive Australia and recommendations, final report,' September 2023, available here

[15] Women's Health East 2023, 'Sexual and reproductive health and women with disabilities,' Melbourne, Australia, available here

[16] Australian Bureau of Statistics 2021, 'Personal Safety, Australia,' available here

[17] Flehr A, Coles J, Dixon J, Gibson S, Brilleman S, Harris M & Loxton D 2021, 'Epidemiology of Trauma History and Body Pain: A Retrospective Study of Community-Based Australian Women,' *Pain medicine*, vol. 22, issue 9, available here

Research further points to the importance of trauma-informed care across all health treatments for women, given the interrelated impact.[18] The negative impacts of health services that fail to recognise and address trauma include the exacerbation of mistrust and anxiety that can be a part of the impact of trauma. In the long term, this can lead to women avoiding accessing care and treatment.[19] The healthcare system needs to prioritise safety and trauma-informed care. This is essential for all women and particularly those who experience high rates of violence and discrimination. It is critical that the inquiry and its recommendations include changes to the health system to improve the delivery of trauma-informed care not only in the treatment and management of pain conditions but in all aspects of women's healthcare.

Financial barriers in accessing treatments

Women experiencing pain can face additional barriers accessing healthcare due to the cost of treatment. Financial insecurity and the inability to afford medical treatment is magnified by varying forms of marginalisation for women in Victoria. For example, Australian Bureau of Statistics data shows that the median gross personal income of people with disability is less than half that of people without disability.[20] Similarly, migrant and refugee women are more likely to work in insecure, low income, low skill jobs.[21] The Committee for Economic Development of Australia found that female migrants with a postgraduate degree earned an average of 31 per cent less than Australian-born women in the workforce with similar qualifications.[22] Women's financial inequality can create significant barriers when pain treatments require additional out-of-pocket costs, such as specialist consultations, complementary therapies, or specific medications.

Section three: The findings from Women's Health East's three roundtable consultations with community women from priority populations

Women's Health East is a grassroots organisation with strong regional connections and relationships with women from diverse backgrounds. We leveraged these connections to conduct consultations relevant to this inquiry, focusing on women who face additional inequalities and who are engaged with Women's Health East health promotion and prevention programs. The following findings came from three consultations conducted between June and July 2024 with Hakha Chin women from refugee backgrounds, Chinese women from migrant backgrounds, and women with disabilities.

The consultation with Hakha Chin women included 22 participants aged 25 to 60, many of whom had significant experiences of pain and accessing services in Melbourne's eastern region. Key themes raised by women in this consultation included:

- Language barriers and a lack of access to qualified interpreters

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[18] Grossman S, Cooper Z, Buxton H, Hendrickson S, Lewis-O'Connor A, Stevens J, Wong LY &Bonne S, 2021, 'Trauma-informed care: recognizing and resisting re-traumatization in health care,' *BMJ Journals Trauma surgery & acute care open,* vol. 6, issue 1, available here

[19] Coles J, Lee A, Taft A, Loxton D & Mazza D 2015, 'General practice service use and satisfaction among female survivors of childhood sexual abuse,' *Australian Journal for General Practitioners,* vol. 44, issue 1, available here

[20] Australian Bureau of Statistics 2018, 'Disability, Ageing and Carers, Australia: Summary of Findings,' available here

[21] Federation of Ethnic Communities' Councils of Australia (FECCA) 2017, 'Submission to Independent Inquiry into Insecure Work,' available here

[22] The Committee for Economic Development of Australia (CEDA) 2024, 'Making Better Use of Migrants' Skills,' CEDA, Melbourne available here

- Costly pain management services that were time consuming to access
- No definitive diagnosis and effective treatment given, meaning that women often endured worsening pain and other symptoms resulting in increased anxiety
- Lack of empathy and patient centred care with practitioners and the healthcare system normalising women's pain
- Lack of female general practitioners (GPs) and male GPs' reluctance to support women's healthcare
- Stress and other mental health issues due to family violence, gender norms and religious expectations
- Race-based discrimination and a lack of culturally safe service provision.

A key theme among the Hakha Chin women consulted was a lack of diagnosis resulting in untreated pain.

> *"I (had) six lumps...It (did) bother me (and) nothing ever happened. It had a lot of impact on my mental health"* (Hakha Chin women's roundtable participant, 2024).

Birth trauma was identified as a significant issue contributing to women's pain during the consultation. Women's Health East staff heard about a recent case where a Hakha Chin woman gave birth and was discharged after only four hours at a local hospital, despite the placenta not having yet been delivered. The health providers assured her that she was fine to go home. However, a week later she became very sick and was in immense pain. She went to a local emergency department and underwent emergency surgery to have her placenta removed. Now, she is struggling with mental health issues as a result of this experience. Another woman noted:

> *"I was told to go back home by the hospital because I was not due for delivery yet, even though I was in tremendous pain, they didn't believe me"* (Hakha Chin women's roundtable participant, 2024).

Women spoke about their experiences reflecting a broader pattern where women's pain and symptoms are normalised and not taken seriously, leading to physical and mental health consequences.

Hakha Chin women raised concerns about not speaking English as their first language, and not being able to access information relevant to their pain treatment and care plan. Further barriers to effective and culturally safe pain treatment included race-based discrimination in health services, including hospitals. Several Hakha Chin women reported inappropriate and inadequate use of interpreters.

> *"I had to wait over four hours in the emergency (room) alone. I feel like a burden to my children and family because I cannot speak English"* (Hakha Chin women's roundtable participant, 2024).

> *"A barrier for me is not speaking English...A lot of the times I go and there's no interpreter"* (Hakha Chin women's roundtable participant, 2024).

> *"Sometimes we have to bring family members with us to interpret. They have to take time off work and sometimes we don't want them to know our personal health information. No privacy"* (Hakha Chin women's roundtable participant, 2024).

Women spoke about healthcare professionals not being able to access an interpreter and instead asking them to use a family member, including their children, to interpret. This reliance on family members compromises privacy and confidentiality, creating significant barriers to appropriate care. Migrant and refugee women may be hesitant to share personal information in front of family members.

Women also noted the scarcity of NAATI-accredited interpreters. Younger interpreters were often preferred for medical care, especially for sexual and reproductive health issues, as they were more likely to maintain privacy and confidentiality. This was a common experience among Hakha Chin women, who reported encounters with culturally insensitive interpreters.

Even with the presence of interpreters, migrant and refugee women can still experience a lack of respect when accessing healthcare treatment. For example, a Hakha Chin woman reported being ‘traumatised’ from a doctor’s visit where she was only asked yes or no questions. She felt these questions couldn't be adequately answered with simple yes or no responses and wanted to provide additional details. However, the doctor insisted in a firm voice that she answer only with yes or no, which left her feeling embarrassed. There was an interpreter present at her appointment, who later told the community about what happened. This experience made the woman “[lose] trust in both doctors and interpreters.” This example highlights that simply having an interpreter, without providing adequate training about empathy, privacy and confidentiality, is not sufficient to ensure respectful and transparent communication between migrant and refugee women and health professionals.

Inaccuracies during interpreting were also an issue that led to misunderstandings and miscommunications about medical conditions, treatment plans, and necessary follow-up care. For example, one woman shared an experience where an interpreter incorrectly translated the information about her daughter’s condition. The doctor had described her daughter’s condition as having a “temporary loss of hearing” due to air pressure, however, the interpreter mistakenly told her that her daughter was deaf. The inaccuracy was only discovered during a subsequent appointment with another interpreter. These situations can cause significant anxiety and frustration for women and their families who rely on interpreters to communicate with healthcare providers, demonstrating the importance of upskilling the interpreters in medical terminology.

These experiences highlight an urgent need for professional and confidential interpreting services within the healthcare system to ensure accurate, timely, and culturally safe communication. Women also noted that additional investment in NAATI-accredited interpreters was needed to redress access barriers to women’s pain care and healthcare treatment.

Hakha Chin women also shared experiences highlighting how the health system reinforces multiple intersecting inequalities in other areas of their lives. One woman described her struggle with post-natal depression, while another recounted unnecessary intervention during childbirth that severely impacted her health and wellbeing. Such experiences can contribute to trauma and distrust, making women less likely to seek future healthcare. As one woman shared, "After my third child, I didn't feel right... I went to see the doctor and... I have depression."

Consultations revealed that the lack of patient-centred care in the healthcare system is a significant concern. Many women reported feeling dismissed and unheard during their medical appointments, which are often rushed and insufficient. Not receiving adequate information and care is a universal experience among migrant and refugee women. After long waiting times, appointments typically last only five to ten minutes. For instance, one Hakha Chin woman sought help for an unbearable sore throat and was prescribed Panadol. She then received a bill for $70. This lack of empathy and attention undermines the quality of care, leaving women feeling frustrated and marginalised.

A common experience for Hakha Chin women is the lack of healthcare and poor health knowledge in their country of birth impacting their health outcomes after they have arrived in Australia. One woman shared that by the time they settle in Australia, they already have 'so much pain.' Another woman spoke about learning manual lifting guidelines only once she started working at a factory in Australia. Until this time, she was unaware that the lifting she had been doing back in Burma was 'too heavy' and had caused the back pain she was experiencing. The women felt strongly that health education for their community was integral.

> *"It helps alleviate our pain in older age. And we can educate our children."* (Hakha Chin women's roundtable participant, 2024).

Women participating in this roundtable also spoke of their attempts to improve their health, whether through seeing counsellors or physiotherapists, but having to discontinue due to the high costs. One woman spoke of joining an aquatic exercise class at her local leisure centre, but having to discontinue when the on-site childcare service was de-funded.

Women also highlighted the critical need for health promotion programs and preventative health initiatives to prevent women's pain. They emphasised the importance of more community-based, preventative health information sessions and programs in areas relating to women's sexual and reproductive health, pain management and service navigation. In-language programs for women, run by women, such as those offered by Women's Health East's Bicultural Unit, were noted for their culturally appropriate, safe, and respectful engagement. Additionally, training men in mental health literacy and healthy relationships was identified as another important prevention initiative that will reduce women's pain by preventing violence against women and women's poor mental health and wellbeing.

The consultation with Chinese Mandarin-speaking women included 17 participants aged 30 to 75. All had significant experiences of pain and had sought treatment for a range of symptoms with Victorian healthcare providers. Key issues raised by women during this consultation were:

- It is time-consuming and costly to seek pain treatment
- There is a lack of information provided by doctors, with appointments typically lasting only five to ten minutes
- It's difficult to know where to find further information so more avenues are needed for women to seek information outside of clinical settings
- There is a lack of communication between GPs and specialist healthcare providers
- Seeking Chinese traditional medicine for alternative treatment is costly, as it is not covered by Medicare, despite being an important treatment for women's pain
- Language barriers hinder fluent communication with doctors and specialists
- Women's pain is often normalised, overlooked, or misdiagnosed, resulting in delayed treatment and worsening symptoms, which significantly impact daily life
- There is often no definitive diagnosis or effective treatment provided
- Women reported experiencing a lack of empathy, with health providers not taking their pain or symptoms seriously

- Experiences of discrimination in healthcare settings
- There is limited knowledge and understanding of women's pain, especially from male doctors.

Lack of patient centred care and information

A common experience heard during this consultation was health professionals not providing women with adequate information. One Chinese woman shared her story of waiting over ten years to receive a diagnosis for blisters on her hands, finally confirmed through a biopsy as bullous pemphigoid, a rare autoimmune disease. The dermatologist prescribed prednisone, a type of corticosteroid, as treatment. However, the woman experienced severe side effects and significant pain. She was "shocked" that the dermatologist never provided her with information on common side effects. One of the side effects she endured was insomnia, for which her GP prescribed sleeping pills. She later began experiencing numbness throughout her body, preventing her from driving. Seeking help, the woman consulted neurologists and a vascular specialist, but again encountered long waiting times and multiple referrals, which left her feeling "extremely anxious and distressed."

> *"Ten years ago, I started developing blisters on my hands. I consulted with seven or eight different GPs, but never received a specific diagnosis. The creams they prescribed were either useless or made my skin worse. I went to the emergency department, where they referred me to a dermatologist whom I had to wait another two weeks to see. Finally, I had a biopsy. The whole process took more than 10 years."* (Mandarin women's roundtable participant, 2024).

Other women shared similar experiences. One woman explained that her doctor failed to provide information or instructions after her gallstone removal operation. No further appointment was arranged, and there were no suggestions about dietary requirements or how to prevent gallstones in the future. The lack of information and patient centred care left women feeling frustrated and it often exacerbated their pain and prolonged their recovery.

Normalising women's pain

The issue of normalising women's pain was a significant concern raised throughout all consultations. Many women reported that their pain is often downplayed or dismissed by healthcare providers, who may attribute their symptoms to stress, disability, aging, or other non-specific causes without further follow up or investigation. This tendency to normalise women's pain often resulted in delayed diagnosis and inadequate treatment, leaving many women suffering unnecessarily.

Additional channels for accessing health information, such as community-based health information sessions

A recurring theme that emerged in both the Chinese and Hakha Chin women consultations is frustration with long waiting times. Many women described experiencing multiple referral pathways, often having to see multiple GPs and specialists without receiving a definitive diagnosis or effective treatment. Women highlighted a lack of connection and information sharing between GPs and specialists, which further compounded their frustration, delayed their diagnosis and treatment and exacerbated their pain.

> *"I had to wait two years to hear back from the specialist that I didn't have uterine cancer. I was advised to get another check-up after two to three years. I haven't heard from them since then."* (Mandarin women's roundtable participant, 2024).

Without a definitive diagnosis or effective treatment plan, many women had to endure pain. In some cases, their symptoms worsened, leading them to finally seek emergency care. For example, one Chinese woman waited six months to have her gallstones removed. Throughout the wait, she endured severe pain from the gallstones, kidney stones, back pain and shingles and went to the emergency room twice.

Another woman experienced dizziness and ringing in her ears but was told by the GP that “it is just a part of ageing.” As her symptoms worsened and she worried about fainting, she went to the emergency department and waited seven hours for a scan, then another three hours until 5am. The woman was uncomfortable sitting for 10 hours and was “ready to leave without the results” when she was finally admitted to the ward. To her surprise, “the ward was empty and there were no doctors.” She expressed bewilderment, saying, “I don’t understand. There were other people still waiting outside who were clearly unwell. Even letting them lie down would be better.”

One Chinese woman commented, “Unless you are about to die, no one will care about you.” This sentiment was echoed by many others, highlighting the inefficiencies and gaps in the system that leave women feeling unheard and untreated. There is a consensus among Chinese women that prevention and access to correct health information is important. Many women stated that “going to the GP is the only choice to seek information” and suggest it would be beneficial to have “additional channels to access health information.” This could include health promotion programs that build women’s health literacy, knowledge and ability to optimise their health and wellbeing. Chinese women spoke of the importance of community-based health promotion programs and health information sessions that were delivered in-language by women from their culture and community. These sessions can provide education on common symptoms and pain management strategies, empowering women with the knowledge to recognise and manage pain early, reducing pressure and demand on clinical settings.

High cost of healthcare and related expenses

Women consistently raised concerns about the high cost of seeking medical care. Many women agreed that cost is a significant barrier to accessing pain care and treatment. The expenses associated with medication, treatments, and visits to GPs generally create a substantial financial burden as bulk billing services become scarcer. Specialist care is particularly costly, often requiring multiple appointments, which many women cannot afford. This leads them to discontinue their care and treatment. Although concessions and Medicare are intended to provide financial relief, they often do not cover all of the necessary treatments, leaving women paying out of pocket fees during a cost-of-living crisis. As a result, many women face significant challenges in obtaining the consistent and comprehensive care they need.

Women’s Health East staff also heard that many Chinese women turn to Chinese traditional medicine for alternative treatment and pain relief. However, these alternative medicines, despite women reporting these to be highly effective in managing their pain, are not covered by Medicare, resulting in a significant financial burden. They suggest that traditional and alternative medicines, such as Chinese medicines and naturopathy, should be covered under Medicare and that the Medicare Benefits Schedule should be expanded to cover greater access to allied health services.

Women’s Health East conducted a consultation with nine women with disabilities, aged 30 to 80. This group included women from Aboriginal and Torres Strait Islander backgrounds, migrant and refugee backgrounds and, like other consultation groups, women who were victim/survivors of family violence and other forms of violence.

A lack of respect and dignity provided to women with disabilities by healthcare professionals and the service system

Women reported that their experiences of pain, as well as their disabilities, were invisible and often not considered, understood or deemed important by medical professionals.

> *"[My pain and disability] it's invisible to the health professionals."* (Women with disabilities roundtable participant, 2024).

> *"They don't understand...invisible illness, because they're like, well, you seem fine to me."* (Women with disabilities roundtable participant, 2024).

In some cases, this related to areas of pain that have not been well recognised including neurological pain, which led to misdiagnosis of pain treatments.

Women with disabilities shared experiences of not being listened to because the medical professional was regarded more highly.

> *"I told him I couldn't have it (the medication), and he ignored me. And my GP said to me, you must respect him. It's very disrespectful if you don't take these meds."* (Women with disabilities roundtable participant, 2024).

Women shared when they listen to professionals and ignored themselves, it made their condition worse and contributed to more pain.

> *"We need to acknowledge that people are the owners of their body, their mind, their soul, their spirit."* (Women with disabilities roundtable participant, 2024).

One woman shared her experience where the doctor did not believe she could have children, when in fact she already had children. She had to prove this to the doctor The experience of not being believed caused her unnecessary distress.

As one woman shared, "I said I had chest pain. I was told every part of it, No, dear, you don't have chest pain. You are just fat and overweight." Another woman identified, "They've not been very friendly to me. They've been a little bit rude – it just made them my pain worse." The experience of dismissive, rude, and unempathetic treatment from healthcare providers contributes further to women's pain and psychological distress and it discourages them from seeking further care.

Mental health impacts of pain not being recognised

Women also experienced serious mental health impacts resulting from their pain.

> *"I spent about eight months out of 12 months in hospital because the pain was so debilitating... led to a lot of other issues with just feeling down and not wanting to live."* (Women with disabilities roundtable participant, 2024).

One woman shared, "It's psychological pain at the same time." While the system was often not integrated in recognising these interconnected experiences, women with disabilities talked about how chronic pain (often in the context of an unsupportive system) can lead to significant mental health issues, such as depression and anxiety.

Medical gender bias and a lack of service system accountability

One woman shared her story of a failed operation in which the staff made it clear that a mistake had been made. This error resulted in her experiencing lifelong pain. The woman reported that the hospital tried to cover up the incident which exacerbated the impacts and effects on her wellbeing resulting in her distrusting the system. Other women shared their negative experiences when seeking healthcare and raised the issue of hierarchical power impacts when providing feedback and complaints. As one woman shared, “I’m tired of being treated the wrong way by medical staff.”

Women with disabilities raised the following important areas for change:

- Training for healthcare professionals on invisible illness and chronic pain
- Improved communication and empathy from healthcare providers
- Increased access to pain specialists, mental health services, and alternative therapies
- Improved feedback mechanisms and adequate action taken on patient complaints
- Investment in research on women's pain and the impact of trauma
- Culturally sensitive, disability accessible and trauma-informed healthcare embedded throughout the system
- Empowering women to be active participants in their healthcare decisions
- Involving lived experience in decision making and service system redesign.

Section four: Women’s Health East’s recommendations

In response to the evidence presented and the findings from the three community consultations, Women’s Health East makes the following recommendations to the Victorian Government’s Inquiry into Women’s Pain, coupled with the recommendations detailed in Appendix One from our joint sector submission.

1. **Implement the inquiry’s findings and health systems reform based on the lived experiences of Victorian women from diverse backgrounds and with diverse experiences of pain**

It is recommended that the inquiry’s findings and recommendations be grounded in the feedback from the thousands of women who shared their experiences of pain. The Victorian Government should fully implement these findings, ensuring that health systems reform prioritises the respect, dignity, and inclusion of women. It is essential to centre women experiencing pain, especially those with intersectional attributes, in the planning and implementation of reforms. The Victorian Government should establish a committee, including women’s health services and community leaders, to integrate the lived experiences and expertise of women in pain.

2. **Develop and monitor standards of care for women's pain diagnosis, treatment, and models of care**

It is recommended that standards are developed to guide changes in health services and accreditation requirements, aligning with culturally safe, person-centered, and trauma-informed care. The Victorian Government should work with the Federal Government and relevant stakeholders to integrate these standards into practitioner competencies and training programs. Additionally, health services should be required to include improved performance on addressing women's pain in their Statements of Priorities.

3. **Require health services to implement consumer advisory groups and feedback mechanisms relevant to women's pain**

It is recommended that the Victorian Government collaborate with health services to ensure their consumer engagement and feedback mechanisms effectively capture and address concerns raised by women. This data should be aggregated and used to inform service redesign. Consumer advisory groups should be involved in co-designing services that address the diverse needs of women who experience pain. Additionally, health services should partner with and listen to grassroots women's health services in their region as a critical enabler to support gender responsive, accessible and culturally safe healthcare provision.

4. **Improve access to and quality assurance systems relating to interpreters**

It is recommended that additional investment be made to expand the number of qualified interpreters, including women interpreters, to meet the needs of changing demographics and newly arrived refugee and migrant communities. Health service requirements for interpreter services should be monitored with improved evaluation and quality assurance systems. Women must be able to confidently report instances of poor practice.

5. **Increase investment in long-term place based primary prevention for women who experience marginalisation, discrimination and disadvantage**

It is recommended that the Victorian Government invest in women's health promotion programs and initiatives to prevent women's pain before it occurs. Place-based approaches, co-designed with women across the life-course, are essential for building health literacy and improving understanding of health services. Programs should be gender-sensitive, delivered in-language, and accessible to women with disabilities. Additionally, primary prevention initiatives, including the prevention of violence against women and the improvement of women's mental health and wellbeing, are necessary to further prevent the disproportionate rates and impact of women's pain.

6. **Reduce the cost of services and expand women's access to alternative medicines and allied health services to mitigate the impacts of women's pain**

It is recommended that the Victorian Government work with the Federal Government to ensure that women's pain diagnosis, treatment, and care models are culturally appropriate, accessible, and publicly funded. Additionally, traditional and alternative medicines should be considered for Medicare inclusion, and Medicare subsidies expanded to cover greater access to allied health services to help reduce women's pain. Greater government subsidies for preventive health activities, such as exercise programs, sports clubs, and exercise classes, should also be provided, including options that are accessible outside of working hours and that offer childcare services and women-only activities.

7. Strengthened requirements for Gender Impact Assessments

It is recommended that the Commission for Gender Equality has strengthened compliance powers to enforce Gender Impact Assessments and improve the health system's capacity to fully implement the *Gender Equality Act 2020.* This includes requiring all defined healthcare entities to conduct and apply Gender Impact Assessments to all policies, programs, and services that have a significant and direct impact on the public. This measure ensures that health services consider how their services impact people of different genders and respond to the diverse needs of women, men, and gender-diverse people.

Appendix One – Women's Health Services Network, Submission to the Inquiry into Women’s Pain

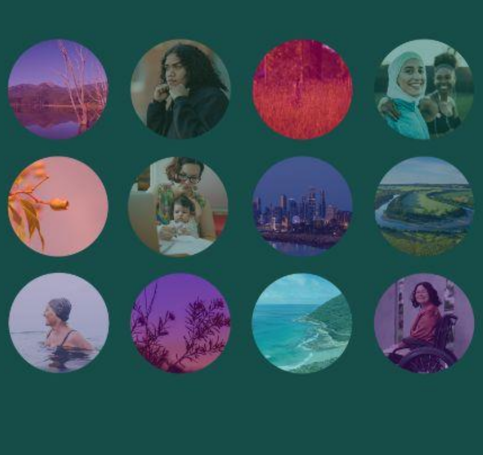
Women's Health Services Network

Submission to
Department of Health

Inquiry into Women's Pain

A response from the Victorian Women's Health Services

July 2024



The Victorian Women's Health Services Network acknowledges the wisdom, continuous living culture and connection to the lands and waterways held by the Traditional Custodians of the unceded lands on which we work, and acknowledge the profound disruption of colonisation and the Stolen Generations on Aboriginal and Torres Strait Islander peoples.

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The Victorian Women's Health Services Network

The Victorian Women's Health Services Network (WHSN) is a collective of the 12 state government-funded women's health services, leading gendered health promotion, primary prevention and intersectional gender equity initiatives across Victoria. With particular attention to addressing the social determinants of health, the WHSN uses evidence-based research to support legislation, policy and programs that ensure women and gender diverse people stay well, and if they do need to access healthcare services, that they receive the care that supports their return to health. This unique infrastructure and reach supports the WHSN to implement initiatives across the regions to embed gender equity and contribute to the health and wellbeing of Victorians.

Our network:

Statewide

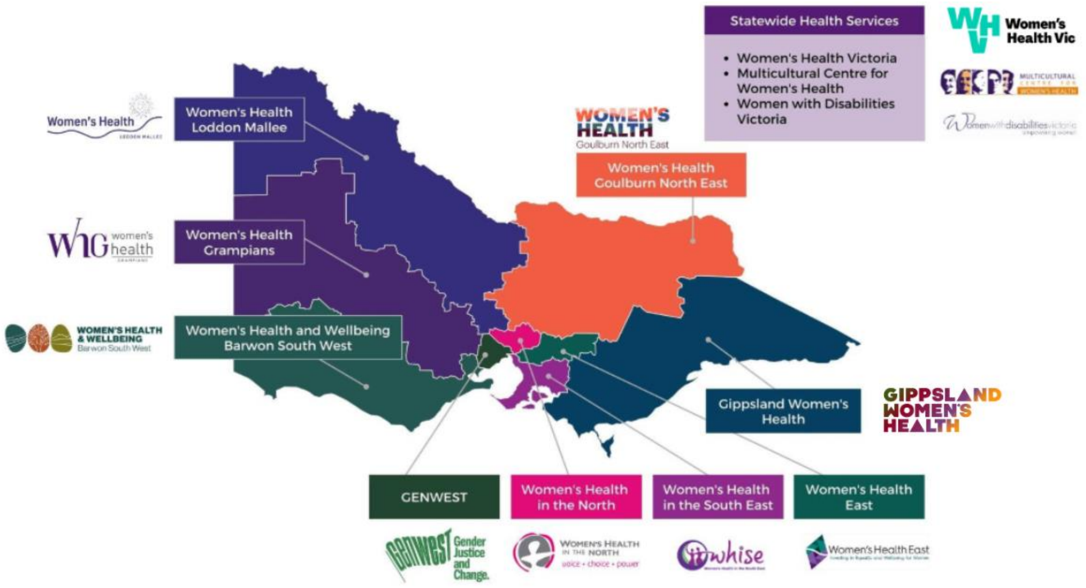
- Women's Health Victoria (WDV)
- Women with Disabilities Victoria (WDV)
- Multicultural Centre for Women's Health (MCWH)

Metropolitan

- Women's Health in the South East (WHISE)
- Women's Health in the North (WHIN)
- Women's Health East (WHE)
- Gen West

Rural

- Women's Health and Wellbeing Barwon South West (WHWBSW)
- Women's Health Goulburn North East (WHGNE)
- Women's Health Loddon Mallee (WHLM)
- Women's Health Grampians (WHG)
- Gippsland Women's Health (GWH)



Introduction

The Women's Health Services Network (WHSN) welcomes the opportunity to make a submission to the Inquiry into Women's Pain. As a group of organisations focused on the health and wellbeing of women and gender diverse people across Victoria, the WHSN is committed to contributing its expertise to the continual improvement of a gender equitable health system, including a more holistic view of how 'care' is delivered and experienced. Through making this submission, the WHSN shares insights gleaned through community consultation, place-based research and decades of experience in applying an intersectional and gender lens at the policy and practice level within a range of settings.

We conducted 10 community consultations in response to the Women's Pain Inquiry across four regions in regional and metropolitan Victoria. This is in addition to a number of recent community consultations around sexual and reproductive health running immediately prior to the Inquiry, including three focus groups and two online surveys which were open across two regional Victorian locations. The WHSN has considerable experience across 30+ years of regional and statewide health promotion and advocacy for women's health. Our recommendations in this submission are underpinned by lived and living experience (captured in the sections titled 'What we heard'), and a deep understanding of how the social determinants of health sit alongside biomedical factors in influencing experiences with chronic pain and ill health, as well as service navigation and accessibility.

What this means to us is that addressing the gender pain gap is about more than pain - it is about acting to dismantle the underlying systemic and cultural inequities that make it permissible to minimise, dismiss and override women and gender diverse people's lived experience. It is about taking a broader, holistic approach to addressing the barriers to equitable, quality healthcare and supporting services, taking into consideration the demography, infrastructure and place-based needs of remote, rural, regional and metro communities. These issues span the breadth of the healthcare system, with both external and internal impacts – that is, the social determinants of health and existing inequities affect health care recipients and workforce alike.

Our submission aligns with the Inquiry's Terms of Reference, providing evidence-based recommendations to address how women and gender diverse people's experiences of pain are shaped. The WHSN emphasises the importance of taking a collaborative and coordinated approach to achieving gender and intersectional equity in healthcare. This involves all levels of government in Victoria working together with the broader healthcare system, health promotion, and community organisations. By leveraging relationships and existing infrastructure, including the 12 Women's Health Services embedded in communities across Victoria, there is an opportunity to reshape the narrative of women's and gender-diverse people's pain.

A fundamental question within our submission and one that begins our substantive response, is how do we define pain and who is privileged with setting that definition? Chronic pain encompasses both physical and mental/emotional symptoms – both of which are subject to a gender bias when under medical and social scrutiny. The myriad causes of chronic mental and emotional pain contain deeply gendered elements that must be examined through an intersectional lens, including gender-based violence, intergenerational trauma, experiences of cultural or linguistic exclusion and the ongoing impacts of colonisation. Experiences with acute pain too, have been cited by women and gender diverse people during consultation, as incurring a similar gender bias to chronic pain, in as much as it is routinely dismissed or written off as unimportant during procedures like IUD insertion or during commonly occurring reproductive stages like the perinatal period or menopause. Feeling unsupported through acute pain can have lingering impacts of trauma and create avoidance in seeking future treatment. Based on these reflections and our consultations with women and gender diverse people, we developed the following definition of 'pain' to inform this submission.

What do we mean by Pain?

The WHSN defines pain as a complex and multifaceted experience recognised in health practice as a sensory and emotional response to actual or potential tissue damage. Informed by community consultations, this comprehensive definition acknowledges that pain can originate from various sources, including:

1. **Physical Illness, Disease, and Injury:** Pain stemming from acute or chronic conditions, infections, inflammations, injuries, or surgical interventions. This type of pain often has identifiable physiological origins and can be categorised as nociceptive or neuropathic pain.

2. **Trauma, Mental Illness, and Family Violence:** Pain arising from psychological trauma, mental health conditions, emotional distress, and experiences of family violence. This type of pain may not have a clear physical cause but is nonetheless real and impactful. It includes pain associated with conditions such as depression, anxiety, post-traumatic stress disorder (PTSD), and other psychiatric disorders, as well as the specific emotional and physical pain inflicted by family violence (Landi *et al*., 2023).

Furthermore, pain can be prolonged and exacerbated by poor social determinants of health, including inadequate access to healthcare, poverty, racism and discrimination, lack of education, and unstable housing. These factors contribute to health disparities and can intensify the experience of pain, making it more challenging to manage effectively. Research indicates that individuals living in socioeconomically disadvantaged conditions are more likely to experience chronic pain and have less access to pain management resources (Marmot, 2005; Wilkinson & Marmot, 2003). Effective pain management requires addressing both the physiological and emotional aspects of pain through interdisciplinary strategies, including medical, psychological, and recovery interventions, with particular attention to the unique challenges faced by women experiencing pain related to family violence and the impacts of adverse social determinants of health.

Our submission and recommendations address the following topics:

1. Listening to local voices

Co-Design Health Policy

Future health policy must be co-designed with the lived and living experiences of women and gender diverse people. This participatory approach ensures that intersectional barriers are recognized and addressed, and that community priorities are valued. Engaging directly with those most affected is essential for creating equitable and effective health policies.

2. Engaging clinicians and strengthening gender equity in the health workforce

Strengthen Gender Impact Assessments

The Victorian Government must strengthen the enforcement of the existing requirement for Gender Impact Assessments. This involves enhancing the capacity of the health system to fully implement the Gender Equality Act. All healthcare providers should be required to effectively integrate gender considerations into their practices and policies, ensuring a systemic and consistent approach to gender equity in healthcare.

3. Research and training

Develop Best-Practice Guidelines

We advocate for the development and resourcing of best-practice guidelines to embed gender equity in research, funding policy, and medical curricula. These guidelines should be informed by the latest evidence and tailored to the unique needs of women and gender diverse people. Ensuring that gender equity is a foundational element in these areas will promote more inclusive and effective healthcare solutions.

4. Service delivery and referral pathways

Increase Access to Care

Increasing access to primary care and specialist services is crucial. The Victorian Government should support and incentivise the healthcare workforce through upskilling, resourcing, and expanding integrated, holistic, patient-centered, trauma-informed care across the state. This approach will ensure that all individuals receive comprehensive and compassionate care, particularly in managing chronic pain.

5. Health promotion and education

Invest in Women's Health Services

Investment in existing infrastructure, such as the Victorian Women’s Health Services, is essential. We call for funding a state-wide program of work that aims to prevent poor health outcomes for women and gender diverse people and increase health equity statewide.

Recommendations and alignment to Terms of Reference (TOR)

LISTENING TO LOCAL VOICES **1. Future health policy should be co-designed with lived and living experience of women and gender diverse people, ensuring intersectional barriers are recognised and addressed and that community priorities are valued.**	**TOR A & B**
1.1 The Victorian Government must develop health policy that comprehensively targets health services for women who have experienced family violence, particularly in addressing their pain-related health issues. 1.2 Expand collaboration with place-based, specialist organisations to leverage relationships and tailor consultation approaches to ensure a truly representative cross-section of the community has the opportunity to participate and inform the Inquiry. 1.3 Include variated consultation approaches to reach underserved communities that address digital inclusion/digital literacy. 1.4 Engage specialist migrant and refugee women's health services to lead the co-design of service options through active outreach and consultation by bilingual and bicultural staff. 1.5 Consider developing place-based needs assessments based on lived experience.	
ENGAGING CLINICIANS AND STRENGTHENING GENDER EQUITY IN THE HEALTHCARE WORKFORCE **2. The Victorian Government should strengthen the enforcement of the existing requirement for Gender Impact Assessments and enhance the capacity of the health system to fully implement the Gender Equality Act. This includes ensuring all healthcare providers effectively integrate gender considerations into their practices and policies.**	**TOR B & C**
2.1 Advocate to the Federal Government to create national legislation for gender-inclusive reproductive leave via both modern awards and in National Employment Standards. 2.2 Build the capacity of health service leadership to foster gender-equitable workplace cultures by allocating appropriate resources and improving understanding and motivation through targeted leadership development initiatives. 2.3 Utilise existing gender equality legislation and structures (e.g. Victorian Gender Equality Act) to build norms such as flexible working arrangements and reproductive leave entitlements for healthcare workers into gender equality action plans.	

2.4 The Victorian Government must urgently address the prevalent implicit and explicit bias in the Victorian health system that prevents women's pain being taken seriously. This needs to be done through a targeted and comprehensive strategy inclusive of:

- Training and Awareness: Work with education providers (e.g. universities, colleges, professional associations) to implement training on gender responsive practice as a standard part of pre/post service health and medical education and training.
- Standardised Protocols and Advocacy: Implement standardised and gender and culturally responsive pain assessment protocols and establish patient advocacy services within healthcare institutions.
- Accountability Mechanisms: Introduce monitoring and reporting systems, performance metrics, and ensure compliance with anti-discrimination laws.
- Support for Women's Health Services: Increase funding for women's health services and promote integrated care models, including a permanent, state-wide multilingual health education infrastructure that delivers in-language health and wellbeing education and support programs across Victoria, including rural and regional areas.
- Stakeholder Engagement: Collaborate with women's health organisations and community stakeholders to inform and assess the strategy.

RESEARCH AND TRAINING

TOR D, E & F

3. The Victorian Government should advocate for the development and resourcing of best-practice guidelines to embed gender equity in research, funding policy and medical curricula.

3.1 Advocate to the Federal Government to transform health funding to be strategically equity focused on women's health, including funding for clinical trials particularly on pelvic pain and menopausal depression.

3.2 Advocate to tertiary institutions, research funding bodies and academic journals to adopt guidelines to embed gender equity in the academic field of medicine and to better represent sex and gender as core elements of medical curricula.

3.3 Work with health and medical education providers to ensure sexual and reproductive health (SRH) and women's health form a core subject of medical study at the tertiary level, and to provide opportunities for upskilling and training for healthcare providers in the area of women's health.

3.4 Advocate for the development of a national standards and competency framework for pain management education which includes the differences, inequalities and varying needs of people of all gender identities.

SERVICE DELIVERY AND REFERRAL PATHWAYS **4. Increase access to primary care and specialist services by supporting and incentivising the healthcare workforce through upskilling, resourcing and expanding integrated, holistic, patient centred, trauma informed care across Victoria.**	**TOR C, D, E & F**
4.1 Advocate to the Federal Government to address Medicare gaps including subsidies for women's health and dentistry and the lack of Medicare coverage for non-citizens or permanent residents, as well as increase rebates for longer consultations/management of complex care. 4.2 Allocate resources for support, treatment and interpreting services that are affordable and available to all migrants and refugees, irrespective of their visa status. 4.3 Utilise the existing and planned SRH hubs and women's clinics to expand access to train the trainer opportunities across Victoria, as well as increased access to tailored, culturally responsive healthcare for women experiencing chronic pain. 4.4 Improve access to diagnostic and treatment services across Victoria, with attention to incentivising services to offer bulk billing. 4.5 Increase rural and regional access to services by prioritising an 'infrastructure of care' that creates pathways for women and gender diverse people to timely, cost effective access to services - including telecommunications, transport, community outreach and translation and interpreting services. 4.6 Improved referral pathways (including mental health services and community support) and greater integration of healthcare services to provide greater access to holistic care. 4.7 Upskilling for healthcare providers around patient centred care, including trauma informed care, size inclusive practice and cultural safety including for women who have experienced female genital cutting.	
HEALTH PROMOTION AND EDUCATION **5. Invest in existing infrastructure such as the Victorian Women's Health Services to fund a state-wide program of work that works to address stigma and increase health literacy in the area of chronic pain through an intersectional lens.**	**TOR F**
5.1 Provide sustainable funding for all parts of the WHS and maximise the expertise, use and impact of this unique service in Victoria - including its reach statewide and place based approach - to effectively implement ongoing reforms of government to advance equity in our health system. 5.2 Make use of the breadth and depth of data and evidence that comes through the work of the Victorian Women's Health Services to understand how services	

and funding are best placed in the region, across settings, places and key population groups. 5.3 Scale up and fund universal early secondary school education, in pelvic pain, from both external providers and school staff. 5.4 Integrate pelvic pain into the curriculum for sexual health and education (pelvic pain) - education to encompass a holistic view of pelvic health and broader health and engage boys to break down stigma associated with menstruation.	

Listening to local voices

***Recommendation 1:** Future health policy should be co-designed with lived and living experience of women and gender diverse people, ensuring intersectional barriers are recognised and addressed and that community priorities are valued.*

Realising the rights of all people to access healthcare and live a life free of bias and discrimination requires that diverse voices are heard from across the community. Opportunities to actively participate in decision making processes around policies and practices that impact people's lives are essential to fostering an equitable, person centred health system that prioritises care, respect and equality. This section will look at three areas identified by women through community engagement activities conducted by organisations within the WHSN: Broadening the definition of pain to better reflect women's experiences, recognising the additional barriers faced by women in rural and regional areas and the imperative of understanding women's pain in the context of gender-based violence.

Why a broader definition of pain is needed

What we have heard:

Member organisations of the WHSN routinely engage our communities around health and wellbeing, including those factors driving poor healthcare experiences for women and gender diverse people with chronic and acute pain. Through Round Tables with women in community, Women's Health in the South East (WHISE) has revealed that a key challenge for the Inquiry to address is the need to think of pain beyond the clinical, physical definition - for example, mental pain as a symptom of depression, or through loneliness, grief and trauma. We know that experiences of persistent pain are associated with mental ill-health - according to Pain Australia, people living with chronic pain have higher rates of mental illness and suicide, including a 30-40 per cent overlap of people diagnosed with major depression and presenting for chronic pain (Bennett, 2020), but it is also important to distinguish that mental or emotional pain is in itself an oftentimes debilitating, pervasive and life-threatening form of pain (Landi *et al.*, 2023).

Further consultation would benefit from broadening the scope of inquiry to gendered experiences of chronic mental and emotional pain within the healthcare system. It should also seek to look at how mental and emotional pain can manifest itself as physical pain (neural pathway pain).

While the main focus of the Inquiry has been on chronic pain (often defined as pain experienced for a period of three months or longer), women told us that they have had multiple experiences of being dismissed when experiencing acute pain, which can also lead to mental distress, mistrust of the healthcare system and lingering trauma, as well as future health-seeking behaviours that delay treatments. From the Long Story Short project:

"I waited in emergency for several hours in the middle of the night without being seen. I left as my pain had subsided and no one could tell me how much longer to wait. Another time, after waiting hours and vomiting in the waiting room bathrooms multiple times, I was told by a male doctor that 'sometimes pregnancy can be uncomfortable' and sent home."

Further consultations would benefit from ensuring women who have had distressing or traumatic experiences with acute pain in the healthcare system are provided an opportunity to tell their stories.

Rural and regional access

What we have heard

Through the Storylines (2018-19) and Long Story Short (2022-24) project, women from Goulburn North East and Loddon Mallee confirmed what the Inquiry has heard from individual women - that their pain is devalued and minimised due to their gender. One participant told us:

"The system is so broken. Especially for people experiencing chronic conditions like endometriosis, not being believed, being gaslit."

Geographically, these experiences are exacerbated by the structural and systemic barriers to accessing healthcare and other supporting services for people living rurally, remotely and regionally. During consultation in Goulburn North East, we heard this sentiment repeated often:

"Living regionally obviously, things that are available to us aren't as great as what is available in the cities, and yeah – through my experiences, I have had to travel to get the care that I've needed."

"Travelling to Melbourne is just too hard when I work full time. It causes me anxiety because I worry that I'm not up to date with my checks."

The barriers to accessing timely, affordable, quality services persistently facing women and gender diverse people living rurally and regionally have been identified consistently by all five of the rural women's health services, covering the breadth of Victoria.

This includes socioeconomic factors, inadequate infrastructure, 'service deserts' and digital exclusion. While innovative solutions like online, telehealth and outreach services have increased access to healthcare, there are still significant barriers to uptake impacting regional and rural communities. Patients who live rurally and access specialist healthcare services will often travel hundreds of kilometres and potentially wait months for a referral to even be triaged. For those without their own transport, with primary care responsibilities, inflexible employment or living with disability, these structural barriers can mean the difference between getting treatment and living in pain.

Women also told us that quality of care and access to services are significantly reduced by a lack of cultural safety, and if supporting services are not available. These factors impact women across metro and regional areas, but can be compounded for women from bilingual and bicultural communities in regional areas, where interpreting service availability can be limited:

"*And when I have a barrier of maybe English not being my first language and trying to explain, or my identification, or my race, I'm very vulnerable at that time, all I need is health. And that's the only important thing to me. But depending on other factors behind that, it affects the service."*

Access issues are further exacerbated as women and gender diverse people living in rural areas, older cohorts, and people from lower socioeconomic backgrounds and facing housing insecurity, can have limited access to the internet. Further barriers include lower educational attainment and poor digital literacy. This impacts the ability to access online services, book appointments and find information about travelling services. Significant gaps in digital inclusion between rural and metro areas still impact social isolation and opportunities to participate in public life - compounded by factors like age and income - with research suggesting that increasing digital inclusion for First Nations people began to stall during the COVID-19 pandemic (Thomas *et al*., 2020).

Therefore, it is crucial to consider improving infrastructure across Victoria as a contributing factor to improving experiences seeking care for chronic pain - public transport, telecommunications, housing and services.

Gender-based violence and pain

What we have heard

Family violence has significant and wide-ranging effects on women's health, particularly in relation to their experience and management of pain. Australian research provides compelling evidence of these impacts. Through our engagement with community for this inquiry, and also throughout all our work, the Victorian Women's Health Services have heard first hand the long term health impacts - including pain - on women because of intimate partner violence, domestic violence and sexual assault. This has ranged from increased anxiety and long term mental illness including PTSD carried by women, acquired brain injury, and also long term impacts on women's bodies due to stress and trauma. Through the engagement we have also learnt of one woman who is in the process of losing her sight as a direct result of being a victim of family violence.

Physical Health and Pain

1. **Physical Injuries:** Women who experience family violence are at higher risk of sustaining physical injuries that can lead to both acute and chronic pain. The Australian Institute of Health and Welfare (AIHW) reports that 1 in 6 Australian women has experienced physical or sexual violence by a current or former partner since the age of 15 (AIWH, 2018).

2. **Pain, Intimate Partner Violence and Women with Disabilities:** Recognising higher prevalence of family violence for women with disabilities, a 2021 retrospective study found that family violence is linked to health problems in women with disabilities including chronic pain, frequent headaches and difficulty sleeping, (Ballan, Freyer and Romanelli, 2022).

Mental Health and Pain

1. **Psychological Stress and Pain Sensitivity:** The psychological trauma associated with family violence can increase pain sensitivity and reduce pain tolerance. This phenomenon, known as central sensitization, makes survivors more vulnerable to chronic pain conditions. A systematic review and meta-analysis found that women who experienced any type of violence showed 2 times greater odds of developing chronic pain (Uvelli *et al*., 2024).

2. **Post-Traumatic Stress Disorder (PTSD):** PTSD, which is commonly diagnosed among survivors of family violence, is associated with somatic symptoms including pain. Australian studies have documented a high prevalence of PTSD among women who have experienced family violence, contributing to their overall pain burden. (AIHW, 2024)

These findings underscore the need for comprehensive support and targeted interventions for women who have experienced family violence, particularly in addressing their pain-related health issues.

Sub-recommendations

1.1 The Victorian Government must develop health policy that comprehensively targets health services for women who have experienced family violence, particularly in addressing their pain-related health issues.

1.2 Expand collaboration with place-based, specialist organisations to leverage relationships and tailor consultation approaches to ensure a truly representative cross-section of the community has the opportunity to participate and inform the Inquiry.

1.3 Include variated consultation approaches to reach underserved communities that address digital inclusion/digital literacy.

1.4 Engage specialist migrant and refugee women's health services to lead the co-design of service options through active outreach and consultation by bilingual and bicultural staff.

1.5 Consider developing place-based needs assessments based on lived experience.

Engaging clinicians, workforce gender equity

Recommendation 2: *The Victorian Government should strengthen the enforcement of the existing requirement for Gender Impact Assessments and enhance the capacity of the health system to fully implement the Gender Equality Act. This includes ensuring all healthcare providers effectively integrate gender considerations into their practices and policies.*

Achieving gender equality is a goal which requires a broad, societal effort. The Victorian Government is a leader in developing and implementing innovative policy to realise gender equality, across a range of systems and settings. This section will address the need for a gender equal healthcare workforce to build the capacity of the sector to provide care and offer services through a gender lens, via the existing mechanisms within the Gender Equality Act. Again, we have included the lived-experience of women to strengthen and humanise this evidence - this time of women working in the healthcare sector. The section will further examine the impacts of workplace gender bias on patient care and the treatment of women's pain and the specific issues facing rural, regional and metro workforces.

Gender equity in healthcare

What we have heard:

Too often, through the engagement for this Inquiry, the Victorian Women's Health Services heard how women were treated glibly, their pain dismissed or their health needs outright ignored. The women that we spoke to described how they had been told to "shush" and "quieten down" during childbirth, that they were "imagining it" when they were trying to get a diagnosis on a painful back (and it turned out to be a fracture) and *countless* women told us how they are often told to "Take a panadol and go home." These deeply gendered experiences extend to women working within the healthcare sector.

We've heard first hand stories of women who work in the medical profession being told to adhere to the 'code of silence' when it comes to being aware of sexual harassment and or sexual assault being perpetrated by male medical practitioners. We've heard stories of women who have not done so, who have been bullied out of the profession for not adhering to the 'brotherhood' code. Other women in the medical profession have told us that they face barriers to opportunities like professional development, upskilling and networking due to a lack of flexibility or consideration for the dual role of professional and primary carer.

In spite of legislation and policies eschewing discrimination based on gender across the healthcare sector, a gender bias exists at an institutional and cultural level in many workplaces.

This has ramifications on quality of care for women experiencing chronic pain conditions, with many rural healthcare professionals citing a lack of accessible training opportunities around IUD insertion in the Goulburn North East and Loddon Mallee regions, for example. This is the case for practitioners across regional Victoria - outside of metropolitan Melbourne, only two options exist for IUD training to serve the entire state - those offered by Sexual Health Victoria and the Royal Women's Hospital. Women and gender diverse people are in turn impacted by a lack of gender equity in the healthcare workforce. Numerous consultees raised the need for more women doctors in rural and regional areas, citing better overall experiences with quality of care for gender-specific healthcare concerns. From WHGNE and WHLM's Long Story Short project:

> *"I really struggle to feel comfortable when seeing a male doctor."*
>
> *"We need more women doctors with long-term tenures."*

It is crucial to incorporate the lived experience of women and gender diverse healthcare workers in strategies to ameliorate gender bias within the medical field.

Applying a gender lens to healthcare workforce

Female doctors routinely experience bias, workplace harassment, disproportionate responsibility for non-medical tasks, as well as being underrepresented in leadership positions. Women are leaving, or planning to leave teaching hospitals at higher rates than male doctors across career stages (Cheung, 2023). This in turn impacts patients - both through a gender imbalance in teaching and mentoring other doctors and because research shows that female doctors are more likely to practice patient-centred care and record lower mortality and readmission rates (Liu, Obuobi and Gulati, 2023). Qualitative data collected by two regional Women's Health Services shows a significant desire among women to have increased access to female doctors - largely due to the perception that they are more knowledgeable about women's health and more likely to practice compassionate, patient-centred care for sexual and reproductive health concerns, including chronic pain.

Structural initiatives that may address the consequences of implicit gender bias in the medical profession include(Hui, *et al*., 2020):

- application blinding
- increased diversity on selection and planning committees
- critical examination of biased language in teaching, evaluation, nomination and selection processes
- support with flexible child care

Recently, individual organisations have begun to implement menstrual and/or menopause policies which include leave entitlements and flexible work arrangements for persons managing symptoms, including pain, or needing clinical support. There is limited research on the effect of these policies on organisations and people experiencing reproductive health issues within a healthcare context. However, paid reproductive health leave policies such as that recently introduced by the Victorian public service, recognise the social and financial pressures experienced by people with conditions like endometriosis and adenomyosis, and provide an alternative to requiring people to deplete their personal leave for issues that may be chronic rather than acute in nature. A lack of support has significant effects on lives, including loss of income and superannuation, as well as the need to take early retirement or lower paid roles. This may also contribute to high attrition rates among women within the health care sector.

Given women comprise 78.5% of the healthcare and social assistance workforce (WGEA, 2023), there are opportunities to acknowledge the specific health experiences of people who menstruate and who may experience associated pain within this industry.

Rural and metropolitan specific contexts

What have we heard

Healthcare professionals working in rural and regional settings face additional barriers in supporting their communities to achieve optimal health and wellbeing. Recent consultations with healthcare providers in the Goulburn North East and Loddon Mallee regions indicate that structural issues impact the capacity of the workforce to undertake training and professional development in the area of sexual and reproductive health, with travel, cost and metro-bias cited as perceived barriers - for example, the minimal opportunities for IUD insertion training for rural and regional practitioners mentioned above. As the first port of call for most people when seeking medical advice, it is particularly important that rural and regional GPs have access to capacity building, upskilling and professional development opportunities to better identify pain conditions in women.

Metropolitan regions also experience a unique set of challenges, with large variations often seen within a region. In some areas, there are high percentages of women from different cultural groups trying to access a predominantly mainstream system that doesn't take into account cultural considerations. There is research to suggest that both race and gender influences pain management in healthcare settings (See for example: Hampton, Cavalier and Langford, 2015). Migrant and refugee women are known to receive disproportionately poorer quality of care - this may be due to provider and systemic bias, including a lack of training and support to deliver culturally safe care and address implicit bias.

In consulting health professionals, the WHSN feels it is crucial that the Inquiry also applies a rural/regional and intersectional gender lens over barriers facing the healthcare workforce.

Sub recommendations

2.1 Advocate to the Federal Government to create national legislation for gender-inclusive reproductive leave via both modern awards and in National Employment Standards.

2.2 Build the capacity of health service leadership to foster gender-equitable workplace cultures by allocating appropriate resources and improving understanding and motivation through targeted leadership development initiatives.

2.3 Utilise existing gender equality legislation and structures (e.g. Victorian Gender Equality Act) to build norms such as flexible working arrangements and reproductive leave entitlements for healthcare workers into gender equality action plans.

2.4 The Victorian Government must urgently address the prevalent implicit and explicit bias in the Victorian health system that prevents women's pain being taken seriously. This needs to be done through a targeted and comprehensive strategy inclusive of:

  - Training and Awareness: Work with education providers (e.g. universities, colleges, professional associations) to implement training on gender responsive practice as a standard part of pre/post service health and medical education and training.
  - Standardised Protocols and Advocacy: Implement standardised and gender and culturally responsive pain assessment protocols and establish patient advocacy services within healthcare institutions.
  - Accountability Mechanisms: Introduce monitoring and reporting systems, performance metrics, and ensure compliance with anti-discrimination laws.
  - Support for Women's Health Services: Increase funding for women's health services and promote integrated care models, including a permanent, state-wide multilingual health education infrastructure that delivers in-language health and wellbeing education and support programs across Victoria, including rural and regional areas.
  - Stakeholder Engagement: Collaborate with women's health organisations and community stakeholders to inform and assess the strategy.

Research and training

Recommendation 3: *The Victorian Government should advocate for the development and resourcing of best-practice guidelines to embed gender equity in research, funding policy and medical curricula.*

Addressing the barriers faced by women and gender diverse people in the treatment of their pain requires action to fill the knowledge gaps in medical research, curricula and course content, as well as the relevant funding policies. This section will examine the ways in which a lack of attention to biological sex and gender as determinants of health and pain across these areas have underserved women and medical professionals.

Increasing the knowledge base and expertise in women's health

What we have heard:

We have heard from women that primary care practitioners have sometimes displayed a lack of expertise around sexual and reproductive health, impacting their ability to receive timely diagnosis and treatment of pain. Women have told us about times that they have received limited or incomplete information around contraceptive options, pain relief and referral pathways. We have heard that women are more likely to bring up concerns around their health if they perceive their GP or other healthcare professional as having some knowledge for and interest in the area of women's health.

We have also heard first hand from young clinicians who have reported to us - through the process of engagement around the Inquiry - of their despair of not being educated in the fundamentals of female anatomy and biology to help them understand how to be equitable in their clinical care. As one young female medical student reported at a forum:

"The only reason that I know that women's bodies are different is because I have a woman's body. From my medical education you would never know it."

Improving and funding women and gender diverse people's health research

In spite of the generally effective efforts to close the gap in medical research on female bodies since the 1990s, there are still research areas in which a gender/biological sex bias limits women's access to equitable healthcare outcomes (See for example: Zucker and Prendergast, 2020). Research into best-practice care to address health and wellbeing outcomes for gender non-conforming patients is another area that, if better prioritised, would have potentially positive impacts on gender diverse people's experience seeking and receiving care for chronic pain. In recent years, Australian medical academics have called for research funding agencies and peer reviewed journals to improve their policies on the "collection, analysis and reporting of sex and gender specific health data", citing concerns that Australia was falling behind the international community in this area (The George Institute, 2019).

Policies that mandate the incorporation of sex and gender dimensions in health research are necessary to ensure that gender bias is addressed in government-funded research.

The Victorian women's health sector welcomed the Victorian Government's commitment in *Our equal state: Victoria's gender equality strategy and action plan 2023-2027* to require all Victorian Government-funded health and medical research to include proactive and routine consideration of sex, gender and gender diversity at all stages. However, to ensure that gender and sex are routinely included in more Australian health research, it is vital that the Federal Government also implements such a policy. It is recommended that the Victorian Government advocates to the Federal Government to require that all health research funded by Australian government agencies incorporates sex and gender at all stages. It is also important that this research includes an equitable number of male and female participants (or demonstrate why this is not required), and that all data is analysed by sex and gender where possible and reported on to improve knowledge gaps. This will increase our understanding of social and biological risk factors for health conditions and how to address them, supporting better targeting of prevention initiatives and treatments for women.

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Foundational training and academic curricula

Research into how biological sex, as well as gender as a social determinant of health, will impact the health of women and gender diverse people has particular relevance to the broader understanding of women's pain and how it manifests differently to men's. In addition to historical and contemporary gender bias within medical research, a gap exists within foundational training and education settings. At a policy level, institutions of higher learning in Australia have neglected to address sex and gender within medical curricula requirements, course outlines and assigned textbooks (Merone, Tsey, Russell and Nagle, 2024). Without framing women's health as a standard area of medical knowledge, and including it in all parts of medical curricula (beyond sexual and reproductive health and women's health specific subjects), deficiencies will continue to impact on women's experiences of pain in healthcare settings.

Embedding sex and gender differences in the identification of symptoms and treatment is crucial to improving the experiences and health outcomes of women and gender diverse people seeking care for chronic and acute pain.

Addressing knowledge gaps in women's intersecting healthcare needs

Education about gender bias

To improve the treatment of women who present with pain, it is vital that healthcare professionals are provided training to understand and address their own gender biases. Conscious and unconscious bias among health professionals significantly contributes to the gender pain gap, impacting the quality of care that women receive. Like all other Australians, health professionals are influenced by prevalent cultural discourses and stereotypes regarding gender. This carries significant implications for their treatment of female patients, particularly those presenting with pain. Research shows that the gender stereotype that women have a lower pain threshold than men influences how women who present with pain are perceived, often resulting in their pain being minimised or dismissed.

Provision of gender sensitivity training to health professionals is recommended to address these biases.

Gender-sensitivity, a key component of patient-centred care, refers to knowledge and understanding of the differences, inequalities and varying needs of people of all gender identities. It involves understanding the regularities of men's and women's morbidity, mortality and their individual experiences, stereotypes and preconceptions about gender that need to be avoided. Studies have found that gender sensitive training is effective at improving gender-related knowledge, attitudes and practice among medical practitioners (Lindsay et al).

Training, upskilling and workforce capacity building

Most health practitioners will be faced with managing individuals experiencing acute or chronic pain during their career. Graduates emerging from many Australian tertiary healthcare education programs do not have adequate knowledge, attitudes, and skills to effectively apply contemporary evidence-based pain management (ANZCA, 2023). It is estimated that up to 80 per cent of Australians living with chronic pain may be missing out on best-practice treatments (ANZCA, 2023).
All registered health care practitioners in Australia have a requirement to maintain their currency of knowledge and practice to support them in the delivery of safe and appropriate care.

Continuing professional development provides the opportunity to fill knowledge and skill gaps resulting from inadequate coverage of pain management, and specifically women's pain, in entry-to-practice and postgraduate education.

Sub recommendations

3.1 Advocate to the Federal Government to transform health funding to be strategically equity focused on women's health, including funding for clinical trials particularly on pelvic pain and menopausal depression.
3.2 Advocate to tertiary institutions, research funding bodies and academic journals to adopt guidelines to embed gender equity in the academic field of medicine and to better represent sex and gender as core elements of medical curricula.
3.3 Work with health and medical education providers to ensure sexual and reproductive health (SRH) and women's health form a core subject of medical study at the tertiary level, and to provide opportunities for upskilling and training for healthcare providers in the area of women's health.
3.4 Advocate for the development of a national standards and competency framework for pain management education which includes the differences, inequalities and varying needs of people of all gender identities.

Service delivery and referral pathways

Recommendation 4: *Increase access to primary care and specialist services by supporting and incentivising the healthcare workforce through upskilling, resourcing and expanding integrated, holistic, patient centred, trauma informed care across Victoria.*

Women and gender diverse people from across Victoria have engaged with the WHSN around their experiences accessing services for diagnosing and treating pain. From these lived experience perspectives we can gain insight into the barriers to receiving timely, effective care and pain management. We can also find the solutions embedded within, from increasing access to ensuring a quality of care that is patient centred and informed by up to date, best practice knowledge, relevant to Victoria's diverse communities. This section will provide the WHSN's community driven findings into the factors that influence women's experiences of accessing healthcare services for pain, and areas in need of improvement.

Navigating the healthcare system as a woman in pain

What we have heard:

Through the forums and conversations held by the WHSN for this submission and other consultations, we heard first hand the challenges faced by women and gender diverse people when seeking care for their pain. The stories from women reveal several concerning themes:

Accessibility and Service Navigation: We heard of the many barriers to accessing primary and specialist services, including cost, wait times, inadequate appointment times, the need to travel and limited availability. Women told us that referral pathways are often inadequately explained or known by primary care practitioners and that there is a need for greater connection and communication between healthcare, therapeutic and social support services.

Lack of Empathy and Dismissal: Many women reported encounters with healthcare providers who demonstrated little to no empathy towards their pain experiences. This lack of understanding often left women feeling unsupported and isolated in their struggles. A common experience among women was feeling "fobbed off" or having their pain concerns dismissed by healthcare providers. This dismissal often resulted in delayed diagnoses and inadequate treatment.

Disrespect and Gender Bias: Women frequently described instances of disrespect from clinicians, often rooted in gender bias. They reported being labelled with dismissive terms like "nervous Nellie" or being characterised as overly emotional or hysterical. Some women were told their pain was "all in their heads," undermining the legitimacy of their experiences.

A recurring theme in women's stories was the critical importance of self-advocacy. Many women found that assertively advocating for themselves was essential to receiving appropriate care and effective pain management. On this last point the WHSN notes that the capacity to self-advocate is for those women in our community who are privileged enough to be able to do this and for many women, this is not a tool that they can employ – because of the intersecting barriers of discrimination and oppression that they face.

It is therefore imperative to address those factors preventing women and gender diverse people from experiencing optimal health and wellbeing across Victoria at a systemic and structural level.

Access to services

What we have heard

Primary care is usually the first port of call for women when seeking treatment for pain. The WHSN has heard that access to GPs in rural and regional areas is often impeded by clinics that are not taking new patients and long wait times in some areas. Wait times are particularly problematic for women who require an interpreter, as a GP appointment must match up with interpreter availability. While the Sexual and Reproductive Health Hubs opening around Victoria have offered improved access for women experiencing some pain conditions associated with sexual and reproductive health, many of these hubs do not currently have the resources to offer full time services and can be reliant on the availability of a prescriber to offer certain of their services.

Best-practice pain care ideally involves a multidisciplinary approach that is timely, personalised, and consistent with current guidelines. Multidisciplinary pain management clinics are most commonly located in the public sector and urban-based (ANZCA, 2023). Demand continues to exceed availability and most services are located in metropolitan areas with services limited or completely lacking in regional, rural, and remote areas of Australia.

The Victorian Government investment in the network of 20 Women's Clinics and Sexual Health Hubs provides an opportunity to build capacity for best-practice women's specific pain care approaches including train-the-trainer and community-based mentoring.

Many women expressed that their various healthcare providers are siloed, leading to further wait times, miscommunication, stress and confusion. Some women have expressed frustration around a lack of knowledge and communication from primary care practitioners when it comes to referral pathways or other treatment options. Women also cited the dwindling number of GPs who offer bulk billed appointments as a further barrier to access in both metro, regional and rural areas. The financial burden of healthcare is significantly increased when a chronic pain condition requires recurring treatment by a specialist, with Medicare rebates often leaving eligible patients considerably out of pocket - and in the case of treatment for dental pain without Medicare coverage at all. When GPs are able to manage pain without referral, financial barriers and time pressures are still impacting service delivery.

The length of appointment times has been identified as a barrier to accessing adequate care for pain conditions. Often treating pain requires longer appointments, resulting in higher costs. The funding model discourages longer appointment times, as GPs are incentivised to fit complex care into 10-15 minutes. Longer appointments are necessary to manage pain conditions and support multidisciplinary management and coordination of care across the health system. Longer appointments are not affordable for patients (lack of bulk billing providers, high out of pocket cost relative to rebate when seeing non-bulk billing providers). A lack of bulk billing or minimal patient rebates disproportionately impacts women, particularly in rural and remote areas. This is because women use more GP services than men and have longer appointments (RACGP, 2023).

Therefore, in order to improve factors limiting access, like cost, availability in rural areas and appointment times, a social determinants of health approach should inform healthcare policy reform, including the prioritisation of prevention strategies.

Quality of care

What have we heard

Through community consultations it is clear to the WHSN that reforms designed to embed patient centred care in the Victorian health system must be made a priority. These measures are fundamental to all aspects addressed within this submission - training and education, health promotion and research - because all of these elements will enable a patient centred approach at the core of service delivery, which will in turn improve women's experiences seeking care for chronic and acute pain. This encompasses culturally safe, trauma informed, intersectionality aware care that considers the psychosocial wellbeing of a patient as well as their biological health. Of course, with the understanding that healthcare professionals are often time-poor and overloaded, a patient centred approach can only be truly realised in alignment with systemic and structural improvements to enable healthcare providers to support patients in a more holistic sense.

This is why structural support for healthcare providers to embed gender and intersectional equity within policy and practice, develop relationships to ensure more accessible referral pathways, access training, professional development and incentives to build capacity in the area of women's health and wellbeing must accompany more interpersonal quality of care improvements. For example, ensuring practitioners understand the importance of size inclusive practice, the mental health impacts of chronic and acute pain and how to provide care that is sensitive to lived experience of war, sexual assault, violence and trauma. Moving towards greater integrated primary care models and closer connections between healthcare and therapeutic practitioners, community support and assistance to enable better pain management outside of medical settings and addressing the medical misogyny that informs dismissive attitudes and underdeveloped knowledge of women's specific health concerns is recommended by the WHSN.

Culturally appropriate care and expertise

Female genital cutting

Female Genital Mutilation/Cutting (FGM/C) is a complex and sensitive subject, therefore it is important that medical practitioners and other health professionals engage in culturally appropriate conversations with women and girls who have experienced FGM/C. There are many consequences of FGM/C including a number of complications causing acute and chronic pain, like recurring urinary and kidney infections, cysts and absesses, sexual disfunction and prolapses, as well as social and psychological impacts (MCWH, 2021). However, there is limited knowledge among health professionals about FGM/C, its impacts on women who have experienced the practice, and how to work with communities who have experience with FGM/C prior to arriving in Australia. Multicultural Centre for Women's Health (MCWH) manages the National Education Toolkit for Female Genital Mutilation/Cutting Awareness (NEFTA) program, which aims to increase understanding and support for women who have experienced FGM/C.

Drawing on the expertise and extensive experience of MCWH in addressing the impacts of FGM/C through NEFTA would benefit the healthcare workforce in better understanding these issues.

Victoria's Family and Reproductive Rights Education Program (FARREP) is another initiative that aims to prevent the practice of FGM/C and support the health and wellbeing of women and girls who have undergone this practice prior to their arrival in Australia. FARREP provides community education as well as professional development training for health professionals on culturally appropriate care for women and girls who have experienced FGM/C.

Efforts to address the needs of affected communities and women who have experienced or are at risk of experiencing FGM/C need to be led by specialist community-led organisations. This includes research to assess the needs and experiences of new arrivals to regional Australia, as well as intersectional health policy and programs that are respectful, and culturally responsive.

Through this work, the professional development and capacity building of health professionals and service providers can be tailored to meet the needs of affected communities

Accessibility and availability of effective pain management for women

What we have heard

Through the Tell Your Story (2024) project, women from the Grampians region described access to adequate pain relief during IUD insertion and removal as an important factor in the decision-making when choosing a contraceptive method.

"I'm still without a long-term contraception. I wish there was someone else I could talk to about it, to find another provider who could offer anaesthetic."

"When I finally found a GP that could insert [an IUD] for me he offered me neither general anaesthesia or paracetamol because "it doesn't hurt"!

"I did not go ahead with [the IUD insertion] as I was worried about the pain and side effects"

Effective pain management is often not easily available or accessible for women. For example, IUDs are the most effective form of contraception and are also used to manage conditions such as PCOS and endometriosis, however, research shows that it is common for IUD recipients to experience pain during insertion. One study found that more than 70% of women who had not given birth experienced moderate pain during IUD insertion, while 17% experienced severe pain (Dermish, 2023). While mild sedation and numbing creams are generally regarded as the most effective pain-prevention methods for IUD procedures, these are often unavailable or very expensive in Australian clinics. Pain associated with IUD placement can be a barrier to IUD use and a key reason patients opt for less effective alternatives. The medical system should follow the lead from Peninsula Health, who have pioneered access to Penthrox, popularly known as the 'green whistle', for procedures like IUD insertion.

Effective pain management should be made available and accessible for intrauterine devices (IUD) insertion.

Sub recommendations

4.1 Advocate to the Federal Government to address Medicare gaps including subsidies for women’s health and dentistry and the lack of Medicare coverage for non-citizens or permanent residents, as well as increase rebates for longer consultations/management of complex care.

4.2 Allocate resources for support, treatment and interpreting services that are affordable and available to all migrants and refugees, irrespective of their visa status.

4.3 Utilise the existing and planned SRH hubs and women’s clinics to expand access to train the trainer opportunities across Victoria, as well as increased access to tailored, culturally responsive healthcare for women experiencing chronic pain.

4.4 Improve access to diagnostic and treatment services across Victoria, with attention to incentivising services to offer bulk billing.

4.5 Increase rural and regional access to services by prioritising an ‘infrastructure of care’ that creates pathways for women and gender diverse people to timely, cost effective access to services - including telecommunications, transport, community outreach and translation and interpreting services.

4.6 Improved referral pathways (including mental health services and community support) and greater integration of healthcare services to provide greater access to holistic care.

4.7 Upskilling for healthcare providers around patient centred care, including trauma informed care, size inclusive practice and cultural safety including for women who have experienced female genital cutting.

Health promotion and education

Recommendation 5: *Invest in existing infrastructure such as the Victorian Women's Health Services to fund a state-wide program of work that works to address stigma and increase health literacy in the area of chronic pain through an intersectional lens.*

Women's experiences of having their pain minimised, dismissed or ignored in healthcare settings are often accompanied by dismissive attitudes within social, professional and community settings. The importance of coordinated, place-based, gender equitable and intersectional health promotion initiatives in these settings, as well as formal and community education around women's health, is integral to reducing the gender bias that informs the societal devaluing of women's pain. This section will discuss strategies for reducing shame and stigma and demonstrate the value of leveraging community-based organisations and networks focusing on gendered health promotion.

Addressing shame and stigma

What we have heard:

Women and gender diverse people across Victoria have told us that shame, stigma and societal attitudes shape their experiences seeking care and support for chronic pain conditions. This is a factor in both community and healthcare settings, with some women telling us that the attitudes and judgement they have experienced around discussing reproductive health has resulted in avoiding or delaying diagnosis and treatment.

When asked the question, 'in the context of SRH, what does 'better' look like?' Women's Health Goulburn North East was told:

"Better understanding of women's issues and that it is not just 'all in our heads'. This can be for both the medical field and general community. We are allowed to speak up about it and not be shut down with 'oh she's just on her period' or it's just hormones."

From a multilingual health educator in northeast Victoria: "[The women perceive that]..*the pain for women is normal and seeking help is a shame. Pain includes chronic muscle pain, pain during period, pain during sex, pain during exercise or passing urine, etc.They feel shaky and unable to ask for help or even share with friends until an emergency."*

Addressing social stigma of reproductive health

Stigma and discrimination are fundamental determinants of health inequities, undermining health seeking behaviours and access to information, health services and support. In Australia, stigma remains a significant barrier for women and gender diverse people seeking medical care, particularly when experiencing pain. Social and cultural taboos often lead to minimisation or dismissal of women and gender diverse people's pain, contributing to a reluctance to discuss symptoms openly or seek timely support. Such stigma is compounded by a lack of comprehensive education about reproductive health, including pelvic pain, resulting in misinformation and a lack of awareness about whether the pain people are experiencing is normal.

Addressing this stigma is crucial to ensure that women and gender diverse people receive the necessary services and support to effectively manage their reproductive health.

A key focus of the Victorian sexual and reproductive health and viral hepatitis strategy 2022-30 is reducing stigma, racism and discrimination. Priority actions include resource development, fostering collaboration and partnerships, building workforce capability, and promoting sexual and reproductive health care as part of routine care in primary and community health settings. It is vital that these actions consider reproductive health-related stigma as a barrier to information, health services and support, compounded by other experiences of stigma, racism and discrimination.

Hard to reach and hidden cohorts

The National Strategy for Health Practitioner Pain Management Education counsels that the need for a consumer voice within pain management is a key principle to effective, culturally safe pain management education for practitioners (ANZCA, 2023).To ensure hard to reach and hidden cohorts are represented within that cohort of consumer voices, the WHSN would like to see expanded collaboration between governmental and institutional departments and place-based and specialist organisations, like our own network. Increasing the breadth of partnerships will strengthen capacity to reach groups of people who experience higher levels of social disadvantage or isolation, a process which has been found to require a commitment to higher resourcing, extended timelines and crucially, community partnerships (Bonevski *et al*., 2014). Engaging with specialist organisations trusted within a given community to codesign and collaborate on future consultation, beginning with identifying hidden cohorts and recruiting hard to reach populations can mitigate any existing mistrust of the research process and motivations (Ellard-Gray, Jeffrey, Choubak and Crann, 2015).

Leveraging the pre-existing infrastructure and relationships fostered with community over time, organisations like the 12 Victorian Women's Health Services and other embedded workforces will increase access to different cohorts on the ground.

In-community health literacy

What have we heard

As part of an MCWH-led initiative, multilingual health educators facilitating an in-language health literacy program in the Goulburn North East area to support women from migrant and refugee backgrounds to navigate the Victorian health system, have identified several barriers to accessing care for chronic pain. These include lack of in-language and linguistically appropriate health information, lack of access to interpreters, limited social connectedness, less trust of and difficulty navigating the healthcare system. Through engaging with the women program facilitators have also identified what is working well to reduce these barriers and what the place-based, tailored solutions might be:

- mentoring and advocating
- educating through informal social activities
- sharing stories in community, in their home language with the support of relevant resources
- Consistency of communication and resources
- Community and individual capacity development in health literacy

Multicultural Centre for Women's Health (MCWH) has over 45 years of experience promoting the health and wellbeing of migrant and refugee women through the delivery of in-language health education, community engagement, research, advocacy and capacity building (see MCWH's submission for specific recommendations related to migrant and refugee women).

The planned approach of the Inquiry to work with First Nations organisations to conduct yarning circles is a positive strategy to ensure cultural safety, highlighting the benefit in tailoring approaches to engaging community members outside of formal focus groups. Engaging women and gender diverse people from across Victoria could benefit by variating the more formal focus groups with models like roundtable discussions and the 'kitchen table conversation' approach, for example. Member organisations of the Women's Health Services Network have had some success in reaching communities using these approaches during consultations.

Working with interpreters

Migrant women who rely on interpreters for sexual and reproductive health (SRH) information may face challenges stemming from a lack of systemic support for interpreter services, such as under-resourcing and a dearth of professional development opportunities. For example, interpreters need to be given opportunities for upskilling to understand the responsibilities and ethics involved in the job and be provided up-to-date, best-practice resources on medical terminology. Given the crucial role they play in increasing access to healthcare for diverse women across Victoria, interpreters need to be recognised as an integral part of the service workforce and the provision of healthcare, and supported to upgrade their skills on an ongoing basis.

Sub recommendations

5.1 Provide sustainable funding for all parts of the WHS and maximise the expertise, use and impact of this unique service in Victoria - including its reach statewide and place based approach - to effectively implement ongoing reforms of government to advance equity in our health system.
5.2 Make use of the breadth and depth of data and evidence that comes through the work of the Victorian Women's Health Services to understand how services and funding are best placed in the region, across settings, places and key population groups.
5.3 Scale up and fund universal early secondary school education, in pelvic pain, from both external providers and school staff.
5.4 Integrate pelvic pain into the curriculum for sexual health and education (pelvic pain) - education to encompass a holistic view of pelvic health and broader health and engage boys to break down stigma associated with menstruation.

References

Australian Institute of Health and Welfare (AIHW) 2018. *Family, domestic and sexual violence in Australia 2018*. Cat. no. FDV 2. Canberra: AIHW. https:/doi.org/10.25816/5ebcc144fa7e6/

Australian Institute of Health and Welfare (AIHW) 2024. (2024, 14 February). *Stress and trauma* [web article]. https://www.aihw.gov.au/reports/mental-health/stress-and-trauma

Australian and New Zealand College of Anaesthetists (ANZCA) 2023. *National Strategy for Health Practitioner Pain Management Education. https://www.health.gov.au/sites/default/files/2023-10/national-strategy-for-health-practitioner-pain-management-education.pdf*

Ballan, M.S., Freyer, M. & Romanelli, M. (2022). Intimate Partner Violence, Disability, and Pain: A Retrospective Study. *Journal of Family Violence,* 37, 1367–1378. https://doi.org/10.1007/s10896-021-00331-z

Bennett, C. (2020). What you need to know about pain and mental health in Australia. *Pain Australia. https://www.painaustralia.org.au/media-document/blog-1/blog-2020/blog-2019/what-you-need-to-know-about-pain-and-mental-health-in-australia#*

Bonevski, B., Randell, M., Paul, C. *et al.* (2014). Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups. *BMC Med Res Methodol* 14, 42. https://doi.org/10.1186/1471-2288-14-42

Cheung, A. (2023, 9 October). Misogyny in Medicine Impacts us all. *Pursuit. https://pursuit.unimelb.edu.au/articles/misogyny-in-medicine-impacts-us-all*

Dermish, A. (2023, April 21). Is IUD insertion painful? Expert answers you need to know. *Healthline.https://www.healthline.com/health/birth-control/is-iud-painful#:~:text=It%27s%20been%20reported%20that%2070,to%20severe%20pain%20at%20insertion.*

Ellard-Gray, A., Jeffrey, N. K., Choubak, M., & Crann, S. E. (2015). Finding the Hidden Participant: Solutions for Recruiting Hidden, Hard-to-Reach, and Vulnerable Populations. *International Journal of Qualitative Methods*, 14(5). https://doi.org/10.1177/1609406915621420

Hampton, B., Cavalier, J., & Langford, R. (2015). The Influence of Race and Gender on Pain Management: A Systematic Literature Review. *Pain Management Nursing.* 16(6), 968-977. https://doi.org/10.1016/j.pmn.2015.06.009

Hui K., Sukhera J., Vigod S., Taylor V. H., Zaheer J. (2020). Recognizing and addressing implicit gender bias in medicine. *CMAJ*. 192(42), 1269-1270. https://doi.org/10.1503%2Fcmaj.200286

Landi, G., Grossman-Giron, A., Bitan, D.T. *et al.* (2023) Mental Pain, Psychological Distress, and Suicidal Ideation During the COVID-19 Emergency: the Moderating Role of Tolerance for Mental Pain. *Int J Ment Health Addiction* 21, 1120–1131. https://doi.org/10.1007/s11469-021-00646-4

Liu, L., Obuobi, S., & Gulati, M. (2023). Redesigning the Future of Medicine. *JAMA Netw Open.* 6(7). https://doi:10.1001/jamanetworkopen.2023.23831

Marmot M. (2005). Social determinants of health inequalities. *Lancet*. 365(9464):1099-104. https://doi:10.1016/S0140-6736(05)71146-6.PMID:15781105.

Multicultural Centre for Women's Health (2021), Data Report: Sexual and Reproductive Health 2021. https://www.mcwh.com.au/wp-content/uploads/SRH-Report-2021-for-web-accessible.pdf

Merone, L., Tsey. K., Russell, D., & Nagle, C. (2024), Representation of Women and Women's Health in Australian Medical School Course Outlines, Curriculum Requirements, and Selected Core Clinical Textbooks. *Women's Health Reports.* 5(1), 276-285. https://doi.org/10.1089/whr.2023.0037

Royal Australian College of General Practitioners. (2023). *General Practice: Health of the Nation 2023. https://www.racgp.org.au/getmedia/122d4119-a779-41c0-bc67-a8914be52561/Health-of-the-Nation-2023.pdf.aspx*

The George Institute. (2019, 25 November). *Medical research community calls time on gender research bias* [press release]. https://www.georgeinstitute.org.au/media-releases/medical-research-community-calls-time-on-health-gender-bias

Thomas, J., Barraket, J., Wilson, C. K., Holcombe-James, I., Kennedy, J., Rennie, E., Ewing, S., & MacDonald, T., (2020). Measuring Australia's Digital Divide: The Australian Digital Inclusion Index 2020. *RMIT and Swinburne University of Technology, Melbourne, for Telstra.* https://doi.org/10.25916/5f6eb9949c832

Uvelli, A., Ribaudo, C., Gualtieri, G. *et al*. (2024). The association between violence against women and chronic pain: a systematic review and meta-analysis. *BMC Women's Health* 24(321). https://doi.org/10.1186/s12905-024-03097-w

Workplace Gender Equality Agency. (2023). WGEA Healthcare and Social Assistance Industry Snapshot. https://www.wgea.gov.au/sites/default/files/documents/WGEA_Health_Care_and_Social_Assistance_Industry_snapshot_2022-23.pdf

Wilkinson, R., & Marmot, M. (2003). Social determinants of health: the solid facts. (2nd ed.) World Health Organization. Regional Office for Europe. https://iris.who.int/handle/10665/326568

Zucker, I., & Prendergast, B. J. (2020). Sex differences in pharmacokinetics predict adverse drug reactions in women. *Biol Sex Differ* 11(32). https://doi.org/10.1186/s13293-020-00308-5