

Submission

Inquiry Into Women's Pain

31 July 2024



About the VHA

The Victorian Healthcare Association (VHA) is the peak body supporting Victoria’s publicly funded healthcare sector to deliver high-quality care. Established in 1938, the VHA represents over 90 per cent of the \$26.8 billion public healthcare sector including Victorian public hospitals, aged care and community health services.

The VHA advocates on behalf of its members on sector-critical issues by engaging and influencing key decision-makers involved in policy development and system reform. As the peak body for Victoria’s publicly funded healthcare services, the VHA is well positioned to engage with the sector to identify opportunities that would provide women and girls experiencing pain with ‘the right care, at the right time, in the right place’.

Our vision: A healthcare system that meets the evolving needs of all Victorians.

Our purpose: To be the voice of the healthcare sector, to support and build the capacity of our members to drive system transformation.

Acknowledgement of Country

The VHA acknowledges the Traditional Custodians of unceded lands throughout Australia. We recognise their continuing connection to land, waters, and culture, and we pay our respects to their Elders past and present.



A note on language

The VHA is committed to the use of inclusive, non-stigmatising language, and welcomes the statement on language from the Inquiry. Any references to woman, women or girls in our submission are intended to include both those who are assigned female at birth and anyone who identifies as a woman, irrespective of their sex at birth.

Glossary

Acute pain	Sudden, usually sharp and intense pain that has a specific cause. Usually relieved by treatment depending on complexity of presentation, or otherwise may go on to be categorised as persistent, complex or chronic pain.
Community Health Services	There are 24 registered independent Community Health Services in Victoria as defined by the <i>Health Services Act (1988)</i> , and 55 integrated services that are embedded within health services (e.g., hospitals).
Chronic pain	Persistent and/or complex pain lasting for more than 3 months.
Health equity	Providing healthcare that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status, as examples.

Executive summary

The Victorian Healthcare Association’s (the ‘VHA’) submission to the Inquiry into Women’s Pain (the ‘Inquiry’) is informed by consultation with our members and is focused on a system-level response addressing the challenges faced by girls and women seeking pain care. Part 1 looks at pain and the treatment of pain through a gendered lens, and Part 2 discusses the barriers to pain care provision for women in Victoria. Part 3 presents innovative and person-centred solutions drawing on case studies from some of our member organisations, and Part 4 outlines opportunities to address the current challenges.

Pain, particularly chronic pain, can be complex in nature and difficult to treat or manage. These complexities, combined with a systemic culture of gender bias in health¹ can result in barriers to identifying, assessing and responding to pain experienced by women and girls. The barriers to care in Victoria identified by VHA members have been categorised into four themes: stigma and discrimination, systemic barriers, workforce barriers, and funding.

Overwhelmingly, the VHA and its membership advocate for a systemic response to the identification, treatment and management of women’s pain. This includes the provision of care within a holistic, coordinated and integrated model, with adequate funding to ensure timely access and achievement of optimal patient outcomes.

Recommendations

Recommendation 1 Undertake system planning and mapping for women’s pain and identify the population need (prevalence, severity and location) and current pain services and supports.

Recommendation 2 Implementation of evidence-based models of care to support women experiencing pain. These would be sustained through resource allocation, service capability and workforce knowledge and skills and informed by evidence of best practice, lived and living experience and have a gender equity focus.

Recommendation 3 Fund training that is accessible for all healthcare professionals about the impact of women’s pain, causes of pain, best practice treatments and strengths-based management approaches.

Recommendation 4 Provide funding for health organisations to develop holistic, interdisciplinary comprehensive responses to pain management for women.

Recommendation 5 Support services to work together to provide holistic, step up/step down supports to women experiencing pain, minimising wait times and maximising a person-centred, trauma-informed, patient-collaborative treatment response.

¹ Gopal, D., Chetty, U., O’Donnell, P., Gajria, C., Blackadder-Weinstein, J.(2021). Implicit bias in healthcare: clinical practice, research and decision making. *Future Healthcare Journal*, 8(1): 40-48. <https://doi.org/10.7861/fhj.2020-0233>

Part 1 - Background

The VHA recognises that pain can have a substantial and a wide-ranging impact on quality of life, impacting everyday activities including attending work or education and maintaining social networks. Chronic pain can have a particularly devastating impact on the individual suffering pain and on their families and communities, leading to broader social and economic impacts. A 2019 report commissioned by PainAustralia² looking at costs associated with chronic pain found:

- The total cost of pain-related conditions in Australia in 2018 was an estimated \$139.3 billion in 2018, with Victoria making up 25% of this (\$35.5 billion). This included costs to the healthcare system, as well as costs associated with lost productivity and reduced quality of life (the ability to take part in everyday activities, including caring responsibilities).
- In 2018, \$12.2 billion was spent on health care services associated with chronic pain in Australia, which represented 6.5% of total health expenditure.

The Commonwealth Government’s *National Strategic Action Plan for Pain Management* identified that “many people living with pain cannot get access to best practice pain management”, and there is a growing body of evidence that this disparity is gendered. Women are less likely to fit into traditional models of care due to their caring responsibilities³, less likely to be believed than men when they disclose pain and more likely to be thought of as exaggerating their pain⁴, and less likely to receive best practice care, treatment and medication for their condition⁵. There are also gender disparities in end-of-life care, with women reporting more pain, nausea and fatigue at end of life, but this is under-reported and under-treated by healthcare professionals⁶.

This inequity increases for women with multiple intersecting identities and experiences, including their socioeconomic status, co-existing health conditions, migration status, and women from non-Anglo cultures⁷. A recent study of Assyrian women of refugee background living in Melbourne identified that the women’s experience of accessing care for chronic pain was shaped by the particular way they explained pain experiences, the influence of culture and gender roles, their awareness of health systems in Victoria and their previous experiences of help seeking in Australia and in their home country.

With such complex and intersecting issues affecting the disclosure, assessment and treatment of women’s pain, this Inquiry and related opportunities is welcomed by the VHA and its members.

² Deloitte Access Economics (2019) *The Cost of Pain in Australia*: <https://www.deloitte.com/au/en/services/economics/analysis/cost-pain-australia.html>

³ Keogh, E. (2022). Sex and gender differences in pain: past, present, and future. *Pain*, 163, S108-S116: <https://doi.org/10.1097/j.pain.0000000000002738>

⁴ Paganini et al. (2023). Women exaggerate, men downplay: Gendered endorsement of emotional dramatization stereotypes contributes to gender bias in pain expectations. *Journal of Experimental Social Psychology*, 109: <https://doi.org/10.1016/j.jesp.2023.104520>

⁵ Dawson, L et al. (2023). Sex Differences in Epidemiology, Care, and Outcomes in Patients with Acute Chest Pain. *Journal of the American College of Cardiology*, 81(10), 933–945. <https://doi.org/10.1016/j.jacc.2022.12.025>

⁶ Wong, A & Phillips, S (2023). Gender disparities in End of Life Care: A Scoping Review. *Journal of Palliative Care*, 38(1): 78-96. doi:10.1177/08258597221120707

⁷ Altun, A et al. (2023). Experiences of Assyrian refugee women seeking care for chronic pain: a qualitative study. *International Journal for Equity in Health*, 22(83): <https://doi.org/10.1186/s12939-023-01891-w>

Part 2 - Consultation with VHA members

VHA consultations

The VHA membership consists of a broad range of publicly funded healthcare services, including:

- Publicly funded hospitals, including specialist, metropolitan, regional and rural health services,
- Registered and integrated community health services and,
- Other community-based services that provide clinical care (e.g., ambulance services, palliative care and Bush Nursing Centres).

In addition, the VHA has an extensive network of associate members (e.g., partner organisations such as other peak organisations) and stakeholders that intersect with Victoria’s publicly funded health services.

All members of the VHA were invited to contribute to the submission, and we directly consulted with members from across the range of service types. Those members undertook informal interviews where we asked them to describe:

- The barriers experienced by women and girls experiencing pain when attempting to access assessment, treatment and support,
- The ways in which their service had worked to minimise the impact of these barriers, and
- The ways in which health services could improve the experiences of women and girls seeking treatment and support.

Through these interviews, a pattern of agreement on the major barriers impacting women and girls seeking support for pain was observed. In addition, members also shared examples of the innovative ways they approached pain management with limited budgets and staffing and suggested systemic enablers to improve women and girl’s experience of healthcare relating to pain conditions.

Barriers and impacts

While pain, particularly chronic pain, can be difficult to assess, treat or manage, VHA members articulated a number of key barriers affecting women and girls experiencing pain when attempting to access assessment, treatment and support (*See Table 1*). The barriers identified by VHA members have been categorised under four themes: stigma and discrimination, systemic barriers, workforce barriers and funding.

It is important to note that the experience of pain is multifaceted and complex and is not always obvious to others. Combined with a culture of systemic gender bias, barriers to pain care are compounded, stigmatised and can be internalised by women. The list of barriers summarised below does not encompass all barriers to assessment, treatment and support, and the interrelationships, impacts and complexity for women and girls to seek help and engage in pain care should not be underestimated.

Theme	Barriers identified by VHA members
<p>Stigma and discrimination</p>	<ul style="list-style-type: none"> • No universal understanding of the complexities of pain in women, especially chronic pain. • Women’s experiences of pain not always validated or responded to by healthcare professionals. • Internalised stigma: lack of education around menstruation, childbirth and peri/menopause leading to women believing pain is ‘just part of being a woman’ and not worthy of medical assessment. • Women’s pain causes and treatment under-researched. • Intersectional discrimination, especially for women with complex trauma, mental health or problems with drug and alcohol use. • Fear that disclosure of pain will lead to questions of capability, especially in caregiving activities, leading to loss of children or loss of jobs.
<p>Systemic barriers to treatment and support</p>	<ul style="list-style-type: none"> • Lack of prevention and early intervention services. • Inadequate in-hospital capacity for treatment. • Long waitlists for specialist pain services increasing risk of chronic pain and reduced quality of life. • Locational inequity of care, including varying quality of diagnostic tools. • Lack of systemic integration. • Concern that budget cuts and health system reforms will increase waiting lists and increase service fragmentation.
<p>Workforce</p>	<ul style="list-style-type: none"> • Not all health professionals have fundamental knowledge about pain or pain management. • Not all healthcare professionals keep up with current or emerging pain practices for women. • No clear responsibility for training and education for women’s pain. • Upskilling all health professionals is crucial but expensive. Need cheaper and sustainable ways of training staff. • Not all of the healthcare workforce funded to undertake pain assessments, leading to issues with timely access and clogs in the referral system.
<p>Funding</p>	<ul style="list-style-type: none"> • Lack of funding to develop innovative and integrated responses to women’s pain. • Current funding structures do not encourage collaboration between services. • Many diagnostic tools are not fully funded, leading to large out of pocket costs for women wanting pain assessments (e.g. ultrasounds).

Table 1: Barriers to managing women’s pain identified by the healthcare sector

Part 3 – VHA Member Case Studies

VHA members have sought to overcome barriers to women accessing care for pain by focusing on empowering service users to work in partnership with health and allied health professionals to create individual treatment and support plans. Below are examples of current models of care that, with ongoing funding and support, could address some of the current barriers to obtaining treatment and support and enable best-practice care for women and girls experiencing pain-related issues.

These case studies show the importance of a joined-up healthcare system with consistent knowledge around women’s pain, as well as the benefits of a multidisciplinary, step-up/step-down approach where individualised care plans are developed by women with their care coordinators, empowering women to find the best options for their circumstances.

Specialist Services providing expert care

Specialist women’s health services play a crucial role in the treatment of women and girls experiencing pain. Not only do they assess and manage complex pain presentations but also provide invaluable support and expertise to other health services.

Case study: The Royal Women’s Hospital

A long history of innovative women-centred care and support

The Royal Women’s Hospital in Melbourne is perhaps the most well-known of the specialist women’s hospitals in Victoria and provides a wide range of services that support women and girls experiencing pain in Victoria. These include managing pain in pregnancy, birth and post-partum pain presentations, assessing and treating pelvic floor-related pain conditions, managing opioid use related to pain in pregnancy and whilst breast feeding, supporting babies with Neonatal Opioid Withdrawal Syndrome, supporting women with menstrual disorders, empowering women to manage peri/menopause, the assessment and treatment of STI’s and supporting women who have experienced violence and sexual assault.

The hospital also offers two specialist pain programs: the Chronic Pelvic Pain Clinic, which was Victoria’s first multidisciplinary service for patients who suffer from persistent pelvic pain and wish to improve their quality of life, and the Chronic Pain – Connect Program, an early intervention program in trial stage. They offer multidisciplinary pain education, medical pelvic pain assessment, physiotherapy pelvic floor assessment and treatment, psychological assessment and treatment and dietetics and nutrition assessment. The Connect Program also offers program participants access to a patient-only website where they can watch videos offering further information and support.

The skills and expertise of the Royal Women’s Hospital program and staff are also used to upskill the wider healthcare sector. The hospital works with other health services to facilitate the co-location of specialist clinicians within community-based services, helping women to manage their pain and lower the chances of needing acute care.

Large metropolitan healthcare providers like Monash Health (below) are also working to improve pain management by upskilling the healthcare workforce to have a deeper understanding and response to women experiencing pain, improving the constantly evolving technology and educating their program participants about self-management strategies for pain:

Case Study: Monash Health

Evidence-based evolution of service delivery

Monash Health is the largest public healthcare service in Victoria, providing healthcare for people at every life stage for over 170 years.

The organisation is passionate about enabling healthcare professionals to work at the top of their scope, believing this also improves outcomes for patients. Nurses and midwives have been upskilled in the use of diagnostic scanning and ultrasound equipment, and medical staff have been upskilled to undertake endoscopy procedures. Recognising the disparity in diagnostic equipment quality throughout the healthcare system, Monash Health has also been working on upgrading and standardising all diagnostic equipment across their sites and services.

The Nurse Manager at the Casey Day Surgery Unit recently embarked on a research project addressing concerns regarding post-operative pain in women after gynaecological procedures. Acknowledging that 70% of women undergoing laparoscopic procedures were dissatisfied with their discharge pain management plan, the research aims to enhance post-operative pain management and improve patient experiences.

Monash Health also runs a Pelvic Pain Clinic, and prior to that, a Pain Management Pre-Clinic Education program to educate and inform program participants. The pre-clinic education program includes education sessions that help participants to understand chronic pain mechanisms, education around treatment and principles of self-management and information on various treatment options to empower patient to select their preferred option. Participants also receive pain diaries to track and manage their progress.

Pain management programs at the Monash consist of interdisciplinary care teams and include group programs. Services offered as part of these programs include exercise, hydrotherapy, active self-management education, goal setting and pain management skill training sessions.

Community-based support

To ensure those with the most need are able to access the finite resources of specialist services, there needs to be a broad base of other services supporting women through the identification, assessment and referral stages of care.

Community health services have a history of developing innovative, community-based responses based on local need. Whilst the program models described in the two case studies below are not currently gender-specific programs, 73% of IPC Health’s Power Over Pain program participants to date and 69% of

Sunraysia Community Health’s pain rehabilitation program participants over the last 18 months identify as women. Both of these programs have the capacity to be adapted to meet the needs of various population groups and could be rolled out across other services to provide a holistic, person-centred and flexible response to women’s pain.

Case Study: Power Over Pain Program, IPC Health

Is care coordination the missing ingredient?

IPC Health is a Community Health Service based in the western suburbs of Melbourne. The area has a culturally diverse population and is also reports a diversity of socioeconomic status. IPC Health has identified a cohort of the local community with a lack of health literacy skills and varying health outcomes and have strong attendance of their free healthcare services.

Chronic pain is a widespread problem that GPs are struggling to manage in the area. Many people living with chronic pain are unable to focus on their health and wellbeing when their basic human needs are not being met. As a result, attending appointments and healthcare become secondary to having somewhere safe to live, food and electricity. Clinicians are often aware of these issues but do not feel they have the capacity or the expertise to address them. IPC Health recognised that there was a need for a pain management program addressing the psychosocial needs of the local community and co-designed the Power Over Pain Program with community representatives and the local public hospital.

A core component of the program is care coordination, which is delivered by a wellbeing coordinator. The nurse who works in this role delivers care alongside a multidisciplinary team including a pharmacist, a physiotherapist, a psychologist, and an occupational therapist. Once a month, a pelvic pain specialist is located onsite for further consultation and support, as well as onward referral if needed.

The wellbeing coordinator provides individualised assessment and co-ordination, working with the person experiencing pain to address their specific needs. Together, they identify the person’s individual needs and goals, also working with the person on self-management strategies for their pain and associated health problems. The person then has appointments with each of the team members, following which the needs and supports identified by each are pulled into a holistic plan by the wellbeing coordinator. With tailored support, such as coordinating and attending health appointments as an advocate/support person, the coordinator also supports the client to navigate health and social service systems, as well as providing pain science education. Progress is monitored through regular check-ins and the program is adapted as needed.

The Power over Pain model has addressed some of the systemic barriers around support by identifying ways to ensure that women experiencing pain receive care that is multi-disciplinary, person-focused and helps participants access specialist services and understand their individual needs and complexities. Their skilled workforce with expertise in women’s pain are also available for consultation and education with the organisation’s workforce and the broader community.

Below, Sunraysia Community Health Services Pain Rehabilitation Program also exemplifies the power of a multi-disciplinary pain program in a community health service:

Case Study: Pain Rehabilitation Program, Sunraysia Community Health Services

‘Think outside the square – we never stop trying to do better’

Sunraysia Community Health Services is based in Mildura, 550km north-west of Melbourne. Recognising the geographical difficulty in accessing specialist services and primary healthcare, Sunraysia offers over 50 different services, including a Pain Rehabilitation program. In the last 18 months, 69% of people accessing the program identified as women.

The program identified that many women needing to access pain services are unable to do so because of their caring responsibilities, which they often undertake on top of paid employment and home-related work. The program offers a care coordination model and explores the psychosocial factors that may be impacting on pain, offering a regular check-in to those who are unable to commit to a treatment program. All participants are given direct contacts for the program so that they can reschedule appointments in case of sudden family commitments (e.g. an unwell child). The program is constantly looking at ways to engage people, recognising that women in particular have often not had any acknowledgement or validation of their pain and the ways in which it impacts their lives.

The program works in conjunction with people to build an individualised plan. A ‘one-stop shop’, the program participants have access to a multidisciplinary team including physiotherapists, occupational therapists, social workers, pain and addiction specialists, as well as all other services within Sunraysia. Referrals from the pain rehabilitation program are prioritised internally, and give participants access to a wide range of other programs, including vestibular physiotherapists, nurse practitioners, dieticians and diabetes educators. The program works with people to demystify and contextualise test results and pathology reports from specialists, enabling people to see how particular parts of their diagnoses interact with each other.

Women accessing the pain rehabilitation program are also offered linkages into complementary supports, including the ‘Care for Carers’ program, a support program for women who have multiple care burdens. This program provides the women with vouchers for services such as house cleaners, hairdressers or massages supporting women to undertake activities that improve their overall wellbeing and quality of life. The underlying aim of the program is to empower their participants to navigate through the health system and find supports that work for them and fit around their individual biopsychosocial presentation.

Sunraysia Community Health’s program exhibits a deep understanding of both the stigma women experiencing pain often encounter, as well as the burden faced by women trying to access support that fits around their responsibilities, such as caring, which disproportionately falls to women. It offers a flexible, non-judgemental service that meets participants where they are at and caters to their current ability to engage with treatment.

Supporting women and girls in remote communities

Like community health services, bush nursing centres are rooted in their local communities and deliver care to small rural and remote communities. In Victoria there are 15 bush nursing centres, most of which are located in remote areas a significant distance from the nearest small rural health service and many hours away from a specialist centre. They have been described by the Victorian Government as ‘*highly valued institutions in small rural communities contributing significantly to both people’s sense of security and the economy and are cost effective and financially viable.*’⁸ Delivering unique health services to their community, the VHA’s bush nursing centre members report their willingness to expand their scope of healthcare delivery and, with appropriate funding and clinical governance frameworks, develop innovative supports for their isolated communities.

Whilst bush nursing centres do not always offer a women’s pain program, they occupy a crucial place in the healthcare system in the support of women experiencing pain. Working with women in remote locations and developing long-term relationships with a deep understanding of each member’s lifestyle and circumstances, bush nurses have the ability to assess, treat and refer women who would otherwise struggle to find appropriate services. Many bush nursing centres have developed close connections with metro specialist centres and utilise services such as the innovative Victorian Virtual Emergency Department to support the care needs of their communities and provide another pathway that alleviates emergency services and responds to tyranny of distance.

These centres are crucial in the identification, assessment and onward referral for women experiencing pain at all stages of life. Each bush nursing centre has a rich history of providing unique support to their communities.

Case Study: Gelantipy Bush Nursing Centre

Innovative responses to women’s pain in rural and remote communities

Gelantipy is located 120 km northeast of Bairnsdale in a remote and mountainous area of East Gippsland. The smallest of all bush nursing centres in Victoria, Gelantipy has 150 community members accessing the Centre and provides services across an area of approximately 3,400 km². Providing both in-service supports and outreach visits, the service provides a wide range of services supporting women experiencing pain, including preventative education and support, pre/antenatal support, general women’s health information, assessment and support, mental health support, post-operative care, aged care services, palliative care support, and initial assessments and onward referrals to GPs and specialist services. The Gelantipy bush nurses, like all bush nurses, are also often the first responders to accidents and emergencies, including births.

⁸ Victorian Department of Human Services (2002) *Bush Nursing Centres Project Final Report*, [https://www.vgls.vic.gov.au/client/en_AU/vgls/search/detailnonmodal/ent:\\$002f\\$002fSD_ILS\\$002f0\\$002fSD_ILS:623855/ada?qu=Nursing.&d=ent%3A%2F%2FSD_ILS%2F0%2FSD_ILS%3A623855%7EILS%7E117&ps=300&h=8](https://www.vgls.vic.gov.au/client/en_AU/vgls/search/detailnonmodal/ent:$002f$002fSD_ILS$002f0$002fSD_ILS:623855/ada?qu=Nursing.&d=ent%3A%2F%2FSD_ILS%2F0%2FSD_ILS%3A623855%7EILS%7E117&ps=300&h=8)

Gelantipy Bush Nursing Centre staff know their community well and can consider a person’s pain needs in the context of their lives, utilising the service-based and outreach model to accommodate all individual needs and circumstances. The centre works with each person to find the plan and referral pathway that works best for them and supports them through their journey.

The centre has identified that many women in remote areas have low access to primary healthcare providers with up-to-date education and information about women’s pain and works with women to facilitate referrals to appropriate services.

Gelantipy Bush Nursing Centre identified the difficulties for women in rural and remote communities accessing support and treatment for pain, recognising that they face not only locational inequity in accessing specialist services, but also a lack of access to local GPs with specialist knowledge around women’s pain as well as a lack of appropriate referral pathways.

Case Study: Swifts Creek Bush Nursing Centre

‘We provide so much more than we are funded for’

Swifts Creek is situated on the single road between Bairnsdale and Omeo in East Victoria. The bush nursing centre has a membership of approximately 519 people and operates a state-funded weekly drop-in clinic from 9am to 5pm Monday to Friday, as well as a 24 hour on-call service and 2-hour weekend clinic funded directly by the membership.

The bush nursing centre’s after-hours service includes a full midwifery service. The centre also has the capacity to assess and immediately respond to pain-related issues such as UTI infections and chest infections. The service aims to provide timely support and prevent placing additional pressure on the limited emergency services in their remote area.

The service also provides antenatal care to women and their babies in the area, noting that demand for this service is increasing as rural health services reduce capacity in response to budgetary pressures and workforce challenges. The service has good connections with Bairnsdale Hospital and works with them to ensure women are supported before and after birth.

Swifts Creek Bush Nursing Centre are one of the many community-based services who conduct constant informal needs assessments for their local communities, and in particular women. With increased funding, particularly funding that stays with the patient, they could continue to innovate in their local area and work closely with health services in their region to embed seamless referral and support processes for women needing increased support.

Care where it’s needed: regional specialist clinics

The Commonwealth Government announced a \$58.3 million package for endometriosis and pelvic pain in the 2022-23 Budget, which included the establishment of 22 dedicated Endometriosis and Pelvic Pain Clinics across Australia. One of the first Clinics has been established at Bendigo Community Health Services.

Case Study: Bendigo Community Health’s Pelvic Pain Clinic

‘The most important thing we do is listen’

In 2023, Bendigo Community Health Service received federal funding to set up one of Australia’s first endometriosis and pelvic pain clinics. Funded for four years, the clinic offers a range of services to women and adolescent girls experiencing pain including STI testing, cervical screening and reproductive care, from puberty through to post-menopause.

The clinic works with a wide range of women, including adolescents, a cohort they have identified as being under-diagnosed and under-treated in their experiences of pain, women with disabilities and refugee and migrant women. The clinic has identified that the range of women they see is a testament to the importance of their integrated, settings-based care approach.

The clinic has an interdisciplinary team including GPs, nurse practitioners, physiotherapists specialising in pelvic floor, and a psychologist who teaches women about the relationship between pain and mental health.

Many of the women accessing the service describe years of being told that their pain is part of the ‘normal’ cycle of life, and that they must learn to live with it. This leads to women disengaging with the health system and utilising whatever methods they can find to live with the pain, including self-medicating with alcohol and other drugs. The clinic identified that a key part of the work that they do is validating and acknowledging the pain of the women and girls who access their service, empowering to listen to their bodies and to know what is not normal, and to feel safe to tell their stories. The clinic also focuses on sexual health and helping women to manage their pain so they can experience pleasure in their sexual relationships, seeing this as an area that has often been ignored.

The clinic has become an integrated part of the local health system, with the local public hospital referring all low-risk cases of IUD insertion to them. They take referrals from a wide area and believe it is crucial that primary care service providers are given information around recognising conversational markers indicating potential pain, ways to explore this and appropriate referral pathways.

Care across the life cycle

End-of-life is another stage of life where there is evidence of gender disparity around the assessment and treatment of pain. In response to this, many palliative care services are working with aged care providers to ensure that women experiencing pain are heard and validated, and that healthcare staff are trained in appropriate ways to manage their pain:

Case Study: Palliative Care Victoria

Supporting women at end-of-life

Palliative Care Victoria is the peak body representing palliative care services in Victoria. They also work directly with the community, providing education and palliative care support for people with an end-of-life diagnosis, their families, friends and carers. They advise that pain is probably the most feared aspect of palliative care, but also the most treatable.

Most healthcare planning for women doesn’t include end-of-life care, yet women are generally older than men at end-of-life and have often outlived their partner. This means they are more likely to be in aged care facilities and less likely to have significant others to advocate for them around their end-of-life needs, including pain recognition and management.

Reflecting research (see Part 1), Palliative Care Victoria describe that many healthcare professionals providing end of life care under-report and under-treat women’s pain in palliative care. They have also found that some healthcare professionals providing end-of-life care have received inadequate training and support around the use of opioids and other pain-relief medication, and/or are reluctant to use these methods of pain relief due to prior bad experiences. In response, palliative care services in Victoria have been offering specialist inreach services at aged care facilities, targeting pain. These specialist services work in partnership with the aged care providers to educate their staff around pain and the under-treatment of women’s pain, ultimately to improve the quality of life for their disproportionately female residents. Palliative Care Victoria believe this work will lead to women in aged care being less likely to need to access emergency and hospital-based care for pain-related symptoms, providing them more stable and supportive end-of-life care and reducing the burden on acute healthcare providers.

Part 4 - Next steps and recommendations

The VHA’s engagement with its member organisations identified the following opportunities to improve outcomes for women living with pain:

Theme	Opportunities to improve the care, treatment and services for pain conditions
Stigma and discrimination	<ul style="list-style-type: none"> • Implement public awareness campaigns to improve knowledge and understanding of women’s pain. • Increase general education and literacy about pain (e.g. education in schools about menstruation pain).
Systemic enablers to treatment and support	<ul style="list-style-type: none"> • Undertake system planning and mapping for women’s pain. This should identify the prevalence and severity of pain need, current pain services and supports to determine gaps in pain treatment and management availability. • Create, communicate and support a co-ordinated, stepped and integrated system for pain assessment and management from community to specialist services. • Through health and consumer leadership, support organisations to take a holistic, interdisciplinary comprehensive care approach to pain management for women. • Gendered-focused pain outcomes are developed, measured and monitored.
Workforce	<ul style="list-style-type: none"> • System-wide, funded mandatory training for all healthcare professionals about patient impact of pain, causes of pain, and best practice, biopsychosocial treatment and strengths-based management approaches. • Mandatory gynaecological clinical indicators and professional registration should require mandated women’s pain modules. • Fund incentives and strategies for existing healthcare providers to stay up to date with pain assessment and management.
Funding	<ul style="list-style-type: none"> • Increase funding for new programs and fund them in a sustainable manner. Members advised that 12 months is not long enough to establish efficacy and embed programs in services. • Incentivise collaboration between services. • Decrease/eliminate gap payments required for women to be assessed for pain conditions. • Design funding mechanisms to follow the patient, rather than services as is currently the case.

Table 2: Opportunities to improve the care, treatment and services for pain conditions for women

The information detailed in this submission will come as no surprise to the Inquiry and brings a system-wide approach to the discussion. We believe that it is important to note that all parts of our healthcare membership described similar barriers and enablers to support the existing system to offer equitable, best practice care and support to all women and girls experiencing pain. Without a well-funded system with universal assessment tools, holistic, staged levels of support, a well-resourced workforce and patient-centred models of care, we believe that the healthcare system will struggle to deliver this.

As evidenced by our case-studies, there are many innovative, patient-centred models of care that can already deliver this level of support. These models can be scaled to support people experiencing pain across a wide range of locations, demographics and co-existing needs, but there needs to be system support and understanding of best-practice healthcare delivery, as well as a commitment to ongoing funding, support and evaluation from the Government.

Based on our interviews with our members, we make the following recommendations:

Recommendation 1: Undertake system planning and mapping for women’s pain and identify the population need (prevalence, severity and location) and current pain services and supports.

Building a fit-for-purpose, responsive system to address women’s pain will require a clear picture of population need (i.e., prevalence, severity and geographical location), as well as an understanding of the existing pain services (from community to specialist pain services). Determining the number of women needing pain services and mapping existing services (and their capacity) will help determine current gaps in pain services for women.

Recommendation 2: Implementation of evidence-based models of care to support women experiencing pain. These would be sustained through resource allocation, service capability and workforce knowledge and skills and informed by evidence of best practice, lived and living experience and have a gender equity focus.

Utilising the system planning from recommendation 1, VHA members would like to see the development and implementation of evidence-based models of care across the health sector so that women experiencing pain can receive the right care, in the right place, at the right time. These models of care would be co-designed by women with lived/living experience of pain and would be both person-centred and trauma informed. Utilising health and consumer leadership, these models of care would be rolled out across healthcare services, with support given to services including adequate resourcing and a workforce who are trained to assess, treat and support women experiencing pain.

Recommendation 3: Fund training that is accessible for all healthcare professionals about the impact of women’s pain, causes of pain, best practice treatments and strengths-based management approaches.

VHA members identified a lack of holistic training across the healthcare system, with many health professionals relying on information that is out of date, and no system that mandates updated training around women’s pain. To build workforce capacity, system-wide funded training for all existing healthcare professionals is required. The training could include causes and impacts of women’s pain, as well as best-practice biopsychosocial treatment and strengths-based management approaches. Additionally, mandatory women’s pain training modules embedded as an essential component in undergraduate training programs would support the healthcare workforce to develop a holistic, consistent response to women’s pain.

The stigma associated with women’s pain, especially sexually related pain, often leads to reluctance to disclose pain or its effects. Tools to aid with identification of ‘clues’ in conversation and training to conduct conversations with women disclosing pain in a safe, validating and supportive way, as well as appropriate referral pathways would enable a ‘no wrong door’ approach for women seeking support.

Recommendation 4: Provide funding for health organisations to develop holistic, interdisciplinary comprehensive responses to pain management for women.

Innovative, systemic responses to women’s pain rely on funding, not just for their initial set up and implementation (i.e., pilot), but for the program’s ongoing sustainability and efficacy. VHA members talked about the uncertainty of ongoing funding impacting on the attraction and retention of staff, as well as the scope of the work, with focus diverted to maintaining ongoing funding. It was also noted that short-term funding (e.g., 12-month trials) did not enable services enough time to embed community-responsive programs and show the efficacy through evaluation.

Our members also spoke of the need for funding to provide education programs within the community to empower women to better understand the mechanisms of pain and to recognise what is not ‘normal’, as well as creating better understand for their families and communities. School-based literacy around menstruation and pain was all considered a crucial part of pain literacy, with healthcare professionals providing inreach to all school pupils to provide understanding about the mechanisms of menstrual-related pain and ways in which support can be provided to women experiencing it.

Recommendation 5: Support services to work together to provide holistic, step up/step down supports to women experiencing pain, minimising wait times and maximising a person-centred, trauma-informed, patient-collaborative treatment response.

Collaboration and co-ordination between services is crucial to creating a holistic response to pain throughout a woman’s lifetime. The creation of a well-planned, co-ordinated, stepped and integrated system for pain assessment and management is required. This will support healthcare organisations from community-embedded services to specialist services to deliver a timely and comprehensive care

approach. Health and consumer leadership will be crucial in this delivery. VHA members also talked about the need to incentivise collaboration, noting that presently there is no funding in this area.

Conclusion

Throughout VHA’s consultation with the healthcare system, we heard consistent messages. Women need to be believed and validated in their experiences of pain. There needs to be a consistent understanding across the healthcare system of how to recognise the signals of women and girls experiencing pain, how to engage sensitively and appropriately, assess, treat, manage and make appropriate referrals.

The VHA believes that our skilled and passionate health workforce already have key knowledge and expertise that will contribute to the establishment of a best-practice, evidence-based systemic response to women’s pain. The voices of women and girls with lived and living experience of pain is a crucial component of any systemic change and must be centred in the development of any models of care.



For further information contact

Leigh Clarke

Chief Executive Officer

Leigh.Clarke@vha.org.au

03 9094 7777