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: 013

Submitter: Australian Medical Association ACT and RACGP NSW & ACT

Date authorised for publication: 14 April 2026

Australian Medical Association ACT Branch
Level 1, 39 Brisbane Ave, Barton ACT 2600
Phone: [redacted]
e: [redacted]

RACGP NSW&ACT Faculty
Level 12, 1 Pacific Highway
North Sydney NSW 2060
Phone: [redacted]
e: [redacted]

AMA ACT AND RACGP NSW&ACT Faculty

JOINT SUBMISSION TO THE ACT LEGISLATIVE ASSEMBLY'S INQUIRY INTO ENDOMETRIOSIS AND OTHER PELVIC PAIN CONDITIONS

The Australian Medical Association ACT and RACGP NSW&ACT Faculty are pleased to make this submission on behalf of ACT doctors and their patients. Our response has been prepared based on:

- Interviews with GPs and non-GP specialists providing medical care to women in Canberra
- A survey of our members on the topic of pelvic pain
- Correspondence received from members and non-members regarding gynaecological care of women in Canberra

Summary: Pelvic pain affects close to half of Australian women and includes endometriosis as well as a range of other conditions. The impact is substantial, including missed school and work, and strain on relationships and mental health. While diagnosis and management have improved with effective new oral hormonal therapies and advances in imaging, misinformation remains a major barrier to timely care. GPs are well placed to initiate assessment, educate patients, coordinate multidisciplinary care and reduce pressure on hospital services, but require adequate support. Their patients need timely access to appropriate imaging, specialist review, and allied health care, which is often not the case in the ACT.

Priorities:

- Strengthen and support general practices in the ACT, in particular for long appointments, given their critical role in early diagnosis and coordination of care and providing appropriate patient education
- Support multidisciplinary models of care (e.g. pelvic floor physiotherapy, pain services, psychology and dietetics)
- Improve access and Medicare rebates for specialised pelvic ultrasound and gynaecology services
- Counter harmful misinformation through evidence-based public messaging

The remainder of this submission addresses the terms of reference in the order set out by the inquiry.

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

Pelvic pain is extremely common among Australian women and is frequently seen by GPs in the ACT. Just under half of Australian women reported experiencing pelvic pain in the preceding five years in the 2023 National Women's Health Survey conducted by Jean Hailes for Women's Health.[1]

Pelvic pain is associated with endometriosis in about half of cases[2]. Other conditions that result in acute or chronic pelvic pain include non-endometriosis menstrual pain, vaginismus, interstitial cystitis and infections, including sexually transmitted infections which can lead to pelvic inflammatory disease, as well as post-herpetic neuralgia.

Whether pain is attributed to endometriosis or another condition makes little difference to severity or management, as all causes of pelvic pain can be debilitating and cause psychosocial dysfunction.

Once pelvic pain is identified by a GP, the focus is on managing symptoms, while diagnostic investigations are also considered. Doctors often consider gynaecological, urological, and gastrointestinal conditions which may contribute to symptoms, as well as musculoskeletal, mental health, dietary and psychosocial factors.[3]

Given complex overlapping factors, it can take years before a patient with pelvic pain receives a diagnosis for their condition. An Australian study found it took an average of five years for pelvic pain patients to receive a diagnosis after presenting to their GP[4]. Nevertheless, there is little evidence that the label itself changes the outcome; rather it is the intervention and appropriate management that is crucial.

2. 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 main barriers to pelvic pain care and treatment in the ACT include:

- GP access
- Long waits and large out-of-pocket costs for specialised pelvic ultrasound
- Delays accessing gynaecological review and surgical services in the public and private sectors
- Difficulties accessing multidisciplinary care, including physiotherapy

These are detailed below.

Barrier 1: GP access

Pelvic pain is a common presentation in general practice. Nevertheless, research shows that only half of women experiencing pelvic pain discuss it with their doctor.[5] This may be due to a common misunderstanding that pelvic pain is normal, and that nothing can be done to relieve it.

Often pelvic pain is identified opportunistically when patients present to their GP for another reason, such as a urinary tract infection, a script for the contraceptive pill, preconception planning or a health check.

Most GPs are aware of the need to be proactive in asking about pelvic pain symptoms and menstrual bleeding patterns when patients present for other reasons. They are equipped to validate patients' concerns, take a clinical history and conduct a physical examination, order appropriate tests and discuss possible referrals and treatments. There are also an increasing number of GPs in the ACT with a special interest in pelvic pain. However, these appointments take time, and the Medicare rebate structure does not adequately support or encourage longer consults.

Given the crucial role of GPs in identifying pelvic pain and undertaking the work-up which needs to include possible musculoskeletal, urinary, gastrointestinal and psycho-social factors, it is concerning that surveys consistently show ACT patients are forgoing GP appointments due to cost.[6]

This is not the fault of GPs, who face inadequate Medicare rebates and rising operating costs. GP access problems are compounded by government policies that encourage patients to see alternative health care providers such as nurses and pharmacists, eroding the chances for opportunistic screening of menstrual related issues.

GPs have raised concerns that policies enabling pharmacists and nurses to dispense oral contraceptives and UTI medications without medical assessment lead to fewer opportunities to screen for pelvic pain. Further, there is a risk of being treated with over-the-counter products (e.g. thrush treatment) without examination and appropriate testing, which can increase the risk of undetected infection or interstitial cystitis.

One doctor wrote:

> *"Pharmacists have no way of examining women and certainly no way of safely managing acute or chronic pelvic pain."*

Barrier 2: Accessing specialised pelvic ultrasound and MRI

The diagnostic process typically begins with the GP taking a clinical history and physically examining the patient. Depending on the findings they may then require blood tests, imaging (specialised pelvic ultrasound, sometimes MRI) and surgical assessment (laparoscopy).

Guidelines recommend a transvaginal pelvic ultrasound as the first-line investigation for women with pelvic pain.[7] Visual assessment is also possible via surgical laparoscopic assessment.

Significantly, some of the oral hormonal therapies that are most effective for treating pelvic pain (e.g. Ryeqo) are only available on the Pharmaceutical Benefits Scheme if there is visual confirmation of endometriosis.

A general ultrasound is not sensitive for picking up deep infiltrating endometriosis. For this reason, a specialised pelvic ultrasound is preferred, for which sonographers and reporting doctors undergo additional training. Even still, deep endometriosis is not always visible on these scans, and so patients are sometimes referred to a non-GP specialist for further evaluation, which may include a recommendation for pelvic MRI or surgical opinion.

There is no public service for specialised pelvic ultrasound in the ACT. Women who are able to pay privately often experience wait times of up to three months and significant out of pocket costs. Further, there is also no Medicare rebate for Pelvic MRI in investigation of pelvic pain.

Doctors have identified accessing visual assessments as a major barrier for pelvic pain patients in the ACT, and something for which patients often travel interstate.

> *"Ultrasound scan is very difficult as deep pelvic ultrasound really should be performed by a team with specialist training and having a gynaecologist as part of the team is important."*
>
> *"The greatest barrier is getting the visual diagnosis via deep ultrasound or laparoscopy. The laparoscopy public wait times are very long. Deep ultrasound is helpful, but the sensitivity is not high enough to rule out endometriosis with certainty."*

Barrier 3: Accessing specialist gynaecological review

Specialist gynaecological opinion may be sought for several reasons, including clarification of the diagnosis (laparoscopy), and expertise in medical management. Women can be referred for gynaecological review in the public or private system.

In the public hospital, laparoscopy for suspected endometriosis is normally considered a Category 3 procedure, meaning it should be performed within 365 days. As of March 2026, there were 242 Category 3 patients on the waiting list for gynaecological surgery in the ACT. 15% of those cases were overdue.[8]

These figures only include patients who have already been triaged. The waiting time for an initial gynaecology appointment in the ACT public health system can be more than three years.

Among patients who undergo surgical assessment for disease, medical management is often recommended. This is because following surgery/ laparoscopy there is a 30% rate of persistent or new pain.[9] Specialist gynaecologists provide expertise in complex medical management, including where first line hormone treatments have not been successful.

Barrier 4: Difficulties accessing multidisciplinary care

Once a pelvic pain has been identified, access to multidisciplinary care is important. The needs of women will differ depending on the patient and the diagnosis, but may include:

- General practice
- Specialist gynaecology
- Specialist fertility
- Pelvic floor physiotherapist
- Dietitian
- Pain psychologist
- Pain physician

The role of physiotherapy is well established in managing chronic pelvic pain, including addressing pelvic floor dysfunction and supporting graded activity and exercise as part of a multidisciplinary plan.

While GPs are well placed to coordinate a patient's care, many express a need for more training and support. Eligible patients may benefit from preparation of a Chronic Condition Management Plan (CCMP) with their GP, which provides them with a Medicare rebate for five allied health sessions in a calendar year. Where appropriate, patients may also be referred under a Mental Health Care Plan for psychologic support for up to ten sessions in a calendar year.

The establishment of a Pelvic Pain and Endometriosis Clinic in the ACT has led to better coordination of multidisciplinary care for patients with pelvic pain, and additional training for GPs in managing the condition via the Pelvic Pain Network.

Nevertheless, limited access to qualified practitioners in this subspecialty and the costs of appointments remain barriers for many patients.

There is no dedicated pelvic pain service in Canberra Health Services. Occasionally patients with pelvic pain receive physiotherapy and nursing support through CHS's Transvaginal Mesh Clinic, for people who underwent surgery for transvaginal mesh (TVM) and are experiencing mesh related complications. However, there is a need for clinically led and integrated care for pelvic pain patients in the public health system.

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

A growing body of evidence supports non- surgical approaches to managing pelvic pain, in favour of oral medication, long acting contraceptives (LARCs) together with physiotherapy and other allied health support.

Professor Sonya Grover, gynaecologist and pain specialist at the Royal Children's Hospital and Mercy Hospital for Women summarised the current treatment approach in a 2024 article for the medical news website, *MJA InSIght:*

> *"This is not a problem that requires a gynaecologist with a scalpel, it requires a team. The woman, her general practitioner and a physiotherapist can solve this problem for most. Some need the backup of a multidisciplinary team, and that's okay.*
>
> *Both the period pain and the heavy bleeding (often associated with painful periods and a known risk factor for endometriosis) can be addressed with tranexamic acid, non-steroidal anti-inflammatory drugs and hormonal approaches including the levonorgestrel intrauterine device.*
>
> *Ovulation pain can be addressed with hormone-based solutions (but not usually the levonorgestrel intrauterine device). The muscular aspects of pelvic pain can be effectively treated (in most women) by physiotherapy and exercise. For some women, there may need to be input from other clinicians: a dietitian for gut-related symptoms and a counsellor or psychologist for poor sleep, depression, anxiety and previous trauma events. Thus, control is handed back to the individual woman and her GP, rather than the solution lying at the edge of a scalpel."*[10]

The following table summarises the main treatments and their accessibility in the ACT.

Treatment	**Evidence Base**	**Canberra availability**	**Interstate Availability**	**Barriers**
Oral Hormonal Treatment - Dienogest (Visanne) - Drospirenone (Slinda)	The progestogen pill dienogest has moderate-quality evidence from randomised trials showing clinically meaningful reductions in endometriosis-associated pelvic pain versus placebo.[11]	Improved availability with PBS listing of oral contraceptive pills for endometriosis	As per ACT	Oral hormone hesitation among some patients

- Relugolix; Estradiol; Norethisterone acetate (Ryeqo)	Drospirenone is also a progestogen pill. A retrospective analysis of 61 adolescents found it was linked with self-reported improvements in dysmenorrhea and pelvic pain in 46% and 62% of users respectively.[12] Two large randomised controlled trials found Ryeqo significantly improved endometriosis-associated pain and was well tolerated.[13] Overall, these hormonal therapies are considered safe and well-tolerated. Side-effects include irregular bleeding, headache and breast discomfort, though these reduce over time.	Some medications (Ryeqo) need visual diagnosis before commencing		Small percentage of population unable to tolerate the treatments due to side effects Inability to prescribe Ryeqo without visual diagnosis on the PBS
Hormonal intrauterine devices (IUDs)	Levonorgestrel-releasing IUDs (e.g., Mirena/Kyleena) have evidence for reducing dysmenorrhoea and pelvic pain, including in women without a diagnosis of endometriosis.[14] IUD side effects, including irregular bleeding, pelvic pain, and headaches, are generally mild and tend to subside within 3 to 6 months.	Many GP clinics have GPs who do insertions Mirena and Kylena are on the PBS Patient out of pocket costs improved with increased Medicare rebates in 2025	As per ACT	Long waiting period for GPs who wish to do IUD training Rising IUD insertion pack costs are eroding Medicare benefit increases Some women experience significant

				pain with insertion Wait times for those patients requiring insertion under anaesthetic
Pelvic Floor Physiotherapy	Pelvic floor physiotherapy has evidence of benefit in chronic pelvic pain, with a systematic review/meta-analysis finding clinically meaningful reductions in pain intensity versus usual care/inert comparators.[15] In endometriosis, small trials and emerging reviews suggest pelvic floor–targeted physiotherapy can improve pain and related function, though study sizes are modest.	Highly skilled clinicians available in Canberra Some have long wait times for initial appointment Free services are available via Canberra Health Services	Telehealth options available or patients travel interstate	Cost of appointments Cost of time off work to attend appointments Severe pain can be a barrier to participation Limited number of sessions available under a care plan (5) that attract Medicare rebate
Specialist Gynaecological Review	For suspected/confirmed endometriosis, laparoscopic surgery (excision/ablation) can improve symptoms for some patients, but systematic reviews conclude it is uncertain whether surgery improves overall pain	Declining number of clinicians in the ACT	Patients sometimes travel to NSW for surgery	Three year wait for public appointment Limited operating

	versus diagnostic laparoscopy alone.[16] Pain can persist or recur after surgery, and evidence supports a long-term management approach (often including postoperative hormonal suppression) rather than viewing surgery as a definitive “cure”. Expertise in medical management for complex presentations			theatre availability for investigative laparoscopy Out of pocket costs due to low Medicare rebate for complex gynaecological surgery

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

The problem of medical misinformation is a major barrier to accessing care for pelvic pain disorders. Most of this information comes by social media and influencers, not from qualified medical practitioners.

Many patients believe that surgery can ‘fix’ them, when the evidence for surgical intervention in isolation is mixed at best. Online influencers often warn that hormonal treatments for pelvic pain are ‘unnatural’, despite strong evidence that oral hormonal treatments are safe and often highly effective.

One doctor wrote:

> *“A big challenge I face is providing education about the safety and importance of using hormonal treatment for endometriosis and polycystic ovarian syndrome. The misinformation around this mostly comes from women on social media and the internet.”*

Another concerning cultural norm is the belief that period pain is ‘normal’ and something women should just ‘put up with’. Thankfully, patient awareness campaigns have gone some way to correcting this view.

On the topic of medical misogyny, no doubt some women have also felt unheard by their doctors when it comes to their pelvic pain and menstrual difficulties. One GP wrote:

> *“I think sometimes this is due to other practitioners’ level of training and experience – i.e. lack of experience with women’s health, periods and contraception services.”*

GPs have received much better training in the last five years about taking a menstrual history and specifically asking about pain and bleeding patterns, however there is still work to do in this space.

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

Doctors described how their patients with pelvic pain are often unable to work or go to school as a result of their illness – often missing several days each month until and an effective treatment is in place. Furthermore, patients need time away from work to attend medical and allied health appointments.

> *"I see many young women missing school due to the severity of their menstrual pain, and women needing time off work."*
>
> *"Women don't have access to menstrual leave. This means that they put up with severe pain, or use their sick leave which runs out quickly. I have patients who have needed to take months off work to manage their pain."*
>
> *"Women worry about being labelled as poor performers at work, and tell me the cost is not the barrier; it's the time off work to go and see the physio or the psychologist."*

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

Aside from the support of colleagues in a multidisciplinary team, the following are trusted resources for ACT doctors involved in caring for patients with pelvic pain.

- ACT Pelvic Pain Network – A multidisciplinary community of clinicians including GPs, gynaecologists, physiotherapists, dietitians and psychologists who meet quarterly for education https://www.shfpact.org.au/index.php/clinic/pelvic-pain-clinic
- Sexual Health Certificate https://www.shfpact.org.au/index.php/43-learn/259-fpaa-certificate-course-in-reproductive-and-sexual-health
- RACGP https://www.racgp.org.au/
- Jean Hailes https://www.jeanhailes.org.au/
- Therapeutic Guidelines https://www.tg.org.au/
- ACT Healthpathways https://actsnsw.communityhealthpathways.org/welcome
- Pelvic Pain Questionnaire https://avonleaclinic.com.au/wp-content/uploads/2020/06/Pain-Patient-Questionnaire-Form-1.pdf
- RANZCOG guidelines https://ranzcog.edu.au/wp-content/uploads/Endometriosis-Clinical-Practice-Guideline.pdf

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

ACT is well placed to host trials with relevance to women with pelvic pain conditions, given ACT's Pelvic Pain and Endometriosis Clinic and the presence of many GPs with a special interest in this area.

Research should focus on the following:

- Collecting ACT-specific data on pelvic pain to inform resource allocation. This should include data on prevalence; quality-of-life and disability measures; waiting times for imaging, surgical and allied health consults; treatment outcomes; and treatment side-effects.
- Developing more accurate non-invasive tests to eliminate the need for surgical assessment
- Understanding the impact of fragmentation of care on women's health outcomes
- Evaluating the effectiveness of multidisciplinary care for women with pelvic pain
- Continuing to explore emerging treatments

REFERENCES

[1] Jean Hailes for Women's Health 2023, *Pelvic pain in Australian women 2023*, viewed 1 April 2026, https://www.jeanhailes.org.au/reports/pelvic-pain-in-australian-women-2023/

[2] Sexual Health and Family Planning ACT

[3] The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) 2021, *Australian clinical practice guideline for the diagnosis and management of endometriosis*, RANZCOG, Melbourne, viewed 1 April 2026, https://ranzcog.edu.au/wp-content/uploads/Endometriosis-Clinical-Practice-Guideline.pdf

[4] Armour M, Sinclair J, Ng, Hyman MS, Lawson K, Smith CA, Abbott J. Endometriosis and chronic pelvic pain have similar impact on women, but time to diagnosis is decreasing: an Australian survey. Sci Rep. 2020 Oct 1;10(1):16253. doi: 10.1038/s41598-020-73389-2. PMID: 33004965; PMCID: PMC7529759.

[5] Jean Hailes for Women's Health 2023, *Pelvic pain in Australian women 2023*, viewed 1 April 2026, https://www.jeanhailes.org.au/reports/pelvic-pain-in-australian-women-2023/

[6] Women's Health Matters 2025, *Report on the 2025 Survey of Women's Health in the ACT*, Women's Health Matters, Australian Capital Territory, viewed 1 April 2026, https://womenshealthmatters.org.au/wp-content/uploads/2025/10/Report-on-2025-Survey-of-Womens-Health-in-the-ACT.pdf

[7] The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) 2021, *Australian clinical practice guideline for the diagnosis and management of endometriosis*, RANZCOG, Melbourne, viewed 1 April 2026, https://ranzcog.edu.au/wp-content/uploads/Endometriosis-Clinical-Practice-Guideline.pdf

[8] Canberra Health Services 2026, *Elective surgery waitlist data*, ACT Government, viewed 1 April 2026, https://www.canberrahealthservices.act.gov.au/about-us/Elective-Surgery-waitlist-data

[9] Zondervan, KT, Becker, CM & Missmer, SA 2020, 'Endometriosis', *New England Journal of Medicine*, vol. 382, no. 13, pp. 1244–1256, https://doi.org/10.1056/NEJMra1810764. [ora.ox.ac.uk]

[10] Grover, S 2024, 'Spotlight on neglected period and pelvic pain', *InSight+*, issue 31, 12 August, viewed 1 April 2026, https://insightplus.mja.com.au/2024/31/spotlight-on-neglected-period-and-pelvic-pain/

[11] Strowitzki T, Marr J, Gerlinger C, Faustmann T, Seitz C. *Dienogest is as effective as leuprolide acetate in treating the painful symptoms of endometriosis: a 24-week, randomized, multicentre, open-label trial.* Human Reproduction. 2010;25(3):633–641. doi:10.1093/humrep/dep469.
Link: https://academic.oup.com/humrep/article/25/3/633/2915724

[12] Garbo G, Barrera E, Shim JY, et al. *Use of Continuous Oral Drospirenone for Menstrual Suppression in Adolescents.* J Adolesc Health. 2025;76(1):148–153.
https://www.jahonline.org/article/S1054-139X(24)00434-8/fulltext

[13] Giudice, LC, As-Sanie, S, Arjona Ferreira, JC *et al.* 2022, 'Once daily oral relugolix combination therapy versus placebo in patients with endometriosis-associated pain: two replicate phase 3, randomised, double-blind, studies (SPIRIT 1 and 2)', *The Lancet*, vol. 399, no. 10343, pp. 2267–2279, https://doi.org/10.1016/S0140-6736(22)00622-5.

[14] Pelvic Pain Foundation of Australia 2025, *Abstract 8*, Pelvic Pain Foundation of Australia, viewed 1 April 2026, https://www.pelvicpain.org/images/2025/2025%20Abstracts/8.pdf

[15] Starzec-Proserpio M, Frawley H, Bø K, Morin M. Effectiveness of nonpharmacological conservative therapies for chronic pelvic pain in women: a systematic review and meta-analysis. Am J Obstet Gynecol. 2025 Jan;232(1):42-71. doi: 10.1016/j.ajog.2024.08.006. Epub 2024 Aug 13. PMID: 39142363.

[16] Cochrane Gynaecology and Fertility Group 2022, *Laparoscopic surgery for endometriosis: a Cochrane update*, Cochrane, viewed 1 April 2026, https://cgf.cochrane.org/news/laparoscopic-surgery-endometriosis-cochrane-update