

# Listening to women's voices

Results of the Victorian women's health survey 2023





#### **Acknowledgement of Country**

The Victorian Government acknowledges the Traditional Owners of the lands on which we all work and live. We recognise that Aboriginal people in Victoria practice their lore, customs and languages, and nurture Country through their deep spiritual and cultural connections and practices to land and water. The Victorian Government is committed to a future based on equality, truth and justice, and acknowledges the entrenched systemic injustices experienced by Aboriginal people endure. We pay our deepest respect and gratitude to ancestors, Elders, and leaders – past and present. They have paved the way, with strength and courage, for our future generations.

#### A Statement on Language

Language is an effective tool for changing community attitudes and promoting inclusion. We know language is always changing, and we recognise that words are powerful and can have different meaning for different people.

Any references to a woman or women or girls include: cisgender women, transgender women, transgender men, non-binary people and gender diverse people who may be perceived as women, female or feminine (regardless of expression or identity), who may experience similar health issues and/or gender-based discrepancies in care.

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# Women's health and wellbeing in Victoria

Women and girls are more than half of our population, yet their health is often overlooked, underdiagnosed and assumed to be only about sexual and reproductive health.

Health and wellbeing are determined by lots of factors, and not all Victorian women enjoy the same health and wellbeing.

We know discrimination, bias and sexism have a profound impact on women and barriers to care can be compounded for some women. For example, Aboriginal women are less likely to achieve good pregnancy and birth outcomes and LGBTIQA+ people are more likely to have poor mental health.

The Victorian Government, through the Women's Health and Wellbeing Program, is working to bridge the gap in women's healthcare and health outcomes.

Better health outcomes for women means better health and care for all.

We are investing in new initiatives that will improve health for Victorian women.

We are also listening to what women say about their experiences of healthcare. We want to make sure their voices guide the way we design and deliver new services and supports.

During September and October 2023, we undertook the Women's Health Engage Victoria, 'Around the table' survey and asked Victorian women about the things that affect their health and wellbeing, their experiences of care, and how we can improve healthcare services for better outcomes.

The survey heard from 1,772 Victorians from across our community. Their experience and advice gave us a rich understanding of the issues women face and what their priorities are.

Overwhelmingly, women told us their health and wellbeing are the foundation of their quality of life.

#### Women's Health and Wellbeing Program initiatives



20 new women's health clinics



10,800 additional laparoscopies over 4 years



\$1.8m to 13 non-government organisations



\$2m in women's health scholarships



A dedicated Aboriginal-led women's clinic



9 new sexual and reproductive health hubs



Inquiry into women's pain



Women's Health Research Institute business case



A mobile women's health clinic



More primary care sites



\$4m for research into women's health



A sex and gender inclusive health system

About 32% of participants told us about respectful and compassionate clinicians who listened carefully and focused on their unique needs and experiences.

Women told us about the importance of team-based care, with 11% of participants sharing the positive impact this approach had on their health outcomes.

We also heard about a broad range of health conditions and issues – but it quickly became clear women had many common experiences and priorities.

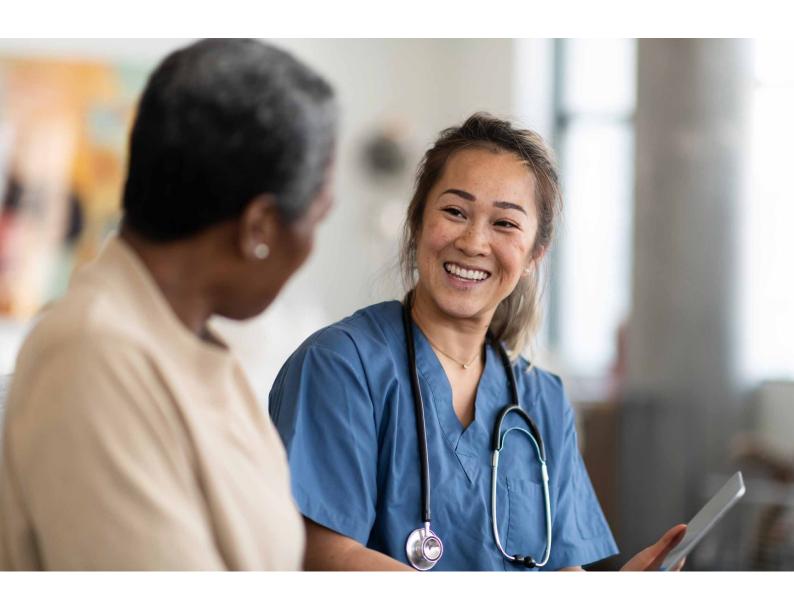
Health issues such as menstruation, pregnancy, the complications of birth and sexual and reproductive health significantly affected the health and wellbeing of about 50% of participants.

We also heard that 40% of participants live with chronic pain that can debilitate and cripple good health and wellbeing.

In this survey, more than 50% of participants told us that poor mental health affects their health and wellbeing. Participants in our LGBTIQA+ community were even more likely to experience poor mental health (81%).

Poor mental health was also a finding from the Royal Commission into Victoria's Mental Health System (2021) which also reported that women are more likely to experience mental illness.

Our work to transform Victoria's mental health system is well under way, with more than \$6 billion invested in mental health services and support since release of the Royal Commission's report in 2021.



# How health conditions impact women

In sharing their stories, women told us how these and other conditions affect their lives.

Women's health conditions routinely affect their capacity to work, with 20% of participants reporting that physical issues such as poor sleep, fatigue and limited mobility routinely and significantly affected their health and wellbeing.

We know that meaningful social connection protects and supports our health and wellbeing. In this survey, 20% of participants told us that poor health and wellbeing often affected their social connections and friendships.

When describing their experiences navigating and accessing Victoria's health system, about 46% of participants mostly or did receive the care they needed.

However, they also told us about service delays and a lack of connected care. More than one third of participants told us they had to wait too long for the care they needed.

Concerningly, around 25% of participants said the financial burden of medical care significantly affects their health and wellbeing.

#### What we can do to improve

Women were clear about how we can improve our healthcare system – listen to them without bias or judgement and treat them with empathy and respect. And make it easier to access services.

Alongside active listening, 10% of participants also said their healthcare provider needed to improve their knowledge about women's health conditions.

In addition, 14% of participants asked that we make healthcare more affordable, and 5% said reducing wait times was a priority.

#### **Next steps**

The survey was a first step in reaching out to Victorian girls and women. We are extremely grateful for the many people in the community who shared their lived and living experiences. In line with survey feedback, we are also working to ensure that how we describe 'woman' better aligns with community expectations and expert advice.

We will use the information we gathered from the survey to inform new services, such as women's health clinics.

We will hold community engagement sessions in 2024 to hear from women in priority populations, including, women with a disability, LGBTIQA+, Aboriginal and culturally and linguistically diverse communities.

The Women's Health Pain Inquiry will commence in early 2024 and will further focus on the experiences of pain and pain management for girls and women in Victoria. More information about engagement opportunities will be shared on the department's website in due course <a href="https://www.health.vic.gov.au/public-health/womens-health-wellbeing-program">https://www.health.vic.gov.au/public-health/womens-health-wellbeing-program</a>.

The Victorian Women's Health Advisory
Council <a href="https://www.health.vic.gov.au/public-health/womens-health-advisory-council">https://www.health.vic.gov.au/public-health/womens-health-advisory-council</a> will also provide expert independent advice on women's health.

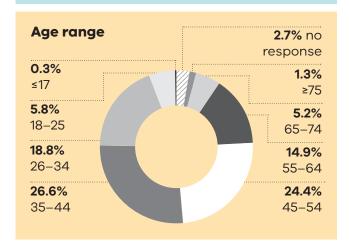
Led by women for women, the shared expertise and lived experience of girls and women and Council members will examine how public health services can work together for better outcomes for all women.

### **Key insights**

#### **Demographic insights**

We heard from **1,772** Victorians

# 94.5% identified as a woman 1.2% identified as non-binary 4.3% other



**1.2%** identified as Aboriginal and/or Torres Strait Islander



13.4% identified as LGBTIQA+



14.2% were of CALD backgrounds



**20.6%** were living with a disability

#### **Geographical representation**





**62.7%** Metro

**29.6%** Regional and rural

**7.7%** no response

#### What we heard

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2 in 5 live with **chronic pain** (that adversely affects their health and wellbeing)



Healthcare they received mostly or did meet their needs



Go to their GP for trusted and reliable information



Positive experiences of health services



1 in 10 asked that clinicians improve their knowledge and clinical skills surrounding women's health

**91.6% accessed services** to manage their health conditions

**6.2%** did not access services **2.2%** no response

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1 in 4 women were impacted by the financial burden of healthcare

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1 in 3 had health conditions that impacted their **ability to work and keep a job** 

had health and wellbeing impacted by at least one of the following:

- mental health
- menstruation
- pregnancy, birth and postnatal care
- sexual and reproductive health

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1 in 3 impacted by perimenopause or menopause

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1 in 5 did not have the social connections they needed to support good health and wellbeing



The survey heard from a wide range of Victorian women about many health conditions and issues that affect them. However common themes and priorities emerged.

# The most prevalent health issues for women

About 50% of participants reported that menstruation-related conditions affected their health and wellbeing. Women living with a disability and the LGBTIQA+ community were 10% more likely to say menstruation affected their health and wellbeing.

Similarly, about 50% of participants told us that pregnancy and the complications of birth had lasting effects on their health and wellbeing. Pelvic pain, incontinence and postnatal depression were most common among women aged 35 and 54 years, as well as those living in regional and rural communities.

We also heard about the lasting effects of fertility challenges and miscarriage and the shadow these experiences cast across women's esteem, relationships and workforce participation. What made it even worse was when they were treated without empathy and alongside pregnant women and new parents.

'I was not treated with kindness or understanding given I have just lost my baby – they just wanted me out of the hospital unit.' Nearly 50% of participants said that sexual and reproductive health issues like endometriosis directly affected their health and wellbeing. This was especially the case for those aged between 18 and 44 years. The impact was even greater for Aboriginal and LGBTIQA+ people.

In this survey, more than 50% of participants told us that poor mental health affected their health and wellbeing. Women of all ages and from all communities reported experiences of anxiety, depression, low self-esteem and stress. Younger women aged 18 to 34 years were 10% more likely to report poor mental health than those aged 36 to 64 years.

About 30% of participants also shared with us that poor mental health was often a result of other health conditions such as endometriosis, menopause and chronic pain.

In sharing their stories about chronic pain, women told us about persistent migraines, debilitating endometriosis, pain associated with the menstrual cycle as well as arthritis and conditions like fibromyalgia.

4 in 10 women live with chronic pain that affects their health and wellbeing.

Despite this, women also told us about feeling under pressure to push through, to ensure they continue to meet work and caring responsibilities.

The data from this survey tells us that people suffering from chronic pain were almost twice as likely to have their capacity to work reduced than those who did not.

Over 30% of participants told us their health and wellbeing was affected by the financial burden of healthcare. They told us that they often defer or miss out on services such as postnatal physiotherapy and neurodivergent diagnosis and treatment because of cost issues.

'The cost of medical care means I delay appointments until I can talk about lots of issues in one appointment.'

25% of participants told us their health conditions affected their productivity, ability to work and keep a job. Women with a disability were 11% more likely to experience this than other participants.

Issues that compounded these challenges included needing time off work to manage medical appointments, to rest when unwell or when pain has escalated.

Around 30% of participants told us their health conditions had physical effects such as disrupted sleep and chronic fatigue. For some women, limited mobility further compounded poor health and wellbeing with weight gain and reduced fitness.

Around 30% of participants also said they were affected by the symptoms of perimenopause or menopause. Women shared their experiences of fatigue and brain fog, which made a real difference to their capacity to work and manage the demands of daily life.



Women also shared their struggle to find a knowledgeable practitioner who could provide high-quality and evidenced-based care such as hormone replacement therapies (HRTs).

'I have struggled to access Hormone Replacement Therapy and other medications related to perimenopause due to my doctor's hesitancy to discuss these issues with me. Instead, I have been prescribed antidepressants.'

They told us that healthcare providers need more training and expertise to better support women as they transition through the stages of menopause.

We also heard that women wanted more education about these conditions. They also wanted better discussions about their shared experiences to reduce stigma.

Meaningful social connection protects and supports our health and wellbeing.



#### Initiatives on the way

Thirteen Women's Health and Wellbeing
Support Groups and Programs are being
rolled out from January 2024 to help Victorian
women feel connected to their community,
reduce the risk of isolation and loneliness
and empower women to make choices about
their own health.

In this survey, about 20% of participants told us they miss out on the social connections they need to support good health and wellbeing.

Some women describing their experiences of loneliness and isolation told us of shame linked to incontinence issues, debilitating pain preventing them from leaving their homes and lower energy levels.

#### **Accessing healthcare**

Despite the barriers and challenges, most women access health services for the care they need. However, the survey showed that younger people aged 18 to 25 were less likely to seek help than other age groups.

Over 70% of participants told us they visited their care provider (usually their GP) to discuss their symptoms and health conditions. This was notably less likely for LGBTIQA+ women, people living with a disability and Aboriginal people.

'As an Aboriginal mum, I feel like I am automatically judged across the medical sector, and this comes through in the way services help and speak to me.'

Family and friends were a more common source of information for the Aboriginal women, and for people aged 18 to 34. Younger people were more likely to turn to social media for health advice.

Additionally, participants identifying as LGBTIQA+ and people living with a disability were 10% more likely to approach a health not-for-profit (such as Endometriosis Australia) than the overall cohort.

People in these communities, were also more likely to use helplines, such as NURSE-ON-CALL.

Nearly 60% of participants reported to have had positive experiences using healthcare services with 30% attributing their positive experiences to a healthcare practitioner. They said they were listened to with respect and empathy over time. They also said their positive experiences were due to expert advice, continuity of care and shared-care planning.

'I was taken seriously, listened to and was given treatment options, as well as the chance to ask advice about those options.'

However, one-third of participants reported insensitive and disrespectful practitioners who left them feeling stressed and frustrated.



In particular, this experience was more common for women suffering pain, autoimmune conditions, infertility, and menopause, as well as women who required pre and post-surgical care.

Around 10% of participants reported that health practitioners did not know enough about women's health to provide high-quality care and advice.





#### Initiatives on the way

The Women's Health Specialist Scholarship program is the Victorian Government's commitment to upskilling the health workforce to meet women's needs in Victoria. Funding has also been allocated to develop a business case for the establishment of the first Women's Health Research Institute in Victoria that will work to address the gender gap in medical research and target conditions that impact women.

Some said they felt 'gaslit' by their healthcare provider, and shared their distress when health concerns and pain were attributed to mental health conditions.

'I was prescribed antidepressants when I had acute pelvic pain that stopped me from sleeping and working. I was later diagnosed with advanced endometriosis.'

Around 11% of participants felt dismissed by their provider.

Women in regional and rural communities told us that they commonly travel long distances to access care. The need to travel had financial and social impacts.









#### Initiatives on the way

The women's health reform package features the establishment of 20 women's **health clinics** over the next four years, an **Aboriginal-led clinic** and a **mobile clinic** for women in rural and remote areas. These clinics will offer specialised services while applying a holistic and integrated approach to women's physical, mental, and emotional wellbeing. We are also establishing nine additional Women's Sexual and Reproductive **Health Hubs** that offer help with information and support on all types of sexual and reproductive health needs.

While women also described the challenges of accessing bulk-billed GP services, long wait lists or limited availability of public services meant many women were left little choice but to access expensive private specialist and allied health appointments.

We know that the health system can be complex and difficult to navigate. Women participating in the survey shared this experience as well.

One-quarter of participants described the challenges they experienced coordinating and navigating care, managing multiple specialists, knowing who to trust and following up lost or delayed referrals. This proportion was even higher for people living with a disability and our LGBTIQA+ community.



#### **Opportunities to improve services**

Again and again, women told us that being listened to is at the centre of good healthcare and directly contributes to their health and wellbeing.

'What matters most is having the ability for all my treating teams to be communicating with one another so that I can get the best possible treatment with everyone on board without having to repeat myself unnecessarily.'

Nearly 50% of participants value practitioners who listen, include them in decision-making and provide high-quality care respectfully and compassionately.

20% of participants also told us that improving timely and affordable access to high-quality and appropriate care should be our priority.

10% of participants believe our healthcare practitioners need more training and support to provide high-quality, evidence-based care. They suggested initiatives such as mandatory empathy training, trauma-informed care and women's health training for medical students and practitioners, including GPs and emergency care frontline staff.

Over 30% of participants told us about financial burden of healthcare, with some delaying or missing out on care. Across all age groups and communities, 25% of women told us that healthcare needs to be more affordable. They asked that we continue to advocate for improved access to NDIS and Medicare bulk-billed services and rebates.

Many women highlighted the value and positive impact of allied or psychology services, but they noted there were not enough subsided sessions to meet their needs.

Women told us that more welcoming healthcare spaces would make it easier to access care, especially for women from diverse backgrounds. Some also told us that free parking for patients would help make healthcare more affordable.

Around 10% of participants wanted a better understanding of how long they had to wait for an appointment. They also wanted wait times to be reduced.

We also heard that more services should be available in regional and rural areas, reducing the need for people to travel to Melbourne for specialist care.

Women shared with us they want to access care from a multidisciplinary team that can provide wrap around care that is well coordinated and offers continuity of care and carers.

'My public health allied health practitioners were not very experienced and after waiting for a long time I was discharged too early.'

We also need to provide better referral pathways so women can access the right care in a timely way. Women want us to encourage GP's to make ongoing referrals that don't expire, as well as allowing for self-referrals and giving preference to bulk-billing providers.

The values, experiences and aspirations of Victorian girls and women are the compass guiding the Women's Health and Wellbeing Program's planning, development and implementation. Your input will inform our model of care and delivery of women's health services.

**Stay informed** about the program's updates by visiting **Women's Health and Wellbeing Program** <a href="https://www.health.vic.gov.au/public-health/womens-health-wellbeing-program">https://www.health.vic.gov.au/public-health/womens-health-wellbeing-program</a>.



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