



Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

Submission number: 016

Submitter: Name withheld

Date authorised for publication: 14 April 2026

Monday, 6 April 2026

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To the members of the Standing Committee on Social Policy and other Members of the ACT Legislative Assembly,

I am a 27-year-old woman living in Canberra with Stage IV endometriosis and chronic pelvic pain. I have lived with symptoms for over a decade and with constant pain for five years. I make this submission not to recount my experience, but to demonstrate how systemic gaps in diagnosis, public specialist access, clinical education and workforce capacity in the ACT are harming people with endometriosis.

Endometriosis affects approximately 1 in 7 women - around 1.8 million people in Australia.¹ In the ACT, this equates to approximately 19,098 women and people assigned female at birth between 10 - 50 years of age.² Despite its prevalence, many still experience prolonged delays in diagnosis, difficulty accessing specialists and inadequate treatment. Nationally, the total economic burden of endometriosis has been estimated at between \$7.4 billion and \$9.7 billion per year.³ Despite this substantial individual and economic impact, care pathways remain fragmented. While the 2018 National Action Plan for Endometriosis was an important policy milestone, it has not translated into consistent improvements in patient experience at the local level.⁴

I have invested in my education and career in the ACT and am committed to contributing meaningfully to our community. I studied psychology as an undergraduate at the University of Canberra and completed a Master of Secondary Teaching. I now work in a Commonwealth department in a role dedicated to public service. I had intended to become a teacher, but endometriosis altered that trajectory. This disease does not discriminate by education, profession or resilience. Endometriosis is a systemic health issue that the ACT is not currently equipped to manage equitably.

The experiences I outline in this submission are not unique; they reflect systemic gaps that affect thousands of people in the ACT. I provide this evidence to inform meaningful, evidence-based reform that ensures timely, fair and compassionate care for all people living with endometriosis in the nation's capital.

¹ <https://www.aihw.gov.au/reports/chronic-disease/endometriosis-in-australia/contents/how-common-is-endometriosis>

² <https://www.abs.gov.au/census/find-census-data/quickstats/2021/8>

³ [The cost of illness and economic burden of endometriosis and chronic pelvic pain in Australia: A national online survey | PLOS One](#)

⁴ <https://www.health.gov.au/sites/default/files/national-action-plan-for-endometriosis.pdf>

TOR 1 - the number of women and other people in the ACT who suffer from endometriosis, adenomyosis, polycystic ovarian syndrome and other chronic pelvic pain conditions; and TOR 2 - 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

An estimated 19,098 people in the ACT live with endometriosis, however the Canberra public health system does not currently appear to have the coordinated workforce or public capacity required to meet this demand.²

My symptoms began more than a decade before my diagnosis. Heavy bleeding lasting months at a time, severe pain and early hospital presentations were normalised. When constant abdominal pain developed during 2021, I presented repeatedly to Canberra Hospital's Emergency Department. I was treated for presumed gastrointestinal upset and discharged. It took more than 18 months of investigations, including consultations with gynaecologists in Canberra before endometriosis was seriously considered. One specialist told me there was "absolutely no chance" I had endometriosis because my pain was not cyclical. He removed my IUD and discharged me. He was, and remains, a specialist affiliated with the Canberra Endometriosis Centre.⁵ A subsequent laparoscopy confirmed Stage IV endometriosis.

Although my laparoscopic surgery was performed following a short-notice cancellation, I had initially been categorised as a Category 2 public patient (semi-urgent, surgery indicated within 90 days⁶), however the estimated wait for this procedure exceeded 18 months. As a young renter balancing study and work, private surgery was financially inaccessible.

The delay between early symptoms and diagnosis was not due to rarity. It was due to dismissal, outdated clinical assumptions, insufficiently trained staff and lack of clear diagnostic pathways in primary care and specialist settings.

TOR 2 - 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; TOR 3 the treatment options and supports available in the ACT compared to other jurisdictions, their evidence-based effectiveness and potential side effects and impacts; and TOR 4 - the role of medical misogyny, underlying gender biases in healthcare and cultural norms that create barriers for women with these conditions;

Two years after laparoscopic surgery, I was admitted to Canberra Hospital under the Department of Obstetrics and Gynaecology for severe pain. That admission profoundly altered my trust in inpatient care. I was denied adequate analgesia on the basis that I was "too constipated." When I became visibly distressed due to unmanaged pain, I was described as "anxious" and "hysterical" by the registrar and prescribed Valium to

⁵ [Canberra Endometriosis Centre - Canberra Health Services](#)

⁶ [National definitions for elective surgery urgency categories \(full publication; 18 July 2013 edition\) \(AIHW\)](#)

manage my emotional response rather than my pain. I was told to ask for pain relief - when I did so, it was refused.

I was placed into pharmaceutically induced menopause without adequate explanation of the medication itself, side effects, fertility implications or long-term impact. I was instructed not to remain on it longer than six months and to see my specialist within that timeframe. My discharge summary contained factual inaccuracies, including incomplete documentation of medications administered and unclear identification of the treating clinician, raising concerns about clinical governance and accountability. Following this experience, I reviewed the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) clinical guidelines for endometriosis care.⁷ My management in Canberra Hospital did not align with those standards.

When I attempted to book a follow-up appointment with my treating specialist, I was informed that they were no longer accepting public patients. Without private health insurance, I could not access my treating clinician. I was unable to secure an appointment with another ACT-based specialist within six months and was ultimately referred to a leading Sydney gynaecologist, recognised nationally and internationally for endometriosis research and treatment. I was seen within three months and now travel interstate every three to four months for specialist care and for procedures unavailable publicly in the ACT.

In 2025, when new symptoms raised concerns about possible malignancy, I faced a six-month wait for deep-infiltrating endometriosis imaging in Canberra and unclear public wait times for a colonoscopy. As a 27-year-old confronting the possibility of cancer, I sought urgent private care. Within one week I underwent a colonoscopy in Canberra and specialist imaging in Sydney, totalling a personal cost of over \$5,000. Three months later, Canberra Hospital offered an initial public gastroenterology appointment. Cancer was fortunately excluded, however bowel endometriosis progression was confirmed. Without financial capacity, I would have waited months for diagnostic clarity. Timely diagnosis should not depend on personal financial means.

Throughout my care, I have been advised to consider pregnancy immediately to mitigate possible infertility and ease pain. This advice was given without full discussion of risks, alternatives, or patient preferences. I have been admitted to Canberra Hospital alongside women celebrating childbirth while questioning whether endometriosis has compromised my own fertility. I have been threatened with withdrawal of care for not following instructions that were never provided. This experience illustrates how reproductive assumptions and gendered biases intersect with clinical decision-making, impacting both access to appropriate treatment and highlighting systemic misogyny.

I have since avoided inpatient admission regardless of severity, requesting instead to remain in the Emergency Department until my pain is controlled. Emergency Department clinicians at Canberra Hospital have consistently provided compassionate, respectful and trauma-informed care. My GP has similarly been unwavering in her

⁷ [Australian Living Evidence Guideline: Endometriosis](#)

advocacy and continuity of care. Privately accessed pelvic physiotherapists and allied health providers have delivered evidence-based, patient-centred management. The contrast between individual clinical excellence and systemic inconsistency is stark.

Gender bias in healthcare is not abstract. It manifests in minimised pain, emotional pathologisation, reproductive assumptions and distrust of women's knowledge of their own bodies. My experience reflects these systemic issues, which persist despite evidence-based clinical guidelines and best practice recommendations.

TOR 5 - the economic and social impacts of people in the ACT with these conditions, including education, employment and lost productivity;

Nationally, endometriosis carries an estimated economic burden of between \$7.4 and \$9.7 billion annually through healthcare expenditure and lost productivity.⁸ My experience illustrates how these macroeconomic costs materialise at the individual and territory level.

I work a four-day week to attend medical appointments and manage flares of pain. This represents a 20% reduction in income, excluding superannuation losses and slowed career progression. I have not pursued a career in teaching despite years of training due to the physical demands and unpredictability of my condition.

During severe flares, my medication regimen escalates from daily neuropathic agents and anti-inflammatories to opioids and anti-emetics. During these periods, I cannot drive and require short notice leave. Many hospital visits are preceded by hours of vomiting, near-unconsciousness and unmanageable pain at home as I attempt to avoid inpatient admission due to my previous experiences.

My annual out-of-pocket medical costs in the 2025 calendar year were over \$14,000. These expenses include private health insurance, interstate specialist appointments and travel, imaging, procedure costs, pelvic physiotherapy, hydrotherapy, GP appointments and medications.

Endometriosis has had a profound impact on every aspect of my life, with direct economic and social consequences. I plan travel around access to hospitals following past emergency admissions for uncontrolled pain. My career progression has required ongoing adjustments to accommodate surgeries, recovery periods and unpredictable flares, resulting in disrupted employment continuity and reduced productivity. The financial burden of specialist care, interstate treatment and ongoing management is significant and sustained. Strong pain medication limits my ability to drive or work safely, reducing independence and workforce participation.

I have also been forced to confront fertility and long-term health decisions far earlier than expected. The practical support I rely on from family - assistance with meals and

⁸ [The cost of illness and economic burden of endometriosis and chronic pelvic pain in Australia: A national online survey | PLOS One](#)

basic routines during severe episodes - reflects not diminished capability, but a health system that does not yet adequately support women with endometriosis to remain fully engaged in education, employment and community life.

TOR 6 - education available to medical professionals, allied health professionals, young women and others, on these conditions and treatment options;

There remains a pervasive misconception that endometriosis is limited to “bad period cramps.” My pain is consistently chronic and non-cyclical. Even among specialists, outdated beliefs about symptom patterns persist, contributing to delayed diagnosis, inadequate treatment, and unnecessary patient distress.

Education must extend beyond awareness campaigns. It must be structured, evidence-based and targeted to all relevant providers and communities. Key initiatives should include:

- Mandatory contemporary endometriosis training for GPs
- Structured education for emergency clinicians and ward staff
- Training for gastroenterologists managing bowel and gastrointestinal symptoms
- Trauma-informed communication training for all clinicians interacting with patients in pain
- Comprehensive menstrual and pelvic health education in ACT schools to empower early recognition, reduce stigma, and encourage timely help-seeking.

Effective education is critical not only to improve clinical outcomes, but to reduce avoidable economic and social burdens by ensuring patients are recognised, triaged and treated appropriately from the first presentation.

TOR 7 - research and trials currently being explored in Australia and opportunities for this to take place in the ACT;

The ACT has the opportunity to position the Canberra Endometriosis Centre as a genuine centre of excellence through partnerships with ANU, national research registries and clinical trial networks. Such collaborations could support high-quality research, improve clinical care and provide ACT patients access to cutting-edge trials without travelling interstate.

However, workforce shortages, long public waitlists and limited procedural capacity currently undermine that opportunity. Without intentional planning, investment and incentives, the ACT risks continued specialist loss to other jurisdictions, ongoing gaps in care and preventable patient travel for services that should be locally available.

To realise the ACT’s potential as a national leader in endometriosis research and care, the government must address these structural barriers, expand procedural and specialist capacity, and integrate research opportunities into public service delivery.

Recommendations

The issues outlined above are not unique to my case. I have connected with multiple ACT patients reporting similar delays in diagnosis, interstate travel for care and inconsistent inpatient pain management. While my submission reflects my lived experience, it is symptomatic of a broader pattern of unmet need.

I recommend that the Committee:

1. Commission an independent review of Canberra Health Services' endometriosis care, including compliance with RANZCOG guidelines, public reporting of findings and clear implementation timelines.
2. Invest to attract and retain highly trained endometriosis specialists in the ACT, prioritising surgeons skilled in excision surgery and establishing structured public-private practice models to strengthen public access.
3. Develop and implement comprehensive workforce planning for endometriosis care, spanning hospital, public and private systems, with clear training and career pathways for nurses, doctors, specialists and allied health clinicians.
4. Strengthen and resource the Canberra Endometriosis Centre as an integrated multidisciplinary hub, bringing together gynaecology, pain medicine, gastroenterology, pelvic physiotherapy, advanced imaging (including DIE ultrasound) and research partnerships.
5. Improve equitable access to diagnosis and treatment in the public system, including transparent wait-time reporting, reinstatement of pelvic floor botulinum therapy and advocacy for expanded PBS access to endometriosis medications.

I am fortunate to have a supportive partner, an exceptional GP, compassionate emergency department clinicians and the financial capacity, at significant personal sacrifice, to seek interstate care. Many in the ACT do not. Access to appropriate treatment should not depend on personal resources, resilience or luck.

Endometriosis is common. Systemic dismissal, diagnostic delay, preventable disease progression and avoidable trauma should not be. When these experiences are repeated across patients, they are not individual shortcomings - they are structural failures.

This inquiry presents a critical opportunity not simply to acknowledge harm, but more importantly to remedy and prevent it. Reform must address how pelvic pain is recognised, triaged, funded, taught and treated across the ACT health system. Without structural change, the cycle of delay, damage and deterioration will continue.

The ACT has the responsibility to lead nationally in equitable, evidence-based pelvic pain care. I urge the Committee to act decisively, so that the current generation of patients is the last to endure preventable harm in seeking diagnosis, treatment and dignity in care. I would welcome the opportunity to appear before the Committee to elaborate on this submission and answer questions based on my lived experience. I consent to this submission being provided in full to the Committee however I request that any version published on the Legislative Assembly's website be anonymised to protect my privacy.