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Inquiry into Women's Pain Sub-Committee Safer Care Victoria GPO BOX 4057 Melbourne, VIC 3001

Submitted via email: paininguiry@safercare.vic.gov.au

Dear Sub-Committee Members,

#### APS Response to the Victorian Inquiry into Women's Pain

The Australian Psychological Society (APS) appreciates the opportunity to contribute to the *Victorian Inquiry into Women's Pain*. Many of our members work with people experiencing chronic health and pain conditions. The APS also has a strong record of advocacy for matters pertaining to women and girls (e.g., <sup>1,2</sup>). We are also strong advocates for multidisciplinary models of care for assessment, treatment and support for people living with chronic health and pain conditions (e.g.<sup>3,4</sup>).

As the first Australian inquiry of its kind, we note that the *Victorian Inquiry into Women's Pain* (the Inquiry) will be a vital platform for understanding, acknowledging and better responding to the experience of pain for girls and women<sup>a</sup> from 12 years of age. While the Inquiry will focus on identifying systemic issues and proposing solutions to enhance women's and girl's care in Victoria, the findings will have more far-reaching significance for Australian women's and girls' health and wellbeing.

#### **About the APS**

The APS is the leading professional association for psychologists in Australia. Psychologists work in diverse ways and contexts to unlock the full potential of individuals, organisations and their communities through the application of psychological science and knowledge. At the APS, we are dedicated to advancing the scientific discipline, ethical practice and application of psychology within our society. Our work is informed by a human rights approach<sup>5</sup> and aligned with the United Nations' Sustainable Development Goals (SDGs)<sup>6</sup>. We advocate for a fair, inclusive and environmentally sustainable world, recognising the evidence that national and global prosperity now and in the future hinges on prioritising the health and wellbeing of people and the planet<sup>7</sup>.

Please find attached our response to the Inquiry terms of reference that focus on barriers, enablers and opportunities to improve care, treatment and services for pain conditions. If any further information is required from the APS, I would be happy to be contacted through the National Office on (03) 8662 3300 or by email at z.burgess@psychology.org.au

Yours sincerely

Dr Zena Burgess, FAPS FAICD Chief Executive Officer

<sup>&</sup>lt;sup>a</sup> The APS acknowledges the diversity of people who identity as women, including transgender people, and that not all people who experience what is referred to as women's pain may identify as women. Given this, we have attempted in this submission to use gender inclusive language. However, when reporting the work of others, we have used the authors' terminology.



## APS Response to the Victorian Inquiry into Women's Pain

In this submission to the Victorian Inquiry into Women's Pain, the APS provides a biopsychosocial perspective, drawing on practice-informed evidence and evidence-based practice about pain and gender-specific pain. We follow this with recommendations for improving pain care for women and girls in Victoria.

While our response to the Inquiry is informed by APS members' professional experiences as psychologists and is supported by research evidence, we recognise that it may not fully capture the entire spectrum of unique issues and experiences faced by women and girls living with pain. Thus, the APS commends Safer Care Victoria for offering women and girls the opportunity to directly share with sub-committee members their lived experience of pain. This will offer a more comprehensive view of the barriers and enablers within the Victorian healthcare system and community that must be addressed to ensure safe, high-quality, person-centred pain care for all women and girls affected.

## 1. Pain is a costly personal and public health concern, especially for women

Around the world, and in Australia, people living with pain are more likely to be women<sup>8,9</sup>. As noted in the Inquiry terms of reference, women and girls are affected by pain diseases more frequently and severely than men, and they experience more recurrent, severe and longer lasting chronic pain than men<sup>10</sup>. It is estimated that almost 2 million Australian women are affected by chronic pain<sup>11</sup>. In Victoria, a survey of over 1,750 women found that 40% live with chronic pain<sup>12</sup>.

As highlighted in the Inquiry terms of reference, women and girls are disproportionately affected by particular forms of pain including head, neck and migraine pain, abdominal pain, rheumatological pain, and musculoskeletal pain, particularly fibromyalgia<sup>9</sup>. Some forms of pain experienced by women and girls are related to female anatomical, physiological and hormonal factors, such as pelvic, menstrual or endometrial pain; pregnancy, childbirth and postpartum pain; and specific female health conditions like cervical or ovarian cancer<sup>9,10</sup>. Pain associated with these conditions may also be experienced by transgender people. Emerging research highlights that gender identity significantly influences the pain experience of transgender women, revealing that they respond to painful stimuli similarly to cisgender women and report higher pain levels than cisgender men<sup>13</sup>.

The experience of pain imposes a substantial personal and economic burden for all Australians, with disproportionate impact on women and girls noting that:

- 93% of Australians report pain such as headaches, menstrual pain, joint pain and more<sup>14,15</sup>.
- 3.4 million Australians are living with chronic pain (persistent or recurrent pain lasting for months)<sup>11</sup>.
- Data on paediatric pain in Australia is limited, but it is thought that one in four children may experience chronic pain<sup>16</sup>.
- Pain is having adverse effects on mobility, sleep and daily activities, including the schooling, work and careers of Australians, noting that 68% of people living with chronic pain are of working age and 40% of early retirements are due to chronic pain<sup>8</sup>.
- Annually, chronic pain costs the Australian economy around \$140 billion. This includes health system, care and productivity costs of \$73.2 billion, plus \$66 .1 billion in costs related to reduced quality of life. If left unaddressed, the annual cost of pain in Australia is projected to rise to \$215.6 billion by 2050<sup>8</sup>.
- Women are disproportionately affected by chronic pain, and represent a significant portion of the economic burden. For example, endometriosis alone is estimated to cost the Australian economy approximately \$7.4 billion annually, with two-thirds of these costs attributed to lost productivity<sup>17,18</sup>.



# 2. The psychological and social impacts of pain are highly significant

Chronic pain often has comorbid mental health concerns, for example:

- Almost one third of Australian adults with severe or very severe pain experience high levels of psychological distress; around three times the rate of those with mild pain and six times the rate of those with no pain<sup>19</sup>.
- 30-40% of people with a diagnosed mental health condition also present for treatment for chronic pain<sup>19</sup>.
- 10%-50% of people with PTSD report chronic pain<sup>20</sup>, and PTSD symptoms tend to be elevated in patients with chronic pain conditions<sup>21</sup>.
- Suicidal behaviour is two-to three times more likely for Australians with chronic pain compared to the general population<sup>22</sup>.
- High levels of comorbid chronic pain and mental health conditions have been reported in paediatric populations, and increases the risk of PTSD, anxiety and depressive disorders later in adulthood<sup>23,24</sup>.

The comorbidity of chronic pain and mental health concerns for girls and women is especially significant, for example:

- Women with chronic pelvic pain are more likely to experience anxiety and depression, than women without chronic pain<sup>25</sup>.
- Endometriosis is often associated with high rates of depression and anxiety, with a recent review finding a prevalence ranging from 9.8 to 98.5% for depressive symptoms and 11.5 to 87.5% for anxiety<sup>26</sup>.
- Among older adolescent girls, chronic pain has been found to be highly comorbid with anxiety<sup>24</sup>.

The relationship between pain and poor mental health is bi-directional - untreated psychological conditions can exacerbate pain, and untreated pain can diminish mental health<sup>27</sup>. Further, poor mental health aggravates the functional and societal impacts of pain. For instance, major depression in individuals with chronic pain is linked to decreased functioning and poorer pain treatment outcomes, which in turn contributes to higher healthcare costs for the person and society<sup>8,28</sup>.

Pain often leads to withdrawal from family, friends and social activity, increased social isolation and loneliness and an erosion of self-identity<sup>29,30</sup>. This is well illustrated in one Australian study of women with endometriosis which identified the losses associated with their pain as: loss of bodily autonomy ('I can barely move/breathe/talk'), loss of liberty ('I'm trapped in the house'); and loss of connection: ('It stops me from being social')<sup>31</sup>.

Further, the mostly invisible nature of pain can lead to misunderstandings, mistrust and conflicts with family, friends and co-workers, precipitating stigmatisation (including self-stigma), discrimination, and exacerbate social and economic inequalities for women<sup>11,30,32,33</sup>.

## 4. There is a culture of disbelief and disenfranchisement of women's and girls' pain

As powerfully stated by an author on the topic of gendered pain: "There's a pain gap, but there's also a credibility gap. Women are not believed about their bodies — period"<sup>34</sup>.

Lived experience accounts and emerging research highlight that women are more likely to be challenged about the 'realness' of their pain, sometimes for years, with a view that their pain is exaggerated and their physical pain is often misattributed to emotional and psychosomatic causes (e.g.,<sup>34,35</sup>). For instance, middle-aged women with chest pain have been found to wait longer for evaluation for heart attack and were twice as likely to be misdiagnosed with mental ill-health such as anxiety compared to men exhibiting the same symptoms<sup>36</sup>. Women are also less likely to receive adequate pain management compared to men, again despite similar symptoms<sup>37,38</sup>. Another study



found that despite girls being more likely to report chronic pain during adolescence, their concerns are also dismissed more often by physicians (35%) compared to boys (17%)<sup>39</sup>.

Additionally, women and girls report that reproductive health complaints are commonly ignored. For instance, women with chronic pelvic pain and endometriosis, impacting around one in seven Australian women<sup>40</sup>, frequently report their severe pelvic pain symptoms are often dismissed as normal menstrual discomfort or they are told their pain is simply a part of being female<sup>34,41</sup>. Girls and adolescents also face dismissal of their pain when it is normalised as "growing pains" or menstrual-related issues, leading to a lack of serious investigation into their pain condition<sup>42</sup>.

Pain-invalidation and disenfranchisement are clear barriers to women and girls engaging in help seeking and accessing appropriate pain management care<sup>30,43</sup>. A recent meta-synthesis about the patient-provider communication experiences of women living with chronic pain conditions confirmed the centrality of gender in their experience of discrediting, silencing and stereotyping communication from health providers. The review found this disenfranchising talk, experienced disproportionately by women and girls, harmed their agency, credibility, care provider relationship and ultimately delayed access to diagnosis, care, support and resources<sup>35,44</sup>.

Minimising, dismissing or questioning the validity of women's and girls' pain and undertreating their pain is a manifestation of longstanding gender bias and medical misogyny<sup>45</sup>, with two out of three women experiencing discrimination in health care<sup>46</sup>. Rooted in societal stereotypes and systemic inequities that pervade our health care systems, women and girls are portrayed as emotional or dramatic and less capable of handling pain than men, yet paradoxically are undertreated for pain<sup>47</sup>. Past negative healthcare experiences for women can be traumatising and lead to heightened pain sensitivity, increased anxiety and reduced trust in medical professionals (e.g.,<sup>48</sup>).

Awareness of gender norms is crucial in both research and clinical practice to address gender bias in healthcare. Our health system is currently inadequate in recognising and addressing the pain of women and girls. Urgent actions are needed to cease the perpetuation of the culture of disbelief and inadequate care within our health systems.

## 5. Intersectional issues

Intersectionality of race, sexuality, ability and more, interact and compound to create unique experiences of oppression that significantly influence how women and girls experience, express and receive treatment for pain<sup>49</sup>.

For example, comorbidity with chronic pain is common in neurodivergent women and girls with autism and ADHD, noting they often have distinct sensory experiences from that of neurotypical people, including hypo- or hypersensitivity to touch and pain<sup>50</sup>, and are at increased risk for certain pain conditions, including joint hypermobility syndromes like Ehlers-Danlos (EDS), fibromyalgia and autoimmune disorders like rheumatoid arthritis and lupus<sup>50,51</sup>. In one longitudinal study, 77% of women diagnosed with autism or ADHD in childhood reported chronic pain and lower health-related guality of life as adults<sup>51</sup>.

Yet, the pain of neurodivergent women and girls is often overlooked, dismissed or attributed solely to their neurodivergent identity based on stereotypes or misconceptions, hindering access to diagnosis of other underlying pain conditions and access to treatment and support<sup>50,52</sup>. Neurodivergent women and girls may also struggle to articulate the severity or nature of pain to health providers<sup>52</sup>. Along with added societal expectations influencing how they believe they are expected to express pain, and past trauma associated with previous encounters with the healthcare system, neurodivergent women and girls may suppress or mask their pain, lack confidence in health care professionals and engage in less help seeking<sup>52,53</sup>. Many of these issues are also perpetuated for women and girls with cognitive and other disabilities (e.g.,<sup>54,55</sup>).



Pain beliefs and experiences vary considerably across and within cultural groups and may conflict with predominant western biomedical models of pain care in Australia. This, along with language barriers, and culturally unsafe attitudes and practices can hinder health system access and accurate pain assessment and treatment for culturally diverse women and girls (e.g., <sup>56</sup>). Although there is a dearth of contemporary studies about the pain experiences of First Nations women and girls in Australia<sup>57</sup>, the limited findings to date have highlighted health practitioner deficits such as discriminatory attitudes, complex communication, erroneous views of the universality of pain experiences, culturally inappropriate pain assessment and the misinterpretation of traditional pain relief strategies(e.g., <sup>58,59</sup>).

Women and girls from other marginalised communities, including LGBTQI+ individuals and those from lower SES backgrounds, have been found to experience more severe pain and pain-related disability in the context of disenfranchising communication about their pain from their health care provider<sup>42</sup>.

## 6. Women and girls must be able to access safe, quality multi-disciplinary models of pain care

As indicated in the preceding sections, pain is a complex experience, encompassing unpleasant sensations and affective responses, and influenced by a multitude of dynamic physical, psychological and sociocultural factors over time<sup>60</sup>. A holistic biopsychosocial model of care that addresses these diverse elements of the pain experience with integrated pathways is essential for providing safe, high quality, person-centred treatment for women and girls<sup>27,61</sup>.

Thus, comprehensive pain management should ideally involve a multidisciplinary team in which the expertise of general practitioners, specialists, psychologists and allied health professionals work together to develop, implement and monitor individualised treatment plans. Multidisciplinary pain management care has been found to be superior to pharmaceutical and other invasive care for chronic pain management<sup>62</sup>.

However, access to effective and affordable multidisciplinary care is limited in Australia. Less than 10% of individuals with chronic non-cancer pain receive effective care, and there are long wait times for multidisciplinary pain services in public hospitals, often exceeding a year<sup>63</sup>. Delayed diagnosis and treatment impacts return to functioning and work, quality of life, the effectiveness of interventions and patient distress<sup>64</sup>. Lack of access to services is especially critical in rural, regional and remote areas and Indigenous communities.

## 7. The role of psychologists

Given the psychosocial influences and outcomes of pain, mental health comorbidities, and the risks and harms associated with opioid use<sup>65</sup>, pain care pathways should include psychological assessments and interventions as standard components. This helps to ensure that patients who exhibit clear psychosocial risks and comorbidities engage with a psychologist as early as possible to developed tailored approaches to reduce long-term disability or pain chronicity<sup>66,67</sup>.

As regulated health professionals, psychologists, including health psychologists, clinical psychologists and counselling psychologists, use evidence-based approaches to help patients identify and manage psychosocial challenges associated with their pain. Psychological interventions, such as cognitive-behavioural therapy (CBT), have been shown to be effective in managing chronic pain(e.g.,<sup>62</sup>). Other psychological approaches, including acceptance and commitment therapy, mindfulness, biofeedback and hypnosis have also demonstrated varying degrees of evidence in their efficacy for treating pain conditions<sup>60</sup>.

Psychologists can provide training and education to health and allied health professionals about the psychosocial care needs of pain patients and others who provide services and support to women and girls with pain conditions. Psychologists also lead and engage in collaborative research about pain and pain care with other health professionals.



Accustomed to working in an interdisciplinary fashion, psychologists are thus central to a shared, biopsychosocial treatment approach<sup>66</sup>. However, psychologists and psychological interventions have been underutilised to date due to factors such as: a lack of awareness among healthcare providers and patients, insufficient funding for psychological treatment, and limited availability of trained psychologists<sup>60</sup>.

- 8. Recommendations for improving Victorian women and girls pain care
- **Patient education and empowerment** The APS emphasises first and foremost the importance of patient education as a powerful tool for people to understand their experience and feel empowered to improve their health<sup>66,68</sup>. This includes ensuring Victoria women and girls receive realistic information from their health care providers, delivered compassionately, about the nature and severity of pain that may be associated with various conditions, while also acknowledging the range of factors involved in each person's unique pain experience, and outlining the range of safe, high quality multidisciplinary care options.
- Evidence-based guidelines for health professionals: The APS calls for the development and dissemination of evidence-based guidelines that incorporate gender-specific considerations for pain care and trauma-informed care. These guidelines should be widely distributed and integrated into clinical practice, partnering with PHNs, allied health peak bodies and other health system stakeholders to embed the guidelines within primary care, hospitals and other health care settings.
- Improving access to multidisciplinary pain care for women and girls The APS calls for Victorian Government funding to increase access to affordable multidisciplinary pain care for women and girls. Funding to support regular case conferences among health professional teams and shared electronic health records to ensure seamless communication among providers are essential foundations for quality and safe multi-disciplinary pain care.

The APS calls for specific funding to ensure women and girls outside of metropolitan regions and First Nations Australians have access to non-pharmacological first line treatments as part of multidisciplinary ongoing pain management and support. This may include the use of telehealth services to improve access to holistic pain management models of care in rural and remote areas. Telepsychology, in particular, can provide remote psychological support and interventions, ensuring that patients receive evidence-based psychological pain care regardless of their location.

Thus, telehealth and other digital treatment modalities may be appropriate options for women and girls in rural and remote areas, but more research specific to telehealth models for women and girls pain care, including culturally safe models of care, is needed<sup>69</sup>.

- Increased access to psychologists and psychological care Expanding access to psychologists and psychological services for women's and girls' pain management is crucial. The APS calls for funding for dedicated psychology services within multidisciplinary care models, training more psychologists, and raising awareness about the benefits of evidence-based psychological interventions among healthcare providers and women and girls who have pain conditions.
- Greater focus on prevention and early intervention Given the strength of evidence in favour of, for example, cognitive behavioural therapy (CBT) for pain management, and the harms associated with pharmacological and other invasive pain treatment options, the APS calls for all women and girls reporting ongoing pain to have early referral and access to a psychologist for psychological assessment and intervention as first line treatments.



- Importance of stigma reduction The APS notes that the "contribution of psychological, social and psychiatric factors should not lead to the conclusion that a pain syndrome is primarily psychogenic<sup>70</sup>(p. 6)". It is important to emphasise both psychological and physical experiences of pain and that a holistic approach to women's and girls' pain must address both. Stigmatising beliefs may create substantial barriers when accessing psychological and other treatments. Psychologists may be able to assist in the reduction of perceived (or self) stigma for individuals and contribute to public health stigma-reducing initiatives.
- Workforce development: The APS calls in the Victoria Government to development a comprehensive workforce development plan, ideally in collaboration with the PHNs, allied health peak bodies and other health system stakeholders, to improve the pain management skills of the Victorian health workforce. Providing education and training to healthcare providers on gender-specific aspects of pain and the importance of non-pharmacological psychological interventions will be essential to help reduce the impacts of gender bias and improve the accuracy of diagnoses and treatment plans for Victorian women and girls with pain conditions.
- **Public awareness campaigns**: The APS calls on the Victorian government to fund and launch public awareness campaigns to educate the community about gender disparities in pain management and the importance of seeking comprehensive care to empower women to advocate for their health needs.

The APS strongly advocates for a comprehensive and integrated approach to pain management in Victoria that addresses the unique needs of women and girls. This includes improving access to coordinated multidisciplinary care, increasing access to psychologists and evidence-based psychological services, addressing gender disparities in the health system and empowering women and girls to advocate for their health needs.

Thank you again for the opportunity to provide input into this Victorian Inquiry into Women's Pain. The APS would welcome the opportunity to collaborate with the Victorian Government to progress the recommendations emerging from this inquiry.

The APS would like to acknowledge and sincerely thank the members who so kindly contributed their time, knowledge, experience and research to the development of this submission.

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