



Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

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Submission to the
Standing Committee on Social Policy
ACT Legislative Assembly

**Inquiry into Endometriosis and
Other Pelvic Pain Conditions**

Individual Submission — Lived Experience



Canberra, ACT

April 2026

I consent to the Committee receiving this document in full. However, prior to any public publication, I request that the Committee redact my name, my age, references to my other diagnosed conditions, and Attachment A in its entirety.

I am available to discuss my experience further or provide a separately redacted version should the Committee require it.

Executive Summary

I am a Canberra woman who spent twenty-two years living with undiagnosed adenomyosis and polycystic ovarian syndrome (PCOS). During that time, I was dismissed by emergency departments, denied surgery because of my weight, refused gynaecological care because I was not trying to conceive, experienced a delay in care resulting in a life-threatening condition, and lost the ability to have children. I was ultimately forced to travel to Sydney for the specialist diagnosis and surgery that the ACT could not provide.

This submission addresses all eight terms of reference. It draws on lived experience and publicly available data to demonstrate that the ACT has the highest out-of-pocket costs for gynaecological surgery in Australia, significant workforce shortages, and systemic gaps in clinical education, mental health support and multidisciplinary care. I offer thirteen recommendations for reform. The barriers I describe are not historical — they are ongoing, and this inquiry is an opportunity to address them.

Introduction

I am a [REDACTED]-year-old woman living in Canberra. I have lived with chronic pelvic pain since my first period at age [REDACTED]. After **more than two decades of symptoms**, I was finally diagnosed with adenomyosis and PCOS at age [REDACTED]. I also live with [REDACTED] and [REDACTED], a [REDACTED] whose diagnosis was itself delayed by two years due to assumptions linked to my gynaecological symptoms. These conditions compound both my symptoms and the barriers I face in navigating the health system.

I cannot have children. This is a direct consequence of delayed diagnosis and inadequate care over more than twenty years. It is the hardest burden I carry, and it was preventable.

I make this submission from lived experience. My story is not unusual — it reflects the systemic failures that this inquiry has been established to examine. I address the terms of reference below, drawing on my personal experience and publicly available data on the cost and availability of care in the ACT.

Why this inquiry matters now

My situation has not improved. I continue to manage multiple chronic conditions with limited local support, high out-of-pocket costs, and the ongoing psychological weight of what was lost. The barriers I describe in this submission are not confined to the past — they are the current reality of navigating pelvic pain care in the ACT. The ACT does host the Canberra Endometriosis Centre, but in more than two decades of seeking care for pelvic pain in the ACT, I was never referred to it. This reveals a deep issue with available care options and public information across the Territory.

With national attention on endometriosis at its highest point in decades, including the expansion of the Endometriosis and Pelvic Pain Clinic program, and updated clinical guidelines from RANZCOG (Royal Australian and New Zealand College of Obstetricians and Gynaecologists), the ACT has both the opportunity and the obligation to act.

1. Prevalence in the ACT

Endometriosis is estimated to affect one in seven women and people assigned female at birth in Australia, with diagnosis taking on average between 6 and 8 years¹. Applied to the ACT's population, this suggests over 30,000 Canberrans may be living with endometriosis alone, with additional numbers affected by adenomyosis, PCOS and other chronic pelvic pain conditions.

However, true prevalence is almost certainly underestimated. People like me — who experienced symptoms for over two decades before receiving a diagnosis — are not captured in statistics during the years they spend undiagnosed. I was placed on the contraceptive pill at [REDACTED], then cycled through multiple birth control options over more than twenty years. During that time, my conditions were never identified. I was simply managed, not diagnosed.

The ACT would benefit from establishing local data collection on the prevalence and diagnosis rates of pelvic pain conditions. Without accurate data, it is impossible to plan services or measure whether outcomes are improving.

2. Barriers to Diagnosis and Treatment in the ACT

The barriers I have experienced in the ACT are systemic, compounding, and deeply personal.

Diagnostic delay

My symptoms began with my first period; heavy, prolonged bleeding, extreme pain, nausea and exhaustion. I was placed on the pill at [REDACTED]. Over the next twenty-two years, I was moved between multiple forms of hormonal birth control, as a management technique. At no point during those years did any clinician investigate the underlying cause of my symptoms. I was finally diagnosed with adenomyosis and PCOS at [REDACTED].

The Australian national average for an endometriosis diagnosis is approximately 6 to 8 years from symptom onset. My experience — more than twenty-two years — is an extreme case, but it is not an outlier in a system where hormonal suppression is routinely offered as a substitute for investigation. The length of my delay reflects a structural failure, not an individual one.

Medical dismissal

I have attended emergency departments in Canberra in excruciating pain, only to be sent home and told I was experiencing a “bad period.” In one instance, I presented to my local general practitioner's office in severe pain, with vomiting and lethargy, and was dismissed as experiencing regular menstrual issues. I was in fact septic due to a [REDACTED] complication. Being sent home whilst suffering from a life-threatening condition because clinicians defaulted to menstrual pain as an explanation is not an inconvenience — it is a failure of clinical care that could have cost me my life. I spent days in emergency hospital care when my body started shutting down, because of the delayed diagnosis.

Misdiagnosis and cascading delays

The consequences of diagnostic assumptions extend beyond gynaecological care. My diagnosis of [REDACTED] — was delayed by two years because

¹ AIHW Endometriosis in Australia report, 20 September 2023

clinicians assumed the underlying cause of my [REDACTED] was endometriosis. It was not. Due to delays in receiving gynaecological care in the ACT, I had to repeatedly travel to Sydney for specialist support and surgery. It was only following that surgery that the true cause of my [REDACTED] could be properly investigated, diagnosed and treated. This is a clear example of how failures in one area of the health system cascade into delays across others, compounding risks to the patient.

Over the course of my conditions, I developed significant scar tissue requiring excision. Finding a specialist willing and able to perform this procedure was a lengthy process, and the cost was substantial. Throughout this period, my pelvic pain — which was caused by severe scarring from [REDACTED] — was repeatedly attributed to “cramps” or “period pain” rather than being investigated as the result of the structural damage it actually was. This pattern of dismissal delayed appropriate treatment and prolonged my suffering.

Weight-based exclusion from surgery

I have been told that I cannot access surgical treatment for my symptoms because of my weight. My body weight is affected by multiple interacting factors, including PCOS itself, [REDACTED], and the side effects of medications I take to manage these conditions. Refusing surgery on the basis of weight — when weight is a symptom of the very conditions requiring treatment — creates a cruel cycle where the patient is blamed for the consequences of their disease.

Fertility-centred gatekeeping

Accessing gynaecological care in the ACT as a woman who was not actively trying to become pregnant proved to be an additional and deeply frustrating barrier. On multiple occasions, my decisions about my own body were undermined or negated by specialists. Gynaecologists declined to take me on as a patient because they specialised in fertility, or were unwilling to pursue surgical options because I was not actively seeking to conceive. My pain, my quality of life, and my right to make informed decisions about my own healthcare were treated as secondary to reproductive outcomes.

This reflects a broader structural problem, gynaecological care in the ACT is disproportionately oriented around fertility rather than the management of pain and chronic disease. Women who are not trying to become pregnant — or who have already lost the ability to do so — are left with fewer pathways to care. The cruel irony is that the very delays caused by this fertility-centred gatekeeping contributed to the loss of my fertility in the first place.

Workforce shortages

Canberra does not have enough doctors, specialists, or allied health professionals to meet demand. Wait times for public gynaecological services in the ACT are lengthy, and the number of specialists who take public patients is extremely limited. Private options are also expensive, and have long wait times, particularly for those not seeking fertility options. My treatment and specialised diagnosis ultimately required repeated travel to Sydney to see a private practitioner. This is a significant barrier for anyone without the financial resources, leave entitlements, or physical capacity to travel interstate for care.

3. Treatment Options, Costs and Comparison with Other Jurisdictions

The ACT health system is heavily weighted towards private provision, with some of the highest out-of-pocket costs for gynaecological procedures in Australia. I have spent tens of thousands of dollars on gynaecological health supports, consultations and diagnostic tests.

Data from the Australian Government’s Medical Costs Finder (2023–24) illustrates the disparity for laparoscopy — a key diagnostic and treatment procedure for endometriosis and pelvic pain conditions.

	NSW	Vic	Qld	WA	SA	Tas	ACT
% with no out-of-pocket cost	27%	12%	11%	43%	5%	19%	5%
Typical specialist fees	\$3,200	\$2,900	\$3,200	\$3,000	\$2,900	\$2,800	\$3,400
Patient typically paid	\$860	\$540	\$930	\$700	\$500	\$500	\$1,600

Source: Australian Government Medical Costs Finder, 2023–24 data. Laparoscopy (MBS item), private setting with private health insurance. NT did not have data available. Retrieved 10 April 2026.

The data tells a stark story. ACT patients face the **highest specialist fees (\$3,400)** and the **highest typical out-of-pocket costs (\$1,600)** of any state or territory in Australia. An ACT patient typically pays nearly three times what a Victorian patient pays for the same procedure. Only 5% of ACT patients had no out-of-pocket cost, compared to 43% in Western Australia and 27% in New South Wales.

These figures do not include hospital fees (typically \$2,700), diagnostic imaging, pathology, pharmaceuticals, aftercare costs, or the cost of services before or after the day of the procedure. The true cost of a single laparoscopy, when all associated expenses are considered, can easily exceed \$10,000 out of pocket (see Attachment A). These are significant costs which I have incurred in trying to resolve my debilitating pain — not optional or elective expenses.

This pattern is not unique to surgery. Even the very first step in seeking diagnosis — an initial appointment with a gynaecologist — costs more in the ACT than in any other state in Australia.

	NSW	Vic	Qld	WA	SA	Tas	ACT
% with no out-of-pocket cost	22%	20%	19%	14%	20%	11%	13%
Typical specialist fees	\$270	\$250	\$250	\$260	\$250	\$255	\$340
Patient typically paid	\$189	\$169	\$169	\$179	\$169	\$174	\$259

Source: Australian Government Medical Costs Finder, 2023–24 data. Initial specialist appointment, obstetrics and gynaecology, out-of-hospital setting. NT did not have data available. Retrieved 10 April 2026.

In the ACT, **87% of patients pay out of pocket** for an initial gynaecology appointment, and the typical out-of-pocket cost (\$259) is **49% higher** than the national average (\$174). My own initial specialist consultations cost between \$215 and \$316 out of pocket — consistent with this picture. For a patient who has already waited years to be taken seriously, who is in pain, and who may already be losing income from missed work, a **\$259 fee is a meaningful barrier to even beginning**

the diagnostic process. It is also a barrier to seeking second opinions when an initial diagnosis feels wrong.

Why private health insurance does not bridge the gap

I hold top-tier hospital and extras cover, yet for nearly every gynaecological service in this submission I have been left with substantial out-of-pocket costs. This is not because my cover is inadequate. It is because of how the system is designed and how specialist fees compare to it.

For in-hospital services, Medicare pays 75% of the Medicare Benefits Schedule (MBS) fee, and private health insurance is required to cover at least the remaining 25%, bringing the total to 100% of the MBS fee. Anything a doctor charges *above* the MBS fee is the patient's "gap" and must be paid out of pocket. Insurers can offer "known gap" or "no gap" arrangements that pay a small amount above the MBS fee, but these are tightly capped and depend on the doctor agreeing to participate in the scheme.

The problem in the ACT is that specialist fees routinely exceed the MBS schedule fee by a significant margin. **I was unable to find a single gynaecological specialist who charged at the MBS rate.** Every quote I received was multiples of the schedule fee.

A concrete example from my own care demonstrates that my endometriosis laparoscopic resection (MBS item 35641) was billed at a provider fee of \$5,000. The MBS schedule fee for this procedure is approximately \$1,416. Medicare paid \$1,061.80 (75% of the schedule fee) and my private health insurer contributed \$379.95 — covering the mandatory 25% of the MBS fee plus a small "known gap" top-up — leaving me with **\$3,558.25 out of pocket** for that single item alone. The provider charged approximately **3.5 times the MBS schedule fee**, and no level of insurance cover commercially available to me would have materially changed this outcome. It is worth noting that this surgery was performed in Sydney, not the ACT — and even so, it was cheaper than the equivalent quotes I received from ACT providers. The ACT is not merely expensive by national standards; it is expensive enough that travelling interstate for surgery was the more affordable option.

The central trap of the ACT health system for gynaecological care is that patients are routinely told to "get private health insurance" as a solution, while the structure of insurance is built around an MBS fee that bears little resemblance to what local specialists actually charge. **Top-tier cover does not help when the entire local market charges above the schedule.**

Surgery can provide relief, but it is not a long-term cure. After my surgery, I required ongoing pelvic health physiotherapy and support, which is rarely covered or even considered by private health insurance. The ACT's health system is built on private provision with expensive outcomes, and there are few affordable options for the ongoing, multidisciplinary management that chronic pelvic pain conditions require.

The need for multidisciplinary care

Chronic pelvic pain conditions are not resolved by surgery alone. Effective long-term management requires a coordinated, multidisciplinary approach that may include gynaecological care, pelvic floor physiotherapy, pain management, psychology, gastroenterology and dietetics. In the ACT, these services are fragmented, expensive, and difficult to access in combination. There is no clear, affordable pathway for a patient to receive coordinated multidisciplinary care. Medicare's Chronic

Disease Management Plans allow access to only five allied health visits per year — grossly insufficient for the ongoing management of complex, multi-system conditions. Patients are left to coordinate their own care across multiple providers at significant personal cost.

Hormonal treatments and Mirena

The Mirena intrauterine device is frequently offered as a frontline treatment for pelvic pain conditions. My experience with Mirena insertion was one of severe pain, prolonged bleeding and debilitating cramps. The pain relief I was offered did not adequately address these issues. The cost of insertion was high, and the outcome did not justify the expense or the physical toll. Yet Mirena is routinely presented to patients as though it is a straightforward solution, with insufficient discussion of the pain of insertion, the likelihood of ongoing side effects, or the possibility that it will not resolve the underlying condition.

Scar tissue and excision

Excision of scar tissue caused by my conditions was both costly and difficult to access. It took a long time to find a specialist willing and able to perform the procedure, and the out-of-pocket costs were significant. These are not optional or cosmetic procedures — scar tissue causes pain, restricts organ function and contributes to the cycle of chronic pain that defines these conditions. The lack of accessible, affordable excision services in the ACT forces patients into extended suffering or interstate travel.

Discontinued treatments

Additionally, evidence-based treatments available in other jurisdictions have been discontinued locally. Pelvic botulinum toxin injections, routinely offered through public health systems at Westmead Hospital (NSW) and Gold Coast Hospital (QLD), were introduced in the ACT in late 2023 but discontinued in early 2025, without consultation or regard to the impact on the patients receiving the treatment. This further limits the treatment options available to ACT patients.

4. Medical Misogyny, Gender Bias and Cultural Norms

Medical misogyny is not an abstract concept in my life. It is the reason I spent more than twenty years without a diagnosis. It is woven through every interaction I describe in this submission.

When I have presented to emergency departments and to GPs in severe pain, I was told it was a “bad period” and sent home. On one of these occasions at my GP’s office, I was septic. The default assumption — that a woman presenting in abdominal pain is simply menstruating — nearly killed me. On another occasion, my [REDACTED] were attributed to endometriosis for two years, delaying the diagnosis of [REDACTED]. Assumptions rooted in gender bias did not just delay gynaecological care — they obscured an entirely separate and serious diagnosis.

Weight bias compounds gender bias. I was refused surgical treatment because of my weight, despite the fact that my weight is directly affected by PCOS, [REDACTED], and the medications I was prescribed to manage these conditions. A pharmacist once told me that sleep was what I needed to cure my [REDACTED], when the actual cause was the side effects of hormonal birth control. My clinical reality was overridden by assumptions about my body, my lifestyle and my mental state.

Perhaps the most insidious form of gender bias I encountered was the reduction of gynaecological care due to fertility. Specialists declined to see me because I was not trying to conceive, or were

unwilling to pursue treatment options because pregnancy was not my goal. My pain and my quality of life were treated as less important than a reproductive outcome. This is medical misogyny in structural form; a system that values a woman's uterus for what it can produce, rather than treating the person who lives with the pain.

The cumulative effect of these experiences is gaslighting. After years of being dismissed, I began to doubt my own pain. I questioned whether I was overreacting, or whether I was simply not coping well enough with something everyone else managed. This severely impacted my mental health, adding to the burdens of my physical health. This self-doubt is not a personality trait — it is the predictable outcome of a healthcare system that repeatedly tells women their pain is not real, not serious, or not worth investigating.

5. Economic and Social Impacts

The economic and social impacts of my conditions have been profound and compounding.

Financial costs

I have spent tens of thousands of dollars on specialist consultations, diagnostic imaging, tests, treatments and surgery. Much of this expenditure occurred in the ACT, where out-of-pocket costs are the highest in the country. When I ultimately needed specialised diagnosis and surgical treatment, I had to repeatedly travel to Sydney, adding travel, accommodation and time-off-work costs to an already substantial financial burden. These are the visible costs. The hidden costs — over-the-counter pain relief purchased week after week, lost income from unpaid leave, the career progression that stalls when you cannot show up consistently — are rarely quantified but are no less real.

Employment and career

I have lost career opportunities and spent significant time out of the workplace due to my symptoms. Chronic pain, fatigue and the unpredictability of flare-ups make consistent participation in employment challenging. This is not a matter of personal resilience — it is the reality of living with conditions that the health system took more than two decades to name.

Fertility and family

I cannot have children. This is a direct consequence of delayed diagnosis. Had my adenomyosis and PCOS been identified earlier — years or even a decade earlier — I would have had the opportunity to make informed decisions about my fertility. That opportunity was taken from me by a system that treated my symptoms as unremarkable for over twenty years. The grief of involuntary childlessness caused by medical neglect is a burden that no amount of policy reform can undo, but earlier intervention could prevent other women in the ACT from experiencing the same loss.

Mental health

The psychological toll of living with undiagnosed chronic pain, repeated dismissal by clinicians, and the loss of fertility has been significant. There are very few trained mental health professionals in Canberra with expertise in the intersection of chronic pain, grief, and reproductive health. Accessing psychological support that genuinely understands these experiences is another gap in the ACT's service landscape.

6. Education for Health Professionals and the Community

My experience strongly suggests that education about endometriosis, adenomyosis, PCOS and chronic pelvic pain remains inadequate across the ACT health workforce. This includes GPs, emergency department staff, pharmacists, and allied health professionals.

A pharmacist who tells a patient that sleep will cure their [REDACTED] — when the problem is a known side effect of hormonal birth control — is demonstrating a gap in pharmaceutical education about these conditions. Emergency staff who default to “bad period” as a diagnosis without investigation are demonstrating a gap in clinical training. GPs who prescribe over twenty years of sequential birth control for heavy and painful periods, without ever investigating the underlying cause are demonstrating a systemic gap in primary care education.

Education should not be limited to health professionals. Young women and people with uteruses need to understand what constitutes normal menstrual pain and what does not. Had I known at [REDACTED] that my symptoms warranted investigation beyond a contraceptive prescription, I would have advocated for myself earlier. But I did not know, because no one told me.

Programs such as the Periods, Pain and Endometriosis Program (PPEP) and the Period ImPact and Pain Assessment (PIPPA) tool being used in some ACT schools are promising. However, reach must be expanded, and programs must be available in all ACT public and private schools, not just a select few.

7. Research and Opportunities for the ACT

Australia’s National Action Plan for Endometriosis, introduced in 2018, was a world-first initiative. The expansion of the Endometriosis and Pelvic Pain Clinic program to 33 clinics nationally, including in the ACT, is a welcome step. However, the ACT’s research infrastructure in this area remains underdeveloped relative to its potential.

Canberra is home to nationally significant health and research institutions. The ACT Government should actively pursue partnerships with the ANU, University of Canberra and Canberra Health Services to establish the territory as a site for clinical trials and translational research into pelvic pain conditions. The recent discontinuation of public pelvic botox treatment in the ACT, despite its continued availability in other jurisdictions, is a missed opportunity — it could have been evaluated locally to build an evidence base for reinstating the service.

8. Recommendations

Based on my lived experience and the evidence available, I respectfully ask the Committee to consider the following recommendations, presented in order of priority and potential impact.

- 1) **Strengthen and expand the Canberra Endometriosis Centre into a true one-stop shop for chronic pelvic pain.** The ACT already hosts the Canberra Endometriosis Centre, which describes itself as a multidisciplinary service involving surgeons, gynaecologists, a nurse coordinator, pelvic physiotherapists, psychologists and dietitians. This is a valuable foundation, but in its current form the Centre is not meeting the needs of Canberrans with pelvic pain conditions. Three issues require urgent attention:
 - a) **Visibility.** The Centre is poorly advertised. In more than two decades of navigating the ACT health system for pelvic pain, I was never referred to it and was not aware of its existence. A

service that cannot be found by the people who need it is not functioning as a single point of entry.

- b) **Scope.** The Centre's stated focus is on education, self-care and self-management. These are important tools, but they are insufficient for patients with moderate to severe disease who require active investigation, surgical assessment, advanced imaging and pain management. A service oriented primarily around teaching patients to cope with their pain replicates, rather than corrects, the broader systemic pattern of telling women to manage symptoms rather than treating causes.
- c) **Capacity and throughput.** A GP referral is required, and patients are triaged before being offered an appointment. The Committee should seek data on referral volumes, wait times and patient outcomes to determine whether current resourcing is sufficient.

The Centre should be expanded, properly resourced and actively promoted as the publicly funded front door for chronic pelvic pain care in the ACT. It should offer clear, navigable pathways through gynaecology, pelvic floor physiotherapy, pain management, psychology, gastroenterology, dietetics and allied health under a coordinated care plan, with treatment options as well as self-management support. The current five-visit annual cap under Medicare Chronic Disease Management Plans is grossly inadequate for the ongoing management of complex, multi-system conditions and should not be the ceiling of what the ACT offers its residents.

- 2) **Ensure advanced diagnostic imaging is available in the ACT.** Endometriosis and related pelvic pain conditions often require specialised imaging — including advanced pelvic ultrasound performed by sonographers specifically trained in endometriosis, and MRI for deep infiltrating disease — that is not widely available in the ACT. Patients are frequently required to travel interstate or to navigate a small number of private providers at significant out-of-pocket cost. The ACT Government should ensure that advanced endometriosis-focused ultrasound and pelvic MRI are available within the public system, and that waiting times for these services are consistent with the clinical urgency of pelvic pain investigation.
- 3) **Improve emergency department and acute pain management for pelvic pain presentations.** Establish clear clinical protocols for ACT emergency departments and urgent care clinics on the assessment, triage and management of acute pelvic pain, including adequate pain relief, appropriate imaging pathways, and clear referral routes to gynaecological services. Patients presenting with severe pelvic pain should not be discharged with a presumptive diagnosis of "bad period" without investigation. Acute pain management should be treated as a clinical priority rather than a matter of patient endurance, and ED staff should have access to on-call or next-day gynaecological consultation where surgical or specialist assessment may be required.
- 4) **Address the cost of care.** The ACT has the highest out-of-pocket costs for laparoscopy in Australia. The Government should explore options to reduce patient costs, including expanded public gynaecological surgery lists, bulk-billing incentives for specialists, and subsidies for allied health care such as pelvic physiotherapy.
- 5) **Reduce the need for interstate travel.** Ensure that diagnosis and treatment pathways for pelvic pain conditions can be completed within the ACT, including access to trained excision surgeons and advanced diagnostic ultrasound.
- 6) **Mandate clinical education.** Require ongoing professional development in endometriosis, adenomyosis and pelvic pain conditions for all ACT GPs, emergency department clinicians, pharmacists and relevant allied health professionals. Make this training affordable for those seeking to specialise in pelvic health, for example, physiotherapists.

- 7) **Eliminate weight-based barriers to treatment.** Develop ACT clinical guidelines that explicitly prohibit the refusal of surgical treatment solely on the basis of body weight, particularly where the patient's weight is influenced by the conditions requiring treatment.
- 8) **Reinstate pelvic botox in the public system.** This evidence-based treatment was discontinued in the ACT in early 2025 despite being routinely available in NSW and QLD public hospitals. It should be investigated, trialled and reinstated subject to outcomes of the trial.
- 9) **Invest in specialist mental health.** Fund training and positions for mental health professionals in Canberra with expertise in chronic pain, reproductive grief and the psychological impacts of pelvic pain conditions.
- 10) **Expand school-based education.** Ensure the PPEP and PIPPA programs are available in all ACT schools so that young people understand what is and is not normal menstrual pain.
- 11) **Fund subsidised telehealth access to interstate specialists.** Where local specialist expertise is unavailable, the ACT Government should subsidise telehealth consultations with interstate experts in endometriosis, pelvic pain and excision surgery, ensuring that geographic isolation does not compound the existing barriers to care.
- 12) **Establish local prevalence data.** The ACT Government should fund ongoing data collection on the prevalence, diagnosis rates and wait times for endometriosis, adenomyosis, PCOS and other pelvic pain conditions in the territory.
- 13) **Position the ACT as a research hub.** Pursue partnerships with the ANU, University of Canberra and Canberra Health Services to attract clinical trials and build local expertise in pelvic pain research.

Conclusion

I welcome this overdue inquiry.

I spent more than two decades in pain before anyone told me why. I lost the ability to have children because no one looked beyond the prescription pad. I was sent home from emergency departments because my pain was assumed to be routine. I was refused surgery because of the way my body looks. I doubted my own reality because the system taught me to.

None of this had to happen. Better education, earlier investigation, more affordable care and a health system that takes women's pain seriously would have changed the course of my life. I urge the Committee to ensure it changes the course for those who come after me.