Legislative Assembly for the
Australian Capital Territory
Standing Committee on Social Policy

Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

Submission number: 015

Submitter: Endometroisis Australia

Date authorised for publication: 14 April 2026

Endometriosis Australia

3rd April 2026

Standing Committee on Social Policy
ACT Legislative Assembly
GPO Box 1020
Canberra
ACT 2601

Via email: LACommitteeSP@parliament.act.gov.au

Dear Committee Members,

Endometriosis Australia welcomes the opportunity to provide a submission to the ACT Inquiry into endometriosis and other pelvic pain conditions.

Endometriosis Australia is the national peak body committed to improving the lives of people with endometriosis by striving to reduce diagnosis time, improving treatment access, and empowering individuals to live well with endometriosis.

This submission outlines the key challenges faced by ACT and surrounding residents in accessing timely diagnosis, appropriate treatment, and ongoing support for endometriosis. It presents recommendations across eleven areas, including health service coordination, workforce development, research investment, mental health support, and education.

Endometriosis affects a significant number of people in the ACT, yet access to care remains inequitable and inconsistent. We urge the Committee to consider the recommendations contained in this submission and to take action to address the systemic gaps in endometriosis care across the territory.

Endometriosis Australia is available to provide further information or to appear before the Committee should that be of assistance.

Yours sincerely.

Donna Ciccia
Director and Co-Founder
Endometriosis Australia
[redacted]

Endometriosis Australia’s Response to the ACT Inquiry Terms of Reference

To inform this submission, Endometriosis Australia has consulted with health professionals and people living with endometriosis in the ACT and surrounding regions. Their perspectives have been incorporated into the responses to the Inquiry Terms of Reference below.

Women and other people in the ACT who suffer from endometriosis, adenomyosis, polycystic ovarian syndrome and other chronic pelvic pain conditions

Despite progress made through the National Action Plan for Endometriosis by Australian Governments and stakeholders, such as Endometriosis Australia, urgent action on endometriosis remains essential.

Data on endometriosis specific to the Australian Capital Territory (ACT) is limited and available figures are derived from older national prevalence estimates rather than ACT-specific research.

National data indicates:

- Endometriosis in Australia is now **estimated to impact 1 in 7 females** and those assigned female at birth (AIHW, 2023).
- **Delay to diagnosis** remains high, with an average of **6-8 years** between onset of symptoms and diagnosis (AIHW, 2023).
- **18 out of every 1,000 hospitalisations** among females aged 15-44 were related to endometriosis (AIHW, 2023).
- Endometriosis is one of the **top conditions associated with pain** (Victorian Government, 2025), requiring targeted support to minimise health system impact.
- The **burden of living with endometriosis remains unchanged**, and quality of life improvements are not yet fully realised; and
- **Health inequalities persist** as stigma, cultural norms, and limited access create ongoing barriers to care (Endometriosis Australia, 2025).

The barriers in the ACT to getting a diagnosis and gaining access to treatment including primary care, specialist clinics and ongoing pain management for these conditions.

The ACT has a population of just over 450,000 and it is predicted that over the next decade, population growth will occur due to net overseas migration. The ACT has a relatively young population due to education and employment opportunities (Australian Government Centre for Population, 2025). These demographic factors have direct implications for the planning and delivery of endometriosis services and support now and into the future.

Current service provision for those with endometriosis in the ACT includes both public and private options. The Canberra Endometriosis Centre, is the only public service that provides care for people (including teenagers and adults) with period pain, pelvic pain and endometriosis. Access to this service requires a referral from a general practitioner (GP).

Health professionals and people living with endometriosis in the ACT and surrounding areas have identified a number of barriers to getting a diagnosis and accessing treatment. These are outlined as follows:

Misdiagnosis or Limited Understanding by Medical Professionals

Endometriosis presents differently across patients, and its symptoms can resemble those of other conditions. Where health professionals have had limited training in the diagnosis and management of endometriosis, symptoms may be misattributed, leading to delayed or incorrect diagnoses.

> *“Some of my symptoms that were not specifically period related (chronic constipation, bloating) were referred to gastrointestinal specialists. When nothing was found, it was assumed I just needed ‘more fibre’ and weight loss” - a consultation participant from ACT and surrounds.*

Limited understanding of endometriosis among health professionals, and the misdiagnosis that can result, may have significant consequences for patients. Individuals may go without a confirmed diagnosis for a number of years, during which time they may seek and trial multiple treatments in an attempt to manage their symptoms. This can result in a prolonged period of unresolved symptoms and inadequate care.

> *“I first started showing symptoms when I was 12-13. I was having stomach migraines, projectile vomiting, fainting, and in agonising pain. I went to the doctor and he just gave me an anti-nausea tablet. Every time I went to see a doctor about it, male or female, they told me to just keep taking Panadol and Nurofen. I had no answers for years, and it wasn’t until I begged my GP to refer me*

to a gynaecologist that I was finally diagnosed with endometriosis at the age of 21. I can't imagine how much damage the endometriosis had done over those years, if I was taken seriously I would've known." - a consultation participant from ACT and surrounds.

A lack of understanding among health professionals may also require those with endometriosis to undertake their own research into their condition and symptoms. This can place the responsibility of advocating for appropriate care and treatment onto the patient, rather than the treating health professional.

"I wasn't referred to a specialist until I did my own research and asked for it." - a consultation participant from ACT and surrounds.

Pain associated with endometriosis can be debilitating. People in the ACT have reported that their symptoms and concerns have been dismissed or minimised by health professionals when seeking care. This has affected both their ability to access appropriate care and their willingness to continue seeking it.

"I have been struggling with endometriosis since age 15. I am now 35. I have ended up in ER at least 15 times. Teachers at schools, doctors and gynecologists (especially women) were telling me not be so dramatic and it was just a period. I once endured 2 straight days of extreme endo pain at home. I couldn't get up nor walk. I took a bunch of painkillers but nothing worked. I called the ER and they told me to wait. That time, after two full days of extreme and severe pain, I wanted to die. Thankfully, the pain soon after eased and in the next week I got diagnosed with endometriosis" - a consultation participant from ACT and surrounds.

"I will never go to ED for pain. I was told they couldn't do anything and I needed to see my specialist in Sydney. The last time I had lost 20+kg in 3 months because I couldn't hold any food down and I was doubled over in pain unless I was lying down then the pain was bearable. My experiences have left me feeling like they view me as a junkie" - a consultation participant from ACT and surrounds.

Long wait times to see a health professional

The number of service providers available to diagnose and support people with endometriosis in the ACT is limited. This contributes to lengthy wait times, particularly within the public health system.

"There are limited specialists in the ACT, with long wait times (I have to wait 12 months as a private patient) and it's expensive!" - a consultation participant from ACT and surrounds.

"Excessively waiting time to get a pelvic ultrasound and be seen by a specialised gynecologist in endometriosis in public healthcare (put to 1 year and 6 months)" - a consultation participant from ACT and surrounds.

"It took 2 years to see the public health gyno and when I did they said you're better going private they can do more." - a consultation participant from ACT and surrounds.

The pathway to appropriate care for endometriosis involves multiple steps, which can further extend the time taken to reach a diagnosis or access specialist treatment. For example, a person must first obtain a referral from a GP, wait for test results, and then be referred to a specialist. Further investigations may also be required before a diagnosis is confirmed, or a treatment plan is established.

"Very long waiting lists for gynaecology clinic in public hospitals. Many steps to get in all with a waiting time. For example - see GP. Then GP organises investigations. More waiting time for scans. Two - 4 months. Then review with GP. Then send a referral to the public clinic. Wait for the public hospital to review referral if ever reviewed. Could be weeks. Then wait for gynecology appointment. Could be months - potentially 12 months. See specialist. More waiting if further investigations needed. (maybe GP didn't organise the right investigations). If surgery booked. Can be 12-18 months waiting at least for surgery." - a consultation participant from ACT and surrounds.

For some patients, these delays can have particularly significant consequences. One health professional in the ACT has highlighted that timely access to care is critical for patients with fertility considerations, who may require surgery within a specific timeframe due to their circumstances and are unable to wait for appointments and procedures within the ACT system.

The Canberra Endometriosis Centre was established in 2007. Feedback from the ACT community indicates that the Centre is currently staffed by locum practitioners, with no permanent specialists in place. Some individuals have reported that their treating specialists are no longer working within the public health system. This has significant implications for continuity of care.

The departure of health professionals from these roles also has a direct impact on wait times, compounding existing pressures on service availability.
This issue is not limited to medical specialists, with access and continuity of care also a concern across allied health services such as physiotherapy.

"I was on the wait list for 9 months for public pelvic physio as they didn't even have one for a long time." - a consultation participant from ACT and surrounds.

Seeking support interstate

Our consultations identified that some individuals with endometriosis in the ACT are travelling interstate to access specialist care. This decision is driven by a few key factors. First, extended wait times for specialist services in the ACT lead some individuals to seek more timely care elsewhere. Second, travel is often driven by a need to access health professionals who are perceived to have greater expertise and understanding of endometriosis, and who can adequately support individual health needs.

For some individuals, experiences of being dismissed or misdiagnosed, or feeling that their concerns have not been adequately addressed locally, have further contributed to seeking care interstate. This highlights that the decision to travel is not solely a result of limited local services but also reflects the importance of the quality and perceived capability of care available to patients.

> *"My biggest barrier was access to a specialist who had the experience, reputation and expertise that I can trust." - a consultation participant from ACT and surrounds.*

> *"There are long wait times to see a specialist in Canberra, so it's not something I pursued until my pain became unbearable and my fertility was impacted. I was told by numerous healthcare advisors and fellow endo sufferers to seek help in Sydney, and not in Canberra." - a consultation participant from ACT and surrounds.*

Endometriosis can affect young people, including teenagers. A lack of awareness or understanding of endometriosis symptoms at this life stage, both among young people themselves and the health professionals who treat them, can result in symptoms being overlooked or misidentified. This presents a particular barrier to timely diagnosis and early intervention, which are important factors in effective long-term management of the condition.

> *"Teenage girls are still being told they are too young to have endometriosis without any testing to rule it out despite significant symptoms". - a consultation participant from ACT and surrounds.*

Costs of appointment or tests

The limited availability of public service providers in the ACT, combined with lengthy wait times and difficulty accessing health professionals suited to individual needs, has led some individuals to seek diagnosis and treatment through private health services.

Accessing private care can result in significant out-of-pocket costs for appointments, tests, and procedures that may otherwise be available at reduced or no cost through the public health system.

> *"Limited multi-disciplinary specialists in Canberra who can manage the multitude of conditions than run along-side Endo. Best care is in the private sector and inaccessible to many patients due to costs. Waiting upwards of 12 months to access preliminary appointments". - a consultation participant from ACT and surrounds.*

Accessing endometriosis care interstate places additional financial, logistical, and personal burden on individuals living with endometriosis, including costs associated with travel, accommodation, and time away from work or family.

“One of the main specialists in the ACT requiring ultrasound tests for diagnosis to be done in Sydney meant I needed to drive there and back in a day just for an ultrasound.” - a consultation participant from ACT and surrounds.

“high OOP cost for private surgery here meant that I needed to travel to Sydney to get the expertise and care I required” - a consultation participant from ACT and surrounds.

Those living with endometriosis in the ACT have indicated that the cost of seeking diagnosis and treatment can be significant. This is consistent with national evidence, which estimates the total cost of endometriosis to the Australian economy at between $7.4 billion and $9.7 billion per year (AIHW, 2023).

At an individual level, an Australian study by Armour et al. (2019) found that endometriosis costs $30,900 per person annually, with lost productivity accounting for the vast majority (84%) of this economic burden.

The cost of allied health treatment, such as physiotherapy, is one of a number of contributors to the financial burden faced by patients. While the Australian Government Medicare Benefits Schedule (MBS) includes specific items to support chronic disease management (CDM), the extent to which these adequately offset costs for patients has been reported as limited.

The financial burden associated with diagnosis and support may have a direct impact on an individual's ability to seek timely treatment. For some, the cost of appointments, tests, and procedures may result in delaying care, while others may forgo treatment altogether. This can lead to a prolonged period without appropriate management, potentially worsening symptoms and quality of life over time.

“I couldn't afford to keep seeing doctors to get one who believed me” - a consultation participant from ACT and surrounds.

“We need more cost-effective access to health professionals and ongoing treatment. My surgery cost me $8000 out of pocket. I chose to go with private surgeon and I was able to afford that however I know that I am in a small percentage of endometriosis patients who are able to afford the ongoing treatment and support needed to manage their condition. I know plenty of women who are unable to access pelvic for physios, private gynecologist or even look at the option of having surgery due to the cost, in this day and age it is unacceptable that a condition such as endometriosis which causes debilitating pain and other infertility issues is only accessible for people with a certain income” - a consultation participant from ACT and surrounds.

Lack of mental health and emotional support

Beyond the financial burden, the impact of endometriosis on emotional wellbeing and quality of life can be considerable. A lack of appropriate treatment and support may contribute to psychological distress and increased mental health challenges, and in some cases, trauma resulting from prolonged experiences of pain, misdiagnosis, or feeling dismissed by health professionals.

"I have developed anxiety around seeing doctors and them not believing me due to being dismissed in the past." - a consultation participant from ACT and surrounds.

Some in the ACT have indicated that access to mental health support and trauma-informed care for those living with endometriosis is limited.

"There are limited mental health services and professionals in Canberra that specialise is trauma around health." - a consultation participant from ACT and surrounds.

Not knowing what treatment or support options are available

Some individuals living with endometriosis in the ACT have reported limited awareness of the treatment and support options available to them.

"There is no where to help you navigate where and when to go. Everything is very expensive and takes a lot of time." - a consultation participant from ACT and surrounds.

When asked how they identified a health professional or service that met their needs, many indicated this was through recommendations from family, friends, or community networks, through their own research, or via a GP or other health professional.

Acute and hospital-based care

While some individuals report having their needs met when accessing hospital support, others have indicated that they felt dismissed or not taken seriously and that their pain was undertreated or not adequately managed.

"Doctors in ED do not have adequate training, assume you are drug seeking and there is no continuance of care" - a consultation participant from ACT and surrounds.

A health professional in the ACT has also raised concerns that people with high grade endometriosis may be de-prioritised within the triage system, with capacity pressures and lengthy wait times across the public health system contributing to these patients being categorised as category three.

"All women with significant symptoms or suspected high-grade endometriosis should be afforded the right to a category two triage and waiting time" - a consultation participant from ACT and surrounds.

Service location and accessibility

The Canberra Endometriosis Centre is located in the centre of Canberra, which, while accessible for many, may present barriers for some individuals, including those from culturally and linguistically diverse (CALD) communities where stigma associated with endometriosis and pelvic pain remains a significant concern. The current co-location of the pelvic pain clinic alongside maternity and family planning services may also not be appropriate for all patients and could present an additional barrier to care. A community-based location may reduce this barrier and encourage greater help-seeking among those who might otherwise avoid attending a highly visible clinic.

"Moving the endo centre into community centres to improve accessibility" - a consultation participant from ACT and surrounds.

The treatment options and supports available in the ACT compared to other jurisdictions, their evidence-based effectiveness and potential side effects and impacts.

Schools

Access to endometriosis awareness and education in ACT schools is currently limited. While programs such as PPEP Talk® are available to Catholic and Independent schools, a gap exists in the provision of equivalent education and support within the ACT public school system, which has over 45,000 students from primary to secondary school age (ACT Government, 2025).

Workplace

Access to appropriate workplace support is an important consideration for people managing endometriosis and pelvic pain. In the ACT, employees are able to access personal or sick leave to manage health conditions, including endometriosis. While this provides a level of support, it may not fully address the additional and ongoing impact that endometriosis can have on a person's capacity to work.

Some jurisdictions have introduced dedicated leave provisions to better recognise this impact. For example, in Queensland, public sector employees are entitled to 10 days of paid Reproductive Health Leave (RHL) to reduce the stigma and support workforce participation for those managing reproductive health issues, including endometriosis.

The EndoThrive Workplace Accreditation program offers a practical pathway for workplaces to better understand and respond to the needs of employees with endometriosis. Adopting this program across ACT public service workplaces could complement existing leave entitlements and support a more consistent and informed approach to workplace support for people with endometriosis. Further details about the EndoThrive Workplace Accreditation program are outlined later in this submission.

The role of medical misogyny, underlying gender biases in healthcare and cultural norms that create barriers for women with these conditions.

Medical misogyny and underlying gender biases in healthcare have been identified as contributing factors to the barriers faced by people seeking diagnosis and treatment for endometriosis. These biases can manifest in a number of ways and are reflected in both systemic and individual interactions within the healthcare system.

Complex and historically dismissed symptoms

The symptoms of endometriosis are varied and sometimes overlap with other conditions, making diagnosis and support challenging. Pain and symptoms reported by those with endometriosis have sometimes been attributed to psychological causes or dismissed as a normal part of menstruation, rather than investigated as indicators of endometriosis and other pelvic pain.

“Drs saying period pain was normal and just went straight to the diagnosis of anxiety and depression. A specialist that actually advocates for women's needs and doesn’t just rush an appointment was ridiculously hard to find. A lot of gynaecologists didn’t really explain endometriosis well enough for me to understand and manage it for myself.” - a consultation participant from ACT and surrounds.

A traditionally male-dominated workforce

The medical profession has historically been male dominated. Where health professionals have limited awareness of, or training in, conditions that predominantly affect women, such as endometriosis, this can result in symptoms being underestimated or misattributed.

“One male GP told me "maybe you just don't handle pain well." - a consultation participant from ACT and surrounds.

Limited research into women's health conditions

Endometriosis and other conditions affecting women have historically received less research funding and attention. This has resulted in gaps in clinical knowledge, limited treatment options, and slower progress in developing effective diagnostic tools. The underrepresentation of women's health conditions in research has direct consequences for the quality of care available to those living with endometriosis.

Feeling dismissed by health professionals

People living with endometriosis in the ACT have reported feeling dismissed or not taken seriously by health professionals when presenting with symptoms. This experience is not limited to interactions with male practitioners, with some individuals reporting similar experiences with female health professionals. Feeling dismissed can reduce a person's willingness to seek further care, delay diagnosis, and compound the psychological impact of living with an unmanaged chronic condition.

The economic and social impacts of people in the ACT with these conditions, including education, employment and lost productivity.

Living with endometriosis has wide-ranging economic and social impacts. People in the ACT have indicated that endometriosis and related pelvic pain conditions have significantly affected their ability to work and study. This includes reducing working or study hours, taking extended sick or medical leave, leaving employment, or changing careers altogether. Many individuals also rely on carers, family members, or friends to support them.

Workplace Impacts

The impact of endometriosis on employment can be significant. Some people living with endometriosis in the ACT have reported a lack of understanding and limited support from employers. This can contribute to reduced confidence in disclosing their condition in the workplace.

A lack of flexible work arrangements, such as insufficient access to work from home options, further limits the ability of individuals to manage their symptoms while maintaining employment. These factors collectively contribute to reduced workplace participation and productivity.

Education impacts

Endometriosis can affect young people's ability to participate fully in education. Severe or unpredictable symptoms may result in absences from school and reduced academic engagement. This can have longer-term consequences for educational outcomes and future employment opportunities.

Social Impacts

Endometriosis can have a considerable impact on a person's social life and sense of community. People in the ACT have reported that unpredictable or severe symptoms frequently result in cancelling social commitments, leading to social isolation and a diminished sense of connection. Some individuals have described feeling like a burden to those around them.

Where family members, friends, and social networks minimise or do not acknowledge the severity of symptoms, this can compound feelings of isolation. The lack of understanding from those closest to a person can make it difficult to maintain relationships and access informal support.

“People including family and friends minimise the pain when you talk about it and are not that compassionate when it comes to it. You feel isolated and hopeless” - a consultation participant from ACT and surrounds.

Daily life impacts

Beyond the direct symptoms of endometriosis, people living with the condition may experience a range of secondary health impacts, including chronic pain, frequent migraines and a general deterioration in physical wellbeing. Where access to diagnosis and treatment is delayed, symptoms may worsen over time, further affecting quality of life and the ability to participate in daily activities.

“The pain is not just occasional, it has affected my ability to work, parent, and function day-to-day.” - a consultation participant from ACT and surrounds.

Economic Impacts

The financial burden of managing endometriosis can be considerable. Costs associated with GP appointments, specialist consultations, diagnostic investigations, and ongoing medication contribute to significant out-of-pocket expenses for many individuals. These costs, combined with reduced capacity to work, can place sustained financial pressure on those living with endometriosis and their families.

Mental health impacts

For some individuals, the process of seeking diagnosis and treatment for endometriosis can itself be a source of trauma. Repeated experiences of being dismissed, misdiagnosed, or subjected to invasive procedures without adequate support can be distressing and may discourage further help-seeking.

Productivity

The cumulative effect of these impacts on health, employment, and wellbeing results in a measurable reduction in productivity, both for individuals and at a broader economic level. This is consistent with national evidence cited earlier in this submission, which estimates the cost of endometriosis to the Australian economy at between $7.4 billion and $9.7 billion annually (AIHW, 2023).

“Society thrives when women are taken care of. If we dismiss conditions and symptoms that significantly affect our lives, and chances of reproduction, then what does that mean for future generations? If women are given the resources and

support we need for our health, then we can contribute to our society." - a consultation participant from ACT and surrounds.

Education available to medical professionals, allied health professionals, young women and others, on these conditions and treatment options

Public education

Endometriosis Australia delivers education programs, services and facilitates research alongside key research institutions. Endometriosis Australia supports patient awareness and understanding of endometriosis through webinars, podcasts, blogs and evidence informed education materials.

A 2024 Endometriosis Awareness campaign found that people exposed to the campaign were 25% more likely to be familiar with endometriosis compared to those who were not exposed (SCAiQ, 2024). The campaign is not only raising awareness but driving meaningful health behaviours, with 60% of people taking action after hearing the campaign in 2025, up from 50% in 2024 (SCAiQ, 2025).

Priority population groups

Endometriosis Australia is currently engaging with communities to co-design evidence-based information on endometriosis for priority population groups, to ensure they have timely access to credible information and support to navigate the health system.

Education material is being developed in a variety of languages and will be disseminated through trusted community channels.

The need for health professional education

Those living with endometriosis in the ACT have highlighted the need for training and education of health professionals to better support people with endometriosis.
A recent Endometriosis Coalition report (2025), which included cross-sectoral engagement with over 550 participants from a diverse mix of professional, clinical and consumer voices, identified education of both the public and health professionals as the third top priority for action on endometriosis.

The Parliament of South Australia Select Committee Report (2025) aligns with this, noting that ongoing education for health professionals is essential for a holistic approach to diagnosing, treating, and managing endometriosis.

Gaps in public and health professional knowledge of endometriosis can result in dismissed symptoms, misdiagnosis and patients feeling unsupported.

“GPs I have seen admit they have very little knowledge of endometriosis and I am often given irrelevant or incorrect advice. A lot of the old assumptions about pregnancy and hysterectomy being a cure all still widely exist. It is also seen predominantly as a condition that only effects pelvic organs. I am often

dismissed when suggesting endo may be a contributing factor to conditions elsewhere in the body" - a consultation participant from ACT and surrounds.

"I have extra pelvic endo (diaphragm and lung) and there's just no knowledge about this in the ACT medical community. Specialists are leaving the public system because their private practices are swamped and CHS don't understand that not all gynaecologists can do this work." - a consultation participant from ACT and surrounds.

"No one seems to know enough about my condition to be able to recommend effective next steps. No one is trying to get to the bottom of things. Specialists are unable to address all aspects, leaving me stuck in a constant cycle of appointments and referrals". - a consultation participant from ACT and surrounds.

Building health workforce capability

Health professionals across acute and primary care settings should be better supported to diagnose and manage patients with endometriosis. This includes those in emergency departments through to GPs and nurses in primary care.

Nurses

A partnership between Endometriosis Australia and the Australian College of Nursing Foundation currently offers scholarships to registered nurses across Australia to complete the *Endometriosis and Pelvic Pain Course*. The course strengthens frontline clinical capability in recognising, assessing and managing endometriosis and chronic pelvic pain.

Early evaluation findings demonstrate that the program is delivering significant improvements in workforce capability across Australia.

"As a rural nurse, this course enabled me to deliver specialist-level care locally in a setting with limited access to specialists." – 2025 nurse scholarship recipient

General Practitioners

In 2025, a trial of the Endometriosis Management Plan (EMP) was conducted across eight medical clinics in Australia. The online plan supports GPs and other clinicians to develop a tailored chronic disease management plan with patients, including identifying symptoms, mapping patient goals, and providing evidence-based recommendations and resources to support management. A toolkit, including a video guide for clinicians and a patient resource has also been developed to support implementation. The EMP is planned for national rollout to all primary care settings in 2026.

Specialists

The complexity of endometriosis and its management requires a level of specialist expertise that is not always available within generalist gynaecological practice. A partnership with the relevant peak bodies to establish a formal sub-specialty in complex gynaecology could provide a recognised pathway for specialist training and accreditation, comparable to existing sub-specialties such as reproductive endocrinology and infertility, and gynaecological oncology. This would help to improve the identification of appropriately skilled practitioners for patients and support access to high-quality, specialist care.

Workforce shortages

Addressing workforce shortages in endometriosis care requires a targeted approach to the recruitment and retention of health professionals with expertise in this area. Community feedback has indicated that the ACT currently has a limited number of specialists with the skills and experience required to manage complex endometriosis. There is a need to attract and retain practitioners who are committed to working in this field. Building a sustainable endometriosis workforce in the ACT is essential to improving access to appropriate care and reducing the burden on patients who currently have little choice but to seek treatment interstate or through costly private services.

"Canberra has no specialised excision surgeons currently. As such, patients are required to travel interstate or get care that does not meet gld standard of treatment. My first Laparoscopy was unsuccessful as the surgeon was under qualified. He then put me on a medication which I am suffering long term side effects from. I moved to Melbourne and got a care team who was experienced and knowledgeable" - a consultation participant from ACT and surrounds.

Models of care

Effective care for people with endometriosis requires a coordinated and integrated approach across health services. Currently, dedicated endometriosis services in the ACT, such as the Canberra Endometriosis Centre, operate within standard business hours. Where a person presents with acute pelvic pain or other endometriosis-related symptoms outside of these hours, they may seek care through emergency departments. It is important that health professionals working across these settings have sufficient knowledge of endometriosis and are equipped to manage patients in a manner that is clinically appropriate and sensitive to their needs.

There is a need for clear referral pathways, shared care protocols, and a baseline level of endometriosis awareness across all settings where patients may present, including emergency departments and other primary care providers. A more integrated model of care would help ensure that people with endometriosis receive consistent, informed, and timely support regardless of when or where they seek care.

Workplaces

Through EndoThrive, a workplace accreditation program, Endometriosis Australia supports individuals living with endometriosis and promotes inclusive work environments. The program is based on research and evidence, focusing on practical actions that organisations can implement to support employees affected by endometriosis. It emphasises the importance of workplace modifications, such as flexible work arrangements and informed management, to enhance productivity and well-being for those with endometriosis.

Research and trials currently being explored in Australia and opportunities for this to take place in the ACT

Several national research trials are currently underway across Australia, with some open to ACT residents.

CoDeEndo (Deakin University) is an online modular support care program for people living with Endometriosis, which includes 9 different interventions: Mindfulness, Psychoeducation, Relaxation, Physiotherapy, Acceptance and Commitment Therapy, Hypnotherapy, Yoga, Cognitive Behavioural Therapy, and Dietary Education. Modules are comprised of a mix of video, audio, podcasts, and written resources.

The purpose of this study is to explore whether CoDeEndo is effective in improving outcomes such as quality of life, pain, and mental health for people diagnosed with endometriosis. This online intervention can be delivered in a way that adapts to each participant's needs and interests (i.e., by choosing which modules to engage with). Participation is open to ACT residents, however, a confirmed endometriosis diagnosis is required.

EndoCann (NICM Health Research Institute) a clinical trial examining the efficacy and safety of two different medicinal cannabis interventions in people with endometriosis and associated pain. The study will also explore if the tested interventions reduce other symptoms of endometriosis, improve quality of life, and effect endometriosis lesion size. It is open to participants across Australia, with diagnosis required to be confirmed by laparoscopy, MRI, or ultrasound imaging.

As outlined elsewhere in this submission, significant barriers to diagnosis and treatment exist for ACT residents. These barriers may prevent eligible individuals from meeting the participation criteria for both studies and others with similar requirements.

Dedicated ACT-specific research funding would support the development of locally focused research initiatives, better reflecting the specific challenges faced by those living with endometriosis in the territory, and improving the ability of ACT residents to participate in and benefit from future research.

Recommendations

Recommendation 1: Improve coordination and integration across health services. Clear care pathways and shared care protocols should be developed to ensure consistent and appropriate care for people with endometriosis across all health settings, including emergency departments and primary care. Care should be delivered through an interdisciplinary model that brings together relevant medical, nursing, allied health, and mental health practitioners to address the full range of needs of people living with endometriosis.

Recommendation 2: Address the cost of care. The ACT Government should work with the Australian Government to examine options to reduce out-of-pocket costs for people accessing endometriosis diagnosis and treatment, including through improved public service provision, support for bulk-billing, and reduced reliance on interstate services.

Recommendation 3: Recruit and retain the endometriosis workforce. The ACT Government should develop a targeted strategy to attract and retain health professionals with expertise in endometriosis, including surgeons, allied health professionals such as physiotherapists, and psychologists.

Recommendation 4: Strengthen workforce capacity and training. Health professionals across all care settings, including GPs, nurses, emergency department clinicians, and allied health practitioners, should receive training and education in the diagnosis and management of endometriosis. This should include training in trauma-informed and culturally responsive care.

Recommendation 5: Expand and improve access to endometriosis services. A second endometriosis clinic should be established in the ACT, located in a community-based setting to improve accessibility, including for people from culturally and linguistically diverse communities. Public pelvic pain services should be separated from maternity and family planning services to better meet the needs of patients.

Recommendation 6: Establish a sub-specialty in complex gynaecology. The ACT Government should work with the Australian Government to establish formal medical sub-specialties and accreditation pathways. This would provide a recognised pathway for specialist training and accreditation and improve access to appropriately skilled practitioners for people with complex endometriosis.

Recommendation 7: Improve mental health and trauma-informed support. Dedicated mental health and trauma-informed care should be made available and accessible to people living with endometriosis in the ACT. This should be integrated into existing endometriosis service provision and recognised as a core component of care.

Recommendation 8: Adopt the EndoThrive Workplace Accreditation program. The ACT Government should implement the EndoThrive Workplace Accreditation program across all ACT public service workplaces.

Recommendation 9: Expand and fund school-based education. The ACT Government should provide dedicated funding to extend endometriosis and pelvic pain education programs to all ACT schools.

Recommendation 10: Improve data collection and monitoring. The ACT Government should work with the Australian Government to invest in improved data collection on endometriosis diagnosis, treatment, and service access within the territory. This would support evidence-based planning, identify gaps in service provision, and enable monitoring of progress over time.

Recommendation 11: Invest in ACT-specific endometriosis research. The ACT Government should provide dedicated funding for endometriosis research within the territory. This would support locally focused studies that reflect the specific challenges faced by ACT residents, and improve access to research participation for those who may be excluded from national trials due to barriers to diagnosis and treatment

About Endometriosis Australia

Our Mission

At Endometriosis Australia, we aim to raise awareness, provide support, and advance endometriosis research. We strive to improve understanding, ensure early diagnosis, and promote better treatment through advocacy and education.

Our Purpose

Raise awareness and fund research: Endometriosis Australia is a nationally accredited charity that has helped reduce diagnosis time from 7–12 years to 6.5 years.

Advocacy for healthcare change: Since 2012, we've advocated for better healthcare, provided resources, and highlighted endometriosis's impact on workplaces.

Educate for better outcomes: Our programs include fact sheets, training modules, and fundraising to improve prevention, diagnosis, and treatment. We work with experts in medicine, psychology, physiotherapy, and other fields to improve community and medical understanding of endometriosis.

Empower patients: We are committed to empowering patients with the knowledge they need to manage their healthcare proactively and advocate for patient-centred care solutions.

For further information about this submission contact:

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[redacted]

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