Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

Submission number: 037

Submitter: Sexual Health and Family Planning ACT

Date authorised for publication: 28 April 2026

SHFPACT

SEXUAL HEALTH & FAMILY PLANNING ACT

Committee Secretary, Standing Committee on Social Policy
ACT Legislative Assembly
LACommitteeSP@parliament.act.gov.au

15 April 2026

To Whom It May Concern,

RE: Sexual Health and Family Planning ACT (SHFPACT) submission to ACT Legislative Assembly Standing Committee on Social Policy in response to inquiry into endometriosis and other pelvic pain conditions

Thank you for the opportunity to make a submission into the inquiry. Our clinical staff would welcome the opportunity to appear in person and speak to the committee.

Sexual Health and Family Planning ACT Inc (SHFPACT) is a non-profit community-based organisation in the ACT, providing an integrated suite of sexual and reproductive health services in the Canberra community across the health, education, and community services. SHFPACT is the ACT member of Sexual and Reproductive Health Australia (SRHA) and through SRHA affiliated to the International Planned Parenthood Federation (IPPF).

With support of funding through Capital Health Network (CHN), the ACT's primary health network, SHFPACT is the ACT's provider of the community-based Endometriosis and Pelvic Pain Clinic (EPCC). Our dedicated EPCC opened in 2023 with the aim of providing a best-practice clinical service offering balanced information and tailored evidence-based care to women and gender-diverse people living in the ACT who are experiencing pelvic pain conditions. These conditions may include, but are not limited to, painful periods, endometriosis, pain with sex, vulvovaginal pain, and persistent pelvic pain. Care provided is patient-centred, trauma-informed, and in accordance with current national guidelines.

The clinic is currently staffed by sessional General Practitioners (GPs) and nurses with a special interest in women's health, each of whom have undertaken extensive training in pelvic pain management. The EPCC's clinicians, with the client's consent, collaborate with the client's regular GP to ensure wrap around service provision and continuity of care. We welcome referrals from local GPs or any other healthcare provider; however, community members may self-refer into the service. We aim to educate and advise the treating GP regarding the client's ongoing care from within the primary care setting.

The EPCC is further committed to improving pelvic pain outcomes, by fostering interprofessional collaboration and referral pathways for pelvic pain management and advancing practice through professional development.

This submission specifically addresses the **Terms of Reference 1,2,3,5,6.** We have drawn on feedback from our clients, feedback from medical practitioners, current clinical guidelines, and our clinical experience in evidenced-based care to inform our response.

Please do not hesitate to contact us should you require any further information.

Yours sincerely,

Endometriosis and Pelvic Pain Clinic
Sexual Health and Family Planning ACT (SHFPACT)

RESPONSE TO TERMS OF REFERENCE

TOR 1: NUMBER OF WOMEN IN THE ACT WHO EXPERIENCE PELVIC PAIN CONDITIONS

Chronic pelvic pain is a highly prevalent condition yet significantly underrecognized, undermanaged, and underfunded. There are a number of conditions that cause pelvic pain including, but not limited to:

- Endometriosis
- Adenomyosis
- Vaginismus
- Persistent pelvic pain
- Pelvic congestion syndrome
- Bladder pain syndrome
- Severe dysmenorrhea

Based on the most recent available national data from the 2023 National Women's Health Survey, almost half of all adult Australian women[1] suffer from pelvic pain. Furthermore, the survey revealed that:

- approximately one in four (25%) Australian women report that pelvic pain impacted their ability to participate in daily activities such as work, study and exercise, with significant impacts on mental health and relationships.
- 25% reported having to stop physical activity due to pelvic pain
- 15% reported pelvic pain impacted their relationship with their partners
- 10% reported it impacted their relationships with family and friends

Given that an estimated 25% of Australian women experience negative impacts of pelvic pain, this suggests up to approximately 50,000 women aged 15 and over in the ACT have been or are affected by chronic pelvic pain. To understand the scale of chronic pelvic pain conditions among women in the ACT, it can be helpful to compare it with a more widely recognised condition such as type 2 diabetes. Current data indicates that approximately 20,000 people of all sexes in the ACT live with type 2 diabetes.

Please note: as outlined in the 2023 International Evidence-based Guideline for the Assessment and Management of Polycystic Ovary Syndrome (PCOS) Guidelines, pelvic pain is not a diagnostic feature of PCOS. PCOS is instead a hormonal disorder which is characterised by endocrine, reproductive, cardiometabolic, dermatologic and psychological features.

TOR 2: BARRIERS IN THE ACT TO DIAGNOSIS AND ACCESS TO TREATMENT

Within the healthcare system and as a significant component of public discourse, endometriosis has become synonymous with pelvic pain. As such, the medical system has long focused its attention on treating endometriosis, with diagnosis and surgery dominating the model of care.

However, we know that whilst 1 in 4 Australian women experience significant chronic pelvic pain, only approximately 35-50% of those women have an underlying diagnosis of Endometriosis. The ongoing focus on the diagnosis and surgical management of endometriosis, without adequate recognition of the critical first-line role of medical management, continues to fail a large proportion of Australian women living with chronic pelvic

---

[1] In this document, the term "women" is used in recognition of all people who identify as women. We acknowledge that gender is diverse, and some people who are not women, including transgender men, non-binary people, and gender-diverse individuals may also share experiences related to the topics discussed. Our intent is to be inclusive and respectful of all genders.

pain, leaving many on extended waitlists without access to timely community-based symptom management. This is not to say that we are diminishing the necessity of, or not advocating for, a highly functioning robust public service where diagnosis is possible. Rather, we center the ongoing needs of women with chronic pelvic pain regardless of an endometriosis diagnosis.

Within the current model that chooses to prioritise diagnosis of endometriosis over treatment of chronic pelvic pain, patients can often be waiting for a diagnosis for up to eight years, with significant impacts to their access to first line medical management options during this time. Anecdotally, patients have reported to us that upon being referred to the waiting list for specialist care / diagnosis, they were not supported in the interim with their symptom management and felt left to fend for themselves during the wait.

We also know that for our patients, the impact of chronic pelvic pain does not differ between those with and those without endometriosis. This is supported by Australian data published in 2020. The survey compared women with chronic pelvic pain who had a confirmed endometriosis diagnosis to those with chronic pelvic pain but no identified pathology. It was found that both groups reported moderate to severe dysmenorrhea (painful periods), non-cyclical pelvic pain, and dyspareunia (pain during or after sexual intercourse), with no meaningful difference in the intensity or frequency of symptoms. In other words, women without a diagnosis of endometriosis experienced pain just as severe and debilitating as those with the condition.

An internal audit of SHFPACT's specialised Endometriosis and Pelvic Pain Clinic (EPCC) data showed consistent findings, with no statistically significant difference on the impact of self-reported pelvic pain symptoms between those patients with a diagnosis of endometriosis and those without.

The social, educational, and work impacts demonstrated the same findings and will be discussed under *Terms of Reference 5*.

RECOMMENDATION:
Terminology within policy and public communication should be revised to avoid using the term endometriosis as a substitute for chronic pelvic pain, acknowledging that the majority of women experiencing chronic pelvic pain do not have endometriosis and that accurate inclusive language is essential for trauma-informed patient-centered care.

RECOMMENDATION:
Local health system planning must shift away from a diagnosis intervention model to a patient-centred model of care that prioritises early intervention and management of all chronic pelvic pain experienced by women, regardless of whether endometriosis is diagnosed.

RECOMMENDATION:
Early, equitable access to first-line community-based management must be prioritised for all women with chronic pelvic pain without first requiring confirmation of endometriosis.

TOR 3: TREATMENT OPTIONS AND SUPPORT AVAILABLE

Treatment Options

Standards of care for chronic pelvic pain that focus on diagnosis of endometriosis as the initial priority are rightfully becoming outdated and no longer viewed as best practice. More modern models of care recognise the burden of chronic pelvic pain in its own right and advise prioritising early initiation of medical management within the primary healthcare system. Progression to further investigation and possible surgical management should be sought only if medical management fails to manage symptoms or there are concerns surrounding fertility issues. Again, this is not to suggest that we undervalue the importance of a strong, well-resourced public health system capable of providing timely and accurate diagnosis. Instead, our focus is on meeting the ongoing needs of women living with chronic pelvic pain, regardless of whether they receive an endometriosis diagnosis. Importantly, this contemporary model of care also helps reduce the volume of unnecessary surgical interventions that have become increasingly common within the current system. As discussed further below, where diagnosis is important, there are now specialised ultrasounds that should be available to the community. These advances are less invasive and do not carry the same risk of further pelvic pain from adhesions caused by surgery. We do emphasise, these advances still must be undertaken in partnership with ongoing management of pelvic pain within a community setting.

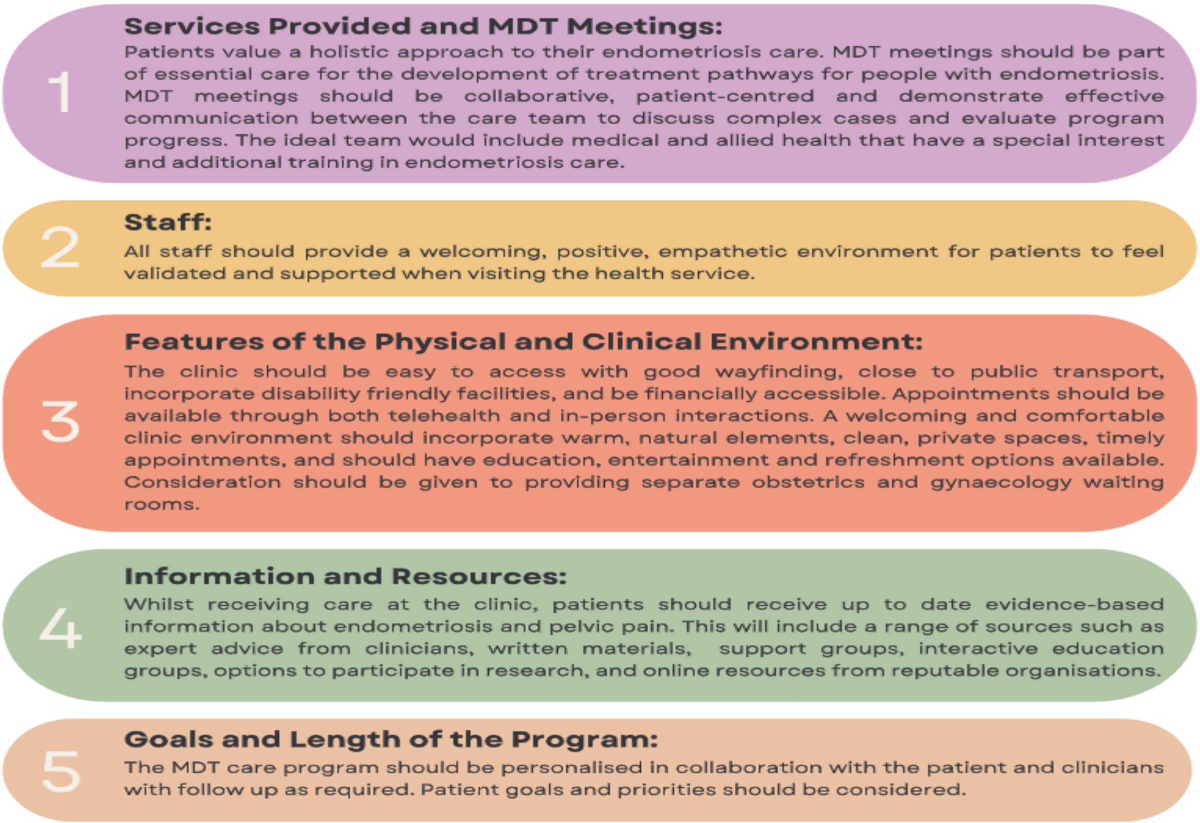
In 2025 the Australian and New Zealand College of Anesthetists Faculty of Pain Medicine released the *Statement on pelvic pain and endometriosis* advocating for a "more comprehensive whole-person approach to PPP [persistent pelvic pain] informed by established evidence".
The statement goes on to confirm:

> "Harm and limitations of the current paradigm of diagnosis and management include:
>
> - delay in provision of symptom directed care at the time most likely to have a transformative impact on health, functioning and wellbeing,
> - exposure to low-value procedures which are often repeated (medical procedures which yield little benefit in relation to the risks/costs involved),
> - inequitable funding, remuneration and perceived value of surgical and percutaneous interventions compared to multimodal whole-person care, leading to wastage of healthcare spending
> - misattribution of PPP to endometriosis without consideration and management of other contributors,
> - invalidation of the lived experiences of those with PPP (those with and without endometriosis)"

This is further supported by an emerging body of research that demonstrates that given the wide range of symptoms and associated conditions experienced by patients with chronic pelvic pain, effective patient-centered care requires a coordinated approach and management from multiple healthcare professionals including allied health. As noted in other sections of this submission, the importance of community-based multidisciplinary team (MDT) models have long been recognised as essential in both chronic disease and pain management.

Such a model for chronic pelvic pain would also result in better access to additional investigations as required. Current Australian guidelines recommend a specialised transvaginal ultrasound, also known as a Deep Infiltrating Endometriosis (DIE) ultrasound, as first line for diagnosis of endometriosis and should always be performed prior to surgery. Currently in the ACT there is no public service for this type of ultrasound scan. Women who are able to pay privately are still met with barriers, with some clinics offering this service reportedly experiencing wait times of up to 3 months. Many women travel to Sydney to access a private DIE ultrasound shouldering the weight of time and cost. Whilst investigation for endometriosis should never delay nor replace access to first line medical management, non-invasive imaging can provide useful information for patients and clinicians around planning a patient's healthcare journey.

Published in February 2026 in the Australian and New Zealand Journal of Obstetrics and Gynaecology, *Perspectives and Priorities for Endometriosis Multidisciplinary Team Care in Australia: A Qualitive Mixed-Methods Study Involving Patients, Caregivers and Health Professionals*, identified the following as priorities by both patients and health professionals:



1 **Services Provided and MDT Meetings:** Patients value a holistic approach to their endometriosis care. MDT meetings should be part of essential care for the development of treatment pathways for people with endometriosis. MDT meetings should be collaborative, patient-centred and demonstrate effective communication between the care team to discuss complex cases and evaluate program progress. The ideal team would include medical and allied health that have a special interest and additional training in endometriosis care.

2 **Staff:** All staff should provide a welcoming, positive, empathetic environment for patients to feel validated and supported when visiting the health service.

3 **Features of the Physical and Clinical Environment:** The clinic should be easy to access with good wayfinding, close to public transport, incorporate disability friendly facilities, and be financially accessible. Appointments should be available through both telehealth and in-person interactions. A welcoming and comfortable clinic environment should incorporate warm, natural elements, clean, private spaces, timely appointments, and should have education, entertainment and refreshment options available. Consideration should be given to providing separate obstetrics and gynaecology waiting rooms.

4 **Information and Resources:** Whilst receiving care at the clinic, patients should receive up to date evidence-based information about endometriosis and pelvic pain. This will include a range of sources such as expert advice from clinicians, written materials, support groups, interactive education groups, options to participate in research, and online resources from reputable organisations.

5 **Goals and Length of the Program:** The MDT care program should be personalised in collaboration with the patient and clinicians with follow up as required. Patient goals and priorities should be considered.

Support Available

SHFPACT is the funded provider of ACT's EPCC, and we have embedded a patient-centered service for the Canberra community. However, funding is financially limited (only $180,000 per annum), time limited, and has not been indexed since its inception in 2023 despite significant rising costs. As a clinic we are well supported by our funder, Capital Health Network, who in turn is funded through the Australian Government Department of Health, Disability and Ageing. Despite the limited funding, we have built a model that supports our patients in their healthcare goals, offers incredible value for money to our funder, offers educational opportunities to clinical and allied health practitioners, and attempts to keep out of pocket costs for the community to a minimum.

SHFPACT's EPCC's model of care reflects current and emerging best practice by prioritising early intervention, person-centered management, and trauma-informed approaches that ensure each patient feels safe, heard, and respected throughout their care journey. We focus on supporting patients to understand their condition, explore evidence-based management options, and make informed decisions aligned with their goals of care. This approach empowers patients and supports long-term, sustainable improvements in health and wellbeing.

We provide extended appointment times to ensure clinicians can fully understand each patient's personal story, unique goals, and care needs. This deliberate design recognises that pelvic pain is best managed through a holistic, collaborative model, and that high-quality care requires sufficient time to build trust, validate experiences, and plan treatment in partnership with the patient.

A patient's first appointment at the EPCC is a long appointment with a specialised pelvic pain nurse, is fully funded (free to the patient), and centers around taking a detailed history and assessing how the patient's current symptoms affect their quality of life. A patient may then book an appointment with one of the EPCC's specialised GPs. Unfortunately, the amount of funding SHFPACT receives means there is an out-of-pocket cost to the patient for the doctor's appointment. SHFPACT minimises this where possible by employing the organisation's concession guidelines. Any future nursing appointments remain fully funded for the patient. Within the GP appointment, the patient is introduced to the biopsychosocial model of pain, where the various biological, psychological and social factors which influence the experience of pain and associated symptoms are discussed to identify where various interventions may improve the patient's wellbeing.

Most commonly during the GP appointment, patients are referred to:

- Pelvic health physiotherapists (patients report increasingly extended wait times to be seen in the public system)
- Psychology, gynaecology, dietetics, and exercise physiology representing smaller but still important components of the referral pathway

Alongside formal referrals, patients are encouraged to engage in pain-science education and bowel-focused self-management strategies, including gut-directed hypnotherapy resources. Together, these approaches highlight the breadth of multidisciplinary team (MDT) input and the central role of education-based interventions in patient care. The clinic's relatively low referrals to gynaecology (5%) and for diagnostic ultrasound (8%) supports the notion that patients' goals are more oriented toward symptom management and functional improvement, rather than pursuing diagnostic investigation.

From July 2023 to December 2025, a total of 338 unique patients were seen in SHFPACT's EPCC across 781 consultations. These consultations comprised 364 fully funded (free to the patient) nurse appointments and 417 doctor appointments. Across this period, patients demonstrated a consistent improvement in self--reported symptom severity, as measured using the Pelvic Pain Impact Questionnaire (PPIQ). Since the commencement of PPIQ data collection in February 2024, average improvements of 3.52 points were observed at 3 months, 4.41 points at 6 months, and 5.7 points at 12 months. As symptom severity can vary between individuals, the proportion of patients showing either improvement or no change in PPIQ was also assessed, with around three-quarters of patients experiencing improvement or no deterioration at each timepoint. Notably, strong patient recommendation ratings among clients whose PPIQ scores did not improve highlight the clinic's perceived value and the positive care experiences it provides. Taken together, these findings indicate that, despite individual variability in symptom severity and the often fluctuating and progressive nature of chronic pelvic pain, SHFPACT's model of care is associated with sustained reductions in pelvic pain impact for the majority of patients, supporting its effectiveness as a long-term management approach.

RECOMMENDATION:
A publicly funded option for specialist endometriosis ultrasounds to give patients and their clinicians additional knowledge to guide the patient journey.

RECOMMENDATION:
The local health system shifts away from an emphasis on diagnosing endometriosis and instead build an inclusive community-based service system that encompasses a holistic approach which supports both the patient, and the management of factors related to chronic pelvic pain. The overarching aim should be multidisciplinary care for individuals with pelvic pain to deliver coordinated, long-term, and holistic support

that is tailored to the patient, ensuring systematic management of the wide range of symptoms associated with the condition.

RECOMMENDATION:
The local health system must work to improve non-surgical referral pathways by embedding healthcare navigation support in community services. Formalised patient navigation services for women with pelvic pain regardless of diagnosis improves equitable access to non-surgical management and treatment options. Embedded navigation further supports continuity of care, early intervention, and the integration of medical, social, and community supports.

RECOMMENDATION:
Increase funding support for publicly funded, community-based allied health services with an emphasis on pelvic physiotherapy as a cost-effective investment that benefits both patients and the local health system.

TOR 5: THE ECONOMIC AND SOCIAL IMPACTS

Data collected from the pelvic pain impact questionnaires distributed to patients of the EPPC found that pelvic pain significantly affected participants' ability to perform and function normally in their home, work, school, or university environments. Out of the ten domains assessed, this area was rated as the third most impactful at intake. Although its relative impact decreased slightly over time, ranking fourth at both the 3-month and 6-month follow-ups and fifth by 12-months, it remained one of the more consistently affected domains reported.

This is further supported by internal auditing which found that 53% of patients presenting for intake to the SHFPACT's EPCC during the period of July – December 2025 missed at least 1 day of work and/or study each month, with an average of 1.4 days missed; however, the rates of loss of productivity with presenteeism is estimated to be much higher. Of the patients audited, 9% were unable to work at all because of their pain, and only 7% had access to work-from-home arrangements that enabled them to continue working while managing their symptoms.

These local findings are consistent with wider research that shows in young women, 35% report missing school and 36% missing university due to dysmenorrhoea, with more than half reporting it impacted the quality of their work. They also indicate frequently missing sporting, exercise, and social commitments due to pain with menstruation, impacting both physiological and psychological wellbeing. In working women, studies find that women with pelvic pain and endometriosis have between 3 and 4 days off per month, and are often required to take unpaid leave having depleted their sick leave, whilst struggling with workplace inflexibility. However, working from home allowances have been found to improve self-reported capacity to manage symptoms.

At a broader systems level, research shows that chronic pelvic pain imposes a substantial economic burden on the healthcare system, particularly through repeated emergency department (ED) presentations. The University of Queensland's *Impact of Persistent Pelvic Pain Clinic: Emergency attendances following multidisciplinary management of persistent pelvic pain* research shows that, prior to accessing specialised care, many patients with chronic pelvic pain had a long history of recurrent ED attendance with short-term symptom management. The report further highlights that fragmented care pathways and delayed access to multidisciplinary team care contributed to this pattern of repeated ED use, creating a cycle of acute care dependence that is both clinically ineffective and economically inefficient. This represents a clear opportunity for the ACT to improve patient outcomes, reduce avoidable ED presentations, and strengthen system-wide efficiency through earlier connection to appropriate care.

RECOMMENDATION:

The ACT public hospitals’ emergency departments are well placed to lead an internal quality improvement project auditing presentations of pelvic pain to local emergency departments. Such an audit would then inform the planning and inclusion into ED discharge summaries of clear referral pathways into community-based supports, such as SHFPACT’s EPCC.

TOR 6: EDUCATION AVAILABLE TO MEDICAL PROFESSIONALS

A medical condition with such a high prevalence in our community with significant impacts, needs a community-based primary care model of care. This is recognised in other common chronic conditions such as diabetes and osteoarthritis where the majority of care is performed in general practice. Chronic conditions such as these require multidisciplinary team care, with a significant burden of care coordination. GPs already have the relevant skills for chronic disease management including skills in individualisation of care, multidisciplinary team care coordination, medication management, and lifestyle management. However, in a recent Australian study only 22% of GP respondents said they felt comfortable managing Chronic Pelvic Pain.

Historically, rather than equipping GPs to manage pelvic pain, education in this area has often effectively discouraged GPs from directly managing these patients. Instead, in the past GPs have been advised to refer patients to already overburdened public specialist clinics. This has left many patients with escalating symptoms feeling as though they have no alternative but to wait when there are management options that could and should have been initiated in the community. Additionally, the clinical resources that are available are almost entirely directed at management of endometriosis, which as discussed above fails to assist at least half of the women affected by chronic pelvic pain.

Changes to our current system in the ACT, including changes to funding and support structures, required to improve the current standard of pelvic pain care by employing learnings from other chronic conditions. To consider how this might be accomplished it is again useful to look at the type 2 diabetes model of care. Type 2 diabetes education is:

- prioritised within medical school
- prioritised within GP training
- supported with regular education provided to GPs about ongoing updates in management
- educational resources and guidelines provided to GPs about how to manage this chronic condition and utilise Medicare items such as Chronic Disease Management plans

An integral component of SHFPACT’s EPCC is providing support to primary care clinicians including allied health through Capital Health Network delivered education, the establishment of the ACT Pelvic Pain Network to support both clinical and allied health practitioners, and by providing a bridge between specialist and primary care. As the secretariat and host of the ACT Pelvic Pain Network, SHFPACT manages a volunteer network of health professionals from a variety of clinical areas who come together with the purpose of improving interprofessional referrals, advocacy, and education for chronic pelvic pain.

The ACT Pelvic Pain Network is committed to improving pelvic pain outcomes by fostering interprofessional collaboration and referral pathways for pelvic pain management and advancing practice through professional development. The network meets every quarter to provide education and case study discussions. Each meeting attracts from 20 – 30 clinicians from around Canberra across disciplines. Interest in contributing to the network has been steadily increasing with long term commitment high.

The network provides members with an up-to-date directory of clinicians in the ACT who have an interest in pelvic pain to help simplify and streamline referral pathways and encourage multidisciplinary teamwork. Members are also invited to professional development opportunities provided by the network through peer presentations and case studies to continue to improve knowledge and care of pelvic pain patients and to keep up to date with latest advances.

Members of the network must hold professional registration and membership is currently free. ACT membership is comprised of:

- Nursing
- General Practice
- Dieticians
- Gynaecology
- Pelvic Health Physiotherapists
- Pain Physiotherapists
- Psychologists
- Sex therapists
- Exercise Physiologists
- Osteopaths
- Pharmacists

Additionally, SHFPACT develops GP support resources and offers them for free, such as a chronic disease management plan for pelvic pain freely available on our website.

RECOMMENDATION:
Fund the creation of structured ACT specific pelvic pain guidance for Canberra GPs. This would require bringing together a range of local relevant parties, for example GPs, SHFPACT, the public gynaecology department, the hospital-based Canberra Endometriosis Centre, pelvic pain physiotherapy, and dieticians to first design the local guidance and then publish clear information through Community HealthPathways.

RECOMMENDATION:
Fund opportunities for knowledge upskilling and resources to support primary care clinicians and allied health to build their confidence and to encourage a community-based management approach. This type of professional development must designed with GPs with specialised skills in the area to ensure that the support delivered is appropriate for primary care.

TOR 6: EDUCATION AVAILABLE TO THE COMMUNITY

Numerous clients accessing the EPCC have lived with their symptoms for many years, in some cases since puberty. It is common for clients to reflect that they were not provided with sufficient education at school about menstruation, including what to expect, how to understand period pain, and what constitutes a ‘normal’ period. These common experiences underscore the need for education about menstruation, puberty, painful periods, and pelvic pain to be embedded within a comprehensive Relationships and Sexuality Education (RSE) framework.

The World Health Organization identifies menstruation and menstrual health as essential components of RSE, highlighting that young people benefit most when these topics are delivered within a structured, scientifically accurate, age-appropriate curriculum that supports healthy development, decision-making, and help-seeking behaviour. UNESCO’s International Technical Guidance on Sexuality Education reinforces this, stating that puberty and menstrual health education must be incremental, curriculum based, age appropriate and embedded within broader learning about relationships, rights, gender dynamics, and wellbeing. The Guidance further stresses that comprehensive sequenced education across year levels is more effective than isolated or one-off sessions. Embedding menstruation education within a comprehensive RSE approach works to normalise conversations about periods as a routine aspect of health, reduces stigma, and ensures repeated, developmentally appropriate learning across year levels and over time.

This is where specialised organisations like SHFPACT play an essential role. SHFPACT delivers age-appropriate RSE across the ACT from Years 3–12, with dedicated age-appropriate content on period pain and endometriosis embedded in every school-based RSE program. SHFPACT's education team takes an integrated, best-practice approach that emphasises body literacy, early recognition of symptoms, and help-seeking pathways. Each of SHFPACT's workshops are age and stage appropriate and informed by the Health and Physical Education subject area of the Australian Curriculum (Version 9). Unfortunately, due to funding limitations, these workshops are only delivered in approximately one third of primary schools in the ACT, and rarely in high schools.

Within these workshops, SHFPACT's education team frequently receive questions about pelvic pain. As noted above, pelvic pain commonly begins during adolescence and many young people are already dealing with significant pain that impacts on their daily lives, including school attendance, participation in sport, and the ability to maintain casual work, yet they do not know what steps to take to get help. While awareness of pelvic pain and endometriosis has certainly grown among students, there remains a clear need for comprehensive education that empowers them to advocate for themselves, understand what symptoms are not 'normal', where to go for support, and navigate the processes of treatment and potentially diagnosis where appropriate.

Please note, due to funding limitations there is a cost recovery fee attached to the workshops that the individual schools must bear. This results in schools who strongly support SHFPACT as the leading experts in RSE being unable to have SHFPACT in their schools every year.

Of course, the need for education does not end in adolescence. A 2023 study, health literacy in women with chronic pelvic pain, found that women with chronic pelvic pain who had limited health literacy had moderately correlated higher pain intensity, more depressive symptoms, and greater pain catastrophizing. In addition, studies find that education on pain science, which aims to develop understanding on how and why pain occurs and can persist, effectively reduces pain severity and improves functionality including in cases of pelvic pain.

Improved community-based adult education about pelvic pain would support earlier help seeking and timely intervention, reducing the need for crisis driven care and preventing condition escalation. For example, using EPPC funding, SHFPACT partnered with NOKA to deliver free to the patient physiotherapist-led pelvic pain science education, finding that participants showed a 6.85-point improvement in COPI scores post-session, indicating a stronger understanding of key pain concepts. There are countless opportunities for these types of relatively simple yet effective community partnerships, but limited funds to do so.

Finally, we hear consistently from patients and clinical colleagues across the community that health related misinformation is rapidly increasing online, particularly through social media. A growing number of social media influencers promote the view that hormonal treatments are inherently 'bad' or 'unnatural', discouraging their use despite decades of robust evidence supporting the safety and effectiveness of options such as oral contraceptives and intrauterine devices. This misinformation serves to undermine informed decision making and, in some cases, reinforces the misguided belief that surgery is the only viable pathway to symptom relief. It is important to note, that while outside the scope of this submission, this prolific spread of online misinformation is affecting health literacy across the field of women's health.

RECOMMENDATION:
Education for children and young people about menstruation, puberty, painful periods, and pelvic pain should always occur within a comprehensive Relationships and Sexuality Education (RSE) framework rather than as isolated lessons. SHFPACT's ongoing RSE program should be adequately resourced to be available to all schools in the ACT to ensure equity of access. The RSE program must also be adequately resourced to be provided across all year levels to ensure the ongoing provision of age-appropriate information and support.

RECOMMENDATION:
Funding for community-based adult education, both individual and group, that specifically focusses on chronic pelvic pain, health literacy, pelvic health, and pain science.

RECOMMENDATION:
SHFPACT and the ACT government work together to design and implement a local social media campaign constructed to separate myth from fact about pelvic pain. This campaign would include local clinicians and present an excellent opportunity to be co-designed with affected community.

This campaign would also have the benefit of following the recommendation in TOR 2 regarding a change in language within policy and public communication to avoid using the term endometriosis as a substitute for chronic pelvic pain.

APPENDIX A

TABLE 4: SOCIAL, EDUCATIONAL, AND WORK IMPACT FROM ENDOMETRIOSIS AND CHRONIC PELVIC PAIN HAVE SIMILAR IMPACT ON WOMEN, BUT TIME TO DIAGNOSIS IS DECREASING: AN AUSTRALIAN SURVEY

Substantial negative impact was reported across both cohorts (those with a diagnosis of endometriosis and those without) in education, employment and social domains.

	Endometriosis (n = 340)	**Chronic Pelvic Pain (n = 69)**
Have you ever lost time to education due to your chronic pelvic pain? n (%)		
Yes	197 (57.9%)	29 (42.0%)
No	57 (16.8%)	26 (37.7%)
Blank, n (%)	86 (25.3%)	14 (20.3%)
How did it effect your education (please select all that apply)? n (%)		
Gave up studies	47 (23.9%)	13 (44.8%)
Changed studies	17 (8.6%)	4 (13.8%)
Delayed exams	114 (57.9%)	15 (51.7%)
Other	64 (32.5%)	3 (10.3%)
Blank	6 (3.0%)	3 (10.3%)
Average number of days lost per month when you were studying due to your pelvic pain, mean (SD)	6.5 (7.1)	5.4 (5.0)
Has chronic pelvic pain affected your job? n (%)		
Yes	199 (58.5%)	35 (50.7%)
No	52 (15.3%)	18 (26.1%)
Blank	89 (26.2%)	16 (23.2%)
If yes, how did it affect your job (please select all that apply)? n (%)		
Lost job	30 (15.1%)	3 (8.6%)
Changed job	25 (12.6%)	2 (5.7%)
Reduced hours	108 (54.3%)	22 (62.9%)
Other	100 (50.3%)	17 (48.6%)
Blank	2 (1.0%)	1 (2.9%)
Average number of days per month you had to take off work due to your chronic pelvic pain? median (IQR)	4 (2–8)	3.5 (2–6.75)
Have you been scared to tell your employer that you have chronic pelvic pain because you feared that it might affect your prospects? n (%)		
Yes	171 (50.3%)	36 (52.2%)
No	67 (19.7%)	13 (18.8%)
Blank	102 (30.0%)	20 (29.0%)

	Endometriosis (n = 340)	**Chronic Pelvic Pain (n = 69)**
Has chronic pelvic pain ever affected your personal relationships in a negative way? n (%)		
Yes	202 (59.4%)	43 (62.3%)
No	43 (12.6%)	9 (13.0%)
Blank	95 (27.9%)	17 (24.6%)
If yes, how did it affect your personal relationships? (please select all that apply), n (%)		
Caused significant problems with partner	120 (59.4%)	27 (62.8%)
Created problems with family	54 (26.7%)	13 (30.2%)
Caused a relationship to split	31 (15.3%)	6 (14.0%)
Difficult to look after children	45 (22.3%)	11 (25.6%)
Affected friendships	122 (60.4%)	20 (46.5%)
Other	70 (34.7%)	14 (32.6%)
Blank	5 (2.5%)	1 (2.3%)

REFERENCES

In order of use, duplicates not included

Jean Hailes for Women's Health 2023, *Pelvic pain in Australian women: A report from the 2023 National Women's Health Survey*, Australian Government Department of Health and Aged Care, https://www.jeanhailes.org.au/wp-content/uploads/2026/01/2023-National-Womens-Health-Survey-Pelvic-Pain-in-Australia-FINAL_TGD.pdf

Australian Bureau of Statistics (2024) *Regional population by age and sex: Australian Capital Territory*. Available at: https://www.abs.gov.au/statistics/people/population/regional-population-age-and-sex/latest-release#australian-capital-territory

Monash Centre for Health Research and Implementation (MCHRI) 2023, *International evidence-based guideline for the assessment and management of polycystic ovary syndrome (PCOS)*, Monash University, https://www.monash.edu/medicine/mchri/pcos/guideline

The Royal Women's Hospital (2024) *WGRC Endo & Pelvic Pain Research Themes*. Available at: https://www.thewomens.org.au/research/research-centres/womens-gynaecology-research-centre/research-themes/wgrc-endo-pelvic-pain

Armour, M, Sinclair, J, Ng, CHM, Hyman, MS, Lawson, K, Smith, CA & Abbott, J 2020, *Endometriosis and chronic pelvic pain have similar impact on women, but time to diagnosis is decreasing: An Australian survey*, Scientific Reports, vol. 10, article 16253 https://pmc.ncbi.nlm.nih.gov/articles/PMC7529759

Mills, J & Joseph, K 2019, *Multidisciplinary team management of chronic pelvic pain*, O&G Magazine, vol. 21, no. 2, https://www.ogmagazine.org.au/21/2-21/multidisciplinary-team-management-cpp/

Ghobrial, S., Ott, J. & Parry, J.P. (2023) 'An overview of postoperative intraabdominal adhesions and their role on female infertility: a narrative review', *Journal of Clinical Medicine*, 12(6), 2263. doi: 10.3390/jcm12062263. https://pmc.ncbi.nlm.nih.gov/articles/PMC10051311/

Faculty of Pain Medicine, Australian and New Zealand College of Anaesthetists 2025, *PS15(PM) Statement on the clinical approach to persistent pelvic pain including endometriosis-associated pain*, ANZCA, Melbourne, https://www.anzca.edu.au/getContentAsset/a0d13f25-234b-46f4-947f-19d96ebc1a68/80feb437-d24d-46b8-a858-4a2a28b9b970/PS15-(PM)-Persistent-pelvic-pain-and-endometriosis-2025.pdf?language=en

Tyson, K, Campbell, N, Mooney, SS & Holdsworth-Carson, SJ 2024, *The endometriosis nurse coordinator – A new paradigm for endometriosis multidisciplinary care: a commentary*, Journal of Endometriosis and Uterine Disorders, vol. 8, article 100086, https://www.sciencedirect.com/science/article/pii/S2949838424000288

Allaire, C, Long, AJ, Bedaiwy, MA & Yong, PJ 2020, *Interdisciplinary teams in endometriosis care*, Seminars in Reproductive Medicine, vol. 38, no. 2–3, pp. 227–234, https://pubmed.ncbi.nlm.nih.gov/33080631/

Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) (2025) *Endometriosis Clinical Practice Guideline*. Available at: https://ranzcog.edu.au/wp-content/uploads/Endometriosis-Clinical-Practice-Guideline.pdf

Cingiloglu, P, Pirotta, S, Beauchamp, A, *et al.* 2026, *Perspectives and priorities for endometriosis multidisciplinary team care in Australia: a qualitative mixed-methods study involving patients, caregivers and health professionals*, Australian and New Zealand Journal of Obstetrics and Gynaecology, vol. 66, no. 1, article e70088, https://obgyn.onlinelibrary.wiley.com/doi/abs/10.1111/ajo.70088

Australian Government Department of Health, Disability and Ageing 2026, *Endometriosis and pelvic pain* https://www.health.gov.au/our-work/endometriosis-and-pelvic-pain-clinics

Chalmers, K. J., Catley, M. J., Evans, S. F., & Moseley, G. L. (2017). Clinical assessment of the impact of pelvic pain on women. Pain, 158(3), 498–504. Clinical assessment of the impact of pelvic pain on women - PubMed

Sanderson, K & Cocker, F 2013, *Presenteeism: implications and health risks*, Australian Family Physician, vol. 42, no. 4, pp. 172–175, https://www.racgp.org.au/getattachment/90c82662-8859-45cc-9ff2-1fb46ac1110d/Presenteeism.aspx

Armour, M, Ferfolja, T, Curry, C, Hyman, MS, Parry, K, Chalmers, KJ, Smith, CA, MacMillan, F & Holmes, K 2020, *The prevalence and educational impact of pelvic and menstrual pain in Australia: a national online survey of 4202 young women aged 13–25 years*, Journal of Pediatric and Adolescent Gynaecology , vol. 33, no. 5, pp. 511–518, https://doi.org/10.1016/j.jpag.2020.06.007

Cameron, L., Mikocka-Walus, A., Sciberras, E., Druitt, M., Stanley, K. & Evans, S. (2024) 'Menstrual pain in Australian adolescent girls and its impact on regular activities: a population-based cohort analysis based on Longitudinal Study of Australian Children survey data', *Medical Journal of Australia*, 220, 466–471. doi: 10.5694/mja2.52288 https://onlinelibrary.wiley.com/doi/10.5694/mja2.52288

Armour, M, Ciccia, D, Stoikos, C & Wardle, J 2022, *Endometriosis and the workplace: lessons from Australia's response to COVID-19*, Australian and New Zealand Journal of Obstetrics and Gynaecology, vol. 62, pp. 164–167, https://doi.org/10.1111/ajo.13458

Wilkinson, R., Wynn-Williams, M., Jung, A., Berryman, J. & Wilson, E. (2021) 'Impact of a persistent pelvic pain clinic: emergency attendances following multidisciplinary management of persistent pelvic pain', *Australian and New Zealand Journal of Obstetrics and Gynaecology*, 61, 612–615. doi: 10.1111/ajo.13358. https://pubmed.ncbi.nlm.nih.gov/33984153/

Vardy, J., Chan, E., Hart, M., Dallin, R., Wise, E., Karantanis, E. & Beales, D. (2024) 'Australian healthcare professionals' beliefs and practice behaviours in management of Chronic Pelvic Pain: a cross-sectional survey', *Australian Journal of Primary Health*, 30, PY24046. doi: 10.1071/PY24046. https://pubmed.ncbi.nlm.nih.gov/39283976/

Pelvic Pain Foundation of Australia 2026, *Pelvic Pain Networks*, https://www.pelvicpain.org.au/ppns

World Health Organization (2026) Comprehensive sexuality education. Available at: https://www.who.int/news-room/fact-sheets/detail/comprehensive-sexuality-education

UNESCO (2019) International technical guidance on sexuality education: An evidence-informed approach. Available at: https://www.unesco.org/en/articles/international-technical-guidance-sexuality-education-evidence-informed-approach.

Sexual Health and Family Planning ACT (2021) Years 5 & 6 Puberty Workshops. Written on 30 March 2021. Available at: https://www.shfpact.org.au/index.php/43-learn/254-years-5-6-puberty-workshops

Bennis, S., Pham, Y.N., Tseng, I., Malisch, B., Joyce, C.J. & Fitzgerald, C.M. 2023, 'Health literacy in women with chronic pelvic pain', *Archives of Gynaecology and Obstetrics*, vol. 308, pp. 919–926. https://link.springer.com/article/10.1007/s00404-023-07066-w

Mardon, A.K., Leake, H.B., Wilson, M.V., Karran, E.L., Parker, R., Malani, R., Moseley, G.L. & Chalmers, K.J. (2025) 'Pain science education concepts for pelvic pain: an e-Delphi of expert cli nicians', *Frontiers in Pain Research*, 6, 1498996. doi: 10.3389/fpain.2025.1498996. https://www.frontiersin.org/journals/pain-research/articles/10.3389/fpain.2025.1498996/full

Noka (2024) *Noka – Pelvic health physiotherapy*. Available at: https://noka.com.au

Pate, J.W., Simons, L.E., Rush, G., Hancock, M.J., Hush, J.M., Verhagen, A. & Pacey, V. (2022) 'The Concept of Pain Inventory for Adults (COPI-Adult): assessing knowledge and beliefs regarding pain science education', *The Clinical Journal of Pain*, 38(1), 32–40. doi: 10.1097/AJP.0000000000000990 https://journals.lww.com/clinicalpain/abstract/2022/01000/the_concept_of_pain_inventory_for_adults.5.aspx

Purnat T D, Scales D. Health information in age of social media and influence BMJ 2025; 391 :r2419 doi:10.1136/bmj.r2419

Baker, S.A. (2024) TikTok and Instagram are full of misleading information about birth control — and wellness influencers are helping drive these narratives. The Conversation. Available at: https://theconversation.com/tiktok-and-instagram-are-full-of-misleading-information-about-birth-control-and-wellness-influencers-are-helping-drive-these-narratives-226836