Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

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ACT Legislative Assembly
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HCCA Submission:
ACT Legislative Assembly Inquiry into Endometriosis and Other Pelvic Pain Conditions

Thank you for the opportunity to contribute to the Inquiry into Endometriosis and Other Pelvic Pain Conditions.

HCCA is a member-based organisation, we draw on the views and experiences of our membership and networks to advocate for consumers. In preparing our response to this Inquiry we have drawn on the knowledge and experiences of our members and wider ACT community, including feedback on access to, and experience of, services sought in relation to pelvic pain conditions. This feedback has been collated and contextualised to address the Inquiry's Terms of Reference in the following submission.

There was significant interest in this Inquiry from consumers, and we are responding to Terms of Reference 1 through 7 in order to adequately reflect the breadth of their experiences and input.

The priority for the consumers who shared their stories with HCCA is **safe, respectful, high-quality care for pelvic pain conditions that is accessible in a timely way and integrates diagnosis, treatment and support across the continuum of care.**

Yours sincerely,

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17 April 2026

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HealthCare Consumers

SUBMISSION

ACT Legislative Assembly Inquiry into Endometriosis and Other Pelvic Pain Conditions

April 2026

Contents

Executive Summary

Women and people in the ACT experiencing endometriosis and other pelvic pain conditions face significant and compounding barriers across the healthcare system. Consumers consistently report long and complex journeys to diagnosis, often spanning years or decades, characterised by a search for the right clinician to help them, dismissal of their symptoms, the need for persistent self-advocacy, and difficulty navigating disconnected services.

Access to multidisciplinary, evidence-based care remains limited, particularly within the public system, with long wait times and insufficient local diagnostic and treatment capacity. These barriers disproportionately affect vulnerable populations, including culturally and linguistically diverse communities, people with low health literacy, and those without financial means.

Once you have access to care, it is a minefield navigating treatment decisions, avoiding low-value, high-risk treatment options and identifying interventions more likely to likely to result in good health outcomes.

The cumulative effect of these factors is not only worsening health outcomes, but also has substantial impacts on education, employment, financial security, and quality of life.

While ACT consumers face many of the same systemic barriers as those in other Australian jurisdictions, including delayed diagnosis, gender bias, and fragmented care pathways, these challenges are exacerbated by the unique structural limitations of the ACT health system, resulting in:

- reduced access to local specialist services
- greater financial burden
- increased reliance on interstate care
- heightened barriers to timely diagnosis and treatment

and warrant a targeted, place-based policy response.

Action to improve the experiences and outcome for ACT residents suffering from chronic pelvic pain should be undertaken as a coordinated, system-wide response that aims to improve early identification, expand access to integrated multidisciplinary care, address gender bias and discrimination, improve early clinical recognition of symptoms, and reduce inequity of access.

HCCA echoes Women's Health Matters' call in their submission to this inquiry for the '*development of an integrated, publicly funded women's health system in the ACT that covers the full continuum of care from early education and community-based assessment through to specialist and multidisciplinary hospital care'*. We see this being achieved through the specific recommendations shared below.

Specific Recommendations

HCCA proposes the following specific actions the ACT Government could take to improve experiences and outcomes for ACT residents experiencing chronic pelvic pain. These recommendations have been developed in response to the issues raised by consumers and explored in our Responses to Specific Terms of Reference (section 3.0). We believe the adoption of these recommendations would support the ACT Government to meet their obligations under the Australian Charter of Health Care Rights[1] – ensuring consumers experiencing pelvic pain can access care that meets their needs, receive safe and high-quality care and are treated as an individual and with dignity and respect.

1. **Early Identification and Diagnosis**
    a. **Establish Standardised Screening Protocols and Clinical Referral Pathways**
    Develop and implement a clear, evidence-based referral pathway for pelvic pain conditions across primary care, emergency departments, and walk-in centres. This pathway should include defined criteria for escalation, imaging, and specialist referral. This should include scaling the Period ImPact and Pain Assessment (PIPPA) tool and embedding it into standard consultations.

    b. **Fund Extended GP Consultations**
    Introduce targeted funding mechanisms to support longer GP consultations for complex pelvic pain presentations, enabling comprehensive history-taking and earlier diagnosis of conditions such as endometriosis.

2. **Multidisciplinary and Coordinated Care**
    a. **Establish an inclusive 'Women's Health' Service with a multidisciplinary model of care**
    Expand existing service models into a fully integrated multidisciplinary service providing coordinated access to gynaecology, pain medicine, physiotherapy, psychology, dietetics, and care navigation.
    b. **Remove Barriers to Specialist Services**
    Reconsider the format of mandatory education sessions to ensure accessibility to information and to specialist care for consumers experiencing significant health impacts. These programs must be delivered flexibly (including online options) and access to specialist services must not be conditional on participation.
    c. **Adopt a Chronic Disease Management Model**
    Recognise endometriosis and chronic pelvic pain as conditions requiring

ongoing management and provide for multidisciplinary care plans accordingly, including subsidised allied health services and condition specific consumer education.

3. **Diagnostic and Treatment Capacity in the ACT**
    a. **Invest in Local Diagnostic Infrastructure**
    Fund advanced imaging technology and specialist radiology training within the ACT to reduce reliance on interstate services.
    b. **Expand the Specialist Workforce**
    Implement targeted workforce strategies to recruit, train and retain clinicians with expertise in pelvic pain conditions, including gynaecologists, pain specialists, and pelvic health physiotherapists.
    c. **Increase Public System Capacity**
    Expand public outpatient and surgical capacity for evidence-based pelvic pain condition assessment and treatment and review triage systems to prioritise patients based on functional impact and quality of life.

4. **Financial Accessibility and Equity**
    a. **Increase Funding for Allied Health Services**
    Enhance funding support for allied health services where there is evidence of benefit for the management or pelvic pain conditions.
    b. **Reform the Interstate Patient Travel Assistance Scheme (IPTAS)**
    Simplify IPTAS processes by introducing upfront payments, and reducing administrative burden. Expand eligibility criteria to account for long wait times within the ACT.

5. **Addressing Gender Bias and Improving Care Culture**
    a. **Strengthen Accountability Mechanisms**
    Embed patient experience and diagnostic delay indicators into health service performance frameworks to monitor and address systemic bias and monitor quality of care.
    b. **Ensure Inclusive and Gender-Affirming Care**
    Develop and implement standards to ensure that all services are inclusive of trans and gender diverse people, including development of appropriate clinical guidelines and clinician training.

6. **Health Literacy and Community Awareness**
    a. **Expand School-Based Education Programs**
    Fully fund and expand the School Youth Health Nurse program to all ACT

schools, ensuring sustainable staffing and equitable remuneration. Strengthen curriculum content to include support to recognise and act on abnormal pelvic pain.

7. **Care Coordination and System Navigation**
    a. **Introduce Care Navigator Roles**
    Fund dedicated care coordinators for individuals with complex pelvic pain conditions to support navigation across services and facilitate continuity of care, particularly for patients accessing care interstate.
    b. **Improve Use of Digital Health Records**
    Introduce safeguards and clinician training to prevent inappropriate labelling and ensure digital records support, rather than hinder, patient care.
    c. **Improve Use of Digital Health Records for education**
    Utilise unrealised capacity in DHR to provide access to information and education that supports consumers to engage in treatment.

8. **Service Environment and Patient-Centred Design**
    a. **Separate Gynaecology and Maternity Services**
    Ensure that hospital infrastructure and service delivery models provide separate environments for complex gynaecology patients, incorporating trauma-informed design principles in support of patient centred care.
    b. **Pain Management Protocols**
    Develop consistent, evidence-based pelvic pain management pathways across emergency and acute care settings.

9. **Economic and Social Participation**
    a. **Support Workplace and Educational Adjustments**
    Encourage policies that support flexible work and study arrangements for individuals affected by pelvic pain conditions. Consider implementing the EndoThrive program in ACT Government workplaces.
    b. **Prioritise Early Intervention**
    Recognise that early diagnosis and treatment reduce long-term health system costs and improve workforce participation, and prioritise funding accordingly.

10. **Research and Data Development**
    a. **Establish ACT-Based Research and Clinical Trials**
    Continue to invest in and drive local research capacity. Provide ongoing funds for embedding of successful pilot interventions long term.
    b. **Improve Data Collection and Monitoring**
    Collect and report ACT-specific data on diagnostic timelines, service access, and health outcomes, disaggregated by population group.

1.0 About HCCA

The **Health Care Consumers' Association (HCCA)** is a health promotion charity and the peak consumer advocacy organisation in the Canberra region.

We speak up for people who use health care.

We work with **community members** to:

- Help people understand how to use health services and get the most out of them.
- Become health care advocates and speak up for themselves, their families and their communities.

We work with **health services** to help them:

- Understand the needs of people who use health care.
- Make services work better for consumers.
- Communicate better with consumers.

This submission was prepared by HCCA staff based on feedback from HCCA individual and organisational members and other ACT health care consumers.

2.0 Response to Specific Terms of Reference:

What consumers told us about their experiences of endometriosis and pelvic pain

2.1 Number of People with Pelvic Pain Conditions

> ***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 impacts almost half of Australian women (47%). A quarter of Australian women report that their pelvic pain negatively impacts their day-to-day lives preventing them from undertaking work, study, and exercise[2]. Approximately half of the women who report negative life impacts from pelvic pain seek medical support. One in three women who report not seeking medical care for their pelvic pain did not do so because they believed nothing could (or would) be done for their pain[3]. It is reasonable to assume that these Australian statistics remain broadly consistent within the ACT.

Women between 20 and 44 years make up 20.7% of the ACT population[4], suggesting that more than 12,000 ACT women may currently be seeking and/or receiving care for pelvic pain and a substantial number more would if they felt they would be heard and their pain appropriately responded to.

Endometriosis specifically impacts up to 1 in 7 women[5] but given the delay between onset of symptoms and diagnosis is so long (on average, between seven and twelve years[6]) it is fair to say we are not yet effective at identifying cases. We do know though that early assessment and intervention can lead to better long-term management, including lessening the impact of symptoms and improving quality of life[7]. So it is vital we get better at identifying women with endometriosis and getting them into multidisciplinary care much earlier.

Something we don't know is how many people from a range of communities are avoiding accessing care or disclosing their symptoms due to cultural reasons, or stigmatisation. The number of people avoiding care is likely higher than thought, particularly amongst people from culturally diverse backgrounds and LGBTQIA+ communities.

One consumer shared the impact of growing up in Uganda on their decisions about seeking care for their pelvic pain:

> *Growing up in Uganda … the general messaging is that periods and period pain shouldn't stop you from going on with normal activities. Any pelvic pain feels like something you manage and tolerate. It also shapes how I interpret my own symptoms, and I still struggle to gauge what level of pain is considered abnormal*.

It is important that any response to this Inquiry addresses the cultural differences and experiences of discrimination that prevent equitable access to accurate diagnosis and appropriate care.

As one consumer reflected:

> *It troubles me deeply that women from First Nations, CALD or disability communities, or those with lower literacy or assertiveness, may not be able to find important information about their gynaecological health or to advocate for themselves as I have had to do.*

The issue of self-advocacy came up again and again with the people sharing their experiences with HCCA. Strong health literacy and self-advocacy skills were required in order to be heard and believed, and to drive investigations and navigate a complex system of disparate and disconnected services to be diagnosed and treated.

This consumer sums up the issue:

> *Women should not have to rely on their own research and self-advocacy to be referred for investigation of a condition that affects at least 1 in 7 of us.*

It is essential that systems, services and clinicians are upskilled to improve the health literacy environment to ensure that every person suffering with pelvic pain receives timely and accurate diagnosis.

2.2 Barriers to Diagnosis in the ACT

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.

Consumers shared with us a wide range of barriers they have encountered in their journey to appropriate diagnosis and access to high quality, evidence-based care. These include the time it takes to get diagnosed, the disbelief and gaslighting in the medical system, diagnostic overshadowing, and not having appropriate technology and services in Canberra requiring travel interstate.

2.2.1 A Long Journey to Diagnosis

As abovementioned there is an average of seven to twelve years between the beginning of symptoms of endometriosis and/or pelvic pain conditions and obtaining a diagnosis. Consumers reflect on the delay in diagnosis telling us:

> *I experienced what I now know to be the symptoms of endometriosis for at least 15 years before I was diagnosed and began to receive treatment.*
>
> …
>
> *Technically, I have never received a diagnosis for endometriosis or any specific condition, as by the time I was able to see a specialist that took me seriously, I was seeking a hysterectomy, and we wanted to avoid unnecessary investigative surgeries.*
>
> …
>
> *As my period pain intensified, it seemed all I could do was take stronger and stronger pain relief…I ultimately spent several years on prescription medication for period pain. Throughout this time, no doctor ever raised the possibility of endometriosis. This seems to reflect the normalisation of even severe period pain among medical professionals.*
>
> …
>
> [it was only when] *I had an IUD inserted, and my GP referred me for an ultrasound to check its positioning and rule out endometriosis. That scan revealed that I have Pelvic Congestion Syndrome, which is the first time I've had a clear explanation for the pelvic pain I've been experiencing.*

The myriad challenges consumers face accessing appropriate support can overlap and compound. For example, the cost of seeing a specialist in the private system, the lack of

appropriately experienced or qualified specialists in the ACT and the lack of capacity and expertise in the public system all compound to prevent or delay care for ACT residents.

> *I was only able to get a clear diagnosis once I had the financial resources and a more holistic approach was taken.*
>
> *…*
>
> *What we need to have is money and coming to find the right doctor or treatment is a tricky one because we don't really get time to explore and get proper guidance.*

Private Health Care Australia's research suggests that ACT consumers pay approximately 146% more in out-of-pocket costs for private specialist care than the national average[8]. The ACT continues to be a significant outlier in costs for private specialist care and in limited access to bulk billing GP appointments[9].

Women's Health Matters' survey found that consumers report consulting with 5 different doctors before commencing an appropriate treatment plan resulting in significant waiting time and out-of-pocket costs (for both primary and specialist care).

The impact of a long lag time between experiencing symptoms and getting effective treatment for endometriosis and pelvic pain can significantly worsen the conditions and have escalating and interlinked side effects on other body systems. For example, long term endometriosis pain can cause structural changes in the brain that reflect changes in mental health over time[10]. Endometriosis can also affect the nerves, muscles, ligaments and other organs of the body as it progresses. Without effective treatment, endometriosis can progress to causing pelvic adhesions that can eventually bind the uterus, ovaries, fallopian tubes and bowel together with fibrous scar tissue. This causes ever increasing debilitating pain and infertility[11]. Consumers said:

> *After such a long wait, pain has changed your body systems.*
>
> *…*
>
> *Compelled to find answers for myself, I eventually discovered that I had almost all the symptoms of endometriosis. This included systemic symptoms such as fatigue and cognitive dysfunction, which profoundly affected my life but which no clinician ever linked to endometriosis.*

2.2.2 Gaslighting and Disbelief

Gaslighting is a relatively new term in healthcare, but it has given language to an all too common experience. It defines the phenomenon of medical professionals dismissing and downplaying consumers symptoms, to make them doubt their own experience, perceptions and reality. This phenomenon was widely mentioned in feedback we received for this inquiry:

> *I still encounter disbelief from GPs and gynaecologists.*
>
> *…*
>
> *Through the Canberra Endometriosis Centre. […] I worked with the nurse to develop a possible plan for diagnosis and treatment going forward, but when I finally got into the doctor (name redacted), he dismissed everything the nurse and I had discussed, offered no further testing or treatment and sent me back to my GP. Again, this shattered my confidence so much, it took **another 7 years** for me to seek specialist care again, once I was finally able to afford a private specialist.*
>
> *…*
>
> *People often forego care due to disbelief, gaslighting and poor-quality care.*

Endometriosis and pelvic pain conditions, and more broadly women's health in general, has been disproportionately affected by the phenomenon of medical gaslighting because of systemic gender bias in healthcare, underrepresentation of women in medical research, and the historical context of women being labled 'hysterical' which led to an ingrained medical bias where women's physical symptoms were attributed to emotional, anxious or depressive causes[12]. One consumer said:

> *I saw around three GPs in the Canberra about my mental health. My symptoms were often framed as stress. I was not asked whether my mood changes were cyclical or linked to my pain. The connection between pelvic pain and mental health was not explored. Those conversations felt separate, even though they were likely connected.*

This unconscious bias is still active in our health system now, with the ABC reporting a strong backlash faced by Canberra Health Services in 2024 when they released a video on their social media platforms where they implied that conditions like 'endometriosis and arthritis' were not emergencies and should not present to ED[13]. To groups like QENDO (Canberra Endometriosis Support Group), this video was yet another demonstration of the dismissal and minimising of the potentially severe nature of endometriosis and pelvic pain conditions.

2.2.3 Finding Appropriate Care Elsewhere

Another strong theme that came through during our feedback sessions for this inquiry was the lack of accessible, supportive and appropriate care located in Canberra. Many consumers felt they had no choice but to seek care interstate where there was access to better trained specialists, better medical technology and shorter waiting times. Consumers told us:

> *I found a more holistic pain and gynaecology specialist in Sydney.*
>
> *…*
>
> *Finding specialist care that was gender affirming was very difficult as so many specialists market themselves only to women and do not accept trans and gender diverse people in their practice. It's not doctor shopping; it is building your team.*
>
> *…*
>
> *You cannot wait on a long public list when it is so debilitating.*
>
> *…*
>
> *Not having the right medical equipment to diagnose, as we have to travel to Sydney for the proper ultrasound which is an additional cost. It is expensive for international students like us.*

One consumer from a multicultural background explained how she had to take time off work and fund her own trip to Sydney to have a scan for deep infiltrating endometriosis because the imaging technology was not available in Canberra. She sought care through a private gynaecology specialist because she had no access to Medicare on her bridging visa. She only received minimal coverage from her overseas visitor health insurance and was not eligible for IPTAS[14]. Getting diagnosed and treated was an extremely expensive out of pocket cost for her when she was on a limited budget. This is an additional barrier for migrant and multicultural people experiencing these conditions.

2.2.4 Travel to Access Care

Needing to access appropriate care for endometriosis and pelvic pain interstate goes hand in hand with the extra barrier of travel. The ACT has a travel reimbursement scheme (IPTAS) for eligible patients, however the administrative system and rules around utilising the IPTAS are prohibitive and consumers often forgo using it because it adds additional stress. For example, we heard from one consumer that to be reimbursed for fuel to travel to Sydney for medical treatment, the consumer had to fill up

the car immediately before leaving Canberra, and then immediately refuel the car upon arriving in Sydney for treatment to show the difference. Therefore, a trip to Sydney would require four trips to the petrol station for a person who is chronically unwell, rather than just providing a kilometre allowance based on the distance like most travel reimbursement schemes used in the public service. This and other intricacies of the IPTAS scheme need to be overhauled to make it more effective for people with endometriosis and pelvic pain conditions to be treated interstate.

> *"The paperwork can be off putting, especially when you're unwell. The forms could be a barrier for people with low literacy, struggle with executive function, or have English as an additional language. Having 3 parts has been confusing for some friends when they first do the forms"*
>
> *Doctors often aren't aware of the scheme, and most don't like filling out forms. You will often have to book a long appointment to get them to do the forms.*
>
> *I find it's not well known about and lots of people in ACT do struggle to pay to get to and from Sydney for treatment*
>
> *The accommodation allowance is a fraction of the actual cost of accommodation in Sydney, especially accessible rooms. You need a private bathroom for many pre-op procedures.*
>
> *People can be unsure if they are eligible- if a procedure is available here but the wait is 2-3 years but significantly shorter in Sydney and their pain is impacting daily life.*
>
> *Having to pay for costs up front then be reimbursed has been a barrier for some friends. Luckily, they will book flights for you as these can be expensive.*

However, one of our interviewees did note the scheme had been effective in booking flights for her to travel to Sydney for treatment because she was unable to sit stationary in a car for that length of time with her chronic pain. The booking of flights was paid for directly through the IPTAS scheme and reduced the upfront cost burden.

> *I've used IPTAS about 5 times in the last 8 years to travel to Sydney for treatment of endometriosis and pain (spinal cord stimulator). I'm not able to sit in a car for long so they have paid for flights for myself and a carer. It's been very helpful for this.*

2.2.5 Biased Assumptions and Diagnostic Overshadowing

An unintentional and negative impact of the implementation of the Digital Health Record for people with endometriosis and pelvic pain conditions has been 'patient profiling' or being labelled as 'frequent flyers' in the emergency departments and walk-in-centres.

Some of the consumers we spoke to told us their history of visits to CHS ED's and WICs seeking support for chronic pain (which are visible on DHR across the different services) was used against them to refuse or reduce treatment for chronic pain. They were labelled as drug seekers or doctor shoppers, and their physical symptoms were dismissed:

> *People go to Queanbeyan to get better care and no DHR.*
>
> *A big issue is being treated as a drug seeker.*

This is not an unfamiliar narrative in the Canberra Health Service with the ABC reporting in 2024 on two separate cases, one where pelvic inflammatory disease was misdiagnosed and the patient was told her pain was "symptomatic of being a woman" and a second case where the patient was repeatedly questioned as to whether her pain was related to mental health. She felt she was being labelled and as a 'drug addict'.[15]

HCCA also spoke to a mother who believed her and her daughter had very different experiences in the treatment of pelvic pain because of their age and appearance. She said:

> *When I presented to emergency with unbearable pelvic/flank regional pain, I was treated dismissively and discharged with instructions to take panadol. I am 40 years old, have had four children and I believe recent unintentional weight loss from some health challenges made me look unwell. I felt like they thought I was a meth addict seeking drugs. My 19-year-old daughter had presented to the same emergency department a week before with unbearable pelvic pain and was admitted and given fentanyl.*

The above examples do not seem to be exceptions to the rule. Similar themes of dismissal, 'diagnosing' people as drug seeking which overshadowed their pain, and biased assumptions based on people's overall presentation were all too common in HCCA's consultations.

2.3 Treatment Options and Support in the ACT

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

While HCCA cannot provide advice on the most appropriate clinical approaches to endometriosis and pelvic pain, we do know that consumers benefit from early diagnosis and coordinated multidisciplinary care, including pain specialist pain management, gynaecology, physiotherapy, dietetics, psychology and general practice and navigational support. Access to medical specialities is constrained in the ACT. To some extent this is true in both the public and private systems. Waiting times for public health appointments are very long, and patients pay a premium to access private care in the ACT.

Consumer experiences of care shared with HCCA suggest that it is siloed, and often not in line with emerging evidence and best practice. These issues are felt across primary, secondary and tertiary care.

Consumers raised their concerns that the triage process was not fit for purpose when they can languish on an outpatient waiting list for years but then be whisked into urgent surgery on the back of a first appointment. They wonder where the support is for women waiting and how we can better manage women's pain while they wait for access to public specialist care.

Canberra Health Services operates the Endometriosis Clinic (also for persistent pelvic pain). This service is accessed via referral and requires consumers to attend a 2 hour education seminar before they can potentially access the 'multidisciplinary' clinical team. Many women do not get beyond this stage, whether due to being triaged by the intake nurse as a low priority or due to the inaccessibility of the seminar, which requires in person attendance for two hours, mid-week, at school pick-up time. This is a trifecta of inaccessibility.

2.3.1 A More Holistic Approach

Finding holistic health providers who are willing to look at pelvic pain conditions in the context of a whole person, their lifestyle, their goals, and other related symptoms/conditions, has offered reprieve for people with endometriosis, adenomyosis, polycystic ovarian syndrome and other pelvic health conditions. Health practitioners who can look beyond the clinical and medical treatment boundaries, to include support in mental health, allied health, alternative therapies and peer/community support has been life-changing for some of the consumers we talked to.

> *After moving to SA, I've been seeing a GP who takes a more holistic approach. I was also able to see a psychiatrist that noted I may have PMDD. When I brought*

that back to my GP, we looked at everything together rather than as isolated issues.

I spent a lot of time before, during and after having three babies trying to lose weight and seeking medical help for my fatigue, brain fog, food cravings, mood swings and the increasing heaviness of my menstrual cycles. 10 weeks post-partum from my third baby I was told by a GP I had high cholesterol and gout and told to have a better diet and eat capsicum for breakfast. I was always made to feel like none of my symptoms were connected, it was just 'being a Mum' and that it was my own fault and I needed to 'fix my diet and lifestyle'. I finally went to see a private gynaecologist ($450) and was able to access a more holistic GP who treated me respectfully and treated my symptoms as interconnected ($424 per hr appt). It turned out I had PCOS and metabolic syndrome. My PCOS was driving a hormone imbalance, insulin resistance, obesity and high cholesterol. I was literally halfway to type 2 diabetes at age 38 because no one had connected the dots before. My first symptoms of PCOS started in my early 20s and I got diagnosed and treated effectively from 38. Now with regular support from my GP, allied health, mental health and education on my condition, I am finally feeling better and not blaming myself.

It was only recently in 2025 that an 'Endometriosis Management Plan' was piloted in eight general practice settings across Australia to encourage GPs to treat endometriosis similarly to chronic disease management where multidisciplinary care is part of the model. The Head of the Monash University Department of General Practice states:

'Traditionally, when we've thought about a chronic disease management plan, we've thought about it for older people with diabetes or heart disease or dementia. We haven't really thought about using one for the management of endometriosis, which often requires allied health input to make the care more holistic and more effective.'[16]

The tides are starting to turn towards treating pelvic pain conditions across multidisciplinary teams, and with holistic practices, but more can be done to encourage this.

2.3.2 Impact of Medical Service Culture and Care Pathways

The most common model of service in primary health care is not well suited to treatment of pelvic pain conditions when GPs focus on high volume, short appointments for single issues. This leads to a focus on isolated symptoms whereby the 'whole picture' is left un-investigated. This has led to endometriosis and other pelvic health conditions being under-recognised and under-diagnosed in the primary health setting, because symptoms can vary widely from person to person and present differently with symptom overlap with IBS, bladder pain, musculoskeletal conditions or neurological disorders,

referred pain and symptoms that extend outside the pelvic area[17]. Diagnosing pelvic pain conditions requires a detailed history and a GP who has the knowledge to recognise patterns in this 'symptom maze'. Something that is not readily achievable in a short 10-minute appointment.

Our interviewees reflected that this is the culture of health care; to get people in and out and solve problems quickly. Some thought that improvement in the management and treatment of pelvic pain conditions was not necessarily about new expensive technology or accessible specialist appointments, but more about shifting the culture of health care towards taking the time, and building the trust, to put the pieces of the puzzle together in investigating complex health conditions. They said:

> *It isn't going to cost that much. A lot of it [the solution] is culture change.*
>
> *…*
>
> *Looking back at my experience in Canberra what stands out is the normalisation of menstrual pain, the lack of a clear referral pathways, and how easy it is for pelvic pain to remain un-investigated if you are still functioning.*

This culture is starting to shift in Australia over the last five years, as clinical practice guidelines are created and updated, and new research is emerging to inform better practices[18], however the policy background does not always translate into on-the-ground culture change, and there still exist pockets of quality care in the ACT that are not uniform across our services. Our consumers told us:

> *The ED has implemented specific pelvic pain pathway. I don't know if this meets needs.*
>
> *…*
>
> *Specific staff are known to be helpful. [a nurse] at NCH is known to be very responsive for ED presentations.*

2.3.3 Services Not Available in the ACT

There is a paucity of specialised allied health and support services for people with pelvic pain conditions in the ACT because historically these networks have not been utilised in a multidisciplinary way to treat pelvic pain conditions, and there was low consumer awareness of their value and availability as treatment options. Additionally, as private allied health providers became available as therapeutic options for people with NDIS plans, the price of appointments increased to $150-250 per appointment, and the specialised focus for many allied health providers trended towards disability support.

For people not on the NDIS, the Medicare rebates were rapidly outpaced, and the out-of-pocket cost for physiotherapy, psychology, dietetics and other supportive therapies became prohibitive. Our consumers told us:

> *You need specifically trained pelvic physios – very few are qualified and are very hard to find in the ACT.*
>
> *…*
>
> *Ideally services would be available here and in a timely manner, however unfortunately that's often not the case.*

In the public health system allied health support can have long outpatient waiting lists and the women's health physiotherapy services are heavily focused on pregnancy and post-pregnancy related conditions[19]. Gynaecology in the hospital system has many overlapping features and spaces with obstetrics and maternity care, and consumers noted that:

> *Having gynae patients on maternity wards is a big issue – for example someone having a hysterectomy when they really wanted to have kids.*

Endometriosis, PCOS and other pelvic health conditions can cause infertility or challenges getting pregnant. To co-locate gynaecology and maternity services and spaces in the public system because they are related to the same body parts does not appropriately consider the importance of trauma informed care provision and the potential for significant consumer distress.

2.4 Gender Bias and Medical Misogyny

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

Medical misogyny, gender bias and discrimination against women in health care is not unknown to the Australian Government. The main finding of the #EndGenderBias survey conducted in 2024's was: Two thirds of women reported they experienced health care related gender bias or discrimination themselves, and almost 80% of caregivers reported that a person they cared for had similar experiences.

Which led to:

- Feelings of abandonment, shame, blame and self-doubt
- Significant financial burden, lost educational and career opportunities
- Delayed diagnosis and treatment led to disease progression, fewer treatment options and worse health outcomes[20].

Medical misogyny, gender bias and the prevailing cultural norms in healthcare delay effective diagnosis and treatment of endometriosis and pelvic health conditions, leading to worsening of symptoms, more debilitating pain, less ability to engage in education, employment, social and community life. This results in progression of these conditions beyond the pelvic area impacting on mental health, physical health, gut and metabolic health, and the creation of co-morbid conditions.

As one consumer shared with HCCA:

> [Being dismissed] *shattered my confidence so much, it took **another 7 years** for me to seek specialist care again, once I was finally able to afford a private specialist.*

The ongoing, negative impact of this legacy (biased) system of beliefs about women's health on people's wellbeing is completely avoidable as long as it is recognised and systemic interventions employed to improve prevailing health service culture – particularly in the public system where consumers do not have the luxury of choice.

2.4.1 Gender Bias and Discrimination

There is a perception among a number of consumers who spoke with us that both provider and consumer gender impacts on quality of care and that female providers may be more likely to offer validating, supportive and ultimately effective care.

> *My care was carried by experienced, passionate, **female** GPs who were willing to go the extra mile to manage my pain and symptoms. They understood my trauma about returning to the specialists at [service] and did their best to manage my pain at minimal cost to me as I could not afford private specialists.*

One consumer we spoke to was particularly passionate about finding the right fit with female primary care providers saying:

> *"I'm very much 'no uterus – no opinion' when it comes to women's health.*

While the misogynistic cultural issues consumers report encountering are by no means exclusive to male providers there was a trend in the stories shared with us. One consumer said:

> *I experienced dismissal of my symptoms starting at 14 by [a male] gynaecologist at TCH, who said that this was "normal" period pain and to "eat more fibre".*

Women's perception of dismissal by male clinicians seems to be a more common experience generally. This may be the result of the 'gender pain gap' and the undertreatment of pain in women.[21] Historically, clinical discourse has characterised women as more emotional or prone to exaggeration, contributing to ongoing systematic underestimation of their reported symptoms. Evidence indicates that these biases persist in contemporary healthcare settings (sometimes in more subtle – even subconscious - forms) influencing diagnostic and treatment decisions[22]. Addressing these ingrained assumptions across the health system is essential to ensuring equitable, evidence-based care and improving health outcomes, and health care experiences, for women.

Of course, not all people experiencing endometriosis and pelvic pain conditions are women. Trans men and non-binary people also experience these conditions and report finding that women's health services are not inclusive or there are perceptions and assumptions about their gender identity that influence the way a clinician will treat them.

With many services specialising in pelvic pain conditions focussing exclusively on women's health this can lead to discriminatory patient selection and to some consumers inevitably falling through the cracks.

> *Finding specialist care that was gender affirming was very difficult as so many specialists market themselves only to women and do not accept trans and gender diverse people in their practice*

It is essential that we consider the impact discrimination incorporated into service design can have on transgender, intersex and non-binary consumers. These consumers can already find that the intersection of their needs increases the complexity of their condition and limits their access to appropriately knowledgeable clinicians.

> *…my long-term GP who specialised in women's health had limited expertise in gender-affirming hormones and how to manage this with the hormonal contraception used for my pelvic pain.*
>
> *… once I legally and socially transitioned to be non-binary treatment became difficult.*

There can also be assumptions made that trans or non-binary people don't want to have children so more invasive treatments are appropriate.

> *I found it much easier to get a hysterectomy once transitioned because there were no longer questions about my fertility. This concerns me as it showed an assumption that trans people do not want to have children.*

The issue of the conflation of gynaecology, fertility and obstetrics within womens' health services can have a range of unintended consequences for consumers.

Perceptions of fertility can impact the treatment of pelvic health conditions. Anecdotally, we hear that clinicians often assume that younger women will automatically want to have children, and therefore offer less invasive, but also less effective treatments in order to 'preserve fertility'. Alternatively, they may be advised that having a baby will 'fix' the problem. We might also reasonably anticipate that there may be unfounded assumptions that older women, or women with children already may not prioritise fertility or hormonal balance impacting the treatments they are offered.

Consumers worry about these issues. As this consumer shared:

> *Will it have any effect on my other parts of the organs, being on pill to stop endometriosis to reform and not having period? Makes me question; will it affect my fertility strength, if I ever plan to have family will it have any impact on my future children?*

Her concerns about preservation of fertility need to be taken seriously. It can be hard for some consumers to push back against clinician assumptions or to question advice which may not be appropriate for their circumstances and goals for their care.

The co-location of these services also often lead to traumatic experiences for consumers whose health outcomes have impacted their fertility. Consumers whose health or treatment options for their debilitating condition will prevent childbearing, but who very much wanted to be a parent, can be faced with receiving treatment and recovering within a maternity service environment and this is understandably distressing

While HCCA supports the development of an integrated 'Women's Health' Service to bring together disparate services and expertise for ease of navigation and enhanced access, the ACT government must ensure that any integrated, multi-disciplinary

services developed in response to this Inquiry are genuinely inclusive of transgender, intersex and non-binary consumers and staffed with appropriate expertise. They must also be trauma aware and ensure that maternity and complex gynaecology services can be provided in an environment sensitive to the distress of patients.

2.4.2 The Importance of Being Believed and Receiving High-Quality, Consumer Centred Care

The experience of eventually being believed, of being understood and having your experience validated by a clinician was momentous for some consumers. Finally offering hope for effective intervention and improved quality of life.

> *It was very emotional for me to finally see a gynaecologist after 30yrs of painful and heavy periods, have her understand and listen to my story. She reviewed all my test results and together we decided on surgery to include an ablation and endometriosis lesion removal, and then ongoing progesterone treatment to balance my hormones.*
>
> *…*
>
> *I sobbed in my gynaecology appointment when she told me it was PCOS and that "none of this was my fault". I didn't realise how much trauma I had been carrying thinking that I was always eating wrong and not exercising enough and not being healthy, which was the narrative I always believed from my healthcare experiences. I sobbed and sobbed.*

Many consumers internalise a sense of blame for their condition, for being unable to cope with their symptoms, for perceived inadequacies in their health behaviours. A proactive and validating response from clinicians first and every time would make a substantial contribution to increased wellbeing for consumers experiencing pelvic pain.

Being believed can change everything:

> *…almost 2yrs on now, the surgery and ongoing progesterone treatment has been life changing. The ablation has created a much-needed pause in my periods, so I no longer bleed. I still have some pelvic pain but it's minimal and I rarely need to take pain killers.*
>
> *…*
>
> *I feel like I have finally been released from 30 years of pain and bleeding, and I can now concentrate on the rest of my life.*

2.5 Economic and Social Impacts

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

Many people experiencing ongoing pelvic pain report significant and compounding impacts on their economic participation and financial security as well as social relationships. This consumer reflected:

> *My more than 15-year wait for diagnosis and treatment not only curtailed my social and economic participation but also prolonged the cumulative damage to my body and thereby increased the overall cost to the health system.*

They make it clear that the impact is not only personal but societal. The long search for accurate diagnosis and evidence based and effective intervention increases the demand placed on our social support systems and public health services.

2.5.1 Medical issues

There are a range of potential medical impacts resulting from undiagnosed and thus poorly treated pelvic pain.

These issues range from infertility:

> *I also had some trouble falling pregnant when planning a family in my 30s, and this could have been due to endometriosis too.*

To significant complications from low iron levels:

> *It was clear that my heavy periods were a likely cause of my ongoing low iron levels. The GP suggested iron supplements and a pelvic ultrasound, the results then precipitated a referral to a gynaecologist (private). I suspect that if I had been referred to the public system in the ACT, I could still be on the waiting list. At this time, my low iron levels seemed to also be causing frequent UTIs, which I had not previously experienced, and a serious eye condition that also seems to have resolved with improved iron levels.*

And comorbid pain:

> *Getting diagnosed and treated for endometriosis brought a major change in terms of pain, headache and everything that used to happen during my period time but it still stresses me out about my future.. I would say women all over the world, especially international students or immigrants should be advocated for this.*

2.5.2 Employment, education and participation

While the consumers who spoke with us shared that they used sick leave as rarely as possible, this was not easy due to severe pain.

> *Once I was working as a young adult, I rarely gave myself permission to use sick leave for period pain, as I could have quickly burned through my leave and not had any left for other times of sickness (or later also for caring for my kids when they needed to be home sick).*

Consumers with chronic conditions report pushing themselves to work to the detriment of their long-term health. This can include times when symptoms are flaring:

> *There feels like an unspoken rule about periods that you just need to get on with life as usual – it shouldn't slow you down or impact on school, work or other activities. For the most part I spent 30 years putting on a brave face, going about everything as usual in the days through my periods, and then collapsing at home at night, curled up in pain with a heat pack to try and rest, and prepare myself for getting through the next day.*

Or when recovering from treatment - including this consumer who felt pressure to risk their recovery from surgery by returning too early to activity:

> *The recovery from the surgery was challenging, and while I had about 10 days off, I should have allowed for at least a month off afterwards.*

Consumers shared that they have been unable to work or study as much as they wanted to and reflected on the impact of this on their ability to pay for care when they public system failed to meet their needs.

> *Unmanaged pelvic pain is one of the main reasons I was never able to work full time, even before the progression of other health conditions. During university and my early career, this meant I lost ~ 20% of my productive time compared to my peers and this is one of the reasons I could not afford specialist care until well into my 20s.*

Endometriosis Australia's EndoThrive workplace program is evidence based and shows that relatively minor accommodations in the workplace could make a significant difference for someone trying to manage their pain and maintain social and economic participation.

Simple accommodations such as facilitating use of heat packs, provision of quiet spaces, flexibility in work hours and the option to work from home (where appropriate) can all make a positive impact[23].

There is an opportunity here for the ACT Government to lead the way by implementing EndoThrive in ACT Government workplaces, making it easier for ACT public servants with endometriosis to work and manage their health and pain appropriately while also encouraging uptake of the program by the Commonwealth and within the private sector.

2.5.3 Costs of care

With local public health care options for specialist treatment so limited and in-accessible (see section 3.3) there is a reliance on expensive private specialist and allied health treatment. The chronic nature of the conditions means these costs are often not one offs and the expense is ongoing in order to manage symptoms long term.

> *[I had] the surgery in a private hospital, and all related costs, left me out-of-pocket around $5,000, despite having private health insurance. I was able to cover this with savings but it was not insignificant. I may need to have a hysterectomy in the future depending on how my symptoms settle as I age.*

The financial impost can be particularly difficult for people who do not have access to Medicare.

> *Financially it did affect me in so many ways. We work hard day and night and try our best to save up for our future and make sure not to fall sick since we don't have Medicare rights and medical expenses for internationals are way higher and a burden. We work and we pay tax but at the same time, everything is more expensive for us.*

2.5.4 Disability support

Despite some consumers experiencing long-term debilitating symptoms, preventing them from working or studying full time – or even at all – they generally reported that they have not been able to access disability support. Those who do have disability support, have gained access via other diagnoses, including through complications of treatment for pelvic pain. One consumer's surgical treatment resulted in significant pain and disability and they relied on the negative outcome of this treatment in their application for support.

> *NDIS has been difficult to navigate, and I relied on my neuro and nerve issues to gain access.*

2.6 Education

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

2.6.1 Self-Advocacy

A recurring theme of all the conversations HCCA has had with people experiencing pelvic pain for this submission was the need for consumers to push past dismissal and advocate for the investigations and treatment they need.

Finding the right clinicians, asking the right questions, and pushing back on assumptions and judgements made by clinicians is not easy and requires strong health literacy. Health literacy is about people having the knowledge, skills and confidence to:

- find, understand, and use health information
- be active partners in their care, and
- navigate health and social support systems.

and is the product of both individual and environmental factors. It is influenced by how well health services and staff communicate and support consumers (of all backgrounds and abilities) to navigate our complex health and community support systems. Health literacy levels can also be influenced by upskilling young people through education initiatives.

A 2024 study found that women with endometriosis had a 4.2-fold higher ovarian cancer risk. It also found that those with endometrioma had an 8.8-fold higher risk[24]. and said women with endometriosis "may benefit from ovarian cancer screening or more aggressive prevention strategies." Yet women are not often proactively offered screening and would be unaware of their heightened risk without conducting their own research.

2.6.2 Making do

A common theme in the discussions HCCA has had with consumers in preparing this submission was the self-management techniques they use and have used to get by day to day. These were used across all phases, from teenagers unsure if their experiences are ‘normal’ to adults who have a diagnosis but don’t have a treatment plan they feel comfortable with.

> *… it is something I have to consider and plan around. Though my diagnosis has helped me understand how to manage my symptoms.*

> *My GP also told me that surgery may be an option to help with pain, but I'm still very hesitant about the long-term implications. For the time being, I just use over the counter pain medication, which does not feel like a sustainable long-term solution.*
>
> *…*
>
> *From the start of my period at age 15, I can remember having a fair amount of pain in the lead up to and during my period every month. I would need to take pain killers consistently over about a week each time. I also know now (but did not have any comparison at the time) that my periods were very heavy – it took a lot of planning every period to make sure that I had enough supplies for being away from home during the day for school/work, back up clothes for if I leaked (which was common) and pockets in my clothes for carrying sanitary items discretely going to the bathroom every few hours.*

2.6.3 Educating Young People

The Australian curriculum includes education on menstrual health from as early as year 5 and 6 now starting with "examining the range of products and resources available to manage the physical changes associated with puberty, including products for managing menstruation" and then broadening out from year 7-10 to focus more on physical and emotional changes, relationships and sexuality, mental health and wellbeing. However, there is no explicit descriptor in the Australian curriculum about pelvic pain and what is considered 'normal' period pain and when it requires more investigation.

Consumers told us that they would have liked to have more information much earlier in their journey with pelvic pain, particularly more support in their teenage years including this consumer:

> *It would have helped to have more information as a teenager, to know what is normal and what is not.*

Given the delay in diagnosis, it is optimal for consumers to start asking for help as soon as possible.

In the ACT, young people can benefit from the "Period ImPact and Pain Assessment" screening tool (PIPPA)[25] which is locally developed and now deployed internationally. The ACT Education Directorate worked with Melissa Parker, a Registered Nurse working with CHS (whose local research led to the development of PIPPA tool) to develop a health module that is delivered by the CHS School Youth Health Nurse

(SYHN) team across Canberra public high schools. The SYHN team has a presence in many, but not all, ACT high schools and colleges. The staff rotate around different schools during the week on a part time basis. The program currently has approximately 7.5FTE, which equates to approximately 10 part time staff across the 18 high schools and 9 colleges. There is a current budget commitment to increase the SYHN program in the ACT so that all schools and colleges have access to the program and a more young people can access education on endometriosis and pelvic pain conditions. A consumer told us:

> *I note that my teenage daughter's class was provided with an education session about endometriosis at school in the early part of high school as part of raising awareness about the condition and what is considered 'normal' in terms of periods. Given the prevalence of endometriosis in Australia, this is an important part of health education and can help support women to learn to advocate for themselves in seeking health care.*

Having the SYHN team delivering this health module in schools and being available to support Health and Physical Education teachers to deliver the module is an effective way to deliver this content. The SYHN team is a trusted presence in schools, and young people can follow up with the SYHN staff individually if they have concerns about endometriosis and pelvic pain conditions, as a first step to accessing treatment. HCCA prefer this model over having outside organisations deliver the content, as there is no follow-on support, and if the one session at school is missed, there is no other opportunity to follow up.

HCCA support the expansion of the SYHN program to cover all ACT high schools and colleges, and we also recognise the need for CHS equivalent nursing pay rates to operate equitably in this program. At present nurses in the SYHN program get paid 88% of the rate they would be paid if working in the hospital to buy enough leave to cover the school holiday periods, which are longer than the standard annual leave periods for nurses. However, this model has not been effective for staff retention as the nurses cannot often afford to take the lower level of pay and have more time off. They also may not necessarily want 12 weeks of annual leave, and working in schools can impact on their currency and accreditation. HCCA support paying a full wage to the SYHN nurses and allowing them to work during the school holidays on other tasks to suit their workloads and maintain their accreditation.

2.6.4 Clinician Education

Consumers report encountering clinicians who do not have the appropriate skills and expertise to diagnose and support their treatment, including helping with pain relief. In some cases this is due to a lack of clarity about care pathways, and standardised protocols for investigations and interventions.

Consumers shared a range of experiences where they felt their clinician did not have the information necessary to provide appropriate care and advice including:

> *…because my long-term GP who specialised in women's health had limited expertise in gender-affirming hormones and how to manage this with the hormonal contraception used for my pelvic pain. I had to switch GPs in the end.*

We heard the concerns from patients who had experienced dismissal of their symptoms and who felt some clinicians had not adequately investigated their symptoms. While this is an issue for having endometriosis adequately addressed, it is also possible that the symptoms are arising from other conditions which should be addressed with more urgency such as ovarian cancer.

> *… endometriosis is a recognised risk factor for ovarian cancer. This is doubly alarming when these conditions share many symptoms, so problems arising from ovarian cancer might be misattributed to existing endometriosis.*

Consumers wondered what training GPs receive around pelvic pain and how this might be improved to ensure that patients receive safe and high-quality care.

> *Is there a way to target GP registrars for training?*

2.7 Research

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

A number of consumers shared their thoughts on research and medical trials. They expressed a belief that more research and innovation needs to happen locally.

They want to see trials that are accessible from or are even run out of the ACT. Some shared the challenge of participating in interstate medical trials. It is onerous for patients to travel to Sydney and Melbourne to be involved in trials without adequate support.

> *How can Canberran's participate in trials being run out of Sydney and Melbourne?*
>
> *You need to be there so often you really need to stay there.*

We would like to see the ACT's role in innovation and research strengthened. There should be opportunities to capitalise on good work already occurring here (such as PIPPA – see section 3.6.3) and being recognised on the global stage.

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