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Submission to the Legislative Assembly for the Australian Capital Territory Standing Committee on Social Policy

Inquiry into Endometriosis and Other Pelvic Pain Conditions

ACKNOWLEDGEMENT OF COUNTRY

As a proud Wiradjuri woman, I celebrate the lands and waters that give us life; into which the songlines, stories, and Dreamings of Aboriginal and Torres Strait Islander peoples are woven, and pay my respect to all Elders, past and present, for their knowledge and custodianship of Country. I commit to walking together in partnership, guided by principles of truth-telling, self-determination, and cultural safety.

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EXECUTIVE SUMMARY

Endometriosis, adenomyosis, polycystic ovary syndrome (PCOS), and other chronic pelvic pain conditions represent a substantial and persistent public health burden in the Australian Capital Territory (ACT). These conditions are widespread, chronic, and clinically significant, but the harms associated with them are not evenly distributed. Instead, outcomes are shaped by the interaction of gendered health systems with race, culture, disability, socioeconomic position, age, and gender identity. As a result, pelvic pain conditions function not only as clinical issues, but as structural equity challenges.

Evidence indicates that a significant proportion of people assigned female at birth in the ACT experience endometriosis, PCOS, adenomyosis, or chronic pelvic pain across the life course, with prevalence estimates likely to understate true burden due to underdiagnosis and data gaps. Diagnostic delay remains a defining feature of these conditions, with significant consequences for disease progression, treatment effectiveness, and quality of life. As outlined in Section 3, this delay is structurally produced through primary care gatekeeping, gendered bias in pain assessment, and constrained referral pathways, rather than individual help-seeking behaviour or lack of symptom severity. These dynamics are intensified for people whose identities or social positions already attract disbelief or misrecognition, including First Nations people, migrants and refugees, people with disability, young people, people in larger bodies, and gender-diverse individuals. In these contexts, pain is more likely to be dismissed, symptoms reframed as psychological or behavioural, and access to investigation delayed or denied.

The ACT's health system context shapes how these inequities are produced and experienced. While geographic access is comparatively high, the Territory's compact and centralised system is characterised by workforce scarcity, limited provider choice, and tightly networked referral pathways. These features mean that individual clinician bias, culturally unsafe practice, or service bottlenecks can have disproportionate and enduring effects. People with financial resources are more able to bypass public pathways and access private care, while those reliant on public services - disproportionately people on low incomes, students, people with disability, and single parents - face longer waits, fragmented care, and reduced continuity.

Access to effective treatment and long-term management further reflects structural inequality. Multidisciplinary care, allied health, and pain management supports are unevenly accessible, with affordability acting as a key stratifying factor. Treatment pathways that rely on self-funded diagnostics, private specialists, or ongoing out-of-pocket allied health care systematically advantage those with economic security while compounding harm for those already experiencing disadvantage. Fragmented care increases both physical and psychological burden, particularly for people with disability, trauma histories, or complex social needs.

Medical misogyny and gendered cultural norms operate across the care continuum, but their effects are not uniform. Aboriginal and Torres Strait Islander peoples experience pelvic pain within the context of colonisation, medical racism, and institutional mistrust. People from culturally and linguistically diverse communities face language barriers and culturally incongruent care models.

Gender-diverse people encounter cis-normative assumptions embedded in reproductive health services. Weight stigma further compounds delayed diagnosis and undertreatment for people with pelvic pain conditions, particularly where symptoms are misattributed to body size rather than investigated clinically. In the ACT context, limited provider choice magnifies the consequences of such bias once it occurs.

The social and economic impacts of pelvic pain conditions are profound. Educational disruption, constrained workforce participation, absenteeism, presenteeism, and income instability are common, with cumulative effects on economic security, superannuation, and social participation.

These impacts fall most heavily on those in insecure employment, without workplace flexibility, or with caring responsibilities, reinforcing existing gendered and class-based disadvantage.

Gaps in education and training for medical and allied health professionals contribute to delayed diagnosis and inappropriate care, while uneven access to menstrual and pelvic health education delays help-seeking and reinforces stigma. Research and data systems continue to under-represent marginalised populations, limiting the visibility of inequities and constraining effective service planning.

This submission identifies opportunities for the ACT to leverage its scale and centralised system to lead nationally in equity-informed service design, education, and research. A consolidated set of recommendations is proposed, focused on reducing diagnostic delay; strengthening integrated, multidisciplinary care; embedding cultural safety, gender affirmation, and disability inclusion into service design; addressing affordability and workforce constraints; improving education and accountability; mitigating social and economic impacts; and positioning the ACT as a leader in intersectional health policy and research.

Endometriosis, adenomyosis, PCOS, and chronic pelvic pain are not solely medical conditions. They are structural issues that sit at the intersection of health, education, employment, and social policy. Without an explicit equity-oriented approach, reforms risk improving average outcomes while leaving the most marginalised behind. With such an approach, the ACT has the opportunity to deliver care that is not only accessible in principle, but effective, safe, and just in practice.

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RECOMMENDATIONS

1. That the ACT Government expand and sustain integrated, multidisciplinary pelvic pain care models incorporating gynaecology, pain medicine, allied health, mental health and primary care, with clear pathways for continuity and long-term management.
2. That ACT Health embed intersectionality as a core principle of service planning, ensuring care models are culturally safe, gender-affirming, disability-inclusive, and responsive to socioeconomic disadvantage.
3. That ACT Health co-design and implement culturally safe pelvic pain pathways in partnership with:
    - Aboriginal and Torres Strait Islander communities,
    - CALD communities,
    - LGBTQIA+ and gender-diverse people,
    - people living with disability.
4. That the ACT Government address financial barriers across the care pathway, including out-of-pocket costs for diagnostics, allied health, and long-term management, to reduce inequitable reliance on private care.
5. That ACT Health invest in workforce development to address specialist scarcity, improve multidisciplinary capacity, and reduce the impact of individual clinician bias in a compact health system.
6. That ACT Health improve data collection, monitoring and evaluation for pelvic pain conditions, including:
    - better differentiation of diagnoses,
    - disaggregated equity data,
    - tracking of diagnostic delay, access and outcomes,
    - indigenous data sovereignty.
7. That ACT Health, professional colleges and education providers embed pelvic pain, gender bias, trauma-informed care and intersectionality into undergraduate education, continuing professional development, and accreditation standards.

8	That ACT Health and the Education Directorate strengthen age-appropriate, culturally tailored education on menstrual and pelvic health to support early recognition and help-seeking.
9	That the ACT Government explicitly recognise the education, employment, and productivity impacts of chronic pelvic pain and integrate flexible supports across health, education, employment and social policy.
10	That the ACT Government support and participate in intersectionally informed research and trials, leveraging the Territory's centralised system to contribute to national innovation while addressing local equity gaps.

1. INTRODUCTION

I am a long term (over 20 years) Canberra resident and an Adjunct Fellow of the Robinson Research Institute (RRI). The Institute conducts internationally recognised research in reproductive, maternal, and early childhood health, and addresses critical challenges in fertility, pregnancy outcomes, and early life health through innovative, evidence-based research conducted in Australia and internationally.

I am a reproductive medicine specialist and an early career researcher specialising in endometriosis and other chronic reproductive health conditions, with a particular focus on intersectionality, health equity, and the social and structural determinants of diagnosis, care, and outcomes. My work draws on interdisciplinary scholarship across public health, medical sociology, feminist health research, and health services research, and engages with both qualitative and quantitative evidence on chronic pelvic pain conditions.

My research examines how gender bias, medical misogyny, and broader social inequalities shape clinical encounters, diagnostic pathways, and access to treatment for endometriosis, adenomyosis, polycystic ovary syndrome (PCOS), and related pelvic pain conditions. In particular, I analyse how experiences and outcomes differ according to race and ethnicity, socioeconomic position, disability, migration status, gender identity, and trauma history, and how these factors intersect within healthcare systems.

This submission is provided in my capacity as a researcher with subject-matter expertise in endometriosis and chronic pelvic pain conditions. It is intended to assist the Committee by synthesising current evidence, identifying structural and systemic issues relevant to the ACT, and highlighting areas where policy and service reform may improve equity, effectiveness, and long-term outcomes

2. THE NUMBER OF WOMEN AND OTHER PEOPLE IN THE ACT WHO SUFFER FROM ENDOMETRIOSIS, ADENOMYOSIS, POLYCYSTIC OVARY SYNDROME AND OTHER CHRONIC PELVIC PAIN CONDITIONS

Chronic pelvic and reproductive health conditions represent a substantial yet historically under-recognised burden among women and people assigned female at birth in the Australian Capital Territory (ACT) (1,2). Conditions such as endometriosis, adenomyosis, and polycystic ovary syndrome (PCOS) are not rare or marginal; rather, they affect a significant proportion of the population and are frequently associated with persistent pain, delayed diagnosis, and long-term impacts on wellbeing, workforce participation, and health system utilisation.

National data indicate that endometriosis alone affects approximately one in seven women and people assigned female at birth in Australia by mid-adulthood (1). The Australian Institute of Health and Welfare reports that around 14% of this population will have received a diagnosis of endometriosis by their late forties, based on longitudinal cohort analysis, underscoring the condition’s status as a common chronic disease rather than a niche reproductive disorder. This national estimate is widely considered conservative, reflecting ongoing challenges in timely diagnosis and consistent data capture across health systems.

Local evidence suggests the burden in the ACT may be equal to or higher than national estimates. The 2025 Survey of Women’s Health in the ACT, conducted by Women’s Health Matters, found that approximately 19% of respondents reported having been diagnosed with or treated for endometriosis and/or adenomyosis at some point in their lives (2). While this figure reflects self-reported diagnosis or treatment rather than population-wide clinical prevalence, it nevertheless indicates that a substantial proportion of people in the ACT are living with these conditions and seeking care.

Adenomyosis, which commonly co-occurs with endometriosis and presents with heavy menstrual bleeding and chronic pelvic pain, remains poorly quantified at the population level. National reporting highlights significant limitations in routine data capture for adenomyosis, with many cases identified incidentally or coded alongside endometriosis in hospital data (1).

International clinical studies suggest prevalence rates ranging from approximately 11 to 19% in some sub-populations, depending on diagnostic criteria and imaging practices (3). The inclusion of adenomyosis within the ACT survey's combined measure reflects both its clinical overlap with endometriosis and its contribution to chronic pelvic pain burden.

Polycystic ovary syndrome is similarly prevalent and carries both reproductive and long-term metabolic implications. National and international evidence consistently estimates that PCOS affects between 8 and 14 % of women of reproductive age. ACT-specific survey data align with this range, with approximately 14% of respondents reporting a diagnosis or treatment history consistent with PCOS (2). This suggests that roughly one in seven people in the ACT sample have experienced PCOS, reinforcing its significance for primary care, specialist services, and preventive health planning.

Beyond discrete diagnoses, chronic or persistent pelvic pain represents a significant health issue in its own right. The ACT survey found that approximately 17% of respondents experienced persistent pelvic pain, defined as pain below the belly button lasting six months or more, within the previous two years. Notably, nearly two-thirds of those experiencing persistent pelvic pain reported missing work or study as a result, highlighting the condition's impact on participation, productivity, and economic security (2). International evidence supports these findings, with prevalence estimates for chronic pelvic pain ranging from around 5 to 26% depending on population and methodology, and with substantial documented societal and economic costs (4).

However, it is important to note that existing prevalence data, both nationally and in the ACT, do not adequately capture the full diversity of people affected by chronic pelvic pain conditions. Current datasets and surveys frequently under-represent Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse communities, trans and gender-diverse people, and people living with disability or chronic comorbidities (1,5).

These gaps reflect both limitations in data collection practices and broader barriers to diagnosis, including cultural safety concerns, gendered assumptions within clinical pathways, and diagnostic frameworks that do not adequately accommodate complex or intersecting health needs.

Prevalence estimates are further distorted by the under-recognition of pelvic pain conditions among people living in larger bodies. Weight stigma within healthcare contributes to delayed investigation and diagnostic overshadowing, with symptoms frequently attributed to body size rather than recognised as potential gynaecological pathology(6,7). As a result, larger-bodied people are less likely to receive timely diagnoses of endometriosis, adenomyosis, PCOS, or chronic pelvic pain, meaning they are systematically undercounted in administrative datasets and surveys that rely on confirmed diagnosis. This invisibility reinforces the misperception that these conditions are less prevalent in this population, when in fact underdiagnosis reflects structural barriers rather than true absence of disease.

These limitations constrain effective service planning in the ACT. Improving prevalence estimates and service responsiveness requires not only earlier and more consistent diagnostic pathways, but also more inclusive and culturally safe data practices that reflect the diversity of people experiencing pelvic pain conditions. Without improved visibility of these populations within routine data, the true scale and distribution of need will remain underestimated, with flow-on effects for resource allocation, workforce planning and equity-focused health policy.

3. 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

Access to timely diagnosis and effective treatment for endometriosis, adenomyosis, polycystic ovary syndrome (PCOS) and other chronic pelvic pain conditions in the ACT is constrained by a range of structural, clinical, and systemic barriers across the care continuum. These barriers do not function independently; rather, they form a reinforcing sequence that produces prolonged diagnostic delay, fragmented care, and inequitable outcomes.

Delays in primary care represent a foundational barrier in the ACT Health Service pathway (8–10). Endometriosis and chronic pelvic pain conditions can take many years to be diagnosed after symptom onset; international and Australian evidence consistently reports an average diagnostic delay of around 6 to 8 years, with some studies suggesting a typical delay of between 7 and 12 years from initial symptoms to professional diagnosis (1). This delay reflects limited recognition of symptoms in primary care, lack of validated symptom-based screening tools, and variability in clinician knowledge and training on pelvic pain conditions.

Primary care gatekeeping represents a critical pressure point. General Practitioners play a central role in recognising symptoms, initiating investigation, and referring to specialist services, yet primary care consultations may not allow sufficient time to explore complex menstrual and pelvic symptoms. Symptoms such as severe dysmenorrhoea, dyspareunia, heavy menstrual bleeding, and non-cyclical pain, which are core manifestations of endometriosis, are frequently normalised or dismissed as “just bad periods” rather than prompting early investigation (11). This normalisation is compounded by broader gender bias in medical diagnosis, where pain reported by women and people with uteruses may be more readily attributed to psychosocial causes than investigated as a biological pathology, leading to misdiagnosis and repeated consultations without escalation (12–14). The structural role of gender bias and medical misogyny is examined in Section 5.

For PCOS, diagnostic complexity is compounded by inconsistent application of diagnostic criteria and gaps in provider familiarity with endocrine and metabolic presentations, contributing to delays and dissatisfaction with care. Research on PCOS reflects gaps in physician knowledge on appropriate screening and comprehensive management, including recognition of associated metabolic and psychological impacts (15–19).

People living in larger bodies experience distinct and compounding barriers to diagnosis and access to treatment due to weight stigma and size-based discrimination within healthcare. Pelvic pain symptoms are frequently reframed as consequences of body size, lifestyle, or “deconditioning,” resulting in diagnostic overshadowing, delayed referral, and repeated cycles of conservative management without escalation. Evidence indicates that weight stigma is associated with diminished credibility of patient-reported pain and reduced diagnostic thoroughness, independent of clinical need (7). These dynamics intersect with medical misogyny, such that larger bodied women experience intensified dismissal of pain and prolonged delays in accessing specialist investigation and care (6,7,13).

While primary care is the initial gateway, diagnostic delay is often entrenched or resolved at the point of specialist referral, making specialist access a critical determinant of outcomes.

Barriers in access to specialist services further entrench delays in diagnosis and management. In the ACT, referral to public gynaecology outpatient clinics and specialist pain services is mediated through prioritisation frameworks that frequently favour acute, surgical, or fertility-related indications (10). This results in people with chronic pelvic pain being placed on extended waiting lists, with symptoms considered lower priority despite significant functional impairment. National advocacy reports highlight waiting lists, lack of access to public specialist services, and high out-of-pocket costs as persistent barriers that funnel individuals into private care or financial distress (20,21).

Where demand outstrips capacity in public pathways, many people pursue private specialist care, which can offer shorter wait times but creates inequity: out-of-pocket costs for consultations, imaging, and interventions can be substantial and unaffordable for people on lower incomes or without private health insurance. This bifurcation of service access reproduces inequity in the ACT context, with socioeconomic status influencing the timeliness and quality of diagnosis and treatment.

Multidisciplinary and ongoing pain management also face systemic obstacles. Chronic pelvic pain is increasingly recognised as a complex biopsychosocial condition that benefits from integrated care involving pain specialists, physiotherapists, mental health professionals, and primary care continuity (14,19,22,23). However, access to multidisciplinary pain services in the ACT and nationally is limited, with eligibility criteria sometimes excluding people whose pain is chronic but not deemed severe or complex enough. Fragmented referral pathways between gynaecology, pain medicine, allied health, and mental health services leave many reliant on episodic, rather than coordinated, care. National stakeholder consultations highlight that pathways to diagnosis and treatment can be “long and complex” with inadequate information and poor continuity of care after diagnosis (23).

Cost and affordability represent cross-cutting barriers. Many evidence-based interventions such as pelvic physiotherapy, psychological support, and hormonal therapies are partially subsidised or not subsidised, leading to significant out-of-pocket expenses for people seeking ongoing management. Costs associated with specialist consultations, allied health interventions, and imaging contribute to unequal access, particularly for those with chronic comorbidities and lower socioeconomic status. Barriers are further magnified for priority and under-served populations. Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse communities, trans and gender-diverse people, larger bodied people, and people living with disability often experience additional obstacles at multiple points in the care pathway due to cultural safety concerns, communication barriers, discrimination, and service design that does not reflect their lived experience. National consultation reports on women's health and pelvic pain identify that structural biases and lack of culturally safe, inclusive services discourage help-seeking and contribute to under-diagnosis and inequitable health outcomes (5).

Across the ACT Health Service pathway, barriers to diagnosis and treatment therefore operate not as isolated failures but as a reinforcing sequence: delayed recognition in primary care limits timely referral; constrained specialist capacity and affordability issues delay definitive diagnosis and treatment; fragmented pain management impedes effective long-term care; and inequitable access practices perpetuate disparities. Without coordinated, system-level reform that addresses these barriers collectively, improvements at any single point are unlikely to produce sustained gains in outcomes for people living with chronic pelvic and reproductive health conditions.

4. THE TREATMENT OPTIONS AND SUPPORTS AVAILABLE IN THE ACT COMPARED TO OTHER JURISDICTIONS, THEIR EVIDENCE-BASED EFFECTIVENESS AND POTENTIAL SIDE EFFECTS AND IMPACTS

ACCESS, QUALITY AND OUTCOMES IN PELVIC PAIN CARE

A comparison of the ACT with other Australian jurisdictions in the provision of care for endometriosis, adenomyosis, PCOS, and chronic pelvic pain must move beyond nominal service availability to interrogate how intersecting social locations shape access, treatment trajectories, and outcomes. While the ACT is aligned with national clinical models and guideline-based care, intersectional determinants operate differently within a small, centralised health system than within larger, more fragmented state systems. These differences have material consequences for equity, effectiveness, and patient experience.

At a national level, Australia's approach to pelvic pain and gynaecological conditions has been characterised by a gradual shift from episodic, specialty-driven care towards multidisciplinary, community-based models (1). The ACT's inclusion in the national Endometriosis and Pelvic Pain Clinics program reflects this shift and positions the Territory as broadly equivalent to other jurisdictions in policy terms. However, intersectionality reveals that equivalence in policy does not translate to equivalence in lived access. Rather, the interaction between individual identities and jurisdictional system characteristics produces distinct patterns of advantage and disadvantage.

Socioeconomic status intersects with jurisdictional scale in particularly salient ways. Across Australia, individuals with financial resources are better positioned to navigate fragmented care pathways, absorb out-of-pocket costs, and access private specialists, allied health services, and elective surgery (4,24). This pattern is well established in national data and is not unique to pelvic pain conditions. In the ACT, however, the concentration of specialist expertise within a small number of providers means that socioeconomic advantage can confer disproportionate benefit.

Those able to access private care can bypass capacity constraints in the public system entirely, while those reliant on publicly funded services may encounter prolonged waits due to limited workforce redundancy. In larger states, socioeconomic inequities are often compounded by geography; in the ACT, they are intensified by scarcity within proximity. This distinction is critical for policy analysis, as it suggests that geographic accessibility alone is an insufficient proxy for equity.

As outlined in Section 3, diagnostic delay is a national phenomenon. Jurisdictional structure determines whether this delay is produced through fragmentation (larger states) or through scarcity and epistemic concentration (ACT).

Aboriginal and Torres Strait Islander peoples experience intersecting forms of disadvantage that manifest differently across jurisdictions but remain structurally embedded nationwide (25). While the ACT does not face the same challenges of remoteness as many regions in other states, the absence of Aboriginal and Torres Strait Islander-led pelvic pain services and the lack of culturally specific diagnostic pathways reproduce inequity through other means. The invisibility of Aboriginal and Torres Strait Islander experiences of endometriosis, adenomyosis, and PCOS within both ACT and national data reflects a broader epistemic gap that undermines comparative assessment.

Larger jurisdictions may contend with geographic barriers and service scarcity in Aboriginal and Torres Strait Islander communities; the ACT contends with a subtler but equally consequential form of inequity rooted in cultural unsafety and under-recognition within mainstream services.

Culturally and linguistically diverse populations likewise experience jurisdictionally distinct but structurally related barriers. In larger states, higher CALD population density may justify the development of specialist services with embedded interpreter support and culturally tailored education, albeit inconsistently implemented. In the ACT, lower population density reduces the likelihood of such service differentiation.

As a result, CALD patients often rely on generalist services that may lack the time, training, or resources to address language barriers and culturally mediated expressions of pain. Intersectionality here operates through the interaction of migration status, gender norms, and service scale, rather than through simple availability.

The experiences of LGBTQIA+ and gender-diverse individuals further underscore how intersectionality complicates jurisdictional comparison. Nationally, pelvic pain and reproductive health services remain anchored in cis-normative assumptions, despite increasing recognition that these conditions affect people of diverse genders. In larger jurisdictions, patients may mitigate this barrier by seeking affirming providers or specialist clinics, even if doing so requires travel or extended wait times. In the ACT, limited provider numbers reduce this possibility, meaning that a single negative encounter can have outsized consequences for ongoing engagement with care. Thus, while the ACT's compact system may facilitate continuity for some patients, it can simultaneously constrain choice for those whose identities fall outside dominant norms.

Disability and chronic comorbidity shape both diagnostic pathways and treatment effectiveness for people with pelvic pain conditions. As discussed later in relation to treatment outcomes, individuals with overlapping physical and mental health conditions face heightened risk of diagnostic overshadowing and undertreatment, particularly in systems with limited capacity for prolonged or complex assessment.

Importantly, these dynamics shape not only access but treatment effectiveness and impact. Evidence-based interventions such as hormonal therapy, physiotherapy, and multidisciplinary pain management are less effective when delivered late, inconsistently, or without cultural and psychosocial safety. Side effects, whether physiological, psychological, or social, are also differentially distributed. For example, the mental health impacts of hormonal treatments may be exacerbated in individuals with trauma histories, insecure housing, or limited social support, all of which correlate with intersecting forms of disadvantage. These impacts are rarely captured in routine outcome measures but are central to understanding comparative effectiveness.

Taken together, an intersectional analysis reveals that the ACT's apparent parity with other Australian jurisdictions masks meaningful differences in how inequity is produced and sustained. Larger states contend with dispersion, fragmentation, and regional inequity; the ACT contends with concentration, scarcity, and limited choice. Neither model is inherently more equitable. Rather, equity outcomes depend on whether policy and service design explicitly account for how intersecting identities interact with local system characteristics.

This analysis has two implications. First, comparisons between jurisdictions must move beyond counting services or clinics and instead assess how different populations experience those services in practice. Second, reforms that are effective in larger jurisdictions may not translate directly to the ACT without adaptation to its scale and workforce constraints.

Intersectionality is therefore not an adjunct consideration, but a necessary analytical framework for interpreting comparative evidence and designing proportionate, context-sensitive responses.

TREATMENT EFFECTIVENESS AND SIDE-EFFECT BURDEN

Clinical effectiveness and adverse impact of treatments for endometriosis, adenomyosis, PCOS, and chronic pelvic pain are not solely determined by pharmacology or procedural technique. Rather, they are mediated by the interaction between treatment modality and patients' intersecting social, economic and cultural positions. An intersectional analysis therefore reveals systematic patterns in both diminished effectiveness and disproportionate side-effect burden, which manifest differently in the ACT compared with larger Australian jurisdictions.

Across Australia, socioeconomic status strongly shapes treatment effectiveness by determining when and how interventions are accessed (30). Evidence-based treatments for pelvic pain conditions such as hormonal suppression, pelvic physiotherapy, psychological therapies, and multidisciplinary pain management are most effective when delivered early, continuously, and in combination (31–34). Individuals with higher socioeconomic resources are more likely to access this sequencing; those with fewer resources often receive treatments in isolation or intermittently.

Consequently, clinical effectiveness in the ACT is heavily stratified by socioeconomic status. Patients able to self-fund private care can bypass the public waitlists described earlier, accessing treatment sequencing that halts disease progression. Conversely, those reliant on public services often face delays that result in treatment being delivered at a more advanced disease stage, reducing the responsiveness of interventions and necessitating a reliance on symptom suppression rather than definitive management.

Side-effect burden is also socially patterned. Hormonal therapies, while clinically appropriate, are more likely to produce unmanaged side effects (e.g. mood disturbance, fatigue, breakthrough bleeding) when patients lack continuity of care or the capacity for regular review. Financial precarity further amplifies psychosocial side effects, as treatment-related functional impairment can exacerbate employment insecurity and stress. This pattern is evident nationally but is intensified in the ACT due to limited alternative service pathways once public capacity is exceeded.

Intersectional identities including youth, disability, body size, racialisation, and socioeconomic disadvantage are associated with longer delays due to symptom dismissal and misattribution. In larger jurisdictions, delay is often compounded by repeated provider transitions; in the ACT, it more commonly reflects epistemic bias within a smaller clinical network. In both contexts, late intervention reduces treatment efficacy and increases the likelihood that patients will experience cumulative side effects from multiple therapeutic trials.

For example, repeated exposure to hormonal treatments without adequate diagnostic clarity increases the risk of mood disturbance and reduced quality of life, particularly among individuals with pre-existing mental health conditions or trauma histories. These effects are not incidental but structurally produced.

For Aboriginal and Torres Strait Islander peoples, intersectionality affects treatment effectiveness primarily through under-diagnosis and under-treatment rather than overt adverse effects. Limited cultural safety within mainstream gynaecological services contributes to delayed engagement, truncated assessments, and lower uptake of invasive interventions such as laparoscopy.
As a result, treatment pathways may skew towards conservative or symptomatic management, even where surgical or multidisciplinary intervention may be clinically indicated. This reduces effectiveness and shifts disease burden into chronic pain states, with associated impacts on physical functioning and mental health.

Side-effect burden may appear lower in aggregate data due to lower treatment exposure; however, this reflects unmet need rather than optimal care. In the ACT, where services are geographically accessible but not culturally differentiated, this pattern persists through invisibility rather than physical inaccessibility, contrasting with larger jurisdictions where remoteness plays a more visible role.
In culturally and linguistically diverse populations, treatment effectiveness is often undermined by miscommunication, culturally incongruent health models, and limited informed consent processes. Hormonal therapies and pain management strategies may be prescribed without adequate discussion of side effects or alternatives, reducing adherence and perceived efficacy.

Language barriers and culturally mediated expressions of pain can result in under-dosing, inappropriate treatment selection, or premature discontinuation. Side effects, particularly those affecting mood, weight or bleeding, may carry heightened social or cultural stigma, amplifying their impact and reducing tolerance.

In larger states, culturally specific services may partially mitigate these effects. In the ACT, smaller population size reduces service differentiation, meaning that CALD patients experience a higher reliance on generalist models that may not adequately accommodate cultural complexity. This leads to systematically reduced treatment effectiveness despite nominal access.

For transgender, non-binary, and gender-diverse individuals, cis-normative reproductive healthcare environments directly affect both treatment uptake and effectiveness. Hormonal treatments commonly used for endometriosis and PCOS may conflict with gender-affirming hormone regimens or exacerbate gender dysphoria, reducing acceptability and adherence.
Side-effect burden is therefore not limited to physiological effects but includes psychological distress, re-traumatisation, and disengagement from care. These impacts reduce treatment effectiveness even where clinical indications are clear.

In larger jurisdictions, patients may mitigate these effects by seeking affirming providers. In the ACT, limited provider choice magnifies the consequences of non-affirming care, leading to higher rates of treatment avoidance and untreated disease progression.

People with disability or chronic comorbid conditions experience a disproportionate side-effect burden across all treatment modalities. Hormonal therapies may exacerbate fatigue, autonomic symptoms, or mental health conditions; surgery may pose higher functional risk; and pain medications may interact adversely with existing regimens.
Treatment effectiveness is further reduced by diagnostic overshadowing, where pelvic pain is attributed to existing

conditions, delaying appropriate intervention. In the ACT, the potential for coordinated care within a smaller system is offset by limited time and capacity for complex case management, increasing reliance on simplified or conservative treatment approaches.

In larger states, fragmentation rather than scarcity is the dominant barrier, but the outcome, reduced effectiveness and increased adverse impact, is comparable.

Weight stigma also shapes the effectiveness and impact of available treatments. People living in larger bodies may encounter higher thresholds for diagnostic imaging, referral for surgical assessment, or access to multidisciplinary pain services, resulting in later-stage intervention and reduced responsiveness to treatment. Where care is delayed, individuals are more likely to cycle through hormonal or symptomatic therapies without diagnostic clarity, increasing cumulative side-effect burden without commensurate benefit. These outcomes are not inherent to body size, but are produced by systems that restrict access and delay care for larger bodied patients, a pattern that may be amplified in the ACT due to limited alternative service pathways once public capacity is exceeded.

Crucially, intersectional disadvantage compounds over time. Individuals experiencing multiple forms of marginalisation are more likely to:

- Receive treatment later
- Cycle through multiple therapies without resolution
- Accumulate side effects without commensurate benefit
- Exit the health system due to treatment fatigue or harm.

These cumulative effects are not captured in traditional efficacy metrics but are central to understanding real-world effectiveness. In the ACT, constrained service options mean that cumulative harm may manifest as stagnation within limited pathways; in larger jurisdictions, it may manifest as endless cycling through disconnected services.

Treatment effectiveness and side-effect burden are socially patterned outcomes, not neutral clinical endpoints. The ACT's compact system reduces geographic barriers but amplifies the consequences of workforce scarcity and limited choice, particularly for patients whose intersecting identities require tailored, culturally safe, or gender affirming care. Larger jurisdictions offer greater variation but introduce geographic and navigational inequities that similarly reduce effectiveness.

Equity-adjusted effectiveness should be the benchmark for comparison between jurisdictions. Without explicit attention to intersectionality, reforms risk improving average outcomes while entrenching disproportionate harm among those least able to absorb treatment failure or side effects.

5. THE ROLE OF MEDICAL MISOGYNY, UNDERLYING GENDER BIASES IN HEALTHCARE AND CULTURAL NORMS THAT CREATE BARRIERS FOR WOMEN WITH THESE CONDITIONS

The persistent under-recognition and undertreatment of endometriosis, adenomyosis, PCOS, and chronic pelvic pain are not solely products of biomedical complexity or system fragmentation; they are deeply rooted in medical misogyny, gendered biases within healthcare, and culturally mediated norms around menstruation, reproductive health, and women's pain. These forces operate simultaneously at individual, institutional, and structural levels, producing patterns of disadvantage that intersect with socioeconomic status, race, age, disability, sexuality, and other axes of marginalisation. Understanding these dynamics is essential for interpreting access, treatment trajectories, and outcomes in the ACT and across Australian jurisdictions.

Medical misogyny manifests in both overt and subtle ways within clinical encounters. Historically, women's pain, particularly pain associated with reproductive organs, has been minimised, normalised, or attributed to emotional instability. Symptoms described by patients are frequently dismissed as "psychosomatic" or interpreted as exaggeration, leading to prolonged diagnostic delay and inadequate treatment. In smaller, centralised systems like the ACT, these biases may be amplified: fewer specialist providers mean that individual epistemic biases within a concentrated clinical network can have disproportionate consequences for patients who are already marginalised along intersecting axes such as age, disability, cultural background, or economic insecurity. Unlike larger jurisdictions, where repeated provider transitions may introduce delay through fragmentation, the ACT's compact network amplifies the impact of a single biased encounter, potentially delaying referral, investigation, and intervention, disproportionately affecting those who cannot navigate alternative pathways due to intersecting disadvantages.

Gender norms embedded in healthcare structures further exacerbate inequity. Biomedical training and clinical practice often implicitly prioritise cis-normative, reproductive-age women as the "default" patient, marginalising both gender-diverse individuals and those whose symptom presentations do not align with classical textbook patterns. For instance, hormonal therapies for endometriosis or PCOS may conflict with gender-affirming hormone regimens, creating barriers to adherence and engagement for transgender and non-binary patients. Even for cisgender women, the prioritisation of fertility-related outcomes over pain relief or functional recovery reflects a gendered hierarchy of health needs, whereby reproductive potential is valued above quality of life, autonomy, and psychosocial well-being. These structural biases shape not only clinical decision-making but also the development of guidelines, research priorities, and health system performance metrics, which historically have focused on objective, fertility-centred outcomes rather than patient-reported pain, functional impairment, or psychosocial burden, effects that are amplified for patients facing intersecting disadvantage.

Cultural norms around menstruation, fertility, and “stoicism” contribute to the social legitimisation of diagnostic delay and undertreatment. Across Australia, societal expectations that women tolerate pain, coupled with stigma around reproductive health, normalise suffering and discourage advocacy for timely care (13,14,26,34,35). Medical misogyny intersects powerfully with weight stigma, creating a unique burden for women living in larger bodies. As noted in Section 3, this frequently results in diagnostic overshadowing; however, the driver of this barrier is often a gendered moralisation of body size. Larger female bodies are frequently viewed through narratives of personal responsibility and failure of self-control, which erodes the credibility of their pain reporting. Consequently, symptoms are not only attributed to weight but are dismissed as a lifestyle issue rather than legitimate pathology, delaying access to specialist investigation and reinforcing medical gender bias.

Patients from CALD backgrounds often experience compounded effects, where language barriers, health literacy, and culturally mediated understandings of pain intersect with gendered expectations, resulting in both under-recognition and misattribution of symptoms.

Similarly, Aboriginal and Torres Strait Islander women face the dual impact of gendered and racialised epistemic bias: their pain is frequently minimised, and culturally unsafe clinical environments discourage disclosure and engagement with mainstream services. In both cases, the intersection of gender with race, culture, language, and historical marginalisation produces barriers that are qualitatively different from those experienced by socioeconomically advantaged, cisgender, or majority-culture patients. In the ACT, where geographic accessibility is relatively high, these barriers persist through relational, institutional, and cultural mechanisms rather than physical isolation, underscoring that equity cannot be assessed solely by service proximity.

Medical misogyny also shapes treatment trajectories and outcomes. Gendered assumptions influence prescribing patterns, referral to allied health, and eligibility for surgical intervention. Women presenting with overlapping conditions, such as chronic fatigue, autoimmune disease, or mental health comorbidity, are at heightened risk of diagnostic overshadowing, where pelvic pain is attributed to pre-existing conditions rather than investigated as a primary pathology. Intersectional disadvantage compounds this effect: younger women, economically insecure women, women with disability, Aboriginal and Torres Strait Islander women, and culturally marginalised women face higher likelihoods of serial misattribution, fragmented care, and exposure to ineffective or purely symptomatic management strategies. The result is a cumulative burden of untreated disease, repeated exposure to side effects from multiple therapies, and erosion of trust in the health system.

Medical misogyny also structures the research and evidence base. Clinical trials, treatment guidelines, and outcome metrics have historically privileged interventions amenable to standardisation or short-term measurement, often ignoring chronic pain experiences, psychosocial outcomes, and culturally specific responses to therapy. This epistemic gap produces a feedback loop: under-recognition in research reinforces under-treatment in practice, and interventions are designed to fit a narrow, often male-centred or cis-normative model of care. In the ACT, the consequences are amplified by system scale: fewer local research initiatives, limited specialist services, and constrained workforce diversity mean that structural bias has a proportionally greater effect on patients with intersecting social, economic, or cultural disadvantage.

Finally, medical misogyny and gender bias intersect with other axes of disadvantage to shape not only access but treatment effectiveness and side-effect burden. Hormonal therapies, surgical interventions, and pain management strategies are less effective when delivered late, inconsistently, or in environments lacking cultural and psychosocial safety. Women with histories of trauma, economic precarity, disability, or limited social support experience amplified psychosocial side effects, which are rarely captured in routine outcome measures but are central to real-world effectiveness.

Taken together, the role of medical misogyny, gendered biases, and culturally entrenched norms is fundamentally intersectional and central to understanding inequities in pelvic pain care. They operate across individual, institutional, and systemic levels, shaping diagnostic delay, treatment pathways, side-effect burden, and patient experience differently depending on intersecting social locations. Effective reform in the ACT requires explicit recognition of these forces, integration of gender-, culture-, and disability-sensitive frameworks into service planning, and accountability mechanisms that measure equity-adjusted outcomes rather than nominal access or policy alignment. Only by confronting the gendered, cultural, and intersectional determinants of care can the ACT achieve outcomes equivalent not just in service availability, but in lived access, treatment effectiveness, and patient-centred equity.

6. THE ECONOMIC AND SOCIAL IMPACTS OF PEOPLE IN THE ACT WITH THESE CONDITIONS, INCLUDING EDUCATION, EMPLOYMENT AND LOST PRODUCTIVITY

Endometriosis, adenomyosis, PCOS, and chronic pelvic pain impose substantial economic and social burdens on individuals, households, and the broader community. These burdens extend beyond direct medical costs to include impacts on education, employment, productivity, and social participation. Importantly, these impacts are shaped by intersecting social determinants, including socioeconomic status, gender identity, cultural background, disability, age, and geographic location, producing unequal consequences across populations in the ACT.

Pelvic pain conditions frequently emerge during adolescence and early adulthood, critical periods for educational attainment. Pain-related absenteeism, fatigue, cognitive impairment from chronic pain or hormonal treatments, and healthcare appointments disrupt schooling, tertiary study, and vocational training. For students from lower socioeconomic backgrounds, the impact is compounded by limited access to private healthcare, learning support services, or flexible study arrangements, resulting in higher risk of delayed progression, reduced completion rates, or early exit from education.

Intersectionality further shapes these outcomes. For example, young people from CALD backgrounds may face language barriers, culturally mediated expectations to tolerate pain silently, or limited family support, increasing the likelihood of educational disruption. Students with disability or chronic comorbidities experience amplified disadvantage, as pain-related absenteeism interacts with pre-existing learning or mobility challenges, creating cumulative barriers to educational engagement. Aboriginal and Torres Strait Islander students in the ACT, while geographically concentrated, may encounter culturally unsafe educational environments, limited recognition of health needs, and systemic barriers to accommodations, all of which exacerbate the social cost of disease.

The employment trajectories of individuals with pelvic pain conditions are similarly affected. Chronic pain, fatigue, and fluctuating symptom severity contribute to reduced workforce participation, lower hours of employment, and career interruptions, including extended leave or resignation. Women and gender-diverse individuals in precarious or casual employment are particularly vulnerable, as symptom-driven absenteeism may threaten job security, income stability, or career advancement.

Socioeconomic position, employment type, and workplace flexibility intersect with disease burden. For instance, individuals in high-demand, inflexible roles or without access to paid sick leave (often young women, culturally marginalised workers, or those with lower education) face disproportionate economic consequences. Gender identity intersects with treatment needs: transgender and non-binary employees may face additional barriers if healthcare appointments or treatment regimens conflict with rigid work schedules, or if workplace discrimination exacerbates the psychosocial impact of chronic conditions.

Chronic pelvic pain and related conditions generate substantial lost productivity, both through absenteeism and presenteeism. Even when individuals remain in employment or study, pain, fatigue, and treatment side effects reduce concentration, task completion, and engagement, representing an invisible but significant economic cost. National modelling suggests that cumulative productivity losses for endometriosis alone amount to billions annually (1,4); within the ACT, these costs are proportionally significant given the Territory’s concentrated workforce and high per-capita employment rates.

Size-based discrimination further compounds the economic and social impacts of pelvic pain conditions. Larger bodied people experience higher levels of workplace stigma, reduced access to accommodations, and increased scrutiny of absenteeism, which amplifies the productivity and income impacts of chronic pain. When pelvic pain is compounded by weight stigma, individuals may be perceived as less credible or less deserving of flexibility, contributing to presenteeism, burnout, and workforce attrition. These effects intersect with gender, socioeconomic insecurity, and disability, producing cumulative and preventable economic harm over time.

Intersectionality shapes these economic impacts. Individuals experiencing compounded disadvantage, for example, younger people in casual employment, with limited financial resources, or with disability, bear higher cumulative productivity losses due to restricted access to early diagnosis, delayed treatment, or fragmented care pathways. In contrast, higher-income individuals with flexible work arrangements or private healthcare access may mitigate these losses through early intervention, treatment sequencing, or leave arrangements. Cultural expectations also influence engagement: CALD and Aboriginal and Torres Strait Islander workers may feel compelled to attend work despite pain due to family obligations, workplace discrimination, or mistrust of employer accommodations, further amplifying presenteeism and associated economic burden.

Beyond education and employment, pelvic pain conditions constrain social participation, leisure, and family engagement, producing psychosocial and relational costs that disproportionately affect those with intersecting disadvantage. Chronic pain can limit participation in community, sporting, or cultural activities; disrupt caregiving responsibilities; and reduce social connectedness. For individuals from culturally marginalised communities, social stigma around reproductive health, menstruation, or chronic pain may compound isolation, reinforcing marginalisation. Women with caregiving responsibilities, particularly those experiencing economic precarity, face amplified strain, as symptom burden interacts with family obligations and limited access to supportive services.

The economic and social impacts of these conditions are not evenly distributed. Intersectional disadvantage compounds outcomes across domains:

- Socioeconomic status influences the ability to absorb income loss, access private healthcare, or negotiate flexible work or study arrangements.

- Cultural and linguistic background shapes access to supportive services, health literacy, and the ability to navigate complex healthcare and employment systems.
- Gender identity interacts with treatment regimens, workplace discrimination, and societal expectations, affecting both productivity and psychosocial outcomes.
- Disability and comorbidity exacerbate absenteeism, presenteeism, and social isolation, magnifying economic and social costs over time.

In the ACT, where healthcare services are geographically concentrated, access is theoretically easier than in larger, more dispersed jurisdictions. However, service scarcity, workforce concentration, and limited culturally safe or gender-affirming pathways mean that intersectional disadvantage can translate into amplified social and economic consequences for those reliant on public services or lacking the resources to self-manage or seek private care.

Understanding the economic and social burden of endometriosis, adenomyosis, PCOS, and chronic pelvic pain in the ACT requires an intersectional lens. Economic loss, educational disruption, reduced employment participation, productivity decline, and constrained social engagement are mediated not only by disease severity and treatment access but also by intersecting social determinants including socioeconomic status, cultural identity, gender identity, age, and disability. Policies and service reforms must therefore address both clinical and social determinants, incorporating flexible, culturally safe, and gender-affirming approaches to minimise cumulative disadvantage and optimise economic, educational, and social outcomes for all affected populations.

7. EDUCATION AVAILABLE TO MEDICAL PROFESSIONALS, ALLIED HEALTH PROFESSIONALS, YOUNG WOMEN AND OTHERS, ON THESE CONDITIONS AND TREATMENT OPTIONS

Education and awareness are central to improving diagnosis, treatment, and lived experience for individuals with endometriosis, adenomyosis, PCOS, and chronic pelvic pain (1,33). Current gaps in knowledge and training across medical professionals, allied health practitioners, young people, and broader community stakeholders contribute to diagnostic delay, suboptimal treatment, and inequitable outcomes. These gaps are amplified when intersecting disadvantage such as socioeconomic status, cultural and linguistic background, gender identity, age, disability, and geographic location, interact with systemic barriers.

Despite national guidelines and clinical models, education on pelvic pain conditions remains inconsistent (34,35). Among general practitioners, gynaecologists, physiotherapists, pain specialists, and mental health professionals, there are well-documented deficiencies in recognising the full spectrum of symptom presentations, understanding overlapping conditions, and providing trauma-informed, gender-sensitive care.

Intersectionality shapes both access to education and the consequences of knowledge gaps. For example:

- Practitioners serving CALD or Aboriginal and Torres Strait Islander populations may require specific training to understand culturally mediated expressions of pain, health beliefs, and communication barriers. Without such training, diagnostic and treatment inequities are perpetuated.

- Gender-diverse and transgender patients are often excluded from traditional education on endometriosis, PCOS, and pelvic pain, meaning clinicians may not consider gender-affirming treatments, interactions with hormone therapy, or the psychosocial impacts of care environments.

- Providers working in smaller jurisdictions such as the ACT may face limited peer learning opportunities or fewer specialist mentors, amplifying the consequences of individual epistemic bias. In a concentrated system, a single clinician’s lack of knowledge can disproportionately affect patient trajectories.

Nationally, professional education programs are often episodic, specialty-specific, and focused on biomedical management rather than holistic, patient-centred care (34,36–39). This narrow approach fails to equip practitioners to address social determinants of health, intersectional disadvantage, or the cumulative psychosocial burden of pelvic pain. Consequently, even when evidence-based treatments are theoretically available, their real-world effectiveness is compromised for those experiencing intersecting disadvantages.

Education gaps also persist in relation to weight stigma and its impact on diagnosis and care (6,7,40). Many clinicians receive limited training on recognising and mitigating size-based bias, resulting in the misattribution of pelvic pain symptoms to body size rather than appropriate investigation. Without explicit education on weight stigma, diagnostic overshadowing, and the interaction between body size, gender bias, and chronic pain, well-intentioned practitioners may inadvertently perpetuate delayed diagnosis and inequitable care. Addressing pelvic pain education therefore requires explicit inclusion of size-based discrimination alongside gender bias, cultural safety, and trauma-informed practice.

Education for young women, adolescents, and other potential patients remains a critical gap. Early recognition of symptoms can reduce diagnostic delay and improve treatment outcomes (41,42). However, intersectional factors shape both access to, and efficacy of, educational initiatives:

- Socioeconomic status: Young people from lower-income households may have limited access to school-based health education, private healthcare, or online resources.

- Cultural and linguistic background: CALD adolescents may lack resources in their first language or culturally tailored materials, reducing awareness of what constitutes abnormal menstrual or pelvic pain.

- Aboriginal and Torres Strait Islander status: Aboriginal and Torres Strait Islander young people often face culturally unsafe educational environments, limited access to health promotion programs, and intergenerational mistrust of mainstream healthcare systems.

- Disability or chronic comorbidity: Adolescents with physical or cognitive disabilities may have additional barriers to accessing information in accessible formats.

Social norms and gendered expectations compound these gaps. Across communities, menstrual pain and reproductive health issues are frequently minimised or considered private, discouraging self-advocacy, disclosure to caregivers or clinicians, and early intervention (13,43). Educational initiatives that fail to consider these norms risk further entrenching inequities, particularly for individuals navigating multiple axes of marginalisation.

Effective education must encompass both clinical and social dimensions:

- Clinical knowledge: symptom recognition, diagnostic pathways, treatment sequencing, side-effect management, multidisciplinary care, and trauma-informed approaches.

- Social and cultural competence: understanding how socioeconomic, cultural, gender, and disability factors affect presentation, access, adherence, and outcomes.

- Patient empowerment: teaching young people and communities about self-advocacy, health literacy, and navigating care pathways.

Delivery methods must also account for intersectional realities:

- Medical and allied health education should combine formal curricula, mentorship, case-based learning, and simulation, with embedded content on diversity, cultural safety, and gender inclusivity.

- Community and adolescent education should be delivered through multiple channels: schools, online platforms, social media, and community organisations with materials tailored to language, literacy, and cultural context.

- Flexible and accessible formats, including multilingual resources, plain-language guides, and disability-adapted content, are essential to reach marginalised groups.

Gaps in professional and community education perpetuate inequities in diagnosis, treatment effectiveness, and patient experience. For instance:

- Young people from low-income households or CALD backgrounds may present later with advanced disease due to lack of awareness.

- Aboriginal and Torres Strait Islander patients may experience delayed referral or culturally unsafe encounters due to clinician knowledge gaps.

- Gender-diverse patients may avoid engagement entirely if healthcare providers lack understanding of gender-affirming approaches.

- Patients with disability may receive incomplete assessments or fragmented care when providers are not trained in managing complex, overlapping conditions.

Education on endometriosis, adenomyosis, PCOS, and chronic pelvic pain is not merely a clinical imperative but a structural intervention to reduce inequities and improve outcomes. Intersectional analysis demonstrates that disparities in provider knowledge, community awareness, and adolescent education intersect with social determinants to shape diagnostic delay, treatment pathways, adherence, and psychosocial impact.

To be effective in the ACT, educational initiatives must be comprehensive, continuous, culturally safe, gender-affirming, and tailored to address intersectional disadvantage. Only by embedding these principles across professional training, allied health curricula, and community outreach can the Territory ensure equitable access to knowledge, timely diagnosis, and effective, patient-centred care.

8. RESEARCH AND TRIALS CURRENTLY BEING EXPLORED IN AUSTRALIA AND OPPORTUNITIES FOR THIS TO TAKE PLACE IN THE ACT

Australian research on endometriosis, adenomyosis, PCOS, and chronic pelvic pain is expanding in scope and sophistication, encompassing biomedical innovation, diagnostic technologies, health systems research, epidemiology, and psychosocial dimensions of lived experience. These research efforts respond to well-documented gaps in diagnostics, treatment effectiveness, and long-term outcomes, but they also reveal critical structural and epistemic patterns. Namely, that traditional research paradigms have under-represented diverse populations, marginalised communities, and intersectional determinants that shape morbidity, access, and outcomes. Embedding intersectionality into research design, implementation, and translation is therefore essential for generating evidence that meaningfully improves care for all affected populations, including those in the ACT.

AUSTRALIAN RESEARCH LANDSCAPE: LEADING PROJECTS AND GAPS

At the national level, research spans multiple domains:

- Biomedical and diagnostic innovation, including work aimed at reducing diagnostic delay through non-invasive technologies. A key example is the IMAGENDO® research program led by Professor Louise Hull, Associate Professor Jodie Avery, and colleagues at the Adelaide University’s Robinson Research Institute, which is developing a machine learning-based medical imaging tool to diagnose endometriosis earlier and without surgical intervention. This project combines specialist ultrasound, magnetic resonance imaging (MRI), and artificial intelligence (AI) to identify endometriosis lesions, with the aim of reducing diagnostic delay and improving clinical pathways.

- Upskilling and implementation research, such as the development of AIMEE (AI Mentor for Endometriosis Ultrasound Education) – an AI-powered e-learning application designed to support sonographers in identifying endometriosis on ultrasound imaging. This initiative addresses workforce capacity gaps and complements broader diagnostic innovation.

- Digital health and community-engaged research, including the EndoZone platform coordinated at the Robinson Research Institute, which supports symptom tracking, patient-clinician communication, and self-management strategies driven by community-identified priorities.
- Interdisciplinary collaborations, such as the Human-Artificial Intelligence Collaborative Multi-modal Multi-rater Learning (HAICOMM) approach to endometriosis classification that integrates clinician expertise with machine learning methods.

Despite these advances, several gaps persist in the Australian research ecosystem:

- Under-representation of diverse populations in trials and cohorts, particularly Aboriginal and Torres Strait Islander peoples, CALD communities, gender-diverse individuals, and those with disability.
- Limited focus on intersectional determinants such as socioeconomic status, rurality, disability, and gender identity in analyses of treatment response, quality of life, or long-term health and social outcomes.
- Insufficient integration of social science, health services research, and economic analysis into clinical trials and translational studies, which limits understanding of how systemic inequities shape lived experience and outcomes.
- Weight stigma and body size are also insufficiently addressed in current research and trial design. Many studies exclude or underrepresent people living in larger bodies, or fail to analyse how size-based discrimination shapes diagnostic pathways, treatment access, and outcomes.

- These gaps constrain the equity and generalisability of findings, perpetuating knowledge hierarchies that reflect dominant populations while marginalising the experiences of those with intersecting vulnerabilities.

OPPORTUNITIES FOR RESEARCH AND TRIALS IN THE ACT

The ACT is well-positioned to contribute meaningfully to Australian research on pelvic pain conditions, and to address specific inequities through strategic investment and partnerships:

- *Establish an ACT research node or collaborative hub.* The ACT's centralised health system, concentration of specialist services, and linked tertiary institutions (including partnerships with national research bodies) create an opportunity to host a coordinated research node focused on pelvic pain conditions. This hub could support locally led clinical trials, health systems research, and longitudinal cohort studies that integrate clinical, psychosocial, and socioeconomic data.

- *Leverage national initiatives such as IMAGENDO®.* The ACT can participate in, or contribute data to, national and international research consortia like IMAGENDO®, ensuring that study populations include individuals from the Territory with diverse socioeconomic, cultural, and gender identities. This engagement can enhance the representativeness of algorithms and diagnostic tools, reducing bias, and improving applicability to marginalised populations.

- *Expand intersectional research frameworks.* ACT-based research should prioritise intersectional designs that explicitly recruit and analyse outcomes for Aboriginal and Torres Strait Islander peoples, CALD communities, gender-diverse individuals, and those with disability. Co-designed research governance structures with these communities can ensure cultural safety, relevance, and ethical engagement.

- *Integrate health services and policy research.* The ACT research agenda should include studies of service delivery models, workforce capability (including training needs for AI-enabled diagnostics like AIMEE), and the impacts of health system characteristics such as service scarcity and concentration on diagnostic delay and treatment pathways.

- *Build local capacity for long-term, patient-centred outcomes research*. Longitudinal studies that document outcomes across education, employment, mental health, and quality of life, disaggregated by intersecting social determinants, will provide critical evidence for policy and program design. These studies can align with national research frameworks and health data infrastructure initiatives to ensure comparability and scalability.

- *Foster transdisciplinary collaboration and translation.* Bringing together clinicians, allied health providers, AI and imaging specialists, social scientists, epidemiologists, and community representatives in ACT-based research will enhance the relevance, translation, and uptake of findings into policy and practice.

INTERSECTIONAL IMPERATIVES FOR ACT RESEARCH

Applying an intersectional lens means more than disaggregating data; it requires embedding equity at every stage of research, including:

- Participant recruitment strategies that proactively include under-represented groups through targeted outreach, community partnerships, and culturally safe consent processes.

- Outcome measurement frameworks that incorporate social and economic dimensions of disease burden (e.g., educational disruption, employment participation, psychosocial wellbeing).

- Co-design and governance that involve patients and communities not just as subjects but as partners in setting research priorities, interpreting findings, and disseminating results.

The current Australian research landscape, exemplified by innovative programs like IMAGENDO® and other work at the Robinson Research Institute, illustrates the potential to transform diagnosis and care for pelvic pain conditions. However, to realise this potential equitably, research must go beyond technological innovation to address the social, cultural, and structural determinants that shape health inequities. The ACT, with its centralised services and policy commitment to equity, has an opportunity to be at the forefront of intersectional pelvic pain research, generating evidence that not only improves clinical outcomes but also informs systems change that benefits all populations, particularly those historically marginalised or underserved.

9. OTHER RELATED ISSUES - ACT-SPECIFIC STRUCTURAL AND JURISDICTIONAL CONSIDERATIONS

Beyond the core Terms of Reference, several structural features unique to the ACT merit explicit consideration in understanding and addressing pelvic pain conditions. These issues emerge from the Territory's distinctive governance arrangements, its geographic and economic relationship with surrounding regions, and its population characteristics.

INTERSTATE PATIENT FLOWS AND CROSS-BORDER CARE

The NSW-ACT Interface

The ACT's proximity to southern NSW creates distinctive care-seeking patterns not present in other jurisdictions. Evidence suggests that:

- Outward flow: ACT residents, particularly those with private health insurance or financial resources, frequently access specialist gynaecological and pain management services in Sydney, Wollongong, or southern NSW regional centers when ACT public wait times are extended or when seeking specific expertise not available locally.
- Information asymmetry: This interstate care-seeking is not systematically captured in ACT health data, meaning that the true burden of unmet need and the financial costs borne by ACT residents remain invisible to Territory health planning.
- Equity implications: Outward flow privileges those with transport access, financial capacity to travel, and ability to navigate unfamiliar health systems. Aboriginal and Torres Strait Islander peoples, CALD communities, people with disability, and those on lower incomes are systematically disadvantaged in accessing interstate care.

Recommendations:

- Establish reciprocal care pathways with NSW tertiary centers to formalize referral processes and ensure continuity
- Track interstate service utilization through Medicare and private health insurance data
- Subsidize travel and accommodation for ACT residents requiring specialized care not available locally
- Develop telehealth partnerships with NSW specialist services to reduce need for travel

PRIVATE HEALTH INSURANCE ACCESS AND AFFORDABILITY

The ACT has Australia's highest median household income and one of the highest rates of private health insurance coverage. However, this aggregate statistic masks significant inequity:

- Bifurcated system: High private health insurance rates create a two-tier system where those with coverage can bypass public wait times, while those without coverage (disproportionately younger people, students, temporary residents, single parents, and lower-income households) face extended delays.
- Out-of-pocket costs persist: Even with private health insurance, gap payments for specialist consultations, imaging, surgery, and allied health create financial barriers. These gaps are particularly high in the ACT due to limited provider competition.
- Temporary residents: The ACT's significant temporary visa holder population (students, diplomatic staff, temporary workers) face particular barriers, as they are ineligible for Medicare and may have limited private health insurance coverage or face waiting periods.

Recommendations:

- Conduct ACT-specific analysis of out-of-pocket costs by insurance status
- Expand public sector capacity to reduce reliance on private system for timely diagnosis
- Advocate for federal policy reform on Medicare eligibility for temporary residents with chronic conditions
- Create ACT Health hardship fund for uninsured or underinsured residents requiring essential pelvic pain care

WORKPLACE ACCOMMODATIONS IN THE ACT PUBLIC SERVICE

The ACT has the highest concentration of public sector employment in Australia, with approximately 25% of the workforce employed in the ACT Public Service (ACTPS), Commonwealth Government, or related sectors. This creates both opportunities and obligations:

Opportunities:
- The ACTPS can lead national practice in workplace accommodations for chronic pelvic pain
- Large, centralised employers can implement consistent policies across workforce
- Public sector employment generally offers better leave entitlements and flexibility than many private sector roles

Current gaps:
- No specific ACTPS policy on chronic pelvic pain or reproductive health conditions
- Variable manager awareness and support across directorates
- Invisible burden: presenteeism and productivity loss not captured
- Career progression impacts: chronic health conditions may affect performance assessments, promotion opportunities

Recommendations:
- Develop ACTPS enterprise agreement provisions specifically addressing chronic pelvic pain
- Create portable medical certification for chronic conditions to reduce repeated medical assessments
- Implement reasonable workplace adjustments framework (e.g., flexible hours, work-from-home, access to appropriate facilities)
- Train managers in chronic health condition awareness and accommodation
- Monitor workforce participation, retention, and progression data disaggregated by health status

TERTIARY EDUCATION IMPACTS AND SUPPORTS

The ACT's two major universities (ANU, University of Canberra) and CIT enroll significant student populations, many experiencing symptom onset or diagnostic delay during their studies:

Barriers identified:

- Limited awareness among student health services of pelvic pain conditions
- Inflexible assessment schedules and attendance requirements
- Financial stress: students have limited capacity to absorb health-related costs
- International students: face additional barriers including insurance limitations, cultural factors, and fear of visa implications

Missed opportunities:

- Universities not leveraging their research capacity to contribute to local evidence base
- Lack of integration between student health services and ACT Health services
- Limited peer support or student-led advocacy for affected students

Recommendations:

- Require ACT tertiary institutions to develop specific support frameworks for students with chronic pelvic pain
- Integrate pelvic pain education into student health services and orientation programs
- Create flexible assessment and attendance policies for students with chronic health conditions
- Establish research partnerships between ACT universities and health services

FEDERAL POLICY IMPACTS ON ACT HEALTH SYSTEM

As a Territory rather than a State, the ACT operates under distinctive constitutional and funding arrangements:

Unique vulnerabilities:

- Medicare Benefits Schedule: The ACT has limited influence over federal decisions about item numbers, rebates, and eligibility criteria that directly affect pelvic pain care affordability
- Pharmaceutical Benefits Scheme: Federal decisions about hormonal therapy subsidies, pain medication listings affect ACT residents but Territory has limited advocacy capacity

- National Disability Insurance Scheme: NDIS eligibility and funding decisions for people with chronic pelvic pain as primary or contributing disability
- Smaller voice: ACT's small population means limited political weight in national policy debates affecting women's health

Recent federal policy changes with ACT implications:
- Changes to Medicare rebates for allied health services
- NDIS eligibility tightening may affect people with severe chronic pelvic pain and associated disability
- National Women's Health Strategy implementation differs by jurisdiction

Recommendations:
- ACT Government advocate at national level for:
    - Expanded Medicare funding for multidisciplinary pelvic pain care
    - PBS listing of all evidence-based hormonal therapies
    - NDIS eligibility criteria recognising chronic pelvic pain as legitimate disability
- Participate in COAG Health Council processes to ensure small jurisdiction perspectives included
- Document ACT-specific impacts of federal policy decisions on pelvic pain outcomes

CLIMATE CHANGE AND ENVIRONMENTAL HEALTH CONSIDERATIONS

Emerging evidence suggests potential links between environmental factors and pelvic pain conditions:

Climate impacts:
- Extreme heat events may exacerbate pain symptoms
- Bushfire smoke exposure (increasingly frequent in ACT region) may affect inflammatory conditions
- Climate-related stress and trauma may interact with chronic pain conditions

Environmental justice:
- Environmental health risks are not evenly distributed; lower-income communities face greater exposure
- Aboriginal and Torres Strait Islander peoples experience disproportionate climate-related health impacts

Research gaps:
- Limited understanding of environmental determinants of endometriosis, adenomyosis, PCOS
- No ACT-specific research on climate-pelvic pain interactions

Recommendations:
- Include pelvic pain conditions in ACT climate and health adaptation planning
- Research links between environmental exposures and symptom exacerbation in ACT context
- Ensure climate-vulnerable populations have access to appropriate healthcare supports during extreme events

COVID-19 PANDEMIC LEGACY EFFECTS

The COVID-19 pandemic disrupted pelvic pain care in ways that continue to affect ACT residents:

Documented impacts:
- Delayed elective surgeries including diagnostic laparoscopies (backlog continues)
- Reduced GP consultations during lockdowns delayed symptom recognition and referral
- Mental health impacts compounding pelvic pain burden
- Telehealth expansion created both opportunities and barriers (digital access inequities)

Ongoing consequences:
- Extended wait times in public system due to surgical backlog
- Workforce burnout affecting specialist availability
- Changed care-seeking behavior (some patients now reluctant to present)

Recommendations:
- Conduct specific analysis of pandemic impacts on ACT pelvic pain diagnostic and surgical wait times
- Develop strategies to address surgical backlog prioritizing those with longest delays
- Optimise telehealth models while ensuring digital equity
- Support workforce recovery and retention

SMALL JURISDICTION ADVANTAGES: OPPORTUNITIES FOR INNOVATION

While this submission has highlighted challenges arising from the ACT's scale, there are also distinctive opportunities:

System-level innovation is more feasible:

- Smaller population enables rapid implementation and evaluation of new models
- Centralised governance allows coordinated policy across health, education, employment
- Strong data linkage potential across sectors
- Geographic concentration enables integrated care without distance barriers

ACT could lead national innovation in:

- Intersectional health equity measurement and reporting
- Co-designed, culturally safe service models
- Integration of pelvic pain care with digital health platforms
- Workplace accommodation models for chronic conditions
- Educational system integration of menstrual and reproductive health

International comparisons:

- The ACT is comparable in population to small European jurisdictions that lead in gender-responsive health policy (e.g., Iceland, Luxembourg)
- Small jurisdictions internationally often demonstrate superior health equity outcomes when policy is intentionally designed

Recommendations:

- Position ACT explicitly as a national demonstration site for pelvic pain care innovation
- Seek federal funding for ACT as "living laboratory" for intersectional health systems reform
- Establish international partnerships with comparable small jurisdictions
- Document and disseminate ACT innovations to inform national policy

STRUCTURAL CONTEXT MATTERS

These additional considerations demonstrate that pelvic pain care in the ACT cannot be understood through clinical or service delivery lenses alone. Jurisdictional structure, governance arrangements, economic context, geographic relationships, and policy legacies all shape who experiences diagnostic delay, who can access effective treatment, and whose outcomes improve.

Addressing these "other related issues" is not peripheral to the inquiry's core concerns; rather, they reveal the structural conditions that enable or constrain reform. Without attending to these contextual factors, even well-designed clinical interventions risk reproducing existing inequities or creating new ones.

The ACT's unique position as a small, affluent, centralised jurisdiction creates both distinctive challenges and genuine opportunities for leadership. The question is whether these opportunities will be leveraged to advance equity, or whether structural advantages will continue to be distributed unevenly, leaving the most marginalised behind.

10. CONCLUSION AND POLICY IMPLICATIONS

Endometriosis, adenomyosis, PCOS, and chronic pelvic pain conditions constitute a significant, persistent, and inequitable burden in the ACT. These conditions are not rare, benign, or confined to reproductive health; they are chronic, system-shaping conditions that affect physical functioning, mental health, education, workforce participation, economic security, and social participation across the life course. The evidence presented makes clear that the harms associated with these conditions are not distributed evenly. Rather, they are produced and amplified through the interaction of biomedical uncertainty with gender bias, medical misogyny, socioeconomic inequality, cultural unsafety, and structural features of the ACT health system itself.

Equity of access cannot be inferred from geographic proximity or nominal service availability. While the ACT benefits from a compact health system and relative geographic accessibility, these features also produce distinct vulnerabilities. Workforce scarcity, limited provider choice, and concentrated clinical networks mean that individual epistemic bias, service bottlenecks, or culturally unsafe encounters can have outsized and enduring consequences. For people experiencing intersecting forms of disadvantage, including Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse communities, gender-diverse individuals, people with disability, people living in larger bodies, young people, and those with limited financial resources, these system characteristics translate into prolonged diagnostic delay, fragmented care, reduced treatment effectiveness, and cumulative harm.

Across all Terms of Reference, a consistent pattern emerges: delays in diagnosis, constrained access to multidisciplinary care, and disproportionate treatment burden are not accidental failures, but predictable outcomes of systems that were not designed with intersectional realities in mind. Medical misogyny and gendered norms continue to shape whose pain is believed, whose symptoms are investigated, and which outcomes are prioritised. Cultural and linguistic barriers remain embedded in service design rather than addressed through it. Education gaps among clinicians, allied health professionals, and communities perpetuate late presentation and ineffective management.

Research and data systems continue to privilege dominant populations, rendering others statistically invisible and politically marginal.

Importantly, the ACT context illustrates that alignment with national strategies is necessary but not sufficient. National frameworks, clinical guidelines, and funding initiatives provide an essential foundation, yet their impact is mediated by local system dynamics. Without adaptation to the ACT's scale, workforce composition, and population diversity, national reforms risk improving average outcomes while entrenching inequity. Equity-adjusted effectiveness, rather than service presence alone, must be the benchmark for policy success.

Chronic pelvic pain conditions generate substantial economic and social costs that extend far beyond the health portfolio. Educational disruption, workforce attrition, presenteeism, income instability, and constrained social participation impose long-term costs on individuals, families, employers, and government. These costs are cumulative and intersectional: those with the least capacity to absorb disruption bear the greatest burden. Addressing pelvic pain therefore requires coordinated, cross-sector responses that integrate health, education, employment, disability, and community services, rather than siloed interventions confined to specialist care.

The policy implications for the ACT are clear. Effective reform must move beyond incremental service expansion toward structural, equity-oriented redesign. This includes strengthening early diagnostic pathways; embedding multidisciplinary, community-based care as standard rather than exceptional; addressing workforce capability and cultural safety; and ensuring that data, evaluation, and research frameworks make visible those who have historically been excluded. It also requires accountability mechanisms that measure what matters to patients: timeliness, continuity, safety, functional outcomes, and quality of life, disaggregated by social location.

The ACT has a genuine opportunity to lead nationally. Its centralised health system, strong research connections, and manageable scale position it well to pilot intersectional, patient-centred models of care, education, and research that could inform broader Australian reform. Doing so would not only improve outcomes for people living with endometriosis, adenomyosis, PCOS, and chronic pelvic pain in the Territory, but also demonstrate how small jurisdictions can deliver equity-driven health system innovation.

Failure to act will perpetuate preventable suffering, economic loss, and institutional distrust. Meaningful action, by contrast, offers the opportunity to reduce diagnostic delay, improve treatment effectiveness, support participation in education and employment, and restore confidence that the ACT health system recognises pelvic pain not as a marginal issue, but as a core matter of public health, equity, and social justice.

11. REFERENCES

1. Australian Institute of Health and Welfare. Endometriosis in Australia [Internet]. Canberra; 2023. Available from: https://www.aihw.gov.au/reports/chronic-disease/endometriosis-in-australia
2. Andrew M. Report on the 2025 Survey of Women's Health in the ACT [Internet]. Canberra; 2025. Available from: https://womenshealthmatters.org.au/wp-content/uploads/2025/10/Report-on-2025-Survey-of-Womens-Health-in-the-ACT.pdf
3. Mishra I, Melo P, Easter C, Sephton V, Dhillon-Smith R, Coomarasamy A. Prevalence of adenomyosis in women with subfertility: systematic review and meta-analysis. Ultrasound Obstet Gynecol. 2023 Jul;62(1):23–41.
4. Armour M, Lawson K, Wood A, Smith CA, Abbott J. The cost of illness and economic burden of endometriosis and chronic pelvic pain in Australia: A national online survey. PLoS One. 2019;14(10):e0223316.
5. National Women's Health Advisory Council. #EndGenderBias Survey Summary Report [Internet]. Canberrra; 2024. Available from: https://www.health.gov.au/sites/default/files/2024-03/endgenderbias-survey-results-summary-report_0.pdf
6. Papadopoulos S, Brennan L. Correlates of weight stigma in adults with overweight and obesity: A systematic literature review. Obesity (Silver Spring). 2015 Sep;23(9):1743–60.
7. Puhl RM, Heuer CA. The stigma of obesity: a review and update. Obesity (Silver Spring). 2009 May;17(5):941–64.
8. Schirmer J, Mylek M. 2022-2023: Living Well in the ACT Region Survey [Internet]. University of Canberra; 2024. Available from: https://www.act.gov.au/wellbeing/explore-overall-wellbeing/health/access-to-health-services
9. ACT Legislative Assembly. Debate on primary care access in the ACT. ACT Legislative Assembly Hansard. 2024;
10. Capital Health Network. 2024-2027 ACT PHN Needs Assessment [Internet]. 2024. Available from: https://www.chnact.org.au/wp-content/uploads/2025/01/Capital-Health-Network-24-27-Health-Needs-Assessment-1-1.pdf
11. RANZCOG. Australian Living Evidence Guideline: Endometriosis [Internet]. Royal Australian College Of Obstetricians and Gynaecologists; 2025. Available from: https://ranzcog.edu.au/wp-content/uploads/Endometriosis-Clinical-Practice-Guideline.pdf

12. Denny E. Women's experience of endometriosis. J Adv Nurs. 2004 Jun;46(6):641–8.
13. Samulowitz A, Gremyr I, Eriksson E, Hensing G. "Brave Men" and "Emotional Women": A Theory-Guided Literature Review on Gender Bias in Health Care and Gendered Norms towards Patients with Chronic Pain. Pain Res Manag. 2018;2018:6358624.
14. Hoffmann DE, Tarzian AJ. The girl who cried pain: a bias against women in the treatment of pain. J Law Med Ethics. 2001;29(1):13–27.
15. Alur-Gupta S, Dokras A, Cooney LG. Management of polycystic ovary syndrome must include assessment and treatment of mental health symptoms. Fertil Steril [Internet]. 2024 Mar 1;121(3):384–99. Available from: https://doi.org/10.1016/j.fertnstert.2024.01.018
16. Dokras A, Saini S, Gibson-Helm M, Schulkin J, Cooney L, Teede H. Gaps in knowledge among physicians regarding diagnostic criteria and management of polycystic ovary syndrome. Fertil Steril [Internet]. 2017 Jun 1;107(6):1380-1386.e1. Available from: https://doi.org/10.1016/j.fertnstert.2017.04.011
17. Sacca L, Lobaina D, Knopf E, Burgoa S, Jimenez S, Okwaraji G, et al. Assessment of the Validity and Quality of Polycystic Ovarian Syndrome (PCOS) Screening Tools Available for Women Globally: A Systematic Review. Vol. 14, Clinics and Practice. 2024. p. 1625–49.
18. Hofmann K, Oehler M, Ruckes C, Dionysopoulou A, Stewen K, Schiestl LJ, et al. Gaps in knowledge regarding the diagnostic criteria and management of PCOS in Germany: An anonymous web-based survey. Heliyon [Internet]. 2024 Nov 30;10(22). Available from: https://doi.org/10.1016/j.heliyon.2024.e40431
19. Infante-Cano M, García-Muñoz C, Matias-Soto J, Pineda-Escobar S, Villar-Alises O, Martinez-Calderon J. The prevalence and risk of anxiety and depression in polycystic ovary syndrome: an overview of systematic reviews with meta-analysis. Arch Womens Ment Health. 2025 Jun;28(3):475–89.
20. Australian Bureau of Statistics. Patient Experiences [Internet]. Canberra; 2025. Available from: https://www.abs.gov.au/statistics/health/health-services/patient-experiences/latest-release.
21. Breadon P, Geraghty J, Jones D, Baldwin E. Special treatment: Improving Australian's access to specialist care [Internet]. 2025. Available from: https://grattan.edu.au/wp-content/uploads/2025/06/Grattan-Institute-Special-Treatment.pdf

22. Eisenberg VH, Decter DH, Chodick G, Shalev V, Weil C. Burden of Endometriosis: Infertility, Comorbidities, and Healthcare Resource Utilization. Vol. 11, Journal of Clinical Medicine. 2022. p. 1133.
23. Australian Institute of Health and Welfare. Appendix D - Menstrual disorders, symptoms and related conditions: Topic overview and data strategy. In: Sexual and Reproductive Health Monitoring Framework and Data Strategy [Internet]. AIHW; 2023. Available from: https://www.aihw.gov.au/getmedia/c3d9ff88-eddd-40f0-a1ba-2084821430a3/aihw-srh-appendix_d_25308.pdf
24. Endometriosis Australia. Endometriosis Out-of-Pocket Costs and Barriers to Care. 2025; Available from: https://endometriosisaustralia.org/endometriosis-out-of-pocket-costs-and-barriers-to-care/
25. Australian Institute of Health and Welfare. Health and wellbeing of First Nations people. Australian Government; 2024.
26. Australian Institute of Health and Welfare. Social determinants of health [Internet]. AIHW; 2024. Available from: https://www.aihw.gov.au/reports/australias-health/social-determinants-of-health
27. Allaire C, Yong PJ, Bajzak K, Jarrell J, Lemos N, Miller C, et al. Guideline No. 445: Management of Chronic Pelvic Pain. Journal of Obstetrics and Gynaecology Canada [Internet]. 2024;46(1):102283. Available from: https://www.sciencedirect.com/science/article/pii/S1701216323006461
28. McReynolds D, Shiraz R, Tangey MA, Egerton T, Frawley H. Effectiveness of Multidisciplinary Treatment Compared to Single Discipline Treatment of Female Chronic Pelvic Pain: A Systematic Review and Meta-Analyses. BJOG. 2025 Nov;132(12):1716–33.
29. Mick Ido, Freger Shay M, van Keizerswaard Jolanda, Gholiof Mahsa, Leonardi Mathew. Comprehensive endometriosis care: a modern multimodal approach for the treatment of pelvic pain and endometriosis. Ther Adv Reprod Health [Internet]. 2024 Sep 23;18:26334941241277760. Available from: https://doi.org/10.1177/26334941241277759
30. Vincent K, Evans E. An update on the management of chronic pelvic pain in women. Anaesthesia [Internet]. 2021 Apr 1;76(S4):96–107. Available from: https://doi.org/10.1111/anae.15421
31. Dydyk A, Singh C, Gupta N. Chronic Pelvic Pain. In: StatPearls [Internet] [Internet]. Treasure Island (FL): StatPearls Publishing; 2025. Available from: https://www.ncbi.nlm.nih.gov/books/NBK554585/

32. Denny E. “I Never Know From One Day to Another How I Will Feel”: Pain and Uncertainty in Women With Endometriosis. Qual Health Res [Internet]. 2009;19(7):985–95. Available from: https://doi.org/10.1177/1049732309338725
33. Armour M, Sinclair J, Ng CHM, Hyman MS, Lawson K, Smith CA, et al. Endometriosis and chronic pelvic pain have similar impact on women, but time to diagnosis is decreasing: an Australian survey. Sci Rep. 2020 Oct;10(1):16253.
34. Australian Government Department of Health. National Action Plan for Endometriosis [Internet]. Canberra; 2018. Available from: https://www.health.gov.au/sites/default/files/national-action-plan-for-endometriosis.pdf
35. Denny E, Mann CH. Endometriosis-associated dyspareunia: the impact on women’s lives. J Fam Plann Reprod Health Care. 2007 Jul;33(3):189–93.
36. Australian Commission on Safety and Quality in Health Care. Creating Safer, Better Health Care – The impact of the National Safety and Quality Health Service Standards. Sydney; 2018.
37. Murray-Parahi P, DiGiacomo M, Jackson D, Phillips J, Davidson PM. Primary health care content in Australian undergraduate nursing curricula. Collegian [Internet]. 2020;27(3):271–80. Available from: https://www.sciencedirect.com/science/article/pii/S1322769617302998
38. Rieffestahl AM, Morcke AM, Mogensen HO, Risør T. When the Patient is Absent in Patient-Centered Communication Training: A Discursive Analysis of How Medical Students Learn to Interact with Patients. Teach Learn Med [Internet]. 2024 May 26;36(3):269–79. Available from: https://doi.org/10.1080/10401334.2023.2217169
39. Jo Delaney L. Patient-centred care as an approach to improving health care in Australia. Collegian [Internet]. 2018;25(1):119–23. Available from: https://www.sciencedirect.com/science/article/pii/S1322769617300422
40. Flynn MK, Hernandez JO, Fraire JV, Hobbs SC, Malnar CS. Weight stigma and healthcare avoidance among women with obesity: The moderating roles of body image-related psychological inflexibility and cognitive fusion. J Contextual Behav Sci [Internet]. 2024;33:100814. Available from: https://www.sciencedirect.com/science/article/pii/S2212144724000942

41. Li W, Feng H, Ye Q. Factors contributing to the delayed diagnosis of endometriosis-a systematic review and meta-analysis. Front Med (Lausanne). 2025;12:1576490.
42. Fryer J, Mason-Jones AJ, Woodward A. Understanding diagnostic delay for endometriosis: a scoping review. medRxiv [Internet]. 2024 Jan 1;2024.01.08.24300988. Available from: http://medrxiv.org/content/early/2024/01/09/2024.01.08.24300988.abstract
43. Seear K. The etiquette of endometriosis: stigmatisation, menstrual concealment and the diagnostic delay. Soc Sci Med. 2009 Oct;69(8):1220–7.

APPENDIX A - DATA SOURCE RECOMMENDATIONS

This appendix identifies specific data holdings and information sources that would strengthen the evidence base for the Committee's inquiry and inform effective policy responses. Many of these datasets exist but are not routinely published or analysed through an equity lens.

SECTION 1: ACT HEALTH DIRECTORATE

A. HOSPITAL ADMINISTRATIVE DATA (CANBERRA HEALTH SERVICES)

1.1 Admitted Patient Care Data

Request:

- Number of hospital admissions with primary or secondary diagnosis codes for:
  - Endometriosis (ICD-10-AM: N80.0-N80.9)
  - Adenomyosis (ICD-10-AM: N80.0)
  - PCOS (ICD-10-AM: E28.2)
  - Chronic pelvic pain (ICD-10-AM: R10.2, N94.8, N94.9)
- Disaggregated by:
  - Age group (5-year bands)
  - Aboriginal and Torres Strait Islander status
  - Postcode of residence (SES indicator)
  - Country of birth / CALD status
  - Admission type (emergency vs. elective)
  - Primary procedure codes (diagnostic laparoscopy, excision surgery, hysterectomy, etc.)
  - Length of stay
- Time series: Last 10 years (2015-2024)

Why this matters:

- Reveals true burden on hospital system
- Shows whether diagnoses are increasing or diagnostic practices improving
- Identifies geographic and demographic patterns
- Emergency presentations may indicate delayed diagnosis or inadequate primary care

Data quality issues to note:

- Adenomyosis often miscoded as endometriosis
- Chronic pelvic pain may be under-captured (coded as symptom rather than condition)
- Aboriginal and Torres Strait Islander status under-identification (~30-50% nationally)

1.2 Surgical Procedure Data

Request:

- Number and type of gynaecological surgeries performed at Canberra Hospital, specifically:
    - Diagnostic laparoscopies for pelvic pain
    - Therapeutic laparoscopy with endometriosis excision/ablation
    - Hysterectomy (with indication)
    - Bilateral salpingo-oophorectomy
- For each procedure:
    - Wait time from specialist referral to surgery
    - Patient demographics (as above)
    - Post-operative diagnosis confirmation
    - Complications and re-admission rateS
- Compare: Public vs. private hospital procedures (request Private Hospital Data Bureau records)

Why this matters:

- Surgical access is key diagnostic and treatment bottleneck
- Wait times reveal system capacity issues
- Comparison shows two-tier system dynamics
- Re-admission rates indicate quality and appropriateness of care

1.3 Emergency Department Presentations

Request:

- ED presentations with primary complaint of:
    - Pelvic pain
    - Dysmenorrhea
    - Menorrhagia
    - Abdominal pain (in reproductive-age patients)
- For each:
    - Triage category
    - Time to treatment
    - Disposition (discharged, admitted, left without being seen)
    - Documented diagnosis
    - Whether referred to gynecology outpatients
- Disaggregated by demographics

Why this matters:

- ED presentations may indicate primary care access gaps
- Shows acute burden of inadequately managed chronic conditions
- "Left without being seen" rates indicate system strain
- Reveals whether pain is triaged appropriately

1.4 Outpatient Clinic Data

Request:

- Gynecology outpatient referrals:
    - Number received annually
    - Referral reasons (diagnostic codes or free text analysis)
    - Triage category assigned
    - Wait time to first appointment (by triage category)
    - DNA (did not attend) rates
    - Patient demographics
- Number of appointments provided
- Provider FTE allocated to pelvic pain conditions
- Whether multidisciplinary clinics exist (integrated gynae + pain + allied health)

Why this matters:

- Referral-to-appointment wait time is critical diagnostic delay measure
- Triage practices may deprioritize chronic pain vs. fertility/cancer
- DNA rates may indicate access barriers (transport, work conflicts, cultural safety)
- Reveals workforce allocation to pelvic pain

B. PAIN MANAGEMENT SERVICES DATA

Request:

- Canberra Hospital Pain Management Unit:
    - Referrals for chronic pelvic pain
    - Wait times
    - Acceptance/rejection rates (and reasons)
    - Service model (individual vs. group programs)
    - Disciplines involved (anesthetist, physiotherapist, psychologist, etc.)
    - Completion rates and patient-reported outcomes
    - Demographics

Why this matters:

- Pain services are critical for multidisciplinary care
- Many pain clinics prioritize musculoskeletal pain; pelvic pain may be excluded
- Reveals whether integrated gynae-pain pathways exist

C. ALLIED HEALTH SERVICES DATA

Request:

- Publicly funded or subsidized allied health for pelvic pain conditions:
    - Pelvic physiotherapy (number of patients, sessions funded, wait times)
    - Clinical psychology for pain management
    - Dietetics for PCOS
    - Social work support
- Provider availability (FTE by discipline)
- Referral pathways and eligibility criteria
- Out-of-pocket costs where applicable

Why this matters:

- Allied health is evidence-based but rarely subsidized
- Affordability is major equity barrier
- Reveals whether multidisciplinary care is available or just theoretical

D. MEDICARE AND PHARMACEUTICAL DATA (via Services Australia, if accessible)

Request:

- Medicare Benefits Schedule (MBS) claims for ACT residents:
    - GP consultations with endometriosis/pelvic pain diagnostic codes
    - Specialist gynecology consultations
    - Pelvic ultrasound (item 55700, 55703)
    - MRI pelvis (item 63460)
    - Diagnostic laparoscopy (item 35571)
- Disaggregated by:
    - Postcode
    - Provider type (bulk-billed vs. private)
    - Patient age

- Pharmaceutical Benefits Scheme (PBS) data:
  - Dispensing of hormonal therapies commonly used for endometriosis/PCOS:
    - Combined oral contraceptives
    - Dienogest (PBS-listed 2022)
    - Levonorgestrel IUD (Mirena) - PBS-subsidized for contraception
    - GnRH agonists (limited PBS)
  - By postcode/demographics

Why this matters:
- Reveals true health service utilisation beyond public hospitals
- Shows private sector reliance and two-tier access
- Pharmaceutical data shows treatment patterns and potential gaps
- Postcode analysis reveals geographic equity within ACT

Note: This requires formal data request through Services Australia; ACT Health may assist with application

E. PRIMARY CARE DATA (Capital Health Network)

Request:
- General practice data on pelvic pain presentations:
  - Recorded diagnoses of endometriosis, adenomyosis, PCOS, chronic pelvic pain
  - Referral patterns (to gynecology, pain clinics, allied health)
  - Prescribing patterns
- GP workforce data:
  - Number of GPs in ACT with interest/training in women's health, reproductive health
  - Distribution by region
  - Bulk-billing rates
- Educational activities:
  - CPD programs on endometriosis/pelvic pain delivered to ACT GPs (attendance, topics)

Why this matters:
- Primary care is first contact point; delays here cascade
- Reveals whether GPs are equipped to recognize and refer appropriately
- Shows geographic access to informed primary care

SECTION 2: ACT EDUCATION DIRECTORATE

A. SCHOOL HEALTH DATA

Request:

- School nurse consultations related to menstrual health or pelvic pain:
    - Number of students presenting
    - Age/year level
    - Actions taken (parent contact, GP referral, etc.)
- Health and Physical Education curriculum:
    - Hours allocated to reproductive health education (by year level)
    - Content on menstrual health, recognizing abnormal pain
    - Teacher training provided
    - Resources used (culturally adapted materials?)
- Student absenteeism data:
    - Can analysis identify patterns of monthly absences (proxy for menstrual-related absence)?
    - Disaggregated by demographics

Why this matters:

- Education is prevention: early recognition reduces diagnostic delay
- School absence data may reveal unrecognized burden
- Shows whether young people have knowledge to self-advocate

B. TERTIARY EDUCATION DATA

Request from tertiary institutions (via Education Directorate coordination):

- Student health service presentations for pelvic pain/menstrual concerns
- Academic accommodations requested for chronic health conditions (number, type)
- Student retention and completion rates for students with disclosed chronic health conditions
- Support services available (counseling, disability services)
- Examination/assessment flexibility policies

Why this matters:

- Symptom onset often during tertiary study years
- Educational attainment affects lifetime earnings and opportunities
- Reveals whether institutions support students with chronic conditions

SECTION 3: CHIEF MINISTER, TREASURY AND ECONOMIC DEVELOPMENT DIRECTORATE

A. ACT PUBLIC SERVICE WORKFORCE DATA

Request:

- Sick leave patterns:
    - Can analysis identify employees with chronic health-related absences?
    - Gender differences in sick leave (may indicate reproductive health burden)
- Workplace accommodations:
    - Number and type of reasonable adjustments requested for chronic health conditions
    - Approval/denial rates
    - Flexible work arrangements
- Workforce participation:
    - Retention rates for employees with disclosed chronic health conditions
    - Part-time vs. full-time employment patterns
    - Career progression and promotion rates

Why this matters:

- ACTPS is major employer (>25% of ACT workforce)
- Can demonstrate policy leadership
- Data reveals employment impacts of chronic conditions

Privacy note: *All data must be de-identified and aggregated to protect employee privacy*

B. ECONOMIC MODELLING DATA

Request:

- ACT Treasury conduct or commission economic analysis:
    - Estimated productivity losses from endometriosis/pelvic pain in ACT
    - Cost-benefit analysis of proposed interventions (e.g., reduced wait times, subsidized allied health)
    - Impact on ACT economy (workforce participation, tax revenue, healthcare costs)
- Compare with existing national modeling (e.g., Armour et al. 2019 economic burden study)

Why this matters:

- Frames health issue as economic priority
- Business case for investment
- Shows return on investment for prevention and early intervention

SECTION 4: ACT HUMAN RIGHTS COMMISSION

A. DISCRIMINATION AND COMPLAINTS DATA

Request:

- Health-related discrimination complaints:
  - Number involving reproductive health conditions
  - Settings (healthcare, employment, education)
  - Outcomes
- Disability discrimination complaints where chronic pelvic pain is involved

Why this matters:

- Reveals extent of discrimination and systemic barriers
- Identifies sectors needing policy/training intervention

SECTION 5: OFFICE FOR ABORIGINAL AND TORRES STRAIT ISLANDER AFFAIRS

A. ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH DATA

Request:

- Consultation with Aboriginal and Torres Strait Islander communities on:
  - Experiences accessing reproductive healthcare in ACT
  - Cultural safety concerns
  - Barriers to diagnosis and treatment
  - Community priorities for service improvement
- Winnunga Nimmityjah Aboriginal Health Service data :
  - Presentations for pelvic pain/reproductive health concerns
  - Referral pathways to mainstream services
  - Follow-up and continuity of care

Why this matters:

- Aboriginal and Torres Strait Islander peoples systematically under-represented in health data
- Community knowledge is essential, not extractive research

Critical: All data requests must:
- Be co-designed with Aboriginal and Torres Strait Islander communities
- Respect Indigenous data sovereignty
- Include community benefit-sharing agreements
- Allow community veto over data use

SECTION 6: OFFICE FOR MULTICULTURAL AFFAIRS

A. CALD COMMUNITY HEALTH ACCESS DATA

Request:
- Analysis of interpreter service utilization in gynecology and pain services:
  - Languages requested
  - Availability and wait times
  - Whether services proceeded with or without interpreter
- Culturally adapted health resources:
  - What exists in languages other than English?
  - Distribution channels
  - Community awareness

Why this matters:
- Language barriers are major diagnostic delay factor
- Reveals whether system is responsive to linguistic diversity

SECTION 7: PRIVATE HEALTH SECTOR DATA

A. PRIVATE HOSPITAL DATA

Request via Private Hospital Data Bureau (national body):
- Surgical procedures at Calvary John James Hospital and National Capital Private Hospital:
  - Gynecological procedures for endometriosis, adenomyosis, PCOS, pelvic pain
  - Patient demographics (limited by privacy but postcode available)
  - Compare volumes with public hospital
- Out-of-pocket costs for common procedures

Why this matters:
- Reveals two-tier system extent
- Private hospitals perform significant proportion of gynecology in ACT
- Cost data shows affordability barriers

B. PRIVATE HEALTH INSURANCE COUNCIL DATA

Request:

- ACT resident coverage rates by:
    - Age group
    - Postcode
    - Hospital vs. extras cover
- Claims data for gynecology and allied health relevant to pelvic pain

Why this matters:

- Insurance status predicts healthcare access in current system
- Identifies populations reliant on public system

SECTION 8: RESEARCH AND TRIALS DATA

A. ACT CLINICAL TRIALS REGISTRY

Request:

- Current and completed trials recruiting in ACT related to:
    - Endometriosis
    - Adenomyosis
    - PCOS
    - Chronic pelvic pain
- For each trial:
    - Lead institution
    - Recruitment targets and actual enrollment
    - Demographic characteristics of participants
    - Whether results have been translated to practice

Why this matters:

- Shows research engagement
- Reveals whether ACT residents can access cutting-edge treatments
- Identifies gaps in local research capacity

B. ANU AND UC RESEARCH ACTIVITY

Request from universities:

- Current research projects on pelvic pain conditions
- Funding sources and amounts
- Community partnerships
- Translation plans

Why this matters:

- ACT has strong research institutions that could contribute more
- Reveals opportunities for government-university partnerships

SECTION 9: DATA QUALITY AND EQUITY CONSIDERATIONS

CRITICAL GAPS TO ACKNOWLEDGE

The Committee should note in its report that existing data systems have significant limitations:

1. Diagnostic Coding Issues
   - Endometriosis and adenomyosis often conflated
   - Chronic pelvic pain under-captured (coded as symptom not condition)
   - PCOS often not coded unless primary reason for admission

2. Demographic Under-Identification
   - Aboriginal and Torres Strait Islander status: ~30-50% under-identification in hospital data
   - CALD status: Country of birth is poor proxy; language spoken at home better but rarely captured
   - Gender identity: Not routinely collected in most datasets
   - Disability status: Inconsistently recorded

3. Missing Populations
   - Private sector data limited
   - People who disengage from care (due to bias, cost, trauma) are invisible
   - Interstate care-seeking not captured

4. Lack of Intersectional Analysis
   - Most existing data reports aggregated statistics; intersectional analysis requires custom analysis

SECTION 10: RECOMMENDED NEW DATA COLLECTIONS

The Committee should recommend ACT Health establish:

A. ACT PELVIC PAIN REGISTRY

Purpose: Prospective cohort study tracking:

- Diagnostic pathways (time from first symptoms to diagnosis)
- Treatment trajectories
- Patient-reported outcomes (pain, quality of life, functioning)
- Healthcare utilization and costs
- Disaggregated by demographics

Model: South Australian Endometriosis Registry, Victorian Women's Health Atlas

Governance: Patient and community representatives on steering committee

B. EQUITY-FOCUSED MONITORING DASHBOARD

Purpose: Public reporting on:

- Wait times for diagnosis and treatment (disaggregated)
- Service access by population group
- Patient experience and satisfaction
- Clinical outcomes
- Updated quarterly

Model: Similar to Victorian healthcare equity dashboards

C. MANDATORY DEMOGRAPHIC DATA COLLECTION

Require all ACT Health services to routinely collect and report:

- Aboriginal and Torres Strait Islander status (with cultural safety protocols)
- Country of birth and preferred language
- Gender identity (with non-binary options)
- Disability status
- Postcode (SES proxy)

Purpose: Enable equity-focused service planning and evaluation

CONCLUSION

Comprehensive, equity-focused data is essential for understanding the true burden of pelvic pain conditions in the ACT and designing effective, just policy responses. Many of these datasets exist but have never been analysed through an intersectional equity lens or made publicly available.

The Committee's inquiry provides an opportunity to:

1. Make visible what has been invisible
2. Establish baseline metrics against which progress can be measured
3. Identify specific populations and pathways requiring urgent intervention
4. Build evidence base for investment and reform
5. Model best practice in equity-focused health data governance

Key principle: Data about communities should benefit those communities. All data collection and analysis must be conducted with appropriate governance, community engagement, and respect for Indigenous data sovereignty and privacy rights.

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- Clinical outcomes
- Updated quarterly

Model: Similar to Victorian healthcare equity dashboards

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CONCLUSION

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APPENDIX B - ILLUSTRATIVE CASE EXAMPLES: HOW INTERSECTIONALITY SHAPES DIAGNOSTIC PATHWAYS

Note: *These are composite cases drawn from research literature, advocacy data, and clinical patterns documented nationally and in the ACT. They represent typical intersectional barriers rather than specific individuals.*

CASE 1: SARAH - LATE DIAGNOSIS THROUGH SOCIOECONOMIC BARRIERS

Background:

- 28 years old, single parent, works casual retail while studying part-time
- First experienced severe period pain at age 16
- No private health insurance

Diagnostic Journey:

- Age 16-20: GP visits during high school, told period pain is "normal," prescribed Panadol and Naproxen
- Age 21: Presents to GP with worsening pain affecting work, prescribed oral contraceptive pill, told to "manage stress"
- Age 24: Requests specialist referral after missing multiple work shifts, GP refers to public gynaecology outpatients
- Wait time: 11 months for first appointment
- Age 25: Initial consult, told ultrasound shows "nothing significant," offered Mirena IUD
- Age 26: Pain worsening, now affecting study, requests second opinion but cannot afford private specialist
- Age 27: Returns to public clinic, different doctor orders MRI, waits 4 months for scan
- Age 28: MRI shows deep endometriosis, referred for surgical opinion, current wait time 8+ months

Total diagnostic delay: ***12 years from symptom onset***

Intersectional factors:

- Socioeconomic: Could not afford private pathway to bypass public wait times
- Employment precarity: Casual work meant no paid sick leave, fear of losing job prevented time off for appointments
- Single parent: Childcare responsibilities limited ability to attend multiple appointments or travel for care
- Age: Young age contributed to dismissal of symptoms as "normal" adolescent pain

Outcomes:

- Career progression delayed due to interrupted study
- Income instability from missed work shifts
- Accumulated debt from unpaid medical leave
- Anxiety and depression from prolonged pain and diagnostic uncertainty
- Disease progression during delay may reduce treatment effectiveness

CASE 2: KYLIE - COMPOUNDED BY ABORIGINALITY AND WEIGHT STIGMA

Background:

- 32 years old, Ngunnawal woman, works in community services
- BMI 38, experiences weight stigma in healthcare settings
- Strong cultural connections, but previous negative hospital experiences

Diagnostic Journey:

- Age 19: Severe period pain since menarche, avoided seeking care due to previous experiences of racism in health system
- Age 25: Presents to GP with pain and heavy bleeding, symptoms attributed to weight, advised to "lose weight and exercise more"
- Age 28: Presents to different GP, again told weight is the problem, not offered investigation
- Age 30: Pain now constant, affecting work, requests ultrasound, GP reluctant, eventually orders scan
- Age 31: Ultrasound shows "bulky uterus" but no clear diagnosis, referred to public gynaecology
- Age 32: First specialist appointment, feels judged, doctor focuses on weight loss before investigation
- Age 33: After advocating strongly, finally scheduled for laparoscopy, wait time 10 months
- Diagnosis: Severe endometriosis and adenomyosis at surgery

Total diagnostic delay: *14 years*

Intersectional factors:

- Aboriginality: Previous experiences of racism created mistrust, delayed help-seeking; lack of culturally safe pathways

- Weight stigma: Symptoms repeatedly misattributed to body size rather than investigated as gynecological pathology
- Gender bias: Female pain dismissed; compounded by stereotypes about Aboriginal women's pain tolerance
- Diagnostic overshadowing: Weight became focus rather than pelvic pathology

Outcomes:
- Advanced disease at diagnosis requiring complex surgery
- Years of preventable suffering
- Workplace impacts on community services role
- Erosion of trust in health system
- Delayed access to fertility counseling (important for reproductive planning)

What would have helped:
- Culturally safe pathways with Aboriginal health worker navigation
- Provider education on weight stigma and diagnostic overshadowing
- No-stigma investigation protocols regardless of body size
- Trauma-informed care approaches

CASE 3: ALEX - GENDER-DIVERSE PERSON NAVIGATING CIS-NORMATIVE SYSTEM

Background:
- 24 years old, non-binary (assigned female at birth), uses they/them pronouns
- On testosterone as part of gender-affirming care
- Has private health insurance through parents

Diagnostic Journey:
- Age 17: Severe dysmenorrhea began, avoided seeking care due to fear of invasive gynaecological exams and misgendering
- Age 21: Began testosterone, periods stopped, pain reduced initially
- Age 23: Breakthrough pelvic pain despite testosterone, presents to GP who seems uncomfortable, refers to gynaecologist without discussing gender-affirming considerations
- Age 24: Private gynecologist visit, repeatedly misgendered despite correcting, felt unsafe during examination, asked invasive questions about "why you're doing this to your body"

- Left appointment without completing examination, did not return
- Currently: No diagnosis, pain continuing, avoiding further care

Diagnostic delay: 7 years and ongoing

Intersectional factors:

- Gender identity: Cis-normative assumptions in reproductive health care created unsafe environment
- Provider bias: Lack of training in gender-affirming gynaecological care
- System design: Intake forms, waiting room materials, clinical language all assumed female identity
- Testosterone use: Complicated symptom picture, required provider with expertise in transgender healthcare + endometriosis, no clear pathway in ACT

Outcomes:

- Disengagement from care despite pain
- Potential disease progression while undiagnosed
- Psychological harm from misgendering and invalidation
- Uncertainty about fertility implications (relevant for some non-binary people)

What would have helped:

- Gender-affirming intake processes (correct name, pronouns from first contact)
- Providers trained in transgender reproductive healthcare
- Options for minimal-touch examination or alternative diagnostic approaches
- Peer navigation from LGBTIQ+ community members with lived experience
- Clear communication that gender-affirming care and gynecological care can coexist

CASE 4: MEI - CALD BACKGROUND WITH LANGUAGE AND CULTURAL BARRIERS

Background:

- 35 years old, arrived in Australia from China 8 years ago on skilled migration visa
- Limited English proficiency, works as accountant in Mandarin-speaking firm
- Private health insurance through employer

Diagnostic Journey:

- Age 20s (in China): Experienced painful periods but cultural norms discouraged discussing reproductive issues
- Age 28 (first year in Australia): Severe pain episode, attended GP with Mandarin-speaking friend translating
- GP visit: Communication difficulties, GP prescribed pain medication without clear diagnosis, advised to return if problems continue
- Age 30: Worsening symptoms, attended different GP with professional interpreter, GP referred to specialist
- Age 31: Private gynaecologist appointment, interpreter not available for this appointment, struggled to explain symptoms, examination performed but felt unable to ask questions
- Ultrasound ordered: Report used technical terms, no explanation provided
- Age 33: Continuing pain, friend researched symptoms online, suggested endometriosis
- Age 34: Returned to new GP specifically requesting female Mandarin-speaking doctor, finally able to fully explain symptoms and cultural concerns
- Age 35: Appropriate referral to gynecologist with interpreter services, investigation underway

Diagnostic delay: ~15 years from symptom onset, ~7 years in Australian health system

Intersectional factors:

- Language barriers: Inability to fully articulate complex symptoms, difficulty understanding medical explanations
- Cultural factors: Stigma around discussing reproductive health, cultural norms about stoicism with pain
- Migration status: Unfamiliarity with Australian health system navigation, fear of being perceived as "difficult patient"
- Gender norms: Cultural expectations about women tolerating reproductive pain

- System gaps: Inconsistent interpreter availability, no culturally tailored patient education materials

Outcomes:
- Years of preventable pain and disability
- Workplace impacts (frequent absences from accounting role)
- Social isolation (avoiding activities due to unpredictable symptoms)
- Financial costs (multiple ineffective treatments before diagnosis)
- Anxiety about navigating unfamiliar health system

What would have helped:
- Guaranteed professional interpreter access at all appointments
- Culturally adapted patient education materials in Mandarin
- Community health worker familiar with Chinese-Australian community
- Clear written information about Australian health system navigation
- Provider cultural competency training on diverse pain expressions and health beliefs

CASE 5: EMMA - DISABILITY AND DIAGNOSTIC OVERSHADOWING

Background:
- 26 years old, has cerebral palsy affecting mobility, uses wheelchair
- University student (Master's degree)
- NDIS participant, lives independently with support workers

Diagnostic Journey:
- Age 18: Severe period pain began, mentioned to GP during routine appointment
- GP response: "Let's focus on managing your CP symptoms first, we can address period pain later"
- Age 20: Increasing pain affecting university attendance, mentioned to disability support coordinator who suggested GP follow-up
- Age 21: GP visit, symptoms attributed to "pain sensitivity" related to CP, prescribed stronger pain medication
- Age 23: Pain now severe, affecting sleep and study, saw different GP who ordered ultrasound

- Ultrasound: Difficult to perform due to positioning challenges, reported as "limited study"
- Age 24: Requested MRI, GP hesitant ("expensive, probably not necessary"), eventually referred
- MRI wait time: 7 months in public system (unable to afford private)
- Age 25: MRI shows endometriosis, referred to gynecologist
- Specialist appointment: Waiting room not wheelchair accessible, examination table not adjustable, physical examination extremely difficult and uncomfortable
- Age 26: Currently trying to find gynecologist with accessible facilities and disability awareness

Diagnostic delay: 8 years, diagnosis obtained but treatment access still problematic

Intersectional factors:

- Disability: Pain symptoms attributed to existing condition
- Healthcare system design: Physical infrastructure not accessible, examination equipment not adapted
- Provider assumptions: Disability viewed as "explaining" all symptoms rather than recognizing co-occurring conditions
- Communication barriers: Providers addressing support worker rather than Emma directly
- NDIS limitations: Gynecological care not covered, creates cost barriers for specialized accessible services

Outcomes:

- Prolonged diagnostic delay due to overshadowing
- Educational disruption (considering deferring)
- Limited specialist options with accessible facilities
- Psychological impact of repeated dismissal
- Uncertainty about fertility (relevant for life planning)

What would have helped:

- Provider education on diagnostic overshadowing in people with disability
- Accessible gynecological facilities and adjustable examination equipment
- Communication directly with patient, not through support workers
- Clear pathways for people with complex accessibility needs
- NDIS coverage for gynecological care related to chronic conditions
- Disability-inclusive pelvic physiotherapy

CROSS-CASE ANALYSIS: COMMON STRUCTURAL BARRIERS

1. Symptom dismissal operates differently across intersections

- Sarah: Age and class - "stress" and "normal periods"
- Kylie: Race and weight - "lose weight"
- Alex: Gender identity - disengagement due to unsafe environment
- Mei: Language and culture - unable to fully articulate symptoms
- Emma: Disability - "pain sensitivity" from CP

2. Wait times compound existing disadvantage

- Those who can't afford private care wait longest (Sarah, Emma)
- Those facing cultural/identity barriers disengage entirely (Alex, Mei initially)
- Public system wait times interact with employment precarity to amplify harm

3. ACT system characteristics matter

- Limited provider choice means negative experience has greater impact (Alex)
- Small network means biased encounters have lasting consequences (Kylie)
- Concentration of expertise means accessibility barriers affect larger proportion (Emma)

4. Cumulative disadvantage produces worst outcomes

- Multiple intersecting factors (Kylie: Aboriginal + weight stigma + gender bias) produce longest delays and most harmful care experiences

Implications for ACT Reform

- These cases illustrate why "one size fits all" reforms will fail. Effective change requires:
- Multiple entry points and pathways, not everyone can or will access mainstream services
- Proactive barrier removal, wait for disadvantaged people to advocate is to wait forever
- Provider capability building, technical gynaecological skills insufficient without cultural safety, gender affirmation, disability inclusion, anti-weight-stigma practice

- System design for equity: interpreter services, accessible facilities, trauma-informed care, peer navigation must be standard, not optional
- Accountability for intersectional outcomes: measure and report diagnostic delay, access, and outcomes disaggregated by Aboriginality, CALD status, gender identity, disability, socioeconomic position

The question for the ACT: Will reforms benefit people like Sarah while leaving Kylie, Alex, Mei, and Emma behind? Or will the Territory design for those facing the greatest barriers, knowing that what works for them will work for everyone?

KEY FINDINGS FROM JURISDICTIONAL COMPARISON

1. ACT is not an outlier, but scale matters

- The ACT offers similar clinical services to other jurisdictions proportionate to population, but:
    - Workforce scarcity means less provider choice
    - Single bottleneck (e.g., one public clinic, limited specialists) has greater impact
    - Cannot achieve same redundancy/capacity as larger states

2. No jurisdiction excels at equity

- Across Australia:
    - Aboriginal and Torres Strait Islander-specific pathways are absent or tokenistic
    - CALD access relies on general interpreter services, not tailored programs
    - Gender-diverse care is emerging but not systematically integrated
    - Weight-inclusive care is not standard anywhere
    - Affordability remains major barrier for allied health and some treatments

3. Victoria shows strongest multidisciplinary integration

- Royal Women's Hospital and Mercy Hospital for Women have most comprehensive models
- Integration of gynecology, pain medicine, psychology, physiotherapy, social work as standard
- Dedicated adolescent services
- ACT could learn from Victorian model while adapting to smaller scale

4. Queensland leads in rural/remote innovation

- Telehealth most advanced due to geographic necessity
- Could inform ACT approaches for reaching surrounding NSW regions
- Demonstrates small populations can be served effectively with right design

5. South Australia leads in research translation

- Robinson Research Institute (Adelaide) is national leader in endometriosis research
- IMAGENDO®, AIMEE, EndoZone platforms emerging from SA
- ACT's geographic proximity and research connections (ANU) create partnership opportunities

6. International comparisons reveal greater gaps

- Small high-income jurisdictions internationally (Iceland, Luxembourg, Singapore) often demonstrate:
    - Universal access to multidisciplinary care without wait times
    - Comprehensive allied health coverage
    - Integrated mental health support
    - Proactive workplace accommodations
    - These outcomes are achievable with intentional policy design

IMPLICATIONS FOR ACT POLICY

The ACT should not aim to simply match other Australian jurisdictions; this would replicate existing national inequities.

Instead, the ACT should:

- Learn from Victorian multidisciplinary integration while adapting to ACT's scale
    - Single coordinated clinic with full multidisciplinary team
    - Standardized care pathways with built-in equity safeguards
- Leverage Queensland's telehealth innovation
    - Partnership with southern NSW for shared care
    - Remote specialist consultation
- Partner with South Australian research excellence
    - ACT as participant site in IMAGENDO® and related trials
    - Research translation pipeline from evidence to ACT practice
- Lead nationally in equity innovation
- First jurisdiction with co-designed Aboriginal and Torres Strait Islander pelvic pain pathway
    - First with mandatory cultural safety and gender affirmation standards
    - First with comprehensive allied health subsidy scheme
    - First with systematic workplace accommodation framework
- Look internationally for inspiration
    - Small jurisdiction comparisons more relevant than NSW/Victoria comparisons
    - Demonstrate that size is not barrier to excellence—policy design is

The ACT's opportunity: Be the jurisdiction that breaks from reproducing national inequities and instead demonstrates what equity-centred pelvic pain care looks like in practice.

APPENDIX C – JURISDICTIONAL COMPARISON

TABLE 1: SERVICE AVAILABILITY ACROSS AUSTRALIAN JURISDICTIONS

Service Component	ACT	NSW	Victoria	Queensland	South Australia	Best Practice Example
Specialist Pelvic Pain Clinics	1 public clinic (limited capacity)	Multiple (Jean Hailes, Royal Hospital for Women, Westmead)	Multiple (Royal Women's Hospital, Mercy Hospital for Women)	1-2 major centers	1 major centre (Royal Adelaide)	Victoria: Integrated multidisciplinary clinics at tertiary centers
Multidisciplinary Care Models	Limited; fragmented referral	Established at major centers	Strong integration at women's hospitals	Emerging models	Limited outside metro	Victoria: Standard of care at Royal Women's includes gynae, pain medicine, physio, psychology
Bulk-Billed Allied Health	Very limited	Limited	Limited	Limited	Limited	None strong - national gap
Endometriosis Specialist Surgeons	2-3 (public + private)	20+	15+	10+	5+	NSW: Largest workforce, but access still inequitable
Public Wait Times	6-12+ months for gynae outpatients	3-12 months (varies by centre)	3-9 months	6-12+ months	6-12+ months	Victoria (some centers): Priority systems reduce waits for complex cases

Service Component	ACT	NSW	Victoria	Queensland	South Australia	Best Practice Example
Dedicated Adolescent Services	None specific to pelvic pain	Jean Hailes has adolescent focus	Royal Children's Hospital transition program	Limited	Women's and Children's Hospital has some capacity)	Victoria: RCH adolescent gynae team
Indigenous-Specific Pathwayss	None formalized	Limited; some Aboriginal health services partner with specialists	Limited	Limited	Limited	National gap - no jurisdiction excels
LGBTIQ+ Affirming Services	Very limited1 public program (general, not pelvic-specific)	Some designated affirming providers	Equinox Gender Diverse Health (integration with gynae)	Limited	Shine SA has some capacity	Victoria: Most explicit gender-affirming reproductive health integration
Pain Management Programs	1 public program (general, not pelvic-specific)	Multiple chronic pain services	Multiple chronic pain services	Multiple	Limited	NSW/Victoria: Dedicated pelvic pain psychology and physio programs

Service Component	ACT	NSW	Victoria	Queensland	South Australia	Best Practice Example
Telehealth Integration	Moderate (COVID-19 expansion)	Strong	Strong	Very strong (large rural population drives innovation)	Moderate	Queensland: Most advanced rural telehealth for gynae
Research Participation	Limited local trials	Extensive (major research centers)	Extensive (major research centers)	Moderate	Strong (Robinson Research Institute - endometriosis focus)	South Australia: IMAGENDO® and related innovations

TABLE 2: SPECIFIC EVIDENCE-BASED TREATMENTS - ACT VS NATIONAL ACCESS

Treatment Type	Evidence Grade	ACT Availability	National Comparison	Equity Issues
Hormonal Supression Therapy				
Combined oral contraceptive pill	Strong evidence (A)	Widely available; PBS-subsidized	Universal access	None, generally equitable
Progestins (dienogest, NETA)	Strong evidence (A)	Available; dienogest PBS-listed 2022	Universal access	Cost barrier reduced by PBS listing
GnRH agonists/ antagonists	Moderate evidence (B)	Available but high cost; limited PBS access	Available nationally; cost barriers	Significant inequity, expensive
Levonorgestrel IUD (Mirena)	Strong evidence (A)	Widely available	Universal access	Upfront cost barrier for some; PBS only for contraception indication

TABLE 2: SPECIFIC EVIDENCE-BASED TREATMENTS - ACT VS NATIONAL ACCESS

Treatment Type	Evidence Grade	ACT Availability	National Comparison	Equity Issues
Surgical Interventions				
Diagnostic laparoscopy	Gold standard	Available; long public wait times (6-12+ months)	Universal access; wait times vary	Socioeconomic, private access faster
Excision surgery (specialist)	Strong evidence for symptom relief	2-3 specialist surgeons; very limited public access	Major centres have more specialists	Significant inequity, mostly private
Hysterectomy ± BSO	Evidence for adenomyosis; limited for endometriosis	Available	Universal access	Younger women, gender-diverse people face additional barriers
Allied Health Interventions				
Pelvic physiotherapy	Strong evidence (A)	Available but mostly private; high out-of-pocket	National gap, rarely bulk-billed	Major inequity, cost prohibitive for many
Pain psychology (CBT, ACT)	Strong evidence (A)	Limited specialized providers	Better in major cities	Access limited in all jurisdictions
Dietetics (PCOS)	Moderate evidence (B)	Available	Universal	Out-of-pocket costs limit access

Treatment Type	Evidence Grade	ACT Availability	National Comparison	Equity Issues
Pain Management				
Opioid analgesics	Limited long-term evidence; potential harms	Available; increasing restrictions	Universal	Risk of under/over-treatment
Neuropathic pain medications	Moderate evidence	Available	Universal	Side effects may limit tolerability
TENS units	Weak evidence but low risk	Self-funded	Universal	Cost barrier (~$50-200)
Cannabis-based products	Emerging evidence	Legal in ACT; TGA approval required; expensive	Legal nationally; access barriers	Significant cost + regulatory barriers
Complementary Therapies				
Acupuncture	Mixed evidence	Widely available; not subsidized	Universal	Cost barrier
Chinese herbal medicine	Limited evidence	Available	Universal	Cost barrier; safety concerns with quality

TABLE 3: SUPPORT SERVICES BEYOND CLINICAL TREATMENT

Support Type	ACT	Leading Jurisdiction	Gap Analysis
Peer support groups	1-2 community-led groups	Victoria has most extensive network	ACT needs formalised peer support funding
Fertility preservation counselling	Limited; mostly private	Victoria (Royal Women's) has comprehensive program	ACT lacks dedicated service
Pregnancy care for high-risk endometriosis patients	Canberra Hospital has capacity	NSW/Victoria tertiary centers	Adequate for population size
Mental health integration	Fragmented; no dedicated pathway	Victoria (Royal Women's) integrated psych in gynae clinic	ACT needs systematic integration
Sexual health counselling	Limited specialized providers	Jean Hailes (NSW) has specialized program	Significant ACT gap
Vocational rehabilitation	General services; no pelvic pain expertise	No jurisdiction excels nationally	National gap
Financial counselling/assistance	General services; no health-specific	Queensland has some hospital-based financial counsellig	National gap; ACT could lead