



# Response to the Inquiry into Women's Pain from the Endometriosis Management Plan project team

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## Who are we?

- We are a team of primary care researchers focused on the diagnosis and management of endometriosis and chronic pelvic pain by general practitioners (GPs) within the NHMRC-funded SPHERE Centre of Research Excellence (CRE). The SPHERE CRE seeks to improve awareness, availability and access to women's sexual and reproductive health services in Australia, with a focus on primary care settings.
- We have undertaken research as part of the Endometriosis Management Plan project to inform the development and implementation of an Endometriosis Management Plan for GPs to support navigation and management of endometriosis and chronic pelvic pain (CPP) for healthcare providers and their patients in primary care. The research and the management plan that we are developing and implementing are funded by the Department of Health and Aged Care.

## Why we have submitted a response to the inquiry into women's pain

Endometriosis and chronic pelvic pain (CPP) are causes of significant pain and health impact for many Australian women and girls. Endometriosis and CPP are health conditions affecting women and girls who have started menstruating. In Australia, one in seven women are diagnosed with endometriosis by the age of 44-49 years (1). Endometriosis is a chronic condition, where tissue that resembles the inner lining of the uterus (endometrium) is found outside of the uterus, mainly on the pelvic organs and tissues (2). The presence of endometriosis tissue causes an inflammatory reaction, with pain being the most common symptom. Endometriosis is one of the potential causes of CPP – pelvic pain with a duration of 6 months or longer (3, 4) – but CPP can also occur without endometriosis. Chronic pelvic pain can be constant or intermittent, and may occur during menstruation or be independent of the menstrual cycle (5). Endometriosis pain may occur during menstruation, during sexual intercourse, with urination and with passing bowel motions; these symptoms may occur individually or in combination. Pain is sometimes so severe that women attend hospital emergency departments, and there were more than 3,600 emergency department presentations in 2021-22 related to endometriosis (1). Of the female reproductive and maternal conditions, endometriosis is the third highest cause of non-fatal disease burden (1).

Delayed diagnosis of endometriosis is common, and Australian women with self-reported endometriosis experienced a delay in diagnosis of approximately eight years from symptom onset (6). The persisting and recurring pain caused by endometriosis and CPP has negative physical, social and psychological impacts on women, affecting fertility, quality of life, mental health and the ability to participate in education, work and social activities, leading to loss of productivity and financial costs for the individual and the community (1, 7-10). There is no identified cure for endometriosis and the intention of treatment is to manage symptoms (11). Endometriosis is a lifelong condition, and even after surgery, women may continue to experience symptoms.

In our submission below, we summarise what we have learnt from the research we have undertaken in relation to women's pain from endometriosis and CPP. The material presented in this submission has not yet been published and is under embargo.

## Executive Summary

Our research focussed on the experiences and views of women with endometriosis or CPP (consumers), as well as general practitioners (GPs) and stakeholders across Australia, about current endometriosis and CPP diagnosis and management in Australian primary care settings.

**Based on our findings, we make the following recommendations in relation to women's pain from endometriosis and chronic pelvic pain:**

- Awareness raising for GPs and the community about the symptoms of endometriosis and CPP, and what is 'normal' menstruation.
- Clear guidance and pathways for GPs to improve timely patient diagnosis and management.
- Better mental health support for women with chronic pain from endometriosis and CPP.
- Improving awareness about and access to the benefits of multidisciplinary care and patient-centred care.

We consulted with consumers, GPs and stakeholders through focus groups, individual interviews and a co-design workshop. **The key issues reported in these consultations related to women's experiences of pain from endometriosis and CPP were:**

- Endometriosis and CPP symptoms can impact multiple areas of a woman's daily life.
- Women's symptoms are often dismissed or normalised by health care professionals.
- Women's endometriosis and CPP pain is often not well understood or managed.
- The complexity of endometriosis and CPP makes the conditions difficult to diagnose and manage.
- Access and affordability of healthcare are significant barriers to women receiving adequate care for endometriosis and CPP.
- Women's healthcare needs are not currently being met.

As a cause of significant pain and health impact to many Australian women and girls, more needs to be done to improve the diagnosis and management of endometriosis and CPP, to enhance the healthcare experiences of women with these conditions.

## Key issues reported

- Endometriosis and CPP symptoms can impact multiple areas of a woman's daily life.
- Women's symptoms are often dismissed or normalised by health care professionals.
- Women's endometriosis and CPP pain is often not well understood or managed.
- The complexity of endometriosis and CPP makes the conditions difficult to diagnose and manage.
- Access and affordability of healthcare are significant barriers to women receiving adequate care for endometriosis and CPP.
- Women's healthcare needs are not currently being met.

We consulted women<sup>1</sup> with diagnosed endometriosis or CPP (consumers), as well as general practitioners (GPs) and stakeholders across Australia, about their experiences, perceptions and views on current endometriosis and CPP diagnosis and management in Australian primary care settings. Initially, we conducted two focus groups with 17 consumers (15 identified as female and two identified as non-binary; 47% from Victoria) and individual interviews with 10 GPs (33% from Victoria) and eight stakeholders (representatives of national endometriosis consumer groups, women's health services, tertiary health services, and academics; 50% from Victoria). We then conducted an online co-design workshop with 43 participants (10 consumers, 15 GPs and health clinicians, nine stakeholder representatives, and nine governance committee representatives; 28% from Victoria). Findings related to women's experiences of pain from endometriosis and CPP are summarised below, followed by key recommendations for consideration. Participant quotes have been de-identified and participants have been given a code number to maintain confidentiality.

## Women's experiences of pain in their own words

We heard from Australian women across a range of ages who had endometriosis or CPP. Consistent with existing literature (6), women in our focus groups experienced a significant delay in diagnosis of endometriosis and CPP. They reported experiencing their first endometriosis and CPP-related symptoms at an average age of 17 years, but didn't receive a diagnosis until an average age of 25 years.

### *The impact on daily life*

Almost all women reported experiencing symptoms such as period pain, pelvic pain outside menstruation, bloating and fatigue. Other symptoms experienced were irregular bowel movements, migraines, leg pain and emotional distress. In terms of the impact of endometriosis and CPP on daily life, almost half of women believed that **endometriosis or CPP interfered with their life "very much"**, and more than half

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<sup>1</sup> We use the term woman as an inclusive and broad term that refers to and acknowledges the diversity in needs and experiences of all people experiencing endometriosis and CPP, including people who do not identify as women.

were dissatisfied with their experience of endometriosis or CPP diagnosis and management in general practice.

Women experienced negative impacts from endometriosis or CPP across various life domains, such as physical, psychological, sexual, social, quality of life, school and employment. **All women experienced significant pain** due to their condition; one woman described their endometriosis pain as “debilitating”. Some women said they experienced poor mental health due to the chronic pain associated with endometriosis. Women described often having to take time off from work or school because of the severity of their symptoms, yet faced challenges receiving supporting documentation (e.g., medical certificates) from health providers.

*“...The impact it has on interpersonal relationships in terms of painful sex, those feelings of just general fatigue. So you start to feel a little bit more like a hypochondriac, and each time you go there [GP] you're going, oh look, I've got this symptom now. And you start to underestimate the impact it's having on your own life and wellbeing, until it becomes really quite impactful.” (Consumer 6)*

*“...[endometriosis] it's not something you can grow out of. It's not something you can just get on with your life with. I think also that it attacks you in, or, affects you in the prime of your life. And so they're the years that you're graduating from high school, that you're graduating from Uni, that you [are]... building your relationships, meeting someone, maintaining your friends, career, having babies, if that's what you choose to do. So it's all in those prime times of your life that this disease impacts. And I don't think, it is truly understood that it has such a breadth of impact on someone's life.” (Stakeholder 4 and endometriosis consumer)*

#### *Women's symptoms are often normalised or dismissed*

Many women reported that their **pain and symptoms were normalised or dismissed by GPs** as psychosomatic. This resulted in women not being open about their pain and symptoms to GPs at subsequent appointments for fear that they would not be believed. Women reported feeling alone in managing their condition, and unsupported by health providers. Although Australian clinical guidelines recommend hormonal treatment (e.g., combined oral contraceptive pill) as a first line treatment for endometriosis (3), its use for this purpose might not always be adequately explained to patients by their GP or patients may prefer alternative treatment options.

*“...Every single time I went to the doctors, it was just, 'You've got bad period pain. That's part of being a girl. Here's a contraceptive pill that should help with the pain.’” (Consumer 16)*

*“...that's when the GP started to dismiss me, as in I'm kind of being... hyper-sensitive about pain and it's all in my head.” (Consumer 11)*

#### *The process of diagnosis*

Women also reported being **frequently misdiagnosed** and having to undergo multiple diagnostic tests, which impacted on their emotional and physical wellbeing. Negative experiences in healthcare settings had led some to become **anxious and fearful about follow-up medical consultations**.



*“I had a lot of period pain... talked about a lot as being the starter period by my GP, like ‘Early times [this] happens, everybody gets this in the first couple of years’. Age 12 I was admitted to hospital [with] what they thought was appendicitis. They did ultrasounds and everything, no appendicitis. They concluded that it was period pains with no further investigation besides an ultrasound, which showed nothing... The pain was just getting worse and worse.” (Consumer 1)*

*“I feel like there's this general anxiety and that sort of experience of, yeah it's sort of that term of medical gaslighting that you feel like the challenge in itself is just feeling like you can go, be believed and have that conversation in the first place, whether it's asking for more medication, whether it's being referred to other services in allied health or whatever it may be. I feel like a massive challenge and barrier is that fear of [not] being believed.” (Consumer 4)*

*The credibility of pain patients is often questioned*

Women with pain symptoms from endometriosis and CPP were often questioned about their use of, and need for pain medication, particularly when attending hospital emergency departments experiencing a pain flare. They described how being **asked to justify their medication needs** made them feel like they were treated as a “drug seeker”, and that their credibility was being questioned.

## **Women’s and clinicians’ experiences of the barriers and enablers to accessing care, treatment and services for pain conditions**

*Endometriosis is individualised and complex*

Endometriosis was described as being a highly individualised condition, affecting women differently. This made it **difficult for health professionals to diagnose and manage**, as the symptoms were not universal and there was not a one size fits all approach to treatment. Further, patient care needs often changed over time, meaning that management of the condition needed to be individualised, flexible and adaptable.

The majority of GPs perceived the diagnosis of endometriosis and CPP to be challenging, particularly in terms of symptom complexity and a lack of clear guidance and pathways for GPs to follow. As mentioned previously, this sometimes led to women’s symptoms being dismissed or normalised by GPs, and these responses were seen as a barrier to women accessing healthcare for their symptoms. The lack of clarity for GPs was a significant barrier to early diagnosis, and led to women undertaking consultations with multiple health professionals before receiving a diagnosis.

*Poor access and affordability of healthcare*

Healthcare access and affordability were significant issues for women with endometriosis and CPP across Australia, but even more difficult for women in rural and remote areas. GPs reported that some women, particularly those in rural areas, had to travel long distances to receive treatment because specialist

services (e.g., gynaecologists, high quality ultrasound, pain specialists) were unavailable locally. GPs and stakeholders identified that difficulty accessing primary and secondary health services (e.g., GPs, specialists, diagnostics and treatment) and lack of affordability of health services were **barriers to women seeking and receiving care**. They commented that the cost of diagnostic tests, and fees for specialists and allied health services were not affordable for many women, especially if referred through the private health system. The cost of health care for endometriosis patients was described as being “immense”. Therefore, affordability of health care can also be seen as an access issue.

*“... someone with limited financial resources would really struggle to get the kind of care that they deserve...” (Stakeholder 1)*

*“... [specialist services] can be tricky to access if [patients] need further management... where it really is quite severe, and being able to access help when required, that's a bit of a gap at the moment.” (GP 8)*

#### *The health system is not meeting patient needs*

Women experiencing endometriosis or CPP pain described feeling vulnerable, requiring support, empathy, and to feel that they were being listened to by health professionals. Stakeholders identified that women should be provided with consistent advice, and stigma-sensitive care (e.g. the language and concepts used by health professionals is non-stigmatising) that was safe and inclusive for women from culturally and linguistically diverse populations, adolescent girls and gender diverse women. According to women, GPs and stakeholders, there were few things working well regarding endometriosis and CPP care in primary care, and the current health system was not adequately meeting patient needs.

Of particular concern were public system waiting lists. Waiting lists to see specialists and receive treatment for endometriosis and CPP were extremely long (up to 3 years), and contributed to delays in diagnosis. However, for women with private health insurance, wait lists were much shorter (i.e., within weeks). This highlights health and social inequalities, and that cost can be barrier to timely health care (e.g., out of pocket expenses for health professional consultations) and treatment (e.g., surgery, medication) with these chronic conditions.

They identified a number of gaps in the current health system that need improvement:

- Too few women who were continually experiencing endometriosis and CPP symptoms were being provided with a Chronic Disease Management plan (Box 1).
- Multidisciplinary team care (e.g., care provided by pelvic floor physiotherapists, psychologists, pain specialists, gynaecologists, along with the GP) was ideal for women with endometriosis, but was only occurring in small pockets, when health professionals developed their own networks. Multidisciplinary team care is recommended in the Endometriosis Clinical Practice Guideline (3).
- The mental health and emotional wellbeing of women with endometriosis and CPP was not well addressed by GPs.

*“So emotional wellbeing is one of the symptoms that is probably not dealt with very well at the moment. We tend to manage people's periods and their pain, but there is a substantial burden of emotional wellbeing issues that are just not being addressed by anybody.” (Stakeholder 6)*

**Box 1.** A Chronic Disease Management plan (CDMP) is a plan developed by a GP for a patient with a chronic medical condition, that provides a structured approach to ongoing care. A CDMP identifies a patient's health care needs, services to be provided by the GP and other multidisciplinary health professionals, and actions the patient can take for self-management. The CDMP is prepared by the GP every 12 months (valid for two years), and can be reviewed with the patient every 3 months. (12,13)

Team care arrangements (TCAs) can be used for a patient with a chronic medical condition and complex care needs, who would benefit from multidisciplinary care. A TCA can be completed when there are at least three or more healthcare providers including the GP, who will provide ongoing treatment and communication with each other in patient care. Completion of a TCA allows the GP to establish multidisciplinary care and in turn, keep all care providers informed about a patient's chronic disease management. The TCA can be prepared by the GP every 12 months (valid for two years). (14)

Specific Medicare item numbers can be billed when preparing and reviewing a CDMP and a TCA. The use of these item numbers enables the patient to access five consultations with allied health professionals for treatments associated with the chronic disease. Information on Medicare item number criteria can be found here:

<https://www9.health.gov.au/mbs/fullDisplay.cfm?type=item&q=721>

## Key recommendations

This research informs the following set of recommendations proposed by SPHERE NHMRC Centre for Research Excellence in relation to women's pain from endometriosis and CPP:

- **Awareness raising for GPs and the community about the symptoms of endometriosis and CPP, and what is 'normal' menstruation.** Improve awareness of the symptoms of endometriosis and CPP, through education for GPs and a community awareness campaign, to ensure that women's symptoms are taken seriously, better understood and not normalised or dismissed.
- **Clear guidance and pathways for GPs to improve timely patient diagnosis and management.** In collaboration with Primary Health Networks and hospital services, ensure there are regional pathways created for GPs and women to use to help them navigate the health system (including guidance on who to refer to and when), and ensure these pathways are transparent.
- **Better mental health support for women with chronic pain from endometriosis and CPP.** Increase awareness among GPs of the impact of pain on the mental health and wellbeing of women with endometriosis and CPP.
- **Improving awareness about and access to the benefits of multidisciplinary care and patient-centred care.**
  - Raise awareness amongst GPs regarding which other health professionals to involve in the multidisciplinary care of endometriosis and CPP patients, as part of a holistic approach (e.g. pelvic floor physiotherapist, pain specialist).
  - Provide GPs and patients with a register of local health professionals including their areas of expertise.





- Raise awareness of the availability of Team Care Arrangements (Box 1) to enable patient access to Medicare rebates for allied health attendances. Through these measures the patient's care can be tailored to suit the individual's goals and priorities, and enhance communication between the care providers.



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