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

Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

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Submission

Legislative Assembly for the Australian Capital Territory Standing Committee on Social Policy - Inquiry into endometriosis and other pelvic pain conditions

Thank you for inviting the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG, the College) to provide a submission to the Legislative Assembly for the Australian Capital Territory Standing Committee on Social Policy's (the Legislative Assembly) inquiry into endometriosis and other pelvic pain conditions (the Inquiry). RANZCOG considers this inquiry to be a critical opportunity to address systemic gender bias, strengthen clinical pathways, and ensure equitable access to evidence-based care for those living with endometriosis.

RANZCOG is the peak professional body for women's health in Australia and New Zealand. The College is responsible for setting clinical standards and overseeing postgraduate education, accreditation, recertification, and continuing professional development for practitioners, including specialist obstetricians, gynaecologists, and GP obstetricians. RANZCOG developed the *Australian Living Evidence Guideline: Endometriosis* through funding support provided by the Australian Government Department of Health and Aged Care.[1] The Guideline incorporates current research to provide evidence-based recommendations to health care practitioners who diagnose and manage people with suspected or confirmed endometriosis or adenomyosis.

Background

Endometriosis is a chronic, estrogen-dependent condition, in which endometrium-like tissue grows outside the uterus. Although symptoms vary widely, the most common symptoms are severely painful periods, dyspareunia, infertility, pelvic pain and heavy menstrual bleeding.[2] Endometriosis affects approximately one in seven women in Australia, representing a significant portion of Australians, many of whom experience long diagnostic delays of 6.5yrs on average, and symptoms recurrence despite optimal medical and surgical treatments[3]. Whilst much is still unknown about endometriosis, emerging evidence suggests that a greater number of cases can be diagnosed with increasing accuracy using non-invasive techniques such as transvaginal ultrasound and magnetic resonance imaging (MRI) in place of surgery. [4,5]

Adenomyosis

It is important to acknowledge the occurrence of adenomyosis in women. Adenomyosis is an oestrogen-responsive condition that can occur with or without endometriosis[6]. As with many conditions affecting women, adenomyosis is an under-researched condition, with relatively few clinical guidelines available to support clinical management. RANZCOG recommends the Legislative Assembly consider the impact of adenomyosis during this inquiry.

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[1] The Royal Australian and New Zealand College of Obstetricians and Gynaecologists. (2025). *Australian Living Evidence Guideline: Endometriosis*. https://ranzcog.edu.au/wp-content/uploads/Endometriosis-Clinical-Practice-Guideline.pdf

[2] Horne, A.W. and S.A. Missmer, Pathophysiology, diagnosis, and management of endometriosis. BMJ, 2022. 379: p. e070750.

[3]

[4] Avery, J.C., et al., Noninvasive diagnostic imaging for endometriosis part 1: a systematic review of recent developments in ultrasound, combination imaging, and artificial intelligence. Fertility and Sterility, 2024. 121(2): p. 164-188

[5] Avery, J.C., et al., Noninvasive diagnostic imaging for endometriosis part 2: a systematic review of recent developments in magnetic resonance imaging, nuclear medicine and computed tomography. Fertility and Sterility, 2024. 121(2): p. 189-211.

[6] Harada, T., et al., The Asian Society of Endometriosis and Adenomyosis guidelines for managing adenomyosis. Reproductive Medicine and Biology, 2023. 22(1): p. e12535.

Chronic pelvic pain

Chronic, or persistent, pelvic pain is pain in the pelvic region (below the umbilicus) that lasts for six months or longer. It affects an estimated 15–25% of women and presents differently for each person. It may arise from gynaecological, gastrointestinal, urinary, musculoskeletal, or neurological causes, and frequently co-exists with other chronic disorders, including irritable bowel syndrome, premenstrual mood disturbances, and migraines. Multi-system involvement usually means a diagnosis is made via exclusion, and effective care often requires coordinated involvement from multiple disciplines, including gynaecologists, pelvic physiotherapists, psychologists, pain specialists, dietitians, and urologists.

Historically, persistent pelvic pain was often dismissed as “normal” or attributed to psychological causes, resulting in delayed diagnosis, stigma, and inadequate care. Contemporary evidence now highlights the critical importance of early identification and multidisciplinary management to reduce long-term disability and improve patient outcomes.[7]

At risk populations

It is important to recognise that chronic pelvic pain conditions, including endometriosis and adenomyosis, can disproportionately affect First Nations women, culturally and linguistically diverse communities (including migrant and refugee women), and those facing financial hardship or geographic isolation. Intersecting risk factors play an important role in the diagnosis and management of complex pelvic pain and as such, the Inquiry must address the barriers faced by these population groups.[8]

Clinicians can improve the equity of care by recognising racism (both individual bias and systemic racism), intergenerational trauma, and ongoing inequities experienced by First Nations people. The important role of ‘women’s business’ and the wishes of many First Nations people to keep women’s health issues private and separate from other health issues must be respected.[9] The Inquiry should build on findings outlined in the National Action Plan for Endometriosis, specifically the endometriosis-specific education and awareness materials tailored specifically for First Nations communities. The limited knowledge of menstruation and menstrual health literacy for Indigenous Australians must also be addressed as this plays a role in diagnostic delays.[10]

Age

RANZCOG wishes to highlight the challenges of diagnosing endometriosis in adolescents, which are exacerbated by the limited availability of appropriate services for referral and ongoing management of suspected or confirmed disease. Pelvic health education within Australian school curricula also tends to focus on physiology, with limited coverage of persistent pelvic pain, when to seek help, or available management strategies. Students have expressed concerns about the lack of pelvic pain education. [11] Understanding menstrual health and its impacts on physical, social and psychological wellbeing is an important part of adolescent care and support.[12]

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[7] Australian and New Zealand College of Anaesthetists. (2025). *Persistent pelvic pain – a common but often overlooked problem: Community information*. https://www.anzca.edu.au/getContentAsset/fcc67f9e-6b4d-4247-8431-10ca140f99bc/80feb437-d24d-46b8-a858-4a2a28b9b970/PS15_Pelvic-Pain_Community-Information_v2-202509.pdf?language=en

[8] Green, C.R., et al., The unequal burden of pain: confronting racial and ethnic disparities in pain. Pain Medicine, 2003. 4(3): p. 277-94

[9] The Royal Australian and New Zealand College of Obstetricians and Gynaecologists. (2025). *Australian Living Evidence Guideline: Endometriosis*. https://ranzcog.edu.au/wp-content/uploads/Endometriosis-Clinical-Practice-Guideline.pdf

[10] Ciccia, D., et al., Indigenous Peoples' Experience and Understanding of Menstrual and Gynecological Health in Australia, Canada and New Zealand: A Scoping Review. International Journal of Environmental Research and Public Health, 2023. 20(13).

[11] Thong, H., A. Mardon, and S. Evans, Pelvic pain education - A short review on pelvic pain and endometriosis educational programs for adolescents. The Australian and New Zealand Journal of Obstetrics and Gynaecology, 2024

[12] Ciccia, D., et al., Indigenous Peoples' Experience and Understanding of Menstrual and Gynecological Health in Australia, Canada and New Zealand: A Scoping Review. International Journal of Environmental Research and Public Health, 2023. 20(13).

Terms of Reference Feedback

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

Research provides solid national and global estimates for the prevalence of endometriosis, adenomyosis, and chronic pelvic pain, but RANZCOG is not aware of data that speaks specifically to the ACT population. A lack of comprehensive local surveillance systems makes it difficult to quantify the impact of endometriosis, adenomyosis, polycystic ovarian syndrome and other chronic pelvic pain conditions on people in the ACT. This data gap presents as an opportunity for the Inquiry to remedy this.

It is important that data be collected collaboratively as gaps result in inaccurate or outdated epidemiological statistics which have a significant impact on resource allocation. If clinicians are unable to demonstrate the number of patients that present to publicly funded clinics with endometriosis symptoms, pursuing funding for better treatment is problematic[13]. Ideally, RANZCOG recommends the establishment of a national data registry to ensure gynaecological key indicators are collected, measured, monitored, reported, and used for quality improvement and educational purposes. The collection of this data will provide the government with the tools required to recognise emerging issues sooner and prevent future harm to women and girls. RANZCOG would provide recommendations on which gynaecological key indicators should be collected, and how they would be used, measured and reported. The College would also provide advice on how this initiative could be implemented.

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

Absence of publicly funded Endometriosis and Pelvic Pain (EPP) service within Canberra Hospital/Canberra Health Service

National data indicates that people with endometriosis experience an average diagnostic delay of around 6.5 years.[14] Patients in the ACT routinely face prolonged waits for both public gynaecology appointments and specialist consultations. At present, Canberra Hospital/Canberra Health Services has no funded Endometriosis and Pelvic Pain (EPP) service. Pelvic floor physiotherapy support is minimal and funded through resources intended for mesh-related patients, rather than for those with chronic pelvic pain. Only one endometriosis nurse is available to provide education and triage support. Critically, the absence of a designated clinical lead or integrated EPP service leaves patients without access to coordinated, multidisciplinary care. RANZCOG acknowledges efforts to address long wait times, however, without appointing a clinical lead, the service cannot deliver the standard of care it was established to provide.[15] RANZCOG recommends that the clinical lead role be appointed to a Level 4–5 AGES fellow or a pain specialist, operating within a collaborative model between both specialties.

Recent funding for pain-related initiatives was directed to community-based primary health care rather than to public hospital–based multidisciplinary teams (MDTs). While these grants benefit some consumers, they have not translated into increased capacity for a publicly funded service. Adequate funding would allow specialist gynaecologists, pain physicians, physiotherapists, psychologists, and nurses to jointly assess and treat patients. Due to ongoing service gaps, ACT residents are still dependent on fragmented and frequently privately funded pathways, with many left to seek appropriate care interstate.

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[13] Royal Australian and New Zealand College of Obstetricians and Gynaecologists. (2025). *Spring 2025 editorial*. O&G Magazine. https://www.ogmagazine.org.au/27/3-27/spring-2025-editorial/

[14] Australian Institute of Health and Welfare. (2025). *Endometriosis: Summary*. https://www.aihw.gov.au/reports/chronic-disease/endometriosis/contents/summary

[15] Legislative Assembly for the Australian Capital Territory. (2025). *QON No. 38: Women's health and gynaecological services – Answer to question on notice (Rattenbury).* https://www.parliament.act.gov.au/__data/assets/pdf_file/0006/2989005/SP-QON-038-Answer-CHS-Womens-health-Gynaecological-services-RATTENBURY.pdf

RANZCOG recommends that the Division of Women, Youth and Children formally recognise endometriosis and chronic pelvic pain as significant women's health conditions that require dedicated attention and resourcing. They must not be subsumed under the already substantial pressures of maternity services and general women's health care.

Workforce sustainability and surgical capacity

As mentioned throughout this submission, workforce sustainability is a critical factor in improving equitable access for ACT residents. RANZCOG is working to address critical gaps in healthcare services, improve clinical outcomes, and support the professional development of health workers in underserved areas, but government support is essential. Without expanding the specialist workforce, equitable access throughout the ACT cannot be achieved. RANZCOG welcomes the opportunity to work with the ACT government to address the workforce shortage issues in a real and sustainable way.

Surgical capacity remains a major limiting factor. Attracting a Level 5 AGES fellow will not be feasible without increased access to operating time. Current waiting times for Category 3 gynaecological surgery exceed 365 days, making expanded surgical lists essential to improving patient care and supporting workforce development.

Complex, fragmented and difficult-to-navigate care pathways

Comorbidities are common in chronic pelvic pain, and a single patient may experience overlapping conditions such as endometriosis, adenomyosis, painful bladder syndrome, IBS, migraine, recurrent vaginal candidiasis, vulvar vestibulitis and food intolerances. This clinical complexity most often leads to fragmented care, with different clinicians managing individual symptoms in isolation rather than through a coordinated, multidisciplinary approach.[16] Without accounting for significant comorbidities, a person with endometriosis may need to separately organise:

- Imaging (often privately funded and poorly rebated)
  - There is currently no public ultrasound service that provides specialist deep invasive endometriosis scan, thus requiring women to travel interstate to access this type of service if required.
- Appointments with gynaecologists and pain specialists (with long wait times due to workforce shortages)
- Pelvic physiotherapy (often needing to be privately funded)
- Mental health or psychological support (often needing to be privately funded)
  - Assessment of past trauma and management of ongoing impacts of chronic pelvic pain on mental health is of critical importance.
- Surgery, if required (long wait times due to workforce shortages)
- Ongoing chronic pain management (often requiring ongoing out of pocket costs)

Without a clearly defined clinical pathway or a single coordinating service, many patients who are unable to afford private care, fall through gaps in the system and experience prolonged, unmanaged symptoms. RANZCOG cannot overstate the importance of implementing a sustainably funded, coordinated, multidisciplinary service for those living with complex pelvic pain.

Significant Cost Barriers

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[16] Evans, S. (2015). *Management of persistent pelvic pain in girls and women*. Australian Family Physician, 44(7), 454–459. https://www.racgp.org.au/afp/2015/july/management-of-persistent-pelvic-pain-in-girls-and

Where services exist, the financial burden associated with chronic pelvic pain diagnosis and management is substantial. Key cost barriers include:

- Pelvic imaging such as specialised ultrasound or MRI, which often requires multiple scans and substantial out-of-pocket fees.
- Laparoscopic diagnosis and treatment, particularly when access to public surgical lists is limited and private surgery becomes the only timely option.
- Pelvic physiotherapy, an evidence-based treatment, but rarely fully subsidised and requiring long-term management.
- Chronic pain management, including psychological support, which even when rebated still incurs considerable out of pocket fees.

For many patients, these costs are prohibitive, leading to delayed care, incomplete treatment, or reliance on emergency departments when symptoms escalate.

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

RANZCOG's *Australian Living Evidence Guideline: Endometriosis* summarises current evidence for assessment and treatment, supporting consistent care regardless of location. However, guidelines cannot be implemented without sufficient workforce and service capacity. As noted under TOR 2, the absence of adequate staffed at the Canberra Endometriosis Centre means ACT residents cannot reliably access coordinated, multidisciplinary, guideline-recommended gynaecological care.

When considering treatment options and supports available in the ACT, it is important to recognise that endometriosis and chronic pelvic pain are not issues confined to one jurisdiction. While the ACT has specific service gaps and opportunities for improvement, the Inquiry should draw on the findings and learnings from other jurisdictions. A collaborative, cross-government approach, rather than isolated ACT-specific resources, would enable services to complement national initiatives, align with evidence-based models of care, and build on what is already known to be effective. This would strengthen the quality, consistency, and sustainability of treatment options and supports available to people with these conditions.

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

The legislative, regulatory, and institutional frameworks governing Australia's health system are embedded with structural bias, with gender bias remaining one of the most persistent. From medical research priorities to systemic funding inequities, gendered disparities continue to shape women's access to care. Women's healthcare is increasingly constrained by financial and logistical pressures, driven by rising out-of-pocket costs, the lack of routine indexation of relevant MBS items, restrictive insurance policies, and diminishing service availability.

Medicare rebates and diagnostic imaging

There remains no dedicated Medicare rebate for MRI in the investigation of pelvic pain, despite endometriosis affecting approximately one in seven Australian women. As a chronic and often debilitating condition, timely access to appropriate imaging is critical to support earlier diagnosis and effective management.

The introduction of new MBS items for complex gynaecological care is a welcome step toward addressing long-standing gaps. However, these items still require refinement and further clinical input to ensure they meet contemporary care needs.

Normalisation and dismissal of girls' and women's pain

Across chronic illness such as endometriosis, Australian studies consistently document women's pain being minimized, not believed, or inadequately treated, with significant emotional and clinical consequences. International quantitative work shows similar gender gaps in assessment and analgesia, reinforcing that this is a systemic, not merely anecdotal, problem.[17,18] Menstrual and pelvic pain in girls and women continues to be routinely dismissed as "normal." Adolescents are frequently told that severe period pain is simply part of growing up, a 'rite of passage'. Families, communities, and even clinicians may inadvertently trivialise symptoms, attributing them to exaggeration or emotional distress. The "just bad periods" narrative is a recognised feature of medical misogyny and diminishes the legitimacy of girls' and women's experiences, discourages help-seeking, delays diagnosis, and contributes to ongoing stigma surrounding menstrual and pelvic health. [19]

Gender supportive childcare frameworks and parental leave policies

The O&G workforce is female-dominated and improvements in parental leave policies and practices for the medical profession are needed to ensure that current and future generations of obstetricians and gynaecologists can build sustainable careers while balancing their own parenting needs. Furthermore, access to 24/7 childcare is needed to support the medical workforce and sustain clinician availability for service delivery. The ACT government is in the position to establish policies and processes that support a truly sustainable workforce, free of gender bias.

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

Endometriosis alone carries a significant personal and economic cost, estimated at approximately AUD $9.6 billion per year (around $30,000 per person with endometriosis). [20,21,22,23] These estimates do not account for those carrying the burden of adenomyosis, persistent pelvic pain, or other chronic pelvic conditions.

National data consistently shows that chronic pelvic pain is associated with:

- Reduced educational participation among adolescents.
- Disruptions to employment, including part-time work, absenteeism, and constrained career progression.
- Increased financial strain due to substantial out-of-pocket health care costs.

Collectively, these impacts reinforce structural gender inequality and contribute to ongoing economic vulnerability for affected individuals. Whilst this data is not isolated to the ACT, the impact can be easily inferred.

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[17] Tarrant, L., Grills, R., & McLeod, K. (2025). Gender Bias in Pain Management: The Case for Updating Analgesia Guidelines for Intrauterine Device Insertion Procedures.. *The Australian & New Zealand journal of obstetrics & gynaecology*. https://doi.org/10.1111/ajo.70010.

[18] Merone, L., Tsey, K., Russell, D., & Nagle, C. (2022). "I Just Want to Feel Safe Going to a Doctor": Experiences of Female Patients with Chronic Conditions in Australia. *Women's Health Reports*, 3, 1016 - 1028. https://doi.org/10.1089/whr.2022.0052.

[19] Arrgawal, S., Uppal, T., & Deslandes, A. (2025). *Ultrasound in endometriosis: Advancing non-invasive diagnosis and patient-centered care*. **O&G Magazine**, 27(3). https://www.ogmagazine.org.au/27/3-27/ultrasound-in-endometriosis-advancing-non-invasive-diagnosis-and-patient-centered-care/

[20] Gete, D. G., Mishra, G. D., et al. (2025, January 16). Endometriosis poses substantial burden on Australia's health system. eClinicalMedicine. University of Queensland News.

[21] Australian Institute of Health and Welfare. (2023). Endometriosis in Australia 2023: Summary. https://www.aihw.gov.au/reports/chronic-disease/endometriosis-in-australia-2023/contents/summary

[22] Armour M, Sinclair J, Chalmers KJ, Smith CA, Abbott JA. The cost of illness and economic burden of endometriosis and chronic pelvic pain in Australia: a national online survey. PLoS One. 2019;14(10):e0223316.

[23] Simoens, S., et al., Endometriosis cost assessment (the EndoCost study): a cost-of illness study protocol. Gynecologic and Obstetric Investigation, 2011. 71(3): p. 170-6.

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

There are a range of education options available for health care professionals in the ACT who care for women with pelvic pain and endometriosis. The RANZCOG *Australian Living Evidence Guideline for Endometriosis* remains the cornerstone of education in this area, supported by resources such as the Endometriosis eLearning Module, and increasing awareness and advocacy from organisations including EndoAware, the Pelvic Pain Foundation of Australia, and the Australasian Gynaecological Endoscopy and Surgery Society. However, due to the absence of a dedicated pelvic pain service within Canberra Health Services, opportunities for Obstetrics and Gynaecology trainees to gain experience in the evaluation, diagnosis, and management of complex and chronic pelvic pain is limited. Most trainee exposure occurs through acute inpatient care of patients hospitalised during severe pain flares, which does not reflect the typical experiences of most women living with chronic pelvic pain who may never require acute admission. Strengthening training pathways and clinical exposure will require the establishment of a dedicated pelvic pain service, and RANZCOG continues to strongly advocate for such expansion, supported by a deliberate and sustainable approach to workforce planning.

Summary

RANZCOG calls for collaboration to improve care for women and girls living with persistent pelvic pain and endometriosis. These conditions have profound impacts on health, education, workforce participation, and quality of life, yet care remains fragmented and inconsistent. Coordinated leadership across jurisdictions is essential to ensure timely diagnosis, equitable access to multidisciplinary care, and evidence-based management. Addressing inequalities experienced by women in the ACT with chronic pelvic pain requires an intersectional approach to policy and service reform that recognises and addresses overlapping inequities.

RANZCOG puts forward the following key recommendations:

- Capture data specific to endometriosis and other chronic pelvic pain conditions to guide accurate planning and funding.
- Establish sustainably funded, appropriately staffed, and fully coordinated multidisciplinary public clinics.
- Work with specialist colleges and relevant professional bodies to develop and implement sustainable workforce strategies for the ACT, including inadequate surgical capacity.
- Work with relevant stakeholders to address medical misogyny and gender bias through policy and system reform.

RANZCOG acknowledges with thanks the contributions of Dr Josie Wright for this submission.

Yours sincerely,

Dr Nisha Khot
President