



Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

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ENDOMETRIOSIS COALITION

Submission to the ACT Endometriosis Enquiry

Introduction

This submission is drafted in response to the ACT Endometriosis Enquiry. It is based on the findings and recommendations presented in the *National Endometriosis Roundtable Findings* and the *Endometriosis Roundtable Findings: ACT*, both released in 2025. This document highlights key areas from these reports that should inform and guide policy and service delivery improvements within the Australian Capital Territory (ACT).

Key Findings and Recommendations from 2025 Roundtables

The 2025 roundtables identified several critical areas requiring attention to improve the lives of individuals with endometriosis.

1. Diagnosis and Awareness

The reports consistently highlighted the significant delay in diagnosis and the need for greater public and professional awareness.

Source	Key Finding	Recommended Action for ACT
National Endometriosis Roundtable	Average diagnostic delay remains unacceptably long.	Implement a public awareness campaign targeting common symptoms and encouraging early consultation.

Source	Key Finding	Recommended Action for ACT
Endometriosis Roundtable: ACT	Gaps in knowledge among General Practitioners (GPs) and school health services.	Develop mandatory, accredited professional development for ACT-based GPs and provide educational resources for high schools.

2. Specialist Care and Multidisciplinary Teams

Access to high-quality, multidisciplinary care was a major concern raised in both reports.

Source	Key Finding	Recommended Action for ACT
National Endometriosis Roundtable	Average diagnostic delay The National findings supported the development of consistent, evidence-based care standards across all jurisdictions to ensure equitable access to specialist services.	Implement a public awareness The ACT should adopt and pilot these national standards as soon as they are finalized.
Endometriosis Roundtable: ACT	Specifically called for the establishment of a dedicated, funded ACT Endometriosis Centre of Excellence.	This centre should offer integrated care, incorporating gynaecology, pain management, physiotherapy, and mental health support.

3. Research and Data Collection

Insufficient high-quality, localized data hinders effective policy and resource allocation.

Source	Key Finding	Recommended Action for ACT
National Endometriosis Roundtable	Insufficient high-quality, localized data hinders effective policy and resource allocation.	Long-term sustainable funding for commit funding to the research and data initiatives.

Source	Key Finding	Recommended Action for ACT
Endometriosis Roundtable: ACT	The ACT government should commit funding to the following research and data initiatives.	<ol style="list-style-type: none"> ACT Endometriosis Patient Register: Establish a secure register to monitor prevalence, care pathways, and patient outcomes within the Territory. Health Economics Study: Conduct a study to quantify the economic burden of endometriosis on the ACT community, including healthcare costs and lost productivity.

Submission Recommendations for the ACT Endometriosis Enquiry

Based on the 2025 findings, this submission proposes the following specific actions for the ACT Government:

A. Education and Prevention

- **Recommendation 1:** Launch a comprehensive, multi-year public health campaign focused on early symptom recognition and reducing diagnostic delay. This campaign should align with the launch of the educational materials developed by [Person](#), as mentioned in the national findings.
- **Recommendation 2:** Introduce mandatory endometriosis education for all ACT public and private school nurses and health teachers by [Date](#).

B. Service Delivery and Access

- **Recommendation 3:** Allocate immediate funding for the planning and development of the ACT Endometriosis Centre of Excellence, located at [Place](#), with a commencement date for patient services by [Date](#). The

initial planning meeting should be scheduled through the following event:

[Calendar event](#).

- **Recommendation 4:** Subsidize or offer specialized training for at least five additional pelvic physiotherapists in the ACT over the next three years to address the current shortfall in pain management specialists.

C. Accountability and Oversight

- **Recommendation 5:** Form a standing ACT Endometriosis Advisory Group, including patient representatives, clinicians, and researchers, to monitor the implementation of the enquiry's recommendations. The first terms of reference for this group are outlined in [File](#).
- **Recommendation 6:** Mandate annual public reporting on the progress made in reducing the average diagnostic delay in the ACT, starting from the next financial year.

The 2025 roundtables provide a clear and current roadmap for action. By prioritizing these evidence-based recommendations, the ACT can position itself as a leader in comprehensive endometriosis care and significantly improve the health and well-being of its residents. We urge the Enquiry to adopt these findings and recommendations in full.

Responses to the ACT Endometriosis and Pelvic Pain Enquiry Questions

Please note these responses were informed by the ACT Endometriosis Roundtable Report 2025, please refer to the Report for reference.

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

It is conservatively estimated that 26,959 people in the ACT suffer from endometriosis. This estimate is based on the national prevalence of 1 in 7 people experiencing the condition. The report does not provide specific numbers for adenomyosis, polycystic ovarian syndrome (PCOS), or other chronic pelvic pain conditions in the ACT population.

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

Barriers to diagnosis and treatment in the ACT include:

- **Diagnostic Delays and Inconsistent Pathways:** Long wait times and inconsistent, confusing diagnostic pathways among different healthcare professionals contribute to delays in diagnosis.
- **Limited Access to Services:** Patients face challenges accessing medical and allied health appointments due to a lack of available services. Multidisciplinary care is limited and concentrated in urban areas.
- **Hospital Strain:** The Canberra Hospital, which services both ACT residents and surrounding rural/regional areas, is strained.
- **Financial Barriers:** High costs for treatments, including specialist consultations, diagnostic tests, and surgical procedures, can be prohibitive for some individuals.
- **Interstate Travel:** ACT residents often travel interstate to access timely or advanced care, which increases the social and economic burden.
- **Education Gaps:** Many healthcare professionals (GPs, sonographers, acute care staff) and the general public lack sufficient knowledge about symptoms, diagnosis, and treatment.
- **Culturally Safe Care:** The lack of culturally responsive care for Aboriginal and Torres Strait Islander people, culturally and linguistically diverse (CALD) communities, and LGBTQIA+ individuals erodes trust and often leads to individuals delaying care until symptoms are severe.

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

The report focuses on the challenges in accessing timely care rather than detailing specific treatment effectiveness:

- **Comparison to Other Jurisdictions:** For ACT patients to access treatment that is more timely, cheaper, or more advanced, they often have to travel interstate.
- **Supports Mentioned:** Individual costs cover specialist appointments, surgery, fertility treatments, medications, and allied health services, such as pelvic physiotherapy and psychological support.
- **Evidence-Based Effectiveness/Side Effects:** The report does not detail the evidence-based effectiveness or potential side effects of specific treatment options.
- **Impact of Delayed Care:** The impact of delays in formal diagnosis and inability to access timely care can result in chronic pain, fatigue, infertility, social isolation, chronic stress, depression, anxiety, and trauma from healthcare experiences.

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

The report frames the issues around lack of recognition and culturally unsafe care:

- **Gender Bias and Clinical Recognition:** People living with endometriosis consistently reported feeling "unseen, unheard, and disempowered within the healthcare system". Many are forced to self-educate and self-advocate due to a lack of appropriate services or "clinical recognition". Endometriosis has a disproportionate burden on women and people assigned female at birth.
- **Cultural Norms and Trust:** The lack of culturally responsive care for Aboriginal and Torres Strait Islander people, CALD communities, and LGBTQIA+ individuals erodes trust in the healthcare system. The absence of supportive environments to discuss pelvic pain and menstruation often causes these individuals to delay medical care until symptoms become severe.

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

The economic and social impacts are significant:

- **National Productivity Loss:** Endometriosis contributes to an estimated national productivity loss of **\$7.4 billion to \$9.4 billion annually**.
- **Individual Economic Costs:** Individual costs are substantial and often unaffordable, including out-of-pocket expenses for surgery, fertility treatments, specialist appointments, medications, travel, and lost income.
- **Education and Employment:** The condition significantly affects individuals' **education, employment**, and social activities. This includes time off work or study due to chronic pain and fatigue, and missed educational and career opportunities.
- **Social and Emotional Impacts:** The emotional and psychological toll includes isolation, chronic stress, depression, anxiety, and trauma from healthcare experiences. When the health needs of women and gender diverse people are unmet, the consequences ripple across the social and economic fabric of households.

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

While education gaps currently exist, the Roundtable recommended several strategies to improve the availability of education:

- **Mandatory Curricula:** Advocate for the inclusion of up-to-date, evidence-based content on endometriosis, adenomyosis, and pelvic pain as a mandatory standard within university and training provider programs for medical, nursing, and allied health curricula.
- **Professional Development (CPD):** Fund Territory-wide Continuing Professional Development (CPD) programs for primary and acute care clinicians, focusing on symptom recognition, trauma-informed care, and appropriate first-line treatments.
- **Young People/Schools:** Partner with existing school-based education initiatives, such as the PEPP Talk program delivered by the Pelvic Pain Foundation of Australia, to equip students with accurate, age-appropriate information.

- **Lived Experience Integration:** Integrate individuals with lived experience as co-facilitators or guest speakers in all training programs to provide real-world context and foster empathy-based care.
- **Service Tools:** Develop and distribute a user-friendly Service Map for referral pathways and clinical resources to health professionals across the ACT.

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

The report details opportunities for the ACT to engage in and lead research:

- **National Engagement:** ACT should advocate for its inclusion in **national endometriosis research trials** and innovation funding rounds. It should also engage with existing national research efforts, such as the Australian Endometriosis Clinical and Scientific Registry and the National Endometriosis Research Network.
- **ACT Research Priorities:**
 - Allocate funding to **culturally sensitive research** co-designed with Aboriginal and Torres Strait Islander communities and other priority groups.
 - Implement a formal data collection process to systematically **track referral wait times** for specialist appointments and treatments.
 - Invest in models where people with lived experience actively participate in research (consumer-led research).
 - Advocate for the development of an **Endometriosis Data and Research Strategy**, including a pelvic pain registry.
 - Gathering data on successful ACT programs, such as the Clinical Centre for Excellence in Pelvic Pain, to support increased local investment and consideration of national expansion.

8) Any other related issue

Other key issues and recommendations raised by the Roundtable include:

- **Top Priorities for Action:** Roundtable participants voted for the three most urgent actions as:
 - 1) Cost** (reducing financial burden),
 - 2) Multidisciplinary Care** (more integrated, collaborative care), and
 - 3) Funding** (to support health professional up-skilling and education).
- **Systemic Fragmentation:** The consultation reported fragmented national leadership and unequal investment, leading to uneven implementation of the National Action Plan for Endometriosis. There is a need for strengthened communication and coordination between Commonwealth and State Governments.
- **Workforce Investment:** This is a top priority, requiring strategic recruitment of specialists (gynaecologists, pain specialists, pelvic physiotherapists, psychologists) and offering financial incentives and comprehensive support packages for professionals in rural and remote regions.

- **Need for Care Hubs:** Sustainable funding is required to establish and maintain multidisciplinary, collaborative care hubs in the ACT to streamline patient care pathways and function as essential referral and training centers.
- **Financial Subsidies:** The report recommends implementing comprehensive financial support for **travel and accommodation subsidies** for patients who must travel long distances to access specialist care.