Submission to the ACT Legislative Assembly Inquiry into endometriosis and other pelvic pain conditions

17 April 2026

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Acknowledgement of Country

Women's Health Matters is committed to reconciliation and acknowledges the First Australians whose cultures are among the oldest living cultures in human history, as the traditional custodians of this continent. We also recognise the history of dispossession experienced by the First Australians and the impact this has and continues to have on Aboriginal and Torres Strait Islanders. We recognise the Ngunnawal People as the traditional custodians of the land on which we live and work, and pay our respects to their Elders past, present and emerging. We recognise the strength of Aboriginal women and their continuing connection and contribution to this land, these waters, and our communities. May we walk gently and treat the earth and each other with care and respect.

About Women's Health Matters

Women's Health Matters (WHM) is an independent, non-partisan organisation that works to improve the health and wellbeing of all women in the ACT and surrounding region. Our vision is that women experience improved health outcomes, have positive experiences when accessing health and social services and can fully participate in all aspects of our community.

We work with the community, government and service providers to address social determinants of health and wellbeing and create better outcomes for women (cis and trans inclusive) and gender diverse people. We do this through health promotion and by providing evidence-based social research, policy development and advocacy services to governments, the corporate sector, policy makers, service providers and peak bodies. Our guidance supports ACT women to make informed health and wellbeing choices and to understand how to access appropriate gender-sensitive services and information in the ACT.

Acknowledgement of work contributing to this inquiry

WHM gratefully acknowledges the input received from community members through our survey research and the advocacy conducted more broadly over decades by people struggling with pelvic pain conditions. We appreciate the reflections, advice and expertise generously shared by people with these experiences.

We also recognise the valuable input provided to this submission by advocacy organisations, service providers and clinicians with whom we have consulted. WHM endorses the submission provided to this inquiry made by Women With Disabilities ACT and urges the Committee to consider its recommendations.

The lead author of this submission was Dr Tayyaba Malik, WHM's Research Officer, who was supported in this work by Dr Merri Andrew, WHM's Research and Policy Manager.

Executive Summary

Women's Health Matters (WHM) is an ACT-based community organisation whose vision is that women experience improved health outcomes, have positive experiences when accessing health and social services and can fully participate in all aspects of our community.

This submission draws on two Surveys of Women's Health in the ACT, conducted by WHM in 2023 (N=1,686) and 2025 (N=1,319), together generating over 870 open-ended qualitative responses specifically about experiences with endometriosis, adenomyosis, persistent pelvic pain and polycystic ovary syndrome (PCOS).

While this submission directly addresses the conditions specified in the Terms of Reference, our data consistently shows that the barriers women face, dismissal, diagnostic delay, financial hardship and a fragmented system, cut across all these conditions. Our recommendations are therefore designed not as condition-specific fixes but as investments in an integrated, publicly funded pelvic health system that serves ACT women across their lives and across conditions. This approach will deliver better outcomes for the specific conditions under consideration and will build lasting infrastructure that benefits ACT women more broadly.

Our key findings are:

- Around a third of all respondents to our 2025 survey had experienced endometriosis/adenomyosis, PCOS and/or persistent pelvic pain. Extrapolated to ABS population estimates, this would equate to around 66,360 people in the ACT.
- Based on our survey, we estimate that up to 37,000 ACT residents may have been diagnosed with or treated for endometriosis or adenomyosis in their lifetime — significantly higher than the commonly cited figure of 27,000.
- Our survey suggests that up to ~34,200 people may have been affected by persistent pelvic pain (PPP) in the last two years, while up to ~27,200 may have experienced PCOS at some point in their lives.
- Pelvic pain conditions were widely reported in our survey, and were reported at higher rates by: people experiencing financial stress; people aged 25-44; people with disabilities; people who are neurodivergent; bisexual, pansexual and queer people; people reporting high levels of psychological distress and/or who had been diagnosed or treated for a mental health condition; and people who had experienced some form of gender-based violence.
- The average diagnostic delay for endometriosis reported in our survey is 6.5 to 8 years, and patients reported consulting an average of five different doctors before a management plan was established.

- Over 230 respondents with endometriosis/adenomyosis, PPP and/or PCOS explicitly described being dismissed, ignored or not taken seriously in relation to their condition/s by medical professionals.
- Many ACT residents are travelling to Sydney or Melbourne for care that should be more readily available in a city of Canberra's size.

Summary of Recommendations

Integrated Pelvic Health System

1. Develop an integrated, publicly funded pelvic health system in the ACT, covering the full continuum of care from early education and assessment through to specialist and multidisciplinary hospital care, which is free or low cost at the point of access, and supported by a well-resourced network of GPs and community clinicians.

Early Identification and Education

2. Implement the Periods, Pain and Endometriosis Program (PPEP) Talk program in ACT secondary schools (Years 9–10) to build health literacy and reduce the normalisation of severe period pain.
3. Expand and properly resource the School Youth Health Nurse (SYHN) program across all ACT high schools and colleges, including equitable pay and conditions for SYHN nurses.
4. Fund community-based organisations to deliver ongoing public health information campaigns and peer support programs for people with pelvic pain conditions at all life stages.

Community-Based Care

5. Expand and make permanent the SHFPACT model of specialised primary care, with 45–60 minute appointments, co-located pelvic health physiotherapy and a dedicated care navigator role.
6. Fund a second clinic in the north of Canberra to serve the growing Gungahlin and Belconnen populations.
7. Support and resource the GP network working in this space so that clinicians are equipped, connected and not working in isolation.
8. Increase investment in established community-based support models to enhance patient care in non-clinical settings, reduce demand on clinical services and improve outcomes for people with pelvic pain conditions.

Hospital Capacity and Specialist Care

9. Invest in building specialist capacity at Canberra Hospital, additional gynaecologists, a properly resourced multidisciplinary team, and dedicated support for clinicians currently operating in an understaffed environment.
10. Once that foundation is in place, establish a formal Hub and Spoke model linking community clinics across Belconnen, Tuggeranong, Gungahlin and Woden, as well as North Canberra Hospital, to Canberra Hospital as the specialist hub.
11. Expand the Canberra Hospital Endometriosis Clinic to operate as a true multidisciplinary centre, gynaecology, pain medicine, physiotherapy and psychology as standard embedded components of care, not optional referrals.

Addressing Barriers to Access

12. Adopt trauma-aware and healing-informed administrative communication as a standard for all waitlist correspondence with patients waiting for gynaecological or pelvic pain services.
13. Reform the Interstate Patient Travel Assistance Scheme (IPTAS) to reduce administrative burden and better support patients travelling interstate for specialist care unavailable in the ACT.
14. Work with researchers, Canberra Health Services and private specialists to improve local access to diagnostic and treatment options that are supported by evidence, including consideration of Deep Infiltrating Endometriosis ultrasound and pelvic Botox injections.

Workforce and Education

15. Develop skills and knowledge on endometriosis, adenomyosis, PCOS and PPP for GPs, gynaecologists and emergency medicine physicians, from initial medical training through to continuing professional development.
16. Establish structured case review and mentoring pathways for ACT-based specialists to build local excision surgery expertise.
17. Embed trauma-aware and healing-informed care training as a standard component of education for health practitioners.
18. Establish a formal advanced practice nursing pathway for endopelvic pain within the ACT public health system.

Hospital Management and Structure

19. Examine whether the current management structure, with gynaecology sitting under maternity and obstetrics, is fit for purpose, and consider a dedicated management pathway for gynaecology and pelvic pain services.

Research and Data

20. Fund a dedicated ACT pelvic health research unit, potentially in partnership with ANU.
21. Establish a longitudinal cohort study tracking diagnostic journeys, treatment outcomes and quality of life among ACT residents with pelvic pain conditions.
22. Partner with Endometriosis Australia and the Australian Coalition for Endometriosis to ensure ACT-specific data is incorporated into national research frameworks.

Care Coordination and Accountability

23. Formalise and fund a care coordination model building on SHFPACT's existing approach, ensuring no patient navigates the system alone.
24. Establish a required reporting framework for pelvic health presentations across ACT health services with a public-facing biennial report card.
25. Adopt outcome-based performance metrics, pain levels at 6 and 12 months, return to work and study, ED presentations, repeat surgery rates and patient-reported quality of life, rather than waitlist reduction alone.
26. Continue meaningful engagement with people with lived experience, peer networks and advocacy organisations in health system reform and service development.

This submission addresses each of the Committee's Terms of Reference and presents evidence-based recommendations for system reform. Our core recommendation is the development of an integrated, publicly funded pelvic health system in the ACT, one that covers the full continuum of care from early education and community-based assessment through to specialist and multidisciplinary hospital care. Care needs to be free or low cost at the point of access, publicly anchored, and supported by a well-resourced network of GPs and community clinicians who are equipped, connected and not working in isolation. The pieces of this system largely exist in the ACT already. Our recommendations are about connecting them, funding them properly, and building the missing components, particularly specialist capacity at Canberra Hospital and a formal care coordination model, so that no one in the ACT has to travel interstate, wait years, or pay out of pocket for care she should be entitled to receive here.

Term of Reference 1: Prevalence of Endometriosis, Adenomyosis, PCOS and Chronic Pelvic Pain Conditions in the ACT

In our most recent Survey of Women's Health in the ACT (2025), we asked respondents (n=1319) a series of questions about endometriosis, adenomyosis, polycystic ovary syndrome (PCOS) and persistent pelvic pain (PPP). As well as the extensive open-ended responses analysed elsewhere in this submission, the survey yielded useful quantitative findings, suggesting widespread prevalence of these conditions.

Condition	**Ever diagnosed or treated (lifetime)** **% of n=1319**	**Diagnosed or treated last two years** **% of n=1319**
Endometriosis & Adenomyosis	18.7%	13%
PCOS	13.7%	8.5%

Condition	**Experienced in last two years** **% of n=1319**
Persistent Pelvic Pain*	17.2%

*Defined as pain below your belly button and above your legs that lasts for six months or more, allowing that the pain might change over time. People who experience persistent pelvic pain include those who have endometriosis and other conditions.

It is important to note that we did not use a random sampling method to conduct our survey, but rather recruited through convenience sampling methods where participants self-selected to complete the online survey. Further, Women's Health Matters' networks and public profile are linked with our advocacy on issues of health equity, so it is possible that we tended to recruit people for the survey whose experiences were more likely than average to be negatively impacted by health inequity. People responding anonymously through our online survey may also be more likely to give frank answers about negative or sensitive experiences compared to phone surveys or in-person surveys, particularly if the latter are conducted by more 'official' agencies.

As a result, while our survey sample is relatively large and broadly representative of the ACT population of women, it does not perfectly match the demographic features of the population, and any extrapolation of its findings needs to be done with caution. Nevertheless, the large sample size of our survey, as well as its overall strong representation across different characteristics such as disability, location, educational attainment, sexuality, and carer status, means we can be confident that the issues raised by the findings are significant in the ACT community.

Noting the limitations summarised above, we can use the survey findings to estimate the potential number of people in the ACT community who are experiencing pelvic pain conditions.

Advocates have previously pointed out that, based on national prevalence figures, around 27,000 people in the ACT may have experience of endometriosis (on a lifetime basis) (Hansard 2025; QENDO 2025), To explore prevalence using our data, we applied the Survey of Women's Health findings to the current ABS population figures estimating the population of female/AFAB people aged 18 years of older at 199,073 in 2025 (ABS 2025). This analysis suggests a potentially even higher number of people in the ACT who have experiences of endometriosis and other pelvic pain conditions:

Condition	**Survey Result - lifetime (%)**	**Estimated ACT Cases (n=199,073) - lifetime**	**Survey Result - last 2 years (%)**	**Estimated ACT Cases (n=199,073) last 2 years**
Endometriosis & Adenomyosis	18.7%	37,227	13%	25,879
PCOS	13.7%	27,273	8.5%	16,921
PPP	---	---	17.2%	34,241

Based on our survey, we estimate that up to 37,000 ACT residents may have been diagnosed with or treated for endometriosis or adenomyosis in their lifetime — significantly higher than the commonly cited figure of 27,000, noting the limitations of our survey as outlined above.

Our survey further suggests up to 34,200 people may have been affected by persistent pelvic pain (PPP) in the last two years, while up to 27,200 may have experienced PCOS at some point in their lives, again noting the limitations of our survey.

Overlapping conditions

When we look at the overlap between experiences of PPP, PCOS and endometriosis/adenomyosis, we can see that around a third of all respondents to our 2025 survey had experienced one or more of these conditions, while around two thirds did not report any of the conditions.

Apart from those who did not report any of the conditions, there were no other significant clusters of responses, with each possible combination being reported by fewer than 8% of survey respondents.

	number	**%**
None of the listed conditions	874	66.3
PPP only	74	5.6
Endo/Adenomyosis only	92	7.0
PCOS only	100	7.6
PPP + Endo/Adenomyosis	98	7.4
PPP + PCOS	25	1.9
Endo/Adenomyosis + PCOS	26	2.0
PPP+ Endo/Adenomyosis + PCOS	30	2.3
Total	1319	100

Note: Endo/Adenomyosis and PCOS are reported here on a lifetime basis, i.e. answered 'yes' to the question 'Have you ever been diagnosed with or treated for…' while PPP is reported as 'yes' answers to the question 'In the last two years, have you experienced persistent pelvic pain (defined as pain below your belly button and above your legs that lasts for six months or more, allowing that the pain might change over time)?' A significant proportion (n=120 or 9%) answered that they were 'Unsure' whether they had experienced PPP. 'These responses are included in "None of the listed conditions". For each variable, there were options to answer 'prefer not to answer/not applicable' and fewer than 4% of respondents selected that option (also included in 'None of the listed conditions.

Prevalence by key demographic indicators

Looking at the demographic profiles of people in our survey who have experiences of PPP, PCOS and/or Endometriosis/Adenomyosis, we can see associations between these conditions and key indicators such as income, financial stress, disability and experiences of violence.

It is important to note that we cannot be sure of the nature of these relationships in the data. For example, being under stress financially might make it harder to access healthcare and other resources that could prevent or alleviate pelvic pain conditions. At the same time, having pelvic pain conditions often interferes with people's work and study, with impacts on income and financial stress, as well as imposing costs from having to pay for healthcare.

Regardless of causation, these findings can help guide health system responses to be appropriate for people who are more likely to be among those experiencing pelvic pain conditions.

Persistent Pelvic Pain

In the survey sample as a whole, 17.2% had experienced PPP, defined as pain below your belly button and above your legs that lasts for six months or more, allowing that the pain might change over time. People who experience persistent pelvic pain include those who have endometriosis and other conditions.

Migration, visa, country of birth and language background

Our survey data indicates little difference in prevalence when comparing on the basis of **country of birth**, **migrant background**, **preferred language** or **main language spoken at home**.

In relation to **visa status**, Australian citizens and permanent residents had rates of PPP similar the average, but temporary visa holders reported lower rates (6.6% compared with 17.2% among the survey respondents as a whole). The reason for this difference is not clear and may need further investigation.

Other research and WHM's experience delivering multilingual health education makes it clear that temporary visa holders, together with recent migrants and people whose preferred or usual language is other than English, experience barriers and difficulties accessing health services generally (AIHW 2024; AIHW 2023).

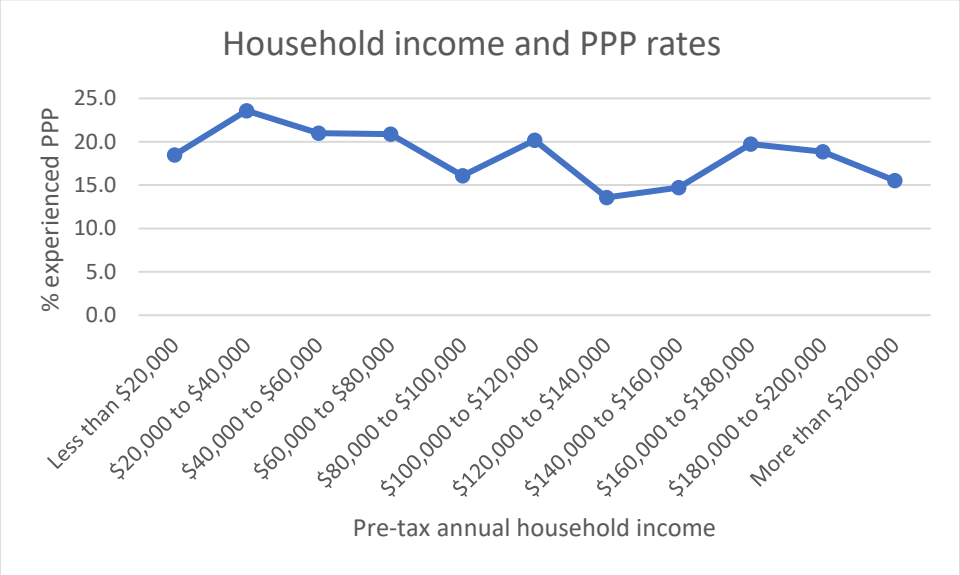
Financial stress

There were significant differences depending on **financial stress**:

- Among people who experienced at least one form of financial stress in the last year, 26% had experienced PPP in the last two years, compared with 11% of those who had not experienced any financial stress.
- Among people who experienced four or more forms of financial stress, over 30% had experienced PPP.
- People with PPP were twice as likely to have gone without medical care or medication in the last year due to not having enough money (38.3% of those with PPP compared with 18.3% of the full sample).

Household income

Interestingly, in our data there appears to be less of a relationship between household income and PPP than between financial stress and PPP, as shown by the following chart, which indicates there may be some relationship, but not a clear-cut one.



Note: 18% of respondents reported having household incomes more than $200,000, while every other income range was reported by fewer than 9% of respondents. This indicates a need to disaggregate higher incomes further in future surveys. As differences in income above $200,000 were not recorded in our 2025 survey, we cannot discern how those differences might relate to rates of PPP (e.g. we cannot compare rates of PPP among people with a household income of $400,000 with rates among people who have a household income of $200,000).

While we cannot be certain, the difference between financial stress and household income in terms of their relationship with PPP might be partly explained by the different reference unit: while financial stress refers to experiences of the individual person, household income refers to the family or household unit and does not necessarily reflect the individual's own financial situation (e.g. their ability to mobilise resources for their own healthcare or other preventative factors).

Age

In terms of age, people in our survey who were aged 25-34 and 35-44 reported PPP at higher than average rates, with 25.1% and 23.6% respectively experiencing PPP.

Gender

In our 2025 survey sample of 1319 people, just over 1% (15) identified their gender in a free-text response as non-binary, trans, agender and/or genderqueer, while 2.3% of respondents selected 'Prefer not to answer'. These results are broadly consistent with the ABS's finding that around 0.9% of people in Australia who are aged 16 years and over are trans and gender diverse, but these responses in our survey do not constitute a large enough dataset to analyse experiences of pelvic pain conditions among trans and gender diverse people in the ACT.

Drawing on input from consumer advocates, Health Care Consumers Association's submission includes discussion of the challenges faced by trans and gender diverse people in accessing healthcare for pelvic pain, which we encourage the Committee to consider. Women's Health Matters' key principle is that health services need to be made inclusive of all people who need them. For services often considered to be "women's health services" (such as services assisting with endometriosis or PCOS) this means working with community members and relevant organisations to make sure services are welcoming, safe and well-informed about the needs of trans men and non-binary people.

Sexuality

While people who told us their sexuality was straight (heterosexual) or gay/lesbian reported close to average rates of PPP (15.4% and 14.6% respectively), people who told us they were bisexual, pansexual or queer had higher rates of PPP (23.9%, 30.3% and 37.8% respectively). This might be related to poorer access to healthcare for some people who are not straight. For example, 36% of queer people who had consulted a GP in the ACT told us they had only fair or poor access to a GP, compared with 20% of survey respondents overall.

Neurodivergence

People who told us they were neurodivergent reported significantly higher rates of PPP: 35.7% of neurodivergent people in our survey reported PPP compared with 12.1% of those who were neurotypical.

Disabilities

People with disabilities experienced PPP at more than twice the rate (30.8%) of people without disabilities (12.5%). The exact nature of this relationship is not clear, for example whether people's reporting of their disabilities includes their pelvic pain condition or refers to other conditions/impairments.

As noted above, WHM endorses the submission provided to this inquiry made by Women With Disabilities ACT and urges the Committee to consider its recommendations.

Mental health

Looking at mental health, among people who reported high levels of psychological distress (measured as scores of 19 or more on the Kessler 6 scale), 31% reported having PPP, compared with only 13.6% of those with lower levels of psychological distress.

People who had ever been diagnosed or treated for a mental health condition reported higher rates of PPP (21%) compared with those who had never been diagnosed or treated (9.7%). Among all of those who reported PPP, 81% had been diagnosed or treated for a mental health condition at some point (compared with 45% of the sample as a whole).

Experiences of violence

People who had experienced some form of violence also had higher rates of PPP, with 22.4% reporting PPP compared with 10.8% of those who did not indicate having experienced any form of violence. Among people who had experienced sexual violence specifically, 26.2% of these respondents also reporting PPP, compared with 13% who told us they had not experienced sexual violence. These findings are consistent with research indicating that people who have experienced violence are more likely to have chronic pain in general (Uvelli et al 2024) and research finding that pelvic pain specifically is associated with sexual abuse experienced during childhood and/or adolescence (Bourdon et al 2023).

Endometriosis/adenomyosis and PCOS

Looking at the rates of endometriosis/adenomyosis and PCOS in our survey in relation to the same variables reported on above, we see similar patterns. While 18.7% of 2025 survey respondents overall reported having ever been diagnosed with or treated for endometriosis/adenomyosis and 13.7% reported having been diagnosed with or treated for PCOS, these conditions were reported at higher rates in our survey by:

- People who reported more financial stress
- People aged 25-34 and 35-44
- People with disabilities
- People who are neurodivergent
- Bisexual, pansexual and queer people (noting relatively small numbers for some cross-tabulations in the analysis)
- People reporting high levels of psychological distress and/or who had been diagnosed or treated for a mental health condition
- People who had experienced some form of gender-based violence

Term of Reference 2: Barriers to Diagnosis and Access to Treatment

2.1 Diagnostic Delay

While formal diagnosis is not necessarily the goal for all people experiencing pelvic pain conditions, many people report needing a diagnosis to obtain treatment and support for conditions that were debilitating. For this reason, delays in obtaining diagnosis have a significant impact on quality of life and compounding health problems. Survey respondents reported waiting an average of 6.5 to 8 years to receive a formal endometriosis diagnosis, consistent with national trends. This diagnostic delay begins at the very first clinical encounter, where symptoms are frequently normalised or dismissed.

2.2 The 'Doctor Merry-Go-Round'

Patients in our survey consulted an average of five different doctors before a management plan was established. Analysis of qualitative responses identified 339 mentions of 'waiting' and 134 mentions of 'cost' as primary barriers, indicating that obstacles to care are predominantly systemic and financial, rather than a matter of individual choice or behaviour.

2.3 Geographic Inequity: Access as a Luxury

A recurring theme in the qualitative data is needing to travel interstate, primarily to Sydney or Melbourne, to access competent specialist care. The lack of specialist care available in Canberra creates a 'geographic lottery' in which quality of care is determined by financial capacity.

> "I had surgery in 2019; I had to go to a specialist in Sydney because the specialists in the ACT were reticent to treat my advanced endometriosis and not confident in their ability to do so." (2023)
>
> "My specialist in Melbourne asked me why I kept seeing him after moving to Canberra and being here for 4 years. I asked him if there was anyone he could recommend... he then took back his question now seeing why I still travel to Melbourne." (2023)
>
> "I was misdiagnosed and spent a lot of money and time on treatments for that condition which obviously did not help. I have had to go to Sydney for specialist help, which should not be the case when we live in the capital of Australia." (2025)

For those who cannot afford private consultations or interstate travel, the main alternative is simply to endure, often through prescription pain relief that manages symptoms while the underlying condition progresses. The shock expressed by respondents regarding this inequity reflects a fundamental breach of expectation, indicating a view that in the capital of Australia, health outcomes should not be determined by the ability to afford a flight to Sydney.

A key component of this geographic inequity is the critical shortage of deep infiltrating endometriosis (DIE) scanning capacity in the ACT. Our consultations with stakeholders suggests that there are currently only two DIE scan providers in Canberra, with a six-month waitlist. This forces many patients to travel to Sydney for imaging, an additional financial and practical burden that falls disproportionately on those least able to absorb it. Compounding this, the Medicare rebate available for ongoing multidisciplinary care is wholly inadequate: patients managing a chronic condition are entitled to only five rebated sessions at approximately $60 each under the chronic disease management scheme, against a typical physiotherapy session cost of around $250. This gap between what Medicare provides and what effective treatment requires is a structural affordability barrier that must be addressed.

While the ACT Government has a scheme in place to help eligible patients cover the costs of travelling interstate for medical treatment, the Interstate Patient Travel Assistance Scheme (IPTAS), evidence presented to this inquiry by the Health Care Consumers' Association indicates that in practice the scheme creates significant barriers for people with pelvic pain conditions. The administrative process is onerous, requiring patients to pay costs upfront before being reimbursed, and the documentation requirements can be particularly difficult to navigate for people who are already unwell, have limited English, or face challenges with paperwork. The reimbursement rates for accommodation do not reflect the real cost of staying in Sydney, and the eligibility criteria do not adequately account for situations where local services technically exist but carry wait times of several years. For many patients the scheme is effectively inaccessible at the point when they need it most. We recommend the ACT Government review and reform IPTAS to reduce the administrative burden, move toward upfront payment rather than reimbursement, and broaden eligibility to account for unreasonable local wait times.

2.4 Administrative Friction and the Psychological Toll of Waitlist Management

A specific structural barrier identified in the data is what respondents described as the “waitlist letter”, a periodic administrative process requiring patients to re-confirm their need for care. We acknowledge that waitlist audits serve a legitimate data-cleaning function. However, the administrative friction created by these communications carries a measurable psychological toll on patients who have already endured years of dismissal and have no private alternative. For this cohort, a routine letter is not a neutral check-in; it functions as a reminder of feeling trapped and, in some cases, a prompt to disengage from a system that has already failed them.

We do not recommend abolishing waitlist audits. We recommend that the ACT Health Directorate adopt trauma-aware and healing-informed administrative communication as a standard for all correspondence with patients waiting for gynaecological or pelvic pain services. In practice, this means acknowledging the patient’s ongoing experience of pain in the letter itself; providing a direct contact number for a named person rather than a generic

inquiry line; and including clear information about interim support options. This is a low-cost, high-impact change that would meaningfully reduce the psychological toll of an already difficult wait.

> ”I was on the wait list to be seen publicly for 7 years with increasing persistent pelvic pain. I am so grateful I could afford to pay for treatment out of pocket, and I am shocked about this inequity in access to treatment." (2025)
>
> "I was placed on the waiting list for the gynaecology clinic at North Canberra Hospital 6 months ago as a Category 2. I have already been sent a letter asking if I wish to remain on the waitlist. I cannot afford a private specialist." (2025)

Term of Reference 3: Treatment Options, Evidence-Based Effectiveness and Comparison with Other Jurisdictions

3.1 Current ACT Treatment Landscape

Respondents describe a treatment landscape in the ACT characterised by overreliance on hormonal suppression (particularly the oral contraceptive pill) and repeat surgery, without the benefit of coordinated, ongoing multidisciplinary care. The Endometriosis Clinic at The Canberra Hospital (TCH) was cited positively in several responses but a few respondents with complex cases noted that the clinic had not provided a correct diagnosis for their condition, which was later confirmed by another practitioner. Access to pelvic health physiotherapy, pain psychology and specialist excision surgery within the ACT is limited. A further gap in the ACT treatment landscape is the absence of publicly funded pelvic Botox injections for complex pelvic pain cases. This treatment is routinely provided in the public health systems of other Australian jurisdictions and is well-supported by leading specialists nationally, yet is not currently available publicly in the ACT. For patients with complex, treatment-resistant pelvic pain, this means either going without or funding it privately at significant personal cost. It is important to note, however, that innovative care models do already exist within the ACT public system. A workshop-based pathway currently operating within Canberra Hospital offers a model that brings together screening, education, and input from physiotherapists, psychologists and dietitians in a single extended session. Early data from this program is promising: many participants have been able to manage their condition without requiring surgical follow-up.

In another promising example (discussed further below), specialised primary care works to define goals with patients, alongside a network of clinicians who have a special interest in pelvic pain conditions (the CHN-funded SHFPACT trial). Through their local branch, QENDO

provides community-led, peer-based support, navigation and referral, and education in the ACT.

Many of these models reflect a broader shift in thinking about pelvic pain management: that the goal should be improving function and quality of life rather than pursuing diagnosis or surgery as the only endpoint. This shift is supported by clinical evidence and is consistent with the experience of patients in our survey who described feeling better served by holistic, person-centred care than by repeated specialist appointments that focused narrowly on a single diagnosis.

The ACT is also home to locally developed research tools with national and international reach. The Period Impact and Pain Assessment (PIPPA) screening tool, developed through ACT-based research involving over 2,000 young people (Parker et al., 2022), provides a validated, non-diagnostic instrument for identifying when menstrual symptoms warrant further investigation. It includes a patient communication resource that helps individuals describe their symptoms to GPs in a way that increases the likelihood of being taken seriously. This tool is already being used internationally and represents exactly the kind of locally developed, evidence-based resource that the ACT Government should be expanding investment in, particularly in school and primary care settings.

These existing innovations represent significant assets that are currently not resourced at a scale large enough to serve all those who need support. More generally, care needs to be taken to make sure that self-management is genuinely supported and resourced, rather than operating as a way that people are channelled away from seeking services in a resource-constrained landscape.

Our consultation also revealed an important tension in how group-based care models are experienced by patients. While extended workshop models have demonstrated clinical value, concerns have been raised that requiring patients to attend group sessions as a prerequisite for referral can itself be a barrier, particularly for those managing severe or debilitating pain. The Committee should examine this tension carefully, as the design of any group-based pathway will need to balance therapeutic benefit with genuine accessibility for all patients. It is important that initiatives such as workshops are accessible and designed in a way that is sensitive to the needs of people who may have been managing their own pain for extended periods, and may also be experiencing other challenges and barriers.

3.2 High-Impact Models from Comparable Jurisdictions

Our meta-analysis of evidence-based care models identifies four approaches with strong evidence and direct applicability to the ACT context. These are summarised in the table below.

Model	Core Concept	Evidence	ACT Application
Team-Based (Whole Person) Care	Integrated gynaecologist, pelvic physio & pain educator working together	ED visits halved after one year (BC Women's Centre, Allaire et al., 2018)	Replaces repeat surgeries with sustained, multidisciplinary treatment
Hub & Spoke System	Specialist hospital “hub” linked to trained community GP “spokes”	Faster treatment, fewer complications across European trials (Keckstein et al., 2020)	Could clear Canberra Hospital bottleneck, enabling consistent care across Belconnen, Tuggeranong, etc.
Specialised Primary Care	Extended GP clinic appointments (45–60 min) for complex cases	SHFPACT trial underway in ACT; management plans initiated at first visit (Dept of Health, 2026)	Stops the doctor “merry-go-round”; reaches the 'missing middle' before hospital escalation
PPEP Talk School Program	School-based health literacy; teaching adolescents to recognise signs that period pain needs more help	Knowledge doubled (47.8% to 95.5% awareness) across 13,000+ students (Tomsett et al., 2025)	Reduces diagnostic delay by empowering young people to seek help in their teens

3.3 Recommended ACT Treatment Pathway

We recommend the ACT adopt a linked pathway that draws on all four models above, framed as an integrated pelvic health system rather than a condition-specific intervention. This system should serve women presenting with endometriosis, adenomyosis, PCOS, persistent pelvic pain and other intersecting conditions across their lives, not just those seeking a diagnosis for a single condition. Critically, every stage of the pathway needs to be free or low cost at point of access, publicly anchored, and designed to complement rather than replace public provision:

- **Stage 1** — Educate Early: Implement the PPEP Talk program in ACT secondary schools (Years 9–10) to build health literacy and reduce the cultural normalisation of severe period pain. Fund community-based organisations to deliver ongoing public health information campaigns and peer support programs for people with pelvic pain conditions at all life stages.

- **Stage 2** — Assess in the Community: Expand and make permanent the SHFPACT model of specialised primary care, with 45–60 minute appointments and co-located pelvic health physiotherapy, and a dedicated care navigator role. Fund a second clinic in the south or north of Canberra to serve the growing populations. Support and resource the GP network working in this space so that clinicians are equipped, connected and not working in isolation. In expanding this model, it is essential that trauma-aware and healing-informed care principles are embedded in the design and delivery of all services, recognising that many patients presenting with pelvic pain conditions carry significant medical trauma from previous healthcare encounters.

- **Stage 3** — Build and then Connect via a Hub and Spoke Network: Canberra Hospital is the natural specialist hub for this system, but it is not yet ready to fulfil that role. The ACT Government must first invest in building specialist capacity at Canberra Hospital: additional gynaecologists, a properly resourced multidisciplinary team, and dedicated support for clinicians currently operating in an understaffed environment. Once that foundation is in place, a formal Hub and Spoke model should be established, with clear referral and communication protocols linking community clinics across Belconnen, Tuggeranong, Gungahlin and Woden to the hospital as the specialist hub.

- **Stage 4** — Treat Complex Cases in a Multidisciplinary Way: Expand the capacity of the Canberra Hospital Endometriosis Clinic to operate as a true multidisciplinary centre with gynaecology, pain medicine, physiotherapy and psychology as standard embedded components of care, not optional referrals. This model should be designed to serve the full range of pelvic health conditions, not endometriosis alone, and should be available as a public service free at point of access.

Term of Reference 4: The Role of Medical Misogyny, Gender Bias and Cultural Norms

4.1 The Architecture of Dismissal

The single most consistent theme across 870 qualitative responses is systemic clinical scepticism directed at women describing pain. More than 230 respondents used language explicitly related to being dismissed, ignored or not taken seriously. We term this pattern the 'Architecture of Dismissal': a structural environment in which a woman's testimony about her own body is routinely treated as secondary to provider assumptions.

> "It took me years to be diagnosed because of how my pain was taken unseriously." (2025)
>
> "Had uterus removed 20 years ago and diagnosed with adenomyosis. The previous 30 years was absolute agony full of discrimination and unhappiness to the point of suicidal thoughts. Just take women seriously when they tell you they've got a problem. Don't tell them they have a low pain threshold, or they are being hysterical." (2025)
>
> "I have endometriosis, advanced, stage 4, bowel involvement, "a complete obliteration of the abdominal cavity" are the exact words from one of the surgeons. I still get treated like a drug seeker." (2023)

When clinicians frame severe physical pain as a function of 'personality,' 'low pain threshold,' or 'hysteria,' they perform what we term a 'linguistic shift': clinical attention is moved away from diagnostic necessity and redirected toward a supposed temperamental deficiency in the patient. Research confirms this cycle is a primary driver of diagnostic delay; when women's symptoms are normalised or dismissed, it produces a breakdown in clinical trust and a reluctance to seek further help (Young, Fisher, & Kirkman, 2015).

4.2 Procedural Trauma and Violations of Bodily Autonomy

Beyond verbal dismissal, the qualitative data documents specific instances of procedural trauma, including gynaecological procedures performed without adequate pain management, fertility decisions made unilaterally by clinicians overriding informed patient consent, and one account of a clinical examination becoming physically rougher in response to the patient's expressed dissatisfaction with that provider.

These represent not merely poor bedside manner, but violations of the foundational medical ethics principles of informed consent, doing no harm, and respect for patient autonomy.

4.3 The Stigma of Presence: Weight Bias

A distinct subset of responses describes how body weight functions as a gatekeeping mechanism, with clinicians refusing diagnostic investigation until weight loss is achieved or attributing all reported symptoms to weight. The consequence is a 'stigma of presence' that causes women to withdraw from healthcare entirely.

> "I will suffer rather than seeing a doctor." (2023 — respondent who had previously experienced body shaming)
>
> "I am so embarrassed about my weight that I don't seek help because of judgemental attitudes." (2025)

This systemic withdrawal is not a personal failing. It is a rational, defensive response to a system that has demonstrated it values aesthetic compliance over patient health and wellbeing.

4.4 The PCOS Gap: When Women's Health is Treated as Reproductive Health

Polycystic ovary syndrome (PCOS) is explicitly named in the Terms of Reference and affects up to 27,200 ACT residents based on our survey data. Yet our qualitative responses reveal a pattern that is distinct from, but parallel to, the dismissal experienced by those with endometriosis: women with PCOS are frequently only taken seriously by the health system when they are trying to conceive. Outside of a fertility context, their symptoms, irregular cycles, pain, metabolic impacts, and mental health effects, are often managed minimally or not at all.

This reflects a broader cultural assumption embedded in the healthcare system: that women's health conditions are primarily relevant in the context of reproduction. A woman with PCOS who is not trying to conceive is still living with a chronic condition that affects her quality of life, her mental health, her metabolic health and her capacity to work and participate in daily life. The integrated pelvic health system we are recommending must treat PCOS as a whole-person, whole-of-life condition, not a fertility problem to be addressed only when pregnancy is the goal.

Term of Reference 5: Economic and Social Impacts

5.1 Workforce and Productivity

The national economic burden of endometriosis has been estimated at between $7.4 billion and $9.7 billion per year (Ernst & Young, 2019; Armour et al., 2019), with productivity loss accounting for approximately 84% of total costs per person (Armour et al., 2019). One Australian study estimated the cost of endometriosis at $30,900 for every person with the condition in 2017 (Armour et al., 2019, as cited in AIHW, 2023).

These national figures have direct implications for ACT budget planning. The ACT represents approximately 1.6% of the national female/AFAB population. The total economic cost of endometriosis in Australia has been estimated at approximately $7.4 billion per year, with estimates ranging as high as $9.85 billion depending on prevalence assumptions (Ernst & Young, 2019). Applying the ACT's 1.6% population share to this range yields an estimated ACT share of between $118 million and $157 million per year in lost productivity and healthcare costs. To the extent that true prevalence in the ACT is higher than the national assumptions underlying these figures, as our survey data suggests, the actual economic burden on the ACT is likely to exceed these estimates.

With an estimated 37,000 people living with endometriosis or adenomyosis in the ACT alone, and 34,200 with PPP, the human dimension of this economic burden is reflected clearly in the survey data. Respondents describe being forced out of full-time employment, missing promotions, reducing to part-time work, and in several cases losing their positions entirely due to unmanaged chronic illness.

> "I've had 6 surgeries and am left disabled and can only work part time, which affects my career and finances." (2023)
>
> "I had to be out of work for eight full weeks... I lost one job (almost two before I could finally 'prove' I am 'sick enough'), and countless life opportunities like promotions and babies and vacations." (2023)

5.2 Educational Participation

National research (Tomsett et al., 2025) found that 22.9% of students are regularly missing school due to pelvic pain. The ACT faces a compounding disadvantage: without school-based education programs, young people cannot identify their symptoms as treatable, and without accessible community clinics, even those who do seek help face multi-year delays. The economic consequence begins before the labour market is even entered.

5.3 Mental Health and Social Isolation

Multiple respondents described the cumulative psychological toll of multi-decade diagnostic journeys: suicidal ideation, depression, and social withdrawal resulting from chronic unmanaged pain and the repeated experience of having their suffering disbelieved. This represents a significant downstream cost to the ACT's mental health system that would be substantially reduced by earlier and more effective pelvic health intervention.

5.4 Fertility and Reproductive Loss

For many respondents, the most devastating economic and social impact was the loss of reproductive choice resulting from delayed diagnosis.

> "It took over 20 years for my endometriosis to be diagnosed; I was consistently told the amount I was bleeding and the pain I had was normal. But I had stage 4 endo; it prevented me from getting pregnant and being able to have the family I wanted." (2025)

Term of Reference 6: Education for Medical Professionals, Allied Health and Young People

6.1 Medical and Allied Health Professional Education

The qualitative data strongly indicates that gaps in clinical knowledge and empathy are not limited to GPs but extend across specialist and emergency settings. Multiple respondents described inadequate ED responses post-surgery, misdiagnosis in specialist settings, and a general absence of curiosity about pelvic pain presentations.

We recommend that the ACT Government advocate for and fund:

- Continuing professional development (CPD) Development of skills and knowledge on endometriosis, adenomyosis, PCOS and PPP for GPs, gynaecologists and emergency medicine physicians, from initial medical training through to continuing professional development (CPD).
- Structured case review and mentoring pathways for ACT-based specialists to build local excision surgery expertise, reducing the need for interstate referral.
- Trauma-aware and healing-informed care training as a standard component of women's health education, addressing the relationship between dismissal and diagnostic delay.

6.2 Education for Young People: The School Health Nurse program and PPEP Talk Model

The ACT is already taking steps toward school-based pelvic health education. The School Youth Health Nurse (SYHN) program, delivered by Canberra Health Services across ACT public high schools and colleges, currently includes a health module on endometriosis and pelvic pain conditions. With approximately 7.5 FTE across 18 high schools and 9 colleges, the program provides a trusted, on-the-ground presence that allows young people to follow up individually with a nurse if they have concerns, something a one-off external program cannot offer. Evidence presented to this inquiry by the Health Care Consumers' Association indicates there is already a budget commitment to expand the SYHN program so that all schools and colleges have access. We strongly support this expansion.

However, the program's sustainability is at risk. SYHN nurses are currently paid at 88% of the hospital nursing rate to cover the longer school holiday periods, a model that has not been effective for staff retention as many nurses cannot sustain the reduced pay. We recommend the ACT Government consider reviewing the remuneration model for SYHN nurses to ensure pay equity with hospital nursing rates, and explore options for nurses to undertake other clinical or educational work during school holidays to maintain their accreditation and professional currency.

Alongside the SYHN program, we strongly recommend the ACT Government pilot and fund the implementation of the PPEP Talk school health program across ACT secondary schools. The national evidence base is compelling: a 2025 study of over 13,000 students found the program doubled health literacy from 47.8% to 95.5% awareness of endometriosis (Tomsett et al., 2025). Given that 22.9% of those students were regularly missing school due to pelvic pain, early education represents not only a health intervention but an educational equity intervention. The PPEP Talk program and the SYHN team are complementary rather than competing, the SYHN nurses provide the trusted follow-up presence that makes school-based education actionable rather than just informational.

Term of Reference 7: Research and Clinical Trials in Australia and Opportunities for the ACT

7.1 Current Australian Activity

The Federal Government's current rollout of Endometriosis and Pelvic Pain Clinics — of which the SHFPACT clinic is an ACT example, represents a tangible research and service opportunity. This model is, in effect, a live trial of specialised primary care for pelvic pain. It is critical that this trial is properly resourced, that outcome data is systematically collected, and that the ACT Government advocates for its permanent funding.

Our consultations also identified a structural barrier within Canberra Hospital that investment alone will not resolve. Gynaecology services within the public hospital system are currently

managed under a maternity and obstetrics structure, which means gynaecology is consistently deprioritised when resources are allocated. Midwifery and obstetrics demands dominate management attention, leaving gynaecology, and pelvic pain services in particular, without adequate internal advocacy or strategic visibility. This structural arrangement limits the ability of even well-resourced and motivated clinical staff to develop and sustain specialised services. We recommend that the ACT Government, in its engagement with Canberra Health Services, specifically examine whether the current management structure is fit for purpose for gynaecology and pelvic pain services, and consider whether a dedicated management pathway would better support service development in this area.

A related workforce issue warrants specific attention. There are currently no advanced practice or nurse practitioner roles for nurses specialising in endo/pelvic pain within the ACT public health system. This absence of a formal career pathway makes it extremely difficult to recruit and retain specialist nurses in this area and means that expertise built over many years of clinical practice has no structural recognition or succession planning attached to it. We recommend the ACT Government work with Canberra Health Services to establish a formal advanced practice nursing pathway for endo/pelvic pain, a relatively low-cost reform that would improve workforce sustainability, expand clinical capacity, and reduce pressure on gynaecologists by enabling specialist nurses to take on greater clinical autonomy within their scope of practice.

7.2 Opportunities for the ACT

The ACT is uniquely positioned to lead national research in this area given its concentrated, urban population, the presence of the ANU Medical School, and the ACT's historically progressive health policy environment. We recommend the Committee consider:

- Funding a dedicated ACT pelvic health research unit, (potentially in partnership with ANU), to build on the survey data collected to date.
- Establishing a longitudinal cohort study tracking diagnostic journeys, treatment outcomes and quality of life among ACT residents with pelvic pain conditions.
- Partnering with Endometriosis Australia and the Australian Coalition for Endometriosis to ensure ACT-specific data is incorporated into national research frameworks.

Term Of Reference 8: Any Other Related Issue (Data, Accountability and Care Coordination)

8.1 Care Coordination

Across our consultations with SHFPACT and HCCA, care coordination was identified as the single most consistent gap in the ACT pelvic health system. Patients are currently required to navigate multiple providers, referral pathways and waitlists independently, a burden that is unsustainable for people already managing chronic pain. SHFPACT currently does some of this work, but is operating with limited resources. We recommend the ACT Government formalise and fund a care coordination model building on SHFPACT's existing approach, ensuring that no patient is left to navigate the system alone. This includes a clearly documented referral pathway from community clinic to hospital that is understood by GPs, patients and providers alike.

8.2 Data Collection and Outcome-Based Accountability

There is currently no systematic ACT-level data collection on pelvic health conditions, which might partly explain why our survey figures are higher than official estimates. Without better data, future governments might continue to underestimate the scale of the problem. We recommend a reporting framework for pelvic health presentations across ACT health services, and a public-facing biennial report card so that progress is visible and measurable over time. Critically, we recommend that performance metrics for pelvic health services move beyond waitlist reduction as the primary measure of success. Reliance on waitlist-based metrics creates perverse incentives that can undermine holistic, patient-centred care models. We recommend outcome-based metrics that track what matters to patients: pain levels at 6 and 12 months, return to work and study, emergency department presentations, repeat surgery rates, and patient-reported quality of life. These measures would provide a far more accurate picture of whether the system is delivering meaningful improvement and would protect innovative care models from being defunded on the basis of narrow operational targets that might not capture the benefits being experienced by patients.

Finally, we recommend that people working on health system reform and service development continue to engage with people who have lived experience of pelvic pain conditions, and with peer networks, advocacy organisations, community health educators, health professionals and other stakeholders who hold valuable knowledge that can contribute to better meeting the needs of people with pelvic pain.

Conclusion

The evidence presented in this submission makes it clear that pelvic health conditions are widespread, and that the barriers to diagnosis and treatment are structural, financial and attitudinal. These barriers compound each another in ways that cause decades of preventable harm. The experiences documented in over 870 qualitative responses represent not isolated incidents but a systemic failure that demands a systemic response. We urge the Committee to recognise that pelvic health gaps in the ACT are not merely clinical failures but social and ethical ones.

The good news is that the ACT does not need to start from scratch. The foundations of an integrated pelvic health system already exist here, in the community clinics working with limited resources, in the locally developed research tools gaining international recognition, in the GPs and specialist nurses who show up every day for patients who have not gotten the care they need from the broader system. The challenge is not a lack of innovation or goodwill, but the investment and coordination needed to bring existing efforts together at scale. We have significant innovation and goodwill, but further investment and coordination are needed to translate the small positive steps into a larger scale system that supports people holistically.

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