Submission to Safer Care Victoria, the Victorian Women's Health Advisory Council and the Inquiry into Women's Pain sub-committee

Inquiry into Women's Pain

VICTORIAN ABORIGINAL HEALTH SERVICE

Caring for the Community

Acknowledgement

The Victorian Aboriginal Health Service (VAHS) acknowledges the Aboriginal lands on which we live and work, we pay our respect to the Traditional Custodians and their Elders, past and present.

VAHS also acknowledges it's past and present Board Members, staff, clients and community members who have contributed and supported the organisation from its early beginnings.

Safer Care Victoria
Victorian Women's Health Advisory Council
Inquiry into Women's Pain sub-committee
(Sent via email: paininquiry@safercare.vic.gov.au)

9 August 2024

To whom it may concern,

Re: Inquiry into Women's Pain

The Victorian Aboriginal Health Service (VAHS) welcomes the opportunity to make a submission to the Victorian Inquiry into Women's Pain.

This submission speaks to the failings of the health system, and the challenges and the barriers experienced by Aboriginal girls and women who experience pain. But more importantly, it provides examples of community led programs that empower and heal girls and women. The impact that these programs have on pain management cannot be understated. We hope that this inquiry supports the recommendations herein.

Please do not hesitate to contact Brad Pearce at brad.pearce@vahs.org.au or 9419 3000 should you require further information.

Yours sincerely

Michael Graham

Chief Executive Officer

Terminology

The term Aboriginal is used in this submission to embrace all Aboriginal and Torres Strait Islander peoples living in Victoria and Australia.

Aboriginal Community Control

“Community Control means that each independent and autonomous health service is controlled by the community it serves, in order to provide that community with health care delivery to meet its health needs, as defined by that community. The solution to each community's health needs is in the hands of that community” - Bruce McGuinness

About VAHS

The Victorian Aboriginal Health Service (VAHS) was established in 1973 by a group of Aboriginal leaders in Fitzroy to address the poverty, injustices, high mortality rates, burden of disease and ill health of Aboriginal people as a direct result of government policies which restricted the access of Aboriginal people to essential health services. VAHS became the first Victorian incorporated Aboriginal Community Controlled Health Organisation (**ACCHO**) and over the last 50 years has evolved with a strong foundation of cultural knowledge and cultural competence in the delivery of comprehensive primary health and Social and Emotional Wellbeing (**SEWB**) care for Aboriginal peoples and communities across metropolitan Melbourne.

Over this time VAHS has expanded its service scope and operations and currently provides a comprehensive suite of medical, dental, mental health, preventative health, SEWB and community support programs. Our vision is to ‘create and inspire healthy Aboriginal people and families through high quality and effective community health and wellbeing services, education and training. VAHS will achieve this with a flexible approach that is innovative, embraced by community and sets a standard as a Centre for Excellence for Aboriginal health internationally’.

VAHS Strategic Objectives are to:

1. Build program and service excellence
2. Extend our reach and improve access
3. Invest in our workforce - making sure our staff are skilled and supported
4. Ensure the future of VAHS is supported by first class systems

Recommendations

VAHS recommends that the Department of Health,

1. Invests in the establishment of a VAHS Women's and Children's Hub that can function as a culturally safe and holistic one-stop-shop for Aboriginal women and children's health and wellbeing.
2. Invests in training of GPs and other health professionals on the benefits of alternative pain management, including Aboriginal Community Controlled programs that connect Aboriginal people with culture, community and Country.
3. Invests in Aboriginal Community Controlled Health Organisations, including VAHS, to support client access and engagement in health services.
4. Provides flexible and secure ongoing funding to ACCHOs including VAHS to invest in preventative health care and healthy lifestyles programs, and associated infrastructure.
5. Further commits to and invests appropriately in cultural safety, and holds programs and services that the Department funds accountable for cultural safety, as per commitments under Priority Reform Three of the National Agreement on Closing the Gap.

General comments

Aboriginal understandings of pain and pain management are different to dominant cultural understandings in the mainstream health system. This is because Aboriginal people view health and social and emotional wellbeing (**SEWB**) in a holistic way that understands that physical health and SEWB are interconnected, and that that there are multiple determinants of health and wellbeing that are interrelated and influence a person's health and wellbeing journey. Individual, family, and community health and wellbeing are all intimately connected, and are dependent on connection to culture, community and Country (Lowitja Institute, 2021).

In Aboriginal health, physical, emotional and spiritual pain are all interconnected; treatment requires treating all these types with equal priority. Pain can be experienced by an individual, but it can also be collective, shared by community and passed down through generations.

Disconnection from culture, community and Country causes pain. Connection heals it.

235 years ago, colonisers understood that disconnection was the most effective way to harm Aboriginal people. Colonisation disconnected Aboriginal people from traditional lands, languages, cultural practices, and from each other. It disconnected Aboriginal people from their own identities. The spiritual pain that this caused rippled across generations, and it is still felt in Aboriginal families and communities today.

As a colonial system, the health system is a source of pain for Aboriginal people. It still disconnects Aboriginal people from the things that keep them healthy and well. This manifests through a lack of cultural safety, rules and processes that keep family members apart, sterile spaces that disconnect people from culture and Country, a lack of prioritisation of cultural practices and respect for cultural protocols and lore, and a lack of holistic service offerings.

Systemic racism in the health system has been found to be a barrier to accessing services (Watego, 2021, p. 3).

Local Aboriginal Community Controlled Organisations (**ACCOs**) and, in particular, Aboriginal Community Controlled Health Organisations (**ACCHOs**) like VAHS are created by community, for community, which makes them highly effective. At the heart of all program and service delivery is an aim to strengthen connection to culture, community and Country.

Aboriginal girls and women disproportionately experience many types of physical, emotional, spiritual and intergeneration pain, which is caused or exacerbated by disconnection. ACCHOs are best suited to provide or support culturally safe pain management and treatment.

Gender diversity

When we speak to women and girls' pain and pain management in this submission, we are including gender diverse people, noting that gender diverse people may access women's or girls' services, such as gynaecology or antenatal care. It is important that Aboriginal gender diverse people are included in policy making around women and girls' health.

Specific terms of reference

We respond to the Inquiry's terms of reference below. We are grateful for the input of VAHS' Women and Children's program leaders, which supported this submission.

Racism and lack of cultural safety

A fundamental issue that creates barriers for Aboriginal women and girls in accessing health services for pain management and treatment is racism and lack of cultural safety.

GP are often racially biased in their assessment of Aboriginal women, which comes from negative and invalid stereotypes about the reasons Aboriginal women are seeking pain relief. GPs often do not believe Aboriginal women when they present with pain, and/or refuse to prescribe appropriate pain relief to Aboriginal women. This creates a cycle where Aboriginal women feel shame asking for pain relief; in some cases, women will not go to a GP and will instead turn to other ways to self-manage their pain, such as alcohol or other drug (AOD) use. Further, disbelief can increase diagnosis times, which are already high. For example, Aboriginal and Torres Strait Islander people are more likely to be diagnosed with cancer at more advanced stages (Australian Institute of Health and Wellbeing, 2024, p. 24).

Similar stories were included in the *Wiyi Yani U Thangani* report showing the scope of this issue. As June Oscar AO, Former Australian Human Rights Commissioner wrote,

> *"In major cities, regional and remote locations across Australia, I heard repeated stories from women about being stereotyped, having their health concerns disregarded or minimised, having serious conditions misdiagnosed, and even made to feel that they had done something wrong by falling ill." (Australian Human Rights Commission, 2020, p. 401)*

We see racism, lack of cultural safety, and a general lack of care or concern for Aboriginal women and girls in health systems putting them in vulnerable situations or creating an

environment with suboptimal care. For example, VAHS staff have observed hospitals discharging Aboriginal women on Friday evenings, with no transport to return home, even when they live regionally. Hospitals can have rules and procedures that limit the ability for them to flexibly respond to the needs of an individual.

Further, when Aboriginal women give birth local councils are notified but not local ACCHOs. VAHS often receives information informally from council providers or community members. If VAHS was notified, health workers could reach out to new mothers to provide timely support, including for pain management.

Wiyi Yani U Thangani speaks to how Aboriginal and Torres Strait Islander peoples 'continue to experience racism, discrimination and cultural disrespect', and receive a lower level of treatment in mainstream healthcare compared with non-Indigenous Australians (Australian Human Rights Commission, 2020, p. 401). This is why cultural safety is vital to improving access for Aboriginal women and girls to health services. While VAHS can provide culturally safe health services and supports, there are limitations in what services can be provided. So mainstream health services also need to be culturally safe. This is the intention behind Priority Reform Three under the National Agreement on Closing the Gap. Governments have an obligation to ensure cultural safety in health systems, and to hold government departments and mainstream services to account.

Culturally safe maternity care

A 2024 study (McCalman, 2024) found improved client care for Aboriginal women who had engaged in culturally tailored caseload midwifery programs. These programs were delivered by the Victorian Aboriginal Community Controlled Health Organisation (**VACCHO**) in partnership with three Melbourne Metropolitan hospitals. It was found that patients in this program had a high satisfaction with their maternity care as they felt actively involved in the decision-making process, their concerns were taken seriously and that their midwives were kind and understanding.

Disproportionate impact on Aboriginal women and girls

Aboriginal women and girls disproportionately experience pain and chronic conditions compared with non-Indigenous women and girls. The Australian Institute of Health and Welfare has reported that Aboriginal people experience higher rates of chronic illness such as asthma and diabetes than non-Indigenous people (2024); with men and women experience similar rates of chronic conditions (Australian Human Rights Commission, 2020, p. 49).

Many VAHS clients have chronic conditions. 2,168 Aboriginal and/or Torres Strait Islander women, gender diverse and girl patients attend VAHS regularly. 20% of those are between 25 – 34 years old (20.01%), and 16% are 15 – 24 years old (16.14%). In 2023, the top five chronic health amongst this demographic were asthma (21.3%), mental health conditions (16.9%), arthritis (6.8%), diabetes (4.3%), and epilepsy (3.8%). All these conditions can cause physical pain, including chronic pain.

Aboriginal women's experiences of pain, pain management and treatment, and barriers to accessing health services

Some of the key causes of pain, or pain causing conditions that Aboriginal women and girls who access our Women's and Children's program present with include back pain, pregnancy, sexual and reproductive health, injury due to family violence, and dental pain. Below we speak to this and offer examples ways to improve access to healthcare and of effective pain management and treatment options, including preventative healthcare.

Nutrition and obesity

Many Aboriginal women that come to VAHS have back pain. Some require walking aids, even at a young age. Healthy lifestyles, including good nutrition and movement is important for prevention and management of back pain as obesity can strain the back and legs and exacerbate other types of chronic pain. However, there are economic barriers to living healthy lifestyles for families. The cost of engaging in sport for families is increasing and many cannot afford it, which leads to inactivity. Further, high cost of living limits Aboriginal families' abilities to purchase fresh fruit and vegetables. It is also difficult to make lifestyle changes without support.

VAHS previously had a gym at the Preston site, which was popular and well utilised by community members. Occupational therapists and physiotherapists could work with VAHS clients there. As VAHS has expanded, due to increased demand, including for the Women's and Children's program, the lack of available space has meant that the VAHS gym could no longer operate. However, VAHS aims to set up a new gym when space is available. There is need for additional workforce such as exercise physiologists to work with VAHS clients; exercise physiology has been previously effective.

The Her Tribe and His Tribe Aboriginal-Designed Empowerment Programs

Thes VAHS pilot programs – one for women and one for men – were Aboriginal-designed empowerment programs that were highly popular with VAHS clients. The programs were designed to be holistic, aiming to 'strengthen mental health, social and emotional wellbeing, community connection, and to reduce psychological distress.' (Gee, 2022). The Her Tribe program ran for sixteen weeks and included camps and activities that encouraged community and cultural connection. 43 women completed assessments pre- and post-program, and the program resulted in 'significant increases in participants' access to personal strengths and resources, relationship–community–cultural strengths and resources, and decreases in psychological distress,' (Gee, 2022) which were found to be maintained at the six month follow up. Aerobic fitness also improved for the women. This program was a pilot, and no additional funding was provided to continue, despite its success.

The positive evaluation of the program shows the benefit of programs that are designed by local Aboriginal people for community and that include physical and cultural activities. This is because they contribute to improved health, mental health and SEWB outcomes. It is our observation that programs like this one are effective in supporting pain management in

Aboriginal women. Community members continue to ask VAHS whether this program will run again, indicating ongoing demand.

Sexual and reproductive health

Ten per cent of Aboriginal girls experience pelvic pain (State of Victoria, 2022, p. 18). Diagnosis of related conditions is a barrier to treatment. While common, Aboriginal women often wait between seven to twelve years after symptom onset for a diagnosis of endometriosis, which can be a debilitating condition (State of Victoria, 2022, p. 18). At VAHS, 34 of the women and girls who attend regularly (1.6%) have a diagnosis of endometriosis. Further, despite affecting between eight and twelve per cent of Aboriginal women of reproductive age, Polycystic Ovarian Syndrome (**PCOS**) is underdiagnosed.

VAHS' Women's and Children's program has observed that Aboriginal girls' menstrual cycles are getting earlier, which means that the number of Aboriginal girls who require pain management for related conditions is increasing. This, coupled with the large waitlists for adolescent paediatricians and limited availability of gynaecologists through VAHS means that the demand for services is greater than what VAHS is resourced to provide.

VAHS sees higher attendance for gynaecology appointments when they are done at VAHS. This is because many Aboriginal women and girls will only go to a culturally safe ACCHO to get treatment.

Further, many Aboriginal women experience pain related to pregnancy, both before and after birth. Pregnancy belts are often used by VAHS to manage women's pain. VAHS has also found alternative therapies for pain management useful, in particular hypnotherapy.

Family violence

Family violence is the leading cause of preventable death, disability and illness in women aged 15–44 years and during pregnancy women are at an increased risk of family violence; the risk is higher with unintended pregnancy (State of Victoria, 2022, p. 18). Aboriginal women are 34 times more likely than non-Indigenous women to experience family violence (National Family Violence Legal Prevention Services Forum, 2015, p. 3).

When women experience family violence, they can experience shame and may be fearful in seeking support for pain management or treatment. They may fear that they will not be believed, they will be judged, or that their children will be taken away from them. Aboriginal women who experience family violence experience judgement and racism in mainstream health services, as well as a lack of cultural safety.

Many Aboriginal women self-medicate to manage pain, especially when there are barriers such as shame or fear of judgment attached to seeking pain relief. When there is family violence, this can increase the likelihood that women will end up in contact with the justice system. There is a therefore a direct link between Aboriginal women's lack of access to culturally safe pain management, family violence, incarceration, and child removal.

When harmful behaviours and underlying causes are left unaddressed, harms such as family violence and substance abuse can escalate, driving offending behaviours:

Women experience domestic violence then they self-medicate to numb the pain with drugs and alcohol until they do something to land them in here. Once they get here, the guards make them go cold turkey. It's excruciating to watch. They get no support coming off … I think they test us in here, you know, how far they can push us and then they wonder why they find us trying to end it all hanging off the door [speaking about suicide attempt]. ***Darwin women's prison engagement*** (*Australian Human Rights Commission, 2020, p. 170*).

Dental

Dental services are very important for preventing and treating dental pain in Aboriginal women and girls. Having healthy teeth directly impacts on what a woman can eat, which impacts on her nutrition, obesity and associated pain; it also impacts on self-esteem and SEWB. VAHS has long wait times for dental services and women are missing out on regular health checks. The most effective way to improve access is for dental services to work with families, which requires a holistic and flexible approach. This is something that ACCHOs like VAHS do well.

VAHS dental van

VAHS has a dental van that can attend at different sites to increase access to dental services for clients. VAHS staff report that this has been very successful at ensuring access. This is a good example of a flexible approach that aims to reduce barriers to accessing healthcare.

Logistical barriers

There are other barriers in being able to access GPs and health services, including accessing tests and treatment, and day surgery: it is difficult for Aboriginal women to access GP appointments due to waitlists and logistical challenges. For example, if no one is available to look after an Aboriginal woman's children during an appointment or if she can't access transport.

VAHS Aboriginal Health Workers (**AHW**) support women to attend appointments by looking after children or providing transport. This is a vital and often overlooked part of improving access to health care. There is an urgent need for more AHWs who can provide culturally safe, flexible support. Respite for mothers with older children is also urgently needed.

VAHS can provide taxis for women to get to appointments. However, taxis are not always culturally safe or accessible. VAHS used to be able to run a transport service, which was crucial in improving access. Were VAHS funded to be able to run this service again it would improve outcomes for Aboriginal women and children.

Workforce

As noted above, another barrier to services is lack of resourcing for workforce. For example, VAHS sees a huge demand for adolescent paediatric care. Paediatrician wait times are 2-3 months for a consultant paediatrician and 1-2 months with a paediatrician registrar.

VAHS' Women's and Children's program, there is a need for significant additional funding for staff, including AHWs, mid-wives, occupational therapists, maternal and child health nurses, and social workers. AHWs are fundamental to culturally safe holistic service delivery. They often know more about the clients' daily lives than the GPs do, including the barriers that women and

children are experiencing and can provide flexible support that is tailored to the individual to ensure that women and children access required services and are able to attend.

Another issue that is that there are inconsistencies in what Aboriginal nurses can bill for compared with AHWs. Aboriginal nurses are highly skilled health professionals who can deliver high quality services to Aboriginal people; the scope of medical care that they can provide is larger than AHWs. Both Aboriginal nurses and AHWs are vital in ensuring holistic and culturally safe healthcare. Yet AHWs can bill for many more items under Medicare than Aboriginal nurses, who can only bill for smaller MBS items. This disincentivises AHWs from continuing training and becoming Aboriginal nurses, contributing to a workforce gap.

Health promotion

Early detection is vital in closing the health gap for Aboriginal women. Breast cancer is the most diagnosed cancer among Aboriginal women. Each year, about 150 Aboriginal women are diagnosed with breast cancer and about 35 women die from the disease. Nationally, only 36 per cent of Aboriginal women between 50-74 years of age are screened for breast cancer, compared with 50 per cent for non-Indigenous women (Australian Institute for Health and Welfare, 2024). Early detection can increase the likelihood of successful treatment and recovery (Australian Government Cancer Australia, 2022).

Aboriginal Community Controlled Organisations' health promotion work can be effective in raising awareness amongst community and encouraging Aboriginal people to get screenings. Health promotion is a core part VAHS' work in community. For example, in 2021 Aboriginal women came together to produce a short video that encouraged Aboriginal women to get breast screens (Breast Cancer Network Australia, 2021).

Alternative pain management and treatment

VAHS Women's and Children's program has identified a need for training for VAHS staff, and in broader health services, including for GPs to better understand and utilise alternative pain management and treatment options. VAHS has found that providing alternatives can be as effective as medication. VAHS has found the following hugely helpful in pain management for Aboriginal women and girls:

- Occupational therapy
- Art therapy
- Walking groups
- Women's and girls' camps
- Hypnotherapy
- Healthy lifestyle and exercise programs, including access to an exercise physiologist.

VAHS has found that women's experiences of pain have decreased after engaging in group activities, such as art groups and camps. The Women's and Children's program has run upwards of 15 camps for women, on Country, with AHWs to support. The camps include empowering activities that encourage self-esteem and self-care. These camps in and of themselves are pain relief and women come away from the camps feeling less pain. These programs also help to prevent pain in the first place.

VAHS has also found engaging Ngangkari healers highly effective for clients and there is high demand for access to healers.

The need for a VAHS Women's and Children's Hub

The increased demand and specific needs of Aboriginal women and children who attend VAHS has meant that the Women's and Children's program has outgrown their current site. As noted above, there are workforce gaps, appointment wait times can be long, and past programs that were effective and popular have been defunded. The Women's and Children's program works well because it can provide holistic, flexible wraparound support for women and children. AHWs can tailor the support provided to ensure that women and children can access appointments and are able to attend follow ups. The provision of alternative pain management, such as hypnotherapy, enables Aboriginal women to reduce or treat pain without relying on, or in addition, to medication.

VAHS recommends that the Department of Health funds the establishment of Women and Children's hub with an increased and dedicated workforce that can build on the success of the current program and expand service offerings. Additional capital investment would be required for a suitable site.

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