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Standing Committee on Social Policy

Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

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ACT Government submission

to the Inquiry into endometriosis and other pelvic pain

Health and Community Services Directorate
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Contents

Introduction

On 8 December 2025, the ACT Government's Standing Committee on Social Policy announced an inquiry into endometriosis and other pelvic pain conditions. In particular, the Committee intends to focus on:

1) The number of women and other people in the ACT who suffer from endometriosis, adenomyosis, polycystic ovarian syndrome and other chronic pelvic pain conditions (Prevalence).
2) The barriers in the ACT to getting a diagnosis and gaining access to treatment including primary care, specialist clinics and ongoing pain management for these conditions.
3) The treatment options and supports available in the ACT compared to other jurisdictions, their evidence-based effectiveness and potential side effects and impacts.
4) The role of medical misogyny, underlying gender biases in healthcare and cultural norms that create barriers for women with these conditions.
5) The economic and social impacts of people in the ACT with these conditions, including education, employment and lost productivity.
6) Education available to medical professionals, allied health professionals, young women and others, on these conditions and treatment options.
7) Research and trials currently being explored in Australia and opportunities for this to take place in the ACT.
8) Any other related issue.

The ACT Government welcomes the opportunity to make a submission to this inquiry and supports initiatives designed to bring attention and more focus to traditionally neglected medical conditions that impact women and girls in the ACT.

The ACT Government is committed to improving women's health and health equity. Health and Wellbeing is a priority area for the ACT Government under the *ACT Women's Plan 2016–2026*, and activities under the *National Action Plan for Endometriosis* are already benefiting women and people with uteruses in the ACT.

In preparing this submission, the ACT Government has used internally sourced information; and data from a range of external sources such as the Australian Institute of Health and Welfare (AIHW), Endometriosis Australia, and Women's Health Matters ACT.

Background

Endometriosis is a chronic, inflammatory condition that can be painful, affect fertility, and lead to reduced participation in school, work and social activities. It involves tissue similar to the lining of the uterus growing outside the uterus.

Endometriosis is commonly misdiagnosed, and other conditions like pelvic inflammatory disease can have similar symptoms.

There is no known cure for endometriosis, but treatments are available to help manage the symptoms associated with endometriosis and improve quality of life. These may include:

- pain relievers;
- hormonal treatments, including hormonal contraceptives, which suppress ovulation and periods;
- allied health or complementary therapies, exercise, and diet modifications; and/or

- surgery for the removal of lesions via laparoscopy (key-hole surgery) or laparotomy (abdominal surgery).

Medical management of endometriosis does not differ significantly between trans and cis-gender individuals.[1]

Other chronic or persistent pelvic pain (CPP) conditions can also have significant impacts on psychosocial wellbeing, with impacts on school and work attendance, social life, sleep, sexual intimacy, relationships and mental health. CPP conditions include (but are not limited to):

- Adenomyosis: Similar to endometriosis, but the tissue grows in the layer of muscle in the wall of the uterus.
- Dysmenorrhoea (period pain): Can range from mild discomfort to severe pain. There is a wide range of how period pain feels, which can include cramps, heaviness or a constant, dull pain in your abdomen and/or sometimes in stomach, back and thighs. Period pain is considered normal if it happens early in the menstrual cycle, doesn't affect daily life and goes away with pain-relief medicines and/or self-care measure such as a heat pack.
- Polycystic ovary syndrome (PCOS): Is a complex hormonal condition often involving irregular or absent periods, acne, excess facial or body hair growth, scalp hair loss or high levels of androgens (testosterone and similar hormones) in the blood, and/or polycystic ovaries (many immature follicles on the ovaries) visible on an ultrasound. People with PCOS also often have reduced fertility.
- Dyspareunia (painful sex): Is lasting or recurrent genital pain that occurs just before, during and/or after sex. It can have several causes and can be due to physiological and/or psychological concerns. Treatments vary widely dependent on the identified cause(s), such as whether the dyspareunia is due to physical and/or emotional factors, and when pain is experienced.
- Fibroids (myomas): Non-cancerous growths of varying sizes in the muscle layer of the uterus. If there are symptoms from fibroids, they may include heavy periods, long-lasting periods, period pain, pain or pressure on the pelvis and lower back, painful sex and/or frequent urination. Symptoms usually improve after menopause.
- Pelvic venous disorders: Enlarged, malfunctioning veins in the pelvis, causing blood to pool, leading to chronic pelvic pain and sometimes varicose veins. It often affects women of childbearing age after multiple pregnancies. Common symptoms include pain in the lower abdomen/pelvis (worsening after standing/walking), painful sex, period pain, bowel and/or bladder issues.
- Vulvodynia: Localised or generalised pain or discomfort at or around the vaginal opening without an obvious ongoing cause.
- Pelvic adhesions: Bands of scar tissue that cause internal organs (like the uterus, ovaries, bowel) to stick together, often after surgery, infection or inflammation (including endometriosis). Sometimes asymptomatic, but symptoms may include chronic pain, infertility, painful sex, and bowel and/or bladder issues.

Submission

1) Prevalence

There is a paucity of recent, definitive data on the prevalence of endometriosis and other chronic pelvic pain conditions, indicating that more research is required. Available information includes:

- Across Australia, endometriosis affects 1 in 7 women, girls and those who are gender diverse.[2] A 2023 Australian Institute of Health and Welfare (AIHW) report states that nationally around 1 in 7 women born between 1973–78 were diagnosed with endometriosis by age 44–49.[3] On average, it takes 6.5 years to receive a diagnosis of endometriosis.[4]
- In 2020–21, the Australian Disease Expenditure Study estimated that $247 million was spent on endometriosis in the Australian health system.[5]
- A research-based approximation from Endometriosis Australia suggests that in 2018 there were approximately 14,783 women, girls or those who are gender diverse, living with endometriosis in the ACT.[6] This equates to approximately 6.8 per cent of the female population of the ACT in 2018.[7]
- A study published in 2008, utilising 2004–05 Australian survey data on 1,983 women aged 16-49 years who were still menstruating and sexually active indicated that prevalences for pelvic pain were 71.7% for dysmenorrhoea, 14.1% for dyspareunia and 21.5% for other CPP.[8]
- The Australian Pelvic Pain Foundation currently uses a 2004 New Zealand study to estimate that CPP may affect 15–25% of Australian women and 8% of Australian men.[9]
- A 2024 paper on transgender and gender diverse people with endometriosis indicates that CPP affects between 51 and 72 per cent of trans and gender diverse people presumed female at birth.[10] While endometriosis is a common cause of CPP, there is limited research investigating the prevalence, symptoms, treatment or experiences of endometriosis in trans and gender diverse people.[11]
- A menstrual disturbance study of over 1,000 teenage girls in the ACT aged between 15 and 19 years indicated that 25 per cent of the cohort experienced significant interference with daily activities or pain that warranted intervention.[12] This cohort was identified as potentially being at risk for developing other pain conditions or CPP without timely intervention.[13]

Women's Health Matters ACT survey data

The Women's Health Matters (WHM) 2025 Survey of Women's Health in the ACT asked respondents:

- If they had ever been diagnosed with endometriosis or adenomyosis: 19 per cent said yes (241 people).[14]
- If they had ever been diagnosed with, or treated for, PCOS: 14 per cent said yes (181 people).[15]
- Whether they had experienced persistent pelvic pain (CPP) in the last two years: 17 per cent said yes (227 people).[16]

Hospital data

According to the Australian Institute of Health and Welfare (AIHW) nationally, in 2022-23:

- There were 44,200 endometriosis-related hospitalisations in 2022–23, a 54 per cent increase since 2012–13 (28,700 hospitalisations). This represents 335 hospitalisations per 100,000 females (up from 250 in 2012–13).[17]
- The rate of endometriosis hospitalisations doubled for those aged 20–24, from 325 hospitalisations per 100,000 females in 2012–13 to 650 per 100,000 in 2022–23.[18]

- Around two-thirds (65 per cent) of endometriosis-related hospitalisations took place in a private hospital.[19]
- Most endometriosis-related hospitalisations lasted 2 days or less, with 44 per cent being same-day hospitalisations.[20]
- There were more than 4,800 endometriosis-related emergency department (ED) presentations in 2023–24. This represents around 35 presentations per 100,000 females. Please note however that due to the way that ED data is coded this is figure is likely to have been significantly undercounted.[21]
- Around three-quarters (76 per cent) of endometriosis-related ED presentations were triaged as needing to be seen within 30 minutes or less.[22]

Endometriosis and chronic pelvic pain represent a substantial and clearly identified area of demand within ACT public gynaecology services. Within Canberra Health Services (CHS), approximately 26 per cent of current gynaecology waitlist referrals relate to endometriosis or pelvic pain, including endometriosis, adenomyosis, PCOS and other CPP conditions.

In the ACT in 2022–23 there were 1,396 gynaecology ED presentations.[23] Nationally, the AIHW states that women may present to the emergency department prior to receiving a diagnosis of endometriosis. In these cases, diagnoses relating to pain, abnormal bleeding or menstrual bleeding may be recorded.[24]

In 2021–22, AIHW reported that the ACT rate of endometriosis-related hospitalisations per 100,000 population for all ages is higher than the national average.[25] Nationally, the number of endometriosis related hospitalisations increased by 43 per cent between 2011–12 and 2021–22, indicating a growing demand for endometriosis-related services nationally and in the ACT.[26]

In 2022–23, within the ACT public health system, there were:

- 2,700 medical gynaecology tier 2 consultation non-admitted clinic events;[27]
- 203 medical gynaecology oncology tier 2 consultation clinic events;[28] and
- 952 allied health and/or clinical nurse specialist intervention tier 2 clinic events.[29]

Longitudinal trends of non-admitted events were not provided within the AIHW data due to changes in data specifications overtime.[30]

In 2022–23, the ACT had 1,174 public gynaecology elective surgery admissions.[31] This was the lowest number of public gynaecology elective surgery admissions for the ACT over the previous five years.[32] AIHW identified that the Covid-19 pandemic resulted in restrictions and disruptions to elective surgeries across Australia, and that this impacted elective surgery waiting times across most procedures from 2019–20 onwards.[33] Since 2022–23, the numbers of gynaecology public elective surgeries have increased and the waiting times have decreased both in the ACT and nationally.[34]

Using the ACT's admitted patient data, the following table (Table 1) illustrates the number of hospital separations between 2000–01 and 2025–26, where endometriosis was the principal diagnosis. Note that an individual can be hospitalised more than once for the same condition. The data therefore reports the number of presentations, rather than the number of people hospitalised.

- Over the past 20 years, the number of hospital separations for endometriosis increased from around 180 in 2000–01 to around 650 in 2023–24.
- Age-standardised rates increased from just over one separation per 1,000 persons in 2000–01 to 2.6 per 1,000 persons in 2023–24.
- On average, between 40 and 50 per cent of separations occur in a public hospital.
- Around 80 per cent of those hospitalised for endometriosis are ACT residents.

Table 1: ACT hospital separations, principal diagnosis of Endometriosis by age, females. Data for private hospitals is not included in data for 2024–25 and 2025–26 (ACT Admitted Patient Collection, Health and Community Services Directorate).

	Age group							Usual place of residency			
	0-19	**20-29**	**30-39**	**40-49**	**50-59**	**60+**	**Total**	**non-ACT**	**ACT**	**Total**	**% ACT**
2000/01	10	53	65	44	6	0	178	31	147	178	82.6
2001/02	7	68	81	56	8	0	220	32	188	220	85.5
2002/03	7	74	109	60	7	0	257	47	210	257	81.7
2003/04	10	81	107	68	6	0	272	43	229	272	84.2
2004/05	14	68	88	65	12	<5	250	32	218	250	87.2
2005/06	19	74	107	82	13	<5	296	46	250	296	84.5
2006/07	17	85	130	55	<5	0	291	40	251	291	86.3
2007/08	7	68	102	46	6	<5	231	34	197	231	85.3
2008/09	13	76	90	62	8	<5	253	41	212	253	83.8
2009/10	13	66	74	55	18	<5	227	47	180	227	79.3
2010/11	12	67	80	60	11	6	236	52	184	236	78.0
2011/12	17	70	84	54	5	0	230	41	189	230	82.2
2012/13	8	64	87	67	7	<5	235	36	199	235	84.7
2013/14	11	83	69	63	8	<5	235	47	188	235	80.0
2014/15	13	92	102	45	9	<5	265	28	237	265	89.4
2015/16	13	106	111	70	12	<5	314	47	267	314	85.0
2016/17	14	127	98	67	9	<5	317	55	262	317	82.6
2017/18	17	143	121	57	6	<5	345	65	280	345	81.2
2018/19	15	181	107	66	10	<5	382	88	294	382	77.0
2019/20	37	196	176	90	17	<5	520	108	412	520	79.2
2020/21	55	226	206	106	22	<5	617	103	514	617	83.3
2021/22	51	225	169	101	11	<5	558	121	437	558	78.3
2022/23	32	188	210	119	16	<5	566	126	440	566	77.7
2023/24	48	232	249	111	21	<5	664	140	524	664	78.9
2024/25 (3)	21	137	134	47	10	0	349	43	306	349	87.7
2025/26 (3, 4)	<5	20	16	5	0	0	44	5	39	44	88.6
Total	**484**	**2,870**	**2,972**	**1,721**	**262**	**43**	**8,352**	**1,498**	**6,854**	**8,352**	82.1

Notes:

1. Includes public and private hospitals.
2. Includes ACT and non-ACT residents.
3. Data for private hospitals are not included in data for 2024/25 and 2025/26.
4. Data for 2025/2026 includes data for the first quarter of the financial year only (3 months).
5. A single person can be hospitalised multiple times
6. A small number of hospitalisations were reported with a sex of ‘male’ or ‘other’. To preserve confidentiality, data presented in this report have been restricted to with a sex of ‘female’ only. The Estimated Resident Population for Australian females is used for the denominator when calculating rates.

Numbers less than 5 are not published

When expanded to include PCOS and pelvic pain as well as endometriosis, the total number of ACT hospital separations increases significantly. On average, around 50 to 60 per cent of separations for PCOS take place in public hospitals. For pelvic and perineal pain, the proportion of separations that took place in public hospitals fluctuated widely, but (on average) were around 50 per cent.

Table 2: Hospital separations, principal diagnosis of Endometriosis or Polycystic ovarian syndrome or Pelvic and perineal pain by age, females, 2000–01 to 2025–26 (ACT Admitted Patient Collection, Health and Community Services Directorate).

	Age group							**Usual place of residency**		
	0-19	**20-29**	**30-39**	**40-49**	**50-59**	**60+**	**Total**	**non-ACT**	**ACT**	**Total**
2000/01	20	80	91	51	10	<5	255	45	210	255
2001/02	19	95	114	70	19	5	322	44	278	322
2002/03	12	105	134	77	11	<5	343	57	286	343
2003/04	19	102	127	78	11	6	343	53	290	343
2004/05	24	95	107	68	16	<5	313	45	268	313
2005/06	26	102	129	100	19	5	381	62	319	381
2006/07	37	125	161	71	10	7	411	53	358	411
2007/08	16	111	123	56	10	<5	320	47	273	320
2008/09	26	125	120	78	13	10	372	58	314	372
2009/10	27	96	102	69	25	6	325	63	262	325
2010/11	28	104	105	81	14	11	343	70	273	343
2011/12	29	116	123	73	11	<5	354	59	295	354
2012/13	19	109	136	97	10	7	378	61	317	378
2013/14	35	139	105	89	13	6	387	68	319	387
2014/15	36	165	156	73	13	8	451	59	392	451
2015/16	37	176	162	89	22	6	492	71	421	492
2016/17	40	223	178	97	20	5	563	84	479	563
2017/18	41	221	182	84	10	6	544	89	455	544
2018/19	39	277	156	105	16	<5	597	128	469	597
2019/20	59	301	258	132	20	10	780	151	629	780
2020/21	92	367	328	167	40	<5	998	178	820	998
2021/22	85	321	251	142	18	6	823	178	645	823
2022/23	58	278	289	148	26	5	804	166	638	804
2023/24	65	336	338	161	37	7	944	205	739	944
2024/25 (3)	35	209	186	73	15	<5	522	76	446	522
2025/26 (3, 4)	7	32	20	9	<5	<5	71	5	66	71
Total	**931**	**4,399**	**4,181**	**2,336**	**431**	**144**	**12,436**	**2,175**	**10,261**	**12,436**

Notes:

1. Includes public and private hospitals.
2. Includes ACT and non-ACT residents.
3. Data for private hospitals are not included in data for 2024/25 and 2025/26.
4. Data for 2025/2026 includes data for the first quarter of the finance year only (3 months).

2) Barriers to treatment

Early diagnosis is important

It takes on average 6.5 years[35] and a great deal of effort to get a diagnosis and/or treatment. Many people suffer pain and distress from the condition for years before obtaining relief (if at all).

The prevalence of menstruation disturbance amongst teenage girls in the ACT and the potential risks to delaying diagnosis and management for women and adolescents with severe dysmenorrhea increases the risk of CPP.

Early recognition of menstruation disorders amongst teenagers and young women is of particular importance due to the potential long-term quality of life impacts that period and or pelvic pain can have.[36] These may include the development of CPP and changes to brain pathways, additional impacts may include bladder sensitivity, myofascial pain or irritable bowel syndrome.[37]

Ongoing dissatisfaction with treatment

The WHM 2025 Survey of Women's Health in the ACT asked about satisfaction with treatment (specifying that treatment can include simply taking medication):

- For endometriosis or adenomyosis, half of all those diagnosed or treated in the last two years said they were dissatisfied or very dissatisfied, compared with only 25 per cent who were very satisfied or extremely satisfied (with "somewhat satisfied" as the midpoint with 26 per cent of responses. This finding is almost identical to the findings of the 2023 survey (noting that the 2023 survey did not only ask those treated in the last two years).[38]
- In 2025 there were overall low levels of satisfaction with PCOS healthcare, with around 50 per cent of people who had PCOS saying they were dissatisfied or very dissatisfied with their healthcare for the condition. However, the results represent a slight improvement from 2023 (noting again that in 2023 there was no differentiation between those who had been recently treated/diagnosed with the condition and those whose treatment/diagnoses was earlier).[39]
- 55 per cent of the 174 who had sought treatment for CPP were either 'Dissatisfied' or 'Very dissatisfied' with the treatment received.[40]

Workforce and financial barriers

Gynaecology and pelvic pain management in the ACT relies on three primary workforce groups: medical professionals, nurses, and allied health professionals:

- Medical professionals such as gynaecologists, urogynaecologists, and general practitioners (GPs) with specialisation in women's health, sexual health, or pelvic pain, provide core diagnostic and clinical care for women's health issues. They lead direct patient management and support holistic care for chronic pelvic pain.
- Nurses specialising in women's health, endometriosis and sexual health, deliver essential patient care and play a vital role in managing long-term gynaecological conditions.
- Allied health professionals, such as exercise physiologists, physiotherapists and psychologists, support a comprehensive, multidisciplinary approach to persistent pelvic pain. Their care includes physical therapy, pain management, and psychological support, all critical to effective pain management.

GPs are often the first point of contact for those with suspected chronic pelvic pain conditions and are therefore instrumental in identifying symptoms, prescribing medication or providing referrals to specialists and allied health for further testing and/or treatment. Although the Commonwealth Government has introduced some new Medicare Benefits Schedule (MBS) items to support bulk billing and scans, the cost of co-payments can be prohibitive and bulk billed services difficult to access.

CHS has been progressively strengthening models of care to improve timely access, care coordination and overall patient experience. Despite these improvements, several barriers continue to affect women's ability to obtain a diagnosis and access appropriate treatment across primary care, specialist clinics and ongoing pain management. Key barriers identified include:

- Specialist capability and workforce capacity:
  - Public sub-specialty services remain limited, particularly in the areas of complex gynaecology and CPP.
  - In response, and in parallel with ongoing specialist (consultant) recruitment and the realignment of specialist care, CHS has prioritised building multidisciplinary capability—enhancing the roles of nursing, physiotherapy and allied health to support earlier assessment, conservative management, and more coordinated care pathways.

- Variability in referral practices:
    - Referrals from GPs remain highly variable in the level of detail provided regarding symptoms, severity and duration.
    - This inconsistency can delay appropriate triage and initial assessment, ultimately slowing access to the most suitable health professional and the right level of care.

Locally, equitable access to allied health professionals for the management of pelvic pain is challenging as most of these support services are private, although some publicly provided allied health services are accessible through CHS.

Desktop workforce analysis across specific professions—including obstetricians and gynaecologists, physiotherapists, physiotherapists specialising in women's health, and psychologists—indicates that on paper the ACT has a higher full-time equivalent (FTE) health professional per capita than NSW. Although this is positive, it does not equate to a large workforce, with small changes in staff numbers creating large per capita impact. According to the Ahpra workforce data, between 2013 and 2022, some relevant health professional coverage in the ACT included:

- Obstetricians and gynaecologists: Decreased by 15%, from 9.7 FTE per 100,000 to 8.3 FTE per 100,000. NSW by comparison had 8.2 FTE per 100,000 in 2022.
- Physiotherapist with specialisation in women's health*: Increased by 114%, from 2.6 FTE per 100,000 to 5.5 FTE per 100,000. NSW experienced a 192% increase, from 1.0 FTE per 100,000 to 2.8 FTE per 100,000.

*Note that the FTE above is based on self-reported weekly working hours by health professionals; and in 2021, Ahpra expanded the 'Women's Health' specialisation for physiotherapists to 'Men's, Women's, and Pelvic Health', likely causing the sudden increase in FTE per capita.

3) Treatment options

There are several services available to assist in managing endometriosis in the ACT. These include the CHS Canberra Endometriosis Centre services, Sexual Health and Family Planning ACT (SHFPACT) and private gynaecology services.

The Australian Government has invested more than $127 million to support women with endometriosis, aligning with the *National Action Plan for Endometriosis*. In 2023, the Australian Government announced the establishment of 22 Endometriosis and Pelvic Pain clinics. The ACT's endometriosis clinic is at Sexual Health and Family Planning ACT (SHFPACT).

This national program was expanded in 2025, with the establishment of 11 additional Endometriosis and Pelvic Pain clinics. The expansion will bring the total number of clinics to 33 nationwide, with at least one in each Primary Health Network region. From 2022–23 to 2027–28, the Australian Government has invested a total of $37 million for the 33 Endometriosis and Pelvic Pain Clinics.

The existing 22 clinics, including the ACT clinic, will also receive an extension of funding to continue providing targeted care and support, as well as start providing menopause-related care and supports from July 2026 based on local community needs.[41]

The Endometriosis Progress Report 2024 provides a summary of activities to progress the six criteria of the National Action Plan for Endometriosis (NAPE), stating that the Department of Health and Aged Care "…has commenced all the programs and activities to meet the objectives of the NAPE. The next phase of the NAPE is to complete these objectives and evaluate their effectiveness."

Collectively, these Australian and ACT Government initiatives demonstrate ongoing progress in expanding gynaecological services nationally and in the ACT and improving care for people experiencing endometriosis and pelvic pain.

The Health and Community Services Directorate (HCSD) also provides funding of $754,088 per annum (until 2031) to SHFPACT to deliver multiple activities related to women's health and reproductive health. This includes SHFPACT's 'Access Clinic', which delivers free or low-cost women's health services such as:

- sexually transmissible infections and blood borne virus screening/testing, treatment and risk reduction counselling;
- cervical screening and follow-up; and
- contraception advice and long-acting contraceptive options.

SHFPACT also provides services such as:

- pelvic pain consultations;
- Canberra Menopause Centre, providing assessment and management of menopause symptoms;
- breast checks and awareness education;
- menstrual cycle issues and fertility-related advice; and
- Referrals to other relevant services.

ACT Endometriosis and pelvic pain clinics

CHS introduced an Endometriosis Pelvic Pain (EPP) pathway in July 2025. Since implementation, the pathway has significantly improved access, triage, and coordinated care for patients experiencing endometriosis-related symptoms.

The program has successfully addressed a substantial backlog of 379 referrals from 2022–2025, ensuring all patients now have identified appointments. In addition, a further 436 new referrals have been triaged through the pathway. Importantly, there are no outstanding referrals to be triaged as all patients have been contacted to discuss timeline and ongoing management, reflecting the efficiency and effectiveness of the pathway.

The pathway incorporates interdisciplinary workshops and early screening processes that support conservative, evidence-based management. These workshops include comprehensive assessment and collaborative decision-making to ensure each patient is directed to the service most appropriate for her symptoms—whether allied health, pain management, or a medical specialist.

A key component of the model is the Period Impact Pain Assessment (PIPA) tool. This screening tool supports clinicians in directing patients to the right health professional early in their care journey. Further information on PIPA is available under section 6, *Education and Training*, below. Depending on individual needs, this may include physiotherapy, clinical psychology, nursing, or a combination of disciplines to optimise symptom management and support overall wellbeing.

4) Gender biases

Lack of awareness, medical misogyny, and gender biases in women's health are well documented. It is clear from the WHM 2025 Survey of Women's Health in the ACT[42] that respondents were experiencing these biases. Gender biases and medical misogyny entrenched in Western medicine are difficult to shift as they are tied to wider cultural biases. These biases can make it difficult for women to obtain a timely diagnosis and appropriate treatment. For example:

- The Australian Government's #End Gender Bias: Survey Summary Report (March 2024) notes the challenges faced in obtaining treatment for endometriosis.
- The wider topic of gender disparity in healthcare has also been extensively discussed, including by the Royal Australian College of General Practitioners (RACGP) in RACGP - How health system 'designed by men, for men' is failing women; and in the media, such as in the

following article relating to the ACT (ABC: Why aren't women being believed when they turn up at emergency departments in agony?

- Respondents to the WHM 2025 Survey of Women's Health in the ACT[43] were given the option of providing free text answers about their experiences with endometriosis/adenomyosis, PCOS and/or CPP. It is clear from their responses that medical gender bias, dismissal and long delays in diagnosis are being experienced by women in the ACT.

There is growing evidence to demonstrate that delays or applying a "watchful waiting" approach to the diagnosis and management of women and adolescents experiencing severe dysmenorrhea results in continued pain and potentially increases the risk of CPP.[44]

- "Severe dysmenorrhea, especially if untreated, is a potential risk factor for the development of CPP, due to hyperalgesic priming and wind-up of the nervous system. Dysmenorrhea can also be a perpetuator or aggravator of CPP through cross-sensitization (Allaire, et al., 2024)".[45]
- A 2014 study conducted in South Australia found that 16.4 per cent of participants progressed from dysmenorrhea to CPP in less than one year and over 50 per cent of women developing CPP within the first 12 years of menarche. With CPP onset as young as 11 years old for some women.[46]
- A comparison study of women with dysmenorrhoea and without dysmenorrhea demonstrated behavioural, imaging, quality of life and endocrine evidence to suggest long lasting central changes for women with dysmenorrhoea that persist beyond the time of menstruation and are similar to many features associated with chronic pain conditions. The authors suggested that as the adolescent nervous system is more plastic than an adult, adolescents may be more susceptible to influence of repeated painful episodes.[47]
- The clinical practice implications of these studies suggest there is need for prompt treatment and investigation for dysmenorrhoea.[48] Noting gender bias, and that young women are likely easily dismissed and may struggle to self-advocate, health care that is accessible and appropriate for young women is vital.

The Victorian Government's *Bridging the Gender Pain Gap: The Inquiry into Women's Pain Report 2025*,[49] indicates that gender biases and lack of awareness in health professions is an ongoing problem for pain management, including for endometriosis and chronic pelvic pain. 71 per cent of respondents cited widespread dismissal by healthcare professionals as a primary challenge when seeking help.

- Experiences of gaslighting and dismissal included instances where women sought help, only to receive little to no acknowledgement or validation of their pain. Instead, women reported being told there was nothing wrong with them, that the pain was only in their heads, or that they were exaggerating the extent of their pain. When advocating for their daughters' health, some parents stated that they were reprimanded for supposedly making their children paranoid about their health.
- Similarly, many women and girls highlighted that their pain was dismissed as being a by-product of a psychological condition or even attention-seeking behaviour. These experiences left women feeling that they were being branded as liars or that they were doing something wrong for coming forward about their conditions.

The Australian Government's *National Action Plan for Endometriosis*[50] provides for research, education and training to assist in addressing the lack of clinical and community knowledge, and to improve diagnosis and treatment, which may assist in dispelling gender bias relating to endometriosis and CPP, and hastening diagnosis and access to treatment. Improved clinical education and training, and improved community education are a step in the right direction.

The ACT Government acknowledges the growing body of national and international evidence demonstrating that pelvic pain conditions are frequently under recognised, under diagnosed and under treated, often due to long standing gender bias and cultural assumptions surrounding women's health.

In response, CHS is actively embedding trauma informed, person centred care principles across services to ensure that women's experiences are validated and that their symptoms are taken seriously. Efforts are underway to strengthen policy and guidelines, clinical education, improve consistency in assessment and management, and reduce over reliance on individual clinician discretion—factors that have historically contributed to inequitable care.

Aligned with international research on addressing medical misogyny and improving access to multidisciplinary, evidence-based care, CHS now delivers monthly interdisciplinary workshops for women experiencing pelvic pain. These workshops promote coordinated, holistic care and reflect leading practice in responding to gendered health inequities.

5) Economic and social impacts

Of the respondents to the Women's Health Matters (WHM) 2025 Survey of Women's Health in the ACT[51] who indicated that they had experienced persistent pelvic pain in the last two years (227 people, or 17 per cent of respondents), 63 per cent of these reported having missed work/study as a result in the last 12 months.

In their report, *Pelvic Pain in Australian Women* (2023), the Australian Women's Health Alliance reported that:[52]

- Four in five of those who experienced pelvic pain in the last five years (or 9 per cent of all Australian women) reported that pelvic pain impacted their daily activities or caused them to miss days of work or study or to miss exercise.
- Three in five of those who experienced pelvic pain in the last five years (or 28 per cent of all Australian women) found it hard to do daily activities, with women of reproductive age significantly more likely than older women to find it hard to work or study, and significantly more likely than women in midlife to miss days of work or study.
- Older women who experienced pelvic pain in the last five years were significantly less likely than women of reproductive age to report finding it hard to do daily activities or to work or study, or to report missing exercise or days of work or study.
- The impact of pelvic pain on daily activities, exercise, or work or study did not differ according to language spoken at home.

It was also found that Australian adolescents face considerable impacts due to CPP:

- One cross-sectional study (n = 1051) demonstrated that 93 per cent of Australian adolescents experience pain with menstruation, 21 per cent experience severe period pain, and 26 per cent had not attended school or work because of their period.[53]
- Teens with higher scores of menstrual pain were found to be more likely to experience higher rates of absenteeism.[54]
- Further, CPP and endometriosis negatively impact adolescents' mental health, social wellbeing and quality of life.[55]
- The early recognition of symptoms suggestive of endometriosis or pelvic pain provide an opportunity for early diagnosis and interventions that are critical to improving the wellbeing of adolescents.[56]
- Endometriosis and CPP impose a large burden on health and workplace economies. In 2019 the economic burden of endometriosis per annum in Australia was estimated to be between $7.4 billion and $9.7 billion.[57]
- Lost productivity due to endometriosis accounted for 84 per cent of the $7.4 billion estimate and cost increased with pain severity.[58]

An Australian study of 1,000 girls aged 16–18 attending school in the ACT has shown that 93 per cent of girls experienced menstruation-associated pain, 21 per cent experienced severe pain.[59] School absenteeism was relatively high amongst respondents, with 26 per cent of respondents overall indicating that they had missed school because of their period, and for those in the severe pain group, 50 per cent of girls reported missing school.[60]

The ACT Government recognises the substantial social and economic burden associated with chronic pelvic pain. The condition can significantly disrupt education, employment participation, daily functioning and overall wellbeing, particularly for women navigating persistent or fluctuating symptoms.

In response, CHS service models increasingly prioritise improving functional outcomes, enhancing self-management skills and strengthening symptom control. By offering earlier, coordinated and multidisciplinary intervention, these approaches aim to reduce recurrent presentations, prevent escalation of symptoms and support women to maintain engagement in work, study and community life.

6) Education and training

Education remains a critical enabler of improved care for people experiencing endometriosis and pelvic pain. The EPP pathway embeds structured patient education, multidisciplinary input and coordinated care planning, while also supporting capability uplift across nursing, physiotherapy, allied health and medical teams.

CHS staff have access to a growing range of education opportunities on endometriosis and pelvic pain, including training provided by national professional bodies, evidence-based resources, and regular knowledge sharing at the monthly multidisciplinary meetings and EPP workshops. These forums strengthen collective clinical knowledge, promote consistency in practice and encourage collaborative problem solving.

CHS continues to enhance alignment with national evidence-based guidance and to invest in professional development opportunities. This focus ensures the workforce is equipped with current, high quality clinical skills to deliver safe, compassionate and effective care for women with complex pelvic pain.

CHS workforce capability includes two nurses who have completed the Australian College of Nurses course in Endometriosis and Pelvic Pain, and nurse/physiotherapist follow-up appointments have commenced as part of the established care pathway. Two psychologists are permanently involved in delivering patient group education sessions for those experiencing endometriosis and pelvic pain. A range of school settings are targeted for education, including culturally and linguistically diverse communities and school-age children in schools across the ACT. Education covers a range of topics, including puberty, sexual health, consent and healthy relationships.

PIPA is a validated screening tool for assessing menstruation disturbance amongst teenagers, that was developed and tested through are large study in the ACT and has now been adopted in other jurisdictions and requests have been received for international use.

In the ACT, the PIPA screening test can be accessed online via the CHS website. Following the completion of the tool, consumers can access advice for managing period pain and other period related symptoms, a self-management pathway, and primary health care pathway via the CHS site. A note to take to their doctor to support conversations around menstruation is also available on the CHS webpage.

SHFPACT provides services to clinicians, schools and the community, including workforce capacity-building for sexual and reproductive health, and women's health. Both clinical and non-clinical professional development training programs are delivered by specialists at SHFPACT, such as the Family Planning Alliance Australia Certificate in Reproductive and Sexual Health for Doctors, and other Continuing Professional Development (CPD) accredited courses. Training to meet CPD requirements about sexual and reproductive health is available for medical practitioners, nurses, allied health professionals, as well as teachers and community service workers. This includes tailored training according to clinician needs and specialist placements for eligible nurses and doctors.

SHFPACT continues to provide non-directive pregnancy options counselling and hold specialist accreditation to provide training, education and resources for Long-Acting Reversible Contraception (LARC) insertion, cervical screening and other health issues, such as pelvic pain, for women and people with a uterus.

7) Research

The ACT Government is supporting research to improve care for endometriosis and pelvic pain.

- Through the Research and Innovation Fund Fellowship Program, HCSD has contributed $199,404 (exc GST) to a project evaluating the PIPA tool.
- The Canberra Health Annual Research Meeting (CHARM) 2025, hosted by HCSD, included a presentation by Canberra Health Services titled "Multidisciplinary Care in Persistent Pelvic Pain: Consumer and Expert Consensus on the Care-Team" outlining research that engaged women with pelvic pain and experts to define essential services for multidisciplinary pelvic pain clinics. This work provides evidence to guide integrated care models for persistent pelvic pain.
- Work is underway to strengthen clinical resources and research. An ethics application is in progress to support the Project Officer and Endometriosis Nurse in converting the initiative into a formal research project.

While there is currently no dedicated ACT based pelvic pain research program embedded within CHS, there is strong potential to generate locally relevant evidence that can inform service design and enhance patient outcomes. The implementation of the EPP pathway provides a valuable opportunity to evaluate clinical outcomes, service utilisation and the impact on progression through the Gynaecology waitlist.

To support this, the CHS Women, Youth and Children Division has invested in a position whose role has included systematic data collection, analysis and reporting. This position will continue for the next six months as part of the physiotherapy service. It will enable CHS to build a foundational evidence base on the effectiveness of the EPP pathway, identify areas for refinement and contribute to national conversations on endometriosis and pelvic pain care.

These early research activities may also serve as a platform for future partnerships with academic institutions, national research bodies and consumer groups, enabling CHS to strengthen innovation, evaluation and evidence-based practice across women's health services.

8) Related issues

Nationally, in 2023, around two-thirds (65 per cent) of endometriosis-related hospitalisations took place in a private hospital;[61]and in 2021–22 two thirds (68.4 per cent) of endometriosis related hospitalisations (all ages) took place in a private hospital.[62] Comparatively only 42.3 per cent of all female hospitalisations (all ages) for any cause took place in a private hospital, suggesting that the private hospital sector admits a disproportionate number of patients with this condition.[63]

There is also significant disparity when comparing admission funding sources for endometriosis hospitalisations and all female hospitalisations. National data shows that endometriosis hospitalisations (all ages) are more likely to be partly or fully funded by private health insurance (58.3 per cent) or self- funded (9.6 per cent) compared with all female hospitalisations (all ages) for any cause (40.4 per cent partly or fully funded private health insurance, 4.3 per cent self-funded).[64]

Private sector access or wait list data for gynaecology is not publicly available. Primary care access and management of women's sexual and reproductive health (including gynaecology related conditions) is not publicly available or readily accessible.

Glossary

AIHW	Australian Institute of Health and Welfare
CEC	Canberra Endometriosis Centre
CHARM	Canberra Health Annual Research Meeting
CPD	Continuing Professional Development
CPP	Chronic or persistent pelvic pain
ED	Emergency department
EPP	Endometriosis Pelvic Pain
FTE	Full-time equivalent
GP	General practitioner
GST	Goods and Services tax
HCSD	ACT Health and Community Services Directorate
LARC	Long Acting Reversible Contraception
OCAHO	Office of the Chief Allied Health Officer, HCSD
OCHO	Office of the Chief Health Officer, HCSD
PCOS	Polycystic ovary syndrome
PIPA	Period ImPact and Pain Assessment
RACGP	Royal Australian College of General Practitioners
SHFPACT	Sexual Health and Family Planning ACT
STI	Sexually transmitted infection
WHM	Women's Health Matters

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