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

Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

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ACT Parliamentary Inquiry into Endometriosis and Other Pelvic Pain Conditions – QENDO Submission

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Improving the QUALITY of life for people with Endometriosis - Q-E-N-D-O

Executive Summary

QENDO, alongside the QENDO – ACT Branch, provides this submission as a collective, community-informed response to the ACT Parliamentary Inquiry. QENDO operates as a national organisation with a federated model, delivering services through state and territory branches across Australia. This structure ensures national consistency while enabling local, community-led delivery.

The QENDO – ACT Branch represents the ACT's local implementation of this model. It has:
- supported thousands of individuals
- been sustained by volunteers for more than a decade
- worked alongside local policymakers to raise awareness and drive change

This submission is informed by:
- ACT-specific community consultation and survey data
- national program delivery insights
- lived experience across the QENDO network
- collaboration with the Endometriosis Coalition, representing 100+ organisations

Community consultation reveals not isolated issues, but a long-standing, systemic failure to adequately support people living with endometriosis and pelvic pain. These challenges have persisted over many years and are deeply embedded across the healthcare and employment sectors, as well as patient experience. The best practice care for endometriosis and pelvic pain is an interdisciplinary approach informed by a biopsychosocial model, however public health services are underfunded and underresourced, highlighted by a lack of expertise in endometriosis and pelvic pain management. The future of endometriosis and pelvic pain care in the ACT must be trauma informed, accessible, and interdisciplinary, with a long-term model for continuation of care and practitioner support.

Key Findings from ACT Consultation: A System Under Sustained Strain

Findings from QENDO's ACT community consultation reveal not isolated issues, but a long-standing, systemic failure to adequately support people living with endometriosis and pelvic pain. These challenges have persisted over many years and are deeply embedded across diagnosis, treatment, workforce capacity, and patient experience.

Findings show that people in the ACT continue to face:
- 7–10+ year diagnostic delays
- high out-of-pocket costs (often $8,000–$15,000 annually)
- limited access to multidisciplinary/interdisciplinary care
- significant workforce gaps
- systemic gender bias and dismissal of symptoms.

Despite these challenges, community-led infrastructure remains unfunded in the ACT, unlike other jurisdictions.

QENDO's approach to this submission

This submission is informed by:

- ACT-specific community consultation and survey data
- national program delivery insights
- lived experience across the QENDO network
- collaboration with the Australian Endometriosis Coalition, representing 100+ organisations
- collaboration with local health care providers.

About QENDO

QENDO, alongside the QENDO – Canberra/ACT Branch, provides this submission as a collective, community-informed response to the ACT Parliamentary Inquiry.

QENDO operates as a national organisation with a federated model, delivering services through state and territory branches across Australia. This structure ensures national consistency while enabling local, community-led delivery.

The QENDO – Canberra/ACT Branch represents the ACT's local implementation of this model. It has:

- supported thousands of individuals, currently representing over 2000 members
- been sustained by volunteers for more than a decade
- worked alongside local policymakers to raise awareness and drive change.

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System Context: National Coordination, Local Delivery

QENDO's organisational model is designed to deliver both strategic coordination at a national level and responsive, place-based support through state and territory branches.

At a national level, QENDO provides:
- evidence-based resources and education
- digital infrastructure, including care navigation tools
- partnerships across health, research, and policy sectors
- alignment with national reform priorities.

At a local level, QENDO's state and territory branches deliver:
- community-led, peer-based support
- local service navigation and referral pathways
- place-based education and engagement
- culturally and contextually relevant care models

The QENDO Canberra/ACT Branch represents the ACT's local interface within this national system. Unlike other jurisdictions, however, it operates without sustained government funding, despite demonstrated and increasing demand.

This creates a structural inequity in the ACT, where:
- community-based support remains informal and volunteer-led
- preventative and early intervention services are limited or inaccessible
- individuals are more likely to enter the system through acute and high-cost pathways.

The current system is therefore reactive rather than preventative, placing both individuals and the health system under avoidable strain.

Response to the terms of reference

While some recent statistics show endometriosis affects around 1 in 7 people assigned female at birth, some experts believe this number to be closer to 1 in 5. A 2025 survey by the Women's Centre for Health Matters revealed 19% of ACT respondents had diagnosed endometriosis.

Around 47% of AFAB teenagers aged 15-18 living in the ACT report experiencing severe period pain, according to a 2025 survey of students participating in the PEPP Talk education program. 18% of students surveyed experienced pelvic pain for six or more days per month. 8.5% of ACT AFAB students had presented to an Emergency Department due to pelvic pain. Prevalence of regular severe period pain was higher in Government schools than Catholic or independent schools, and socio-economic factors appear to impact this prevalence[1].

Other pelvic pain associated conditions such as adenomyosis have less robust prevalence rates, with studies ranging between 10 to 35 per cent occurrence rates in women of chilbearing age. A 2023 study by Jean Hailes found that 47 per cent of women surveyed experienced pelvic pain within the past five years. Four in five of those women that experienced pelvic pain in the past five years reported that it impacted their daily life or caused them to miss work, study, and/or exercise.[2]

A Prolonged and Fragmented Diagnostic Journey - Barriers to Diagnosis and Treatment

"I had (in Canberra) laparoscopic surgery to remove a burst cyst on my ovary. They found significant endometriosis (bowels, bladder, uterus etc.) and did not believe the ACT had the best surgeons to deal with this so they referred me to Sydney." - Alana

For many, the pathway to diagnosis of endometriosis and pelvic pain conditions is not characterised by a single delay, but rather a prolonged, complex, and often distressing journey that can span years, if not decades. Diagnostic delay is both widespread and systemic. In a recent survey conducted by QENDO, over 60 per cent of respondents reported waiting seven years or more to receive a diagnosis that adequately explained their symptoms. More than 38 per cent waited in excess of ten years. Alarmingly, symptoms commonly begin early in life, with respondents indicating an average onset at approximately 13 years of age, meaning many individuals spend their formative adolescent and early adult years navigating unmanaged pain and uncertainty.

This extended diagnostic timeline is further compounded by the fragmented nature of care pathways. Many survey respondents reported consulting five or more healthcare providers, often across multiple disciplines ranging from two to nine different services, before receiving a diagnosis. This reflects a system that lacks clear, coordinated pathways to diagnosis and instead relies heavily on individual persistence and capacity to navigate complex healthcare environments.

Early symptoms are frequently normalised or dismissed, particularly in young people. Many individuals report being told that their pain is "normal" or a routine part of menstruation, resulting in delayed investigation and intervention. Others describe experiences of misdiagnosis or partial treatment, where symptoms are managed in isolation without consideration of an underlying

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[1] Tomsett, K. I., Mardon, A. K., Gao, O. W., Simpson, A. K., Squire, B. C., Warner, I. G., & Evans, S. F. (2026). Prevalence and Impact of Period and Pelvic Pain in Australian Adolescents: The PPEP Talk Schools Program. *The Australian & New Zealand journal of obstetrics & gynaecology*, 66(1), e70015. https://doi.org/10.1111/ajo.70015

[2] Jean Hailes. (2023). Pelvic Pain in Australian Women. Accessed 23 March 2026. Available at: https://www.jeanhailes.org.au/wp-content/uploads/2026/01/2023-National-Womens-Health-Survey-Pelvic-Pain-in-Australia-FINAL_TGD.pdf

condition. As a result, individuals are often required to repeatedly present to different providers, recount their experiences, and advocate for further investigation, placing a significant emotional and psychological burden on patients.

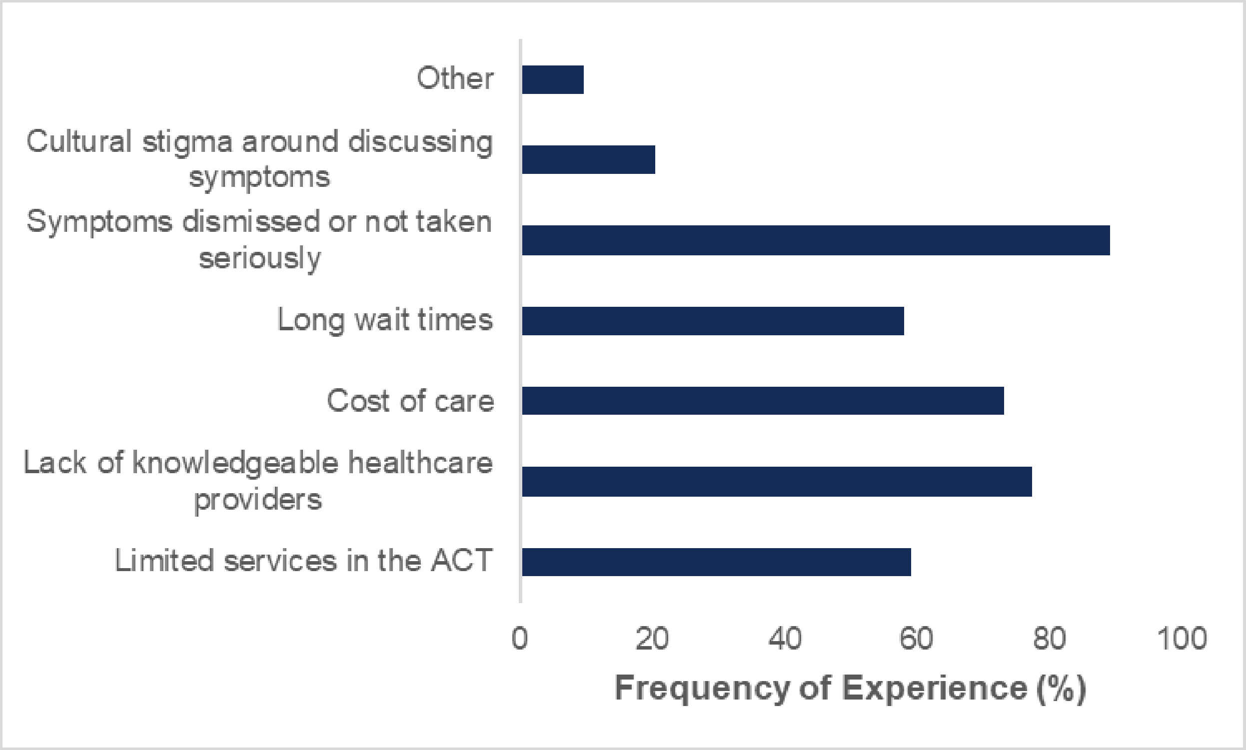

Figure 1. Barriers experienced by survey respondents when seeking a diagnosis

Importantly, these challenges are not solely reflective of patient experience, but also of system-level constraints faced by health professionals. Clinicians have expressed frustration regarding:

- limited training and confidence in recognising complex pelvic pain presentations
- a lack of clear and accessible referral pathways within the ACT
- time constraints within primary care settings that restrict the ability to undertake comprehensive assessments.

These factors contribute to a cycle in which both patients and providers are navigating a system that is not structured to support early identification or coordinated care.

The cumulative effect is a pattern of delayed recognition and repeated system entry, where individuals engage with the healthcare system multiple times over many years before receiving appropriate diagnosis and care. This not only prolongs suffering and reduces quality of life but also increases long-term healthcare utilisation and associated costs.

Cultural and language barriers should also be acknowledged when considering the provision of education and services to people with endometriosis and/or persistent pelvic pain. Intersectional disadvantage amplifies the hurdles faced by patients in accessing appropriate information and care. Some of our members do not identify as women, making some public services inaccessible for them, as they are tied to the Women's and Children's hospital or other areas of the health system dedicated to women.

Canberra's Public Health System

The main public services supporting our community include:

- The Canberra Endometriosis Centre
- Community and hospital based pelvic/continence physiotherapy
- Emergency departments
- Community Health Centres
- Walk-in Centres
- Imaging services that provide ultrasound, CT scans and MRIs, largely (but not exclusively) pelvic
- Operating theatres and recovery spaces

The Canberra Endometriosis Centre

The Canberra Endometriosis Centre (CEC) is the cornerstone of public endometriosis and pelvic pain care in the ACT. At present the Centre operates out of the gynaecology unit at the Centenary Hospital for Women and Children. The Centre has been plagued in recent years by lengthy wait times and staff shortages. While the core and most experienced staff are well regarded in our community, the Centre is under-resourced and historically these staff have appeared to lack support from management and the system in general. They often leave their positions to find temporary work more commensurate with their level of expertise, losing crucial corporate and clinical knowledge for the Centre. Succession planning and strategies regarding retention of core staff must be in place. Recent attempts to revive the service are welcomed by QENDO, and further investment in this model of care is strongly encouraged, being the only interdisciplinary service of its kind in the ACT. The addition of dieticians, pain psychologists, more appropriately trained specialists and DIE sonographers would be welcomed.

Education sessions provided by the Centre include a session on diet, but no funding has been provided for a dietician to deliver these sessions, meaning a nurse or physiotherapist is expected to deliver this component with the support of online content. Passionate and qualified dieticians are in the public system, they are just not funded for this particular activity.

The new northside hospital provides a unique opportunity to build dedicated space for a pelvic pain centre that can deliver a collaborative interdisciplinary service for northside Canberrans. Collaboration across both hospital sites appears to be non-existent at present. There are some passionate, dedicated, experienced staff working in endometriosis care in both hospitals. We would welcome more collaboration between them.

These services should be provided in a standalone service, separate from maternity services, to ensure prioritisation of critical aspects of care that may be misunderstood by management who are not well educated on pelvic pain care. Existing models, such as the pelvic pain clinic at the Gold Coast University Hospital, can provide a roadmap to growing this service into a nation leading centre.

Additionally, some aspects of the Centre's services, such as the education sessions, would be better located in the Community Health Centres. The main benefit of this for community members would be significantly easier access than hospital buildings, especially for disabled people and those with medical trauma associated with hospital buildings.

Community and hospital based pelvic/continence physiotherapy

Pelvic physiotherapy is an essential service for people with persistent pelvic pain. Timely access to a suitably qualified and experienced physiotherapist can prevent patients needing medical and surgical intervention. The community based continence clinic is an essential service for our community, but we would strongly support the establishment of a dedicated pelvic pain physiotherapy clinic, as many consumers accessing the continence clinic do not have continence issues. While access to private pelvic physiotherapy and related allied health services is improving, they are unaffordable for many. Public clinics also seem to have difficulty engaging and retaining staff, despite a clear need for this service. This appears to be, at least in part, due to the lack of clear career pathways for people wanting to specialise in clinical provision of physiotherapy targeted at pelvic pain patients. Senior clinicians are forced to opt for management and team leading positions and must forgo clinical work in order to find positions commensurate with their skills and experience. Given their role in potential reduction of surgical interventions and emergency presentations, it would be financially responsible to invest more in this area of public health care, and to prioritise having the best physiotherapists treating patients in the community and in the Endometriosis Centre, and training new staff. Plans should also be implemented to ensure critical roles like these are not left vacant for months at a time.

Emergency Departments

Emergency Departments in the ACT have a reputation for dismissing endometriosis related severe pelvic pain, and inconsistent treatment. Some patients avoid the Emergency Departments altogether due to experiences of dismissal, inadequate pain management, or feeling unsafe in clinical environments. Patients report being treated as 'drug seekers' when simply seeking pain relief. Some have been offered antipsychotics or other mental health medications in response to presenting with acute pain. Clinical pathways need urgent updating to be in line with other states like Queensland, and to be adequately communicated to staff. These must be developed in consultation with Endometriosis Centre staff and relevant consumer groups, and made publicly available as in other jurisdictions. Transparency about emergency department clinical pathways helps manage patient expectations in regards to what can and cannot be provided in this setting, and patients have the right to know which options can be made available to them when experiencing severe pain.

Community Health Centres

Community Health Centres provide the ACT with a unique opportunity to provide accessible care to endometriosis and pelvic pain patients requiring allied health support. Pelvic physiotherapists and dieticians are the most commonly used professions available in these centres by our community members.

Walk-in Centres and Imaging Services

Walk-in Centres have a limited ability to assist pelvic pain patients, however improving access to Imaging Services like emergency ultrasounds would benefit our community. Sonographers require additional training to be able to confidently identify endometriosis via ultrasound. Ultrasound is increasingly being used to diagnose endometriosis without the need for invasive surgical procedures. This can only be achieved broadly if ultrasound technicians are adequately trained, and timely ultrasounds are made available in the public system. Deep Infiltrating Endometriosis (DIE) ultrasounds cost in excess of $500 in the private sector, making them out of reach for many patients.

Operating theatres and recovery spaces

Operating theatre access directly impacts wait times. Recent attempts to increase operating theatre availability in Canberra is appreciated by our community.

Recovery spaces should be trauma-informed. Patients report waking from hysterectomies or miscarriages in maternity wards, to the sounds of babies crying. This is not just negligent, it directly causes harm. Untangling endometriosis and adenomyosis care from maternity care is important to patients. Dedicated recovery wards are needed to ensure patients can recover well.

Interdisciplinary Care Exists in Theory, Not in Practice

There is strong and consistent agreement among patients and clinicians that best-practice care for endometriosis and pelvic pain is interdisciplinary, coordinated, and grounded in a biopsychosocial model. This approach recognises the complex and interrelated physical, psychological, and social dimensions of these conditions and is widely accepted as the standard for effective, long-term management.

Within the ACT access to interdisciplinary care remains inconsistent, fragmented, and, in many cases, largely inaccessible. While awareness of this model has increased, the ability for patients to meaningfully engage with it in practice is significantly limited.

The ACT endometriosis sector reported strong demand for a range of multidisciplinary supports, including pelvic floor physiotherapy, pain psychology, dietetics, and integrated pain management approaches. Despite this, treatment outcomes remain suboptimal. Fewer than 10 per cent of respondents described the treatments they had accessed as “very effective”, while approximately two-thirds reported only partial effectiveness. This reflects not only the complexity of the condition itself, but also the limitations of a system that does not provide coordinated or comprehensive care.

Many individuals describe navigating their care without structured guidance or integration between providers, often relying on their own research, peer networks, or trial-and-error approaches to piece together a treatment plan. In the absence of coordinated pathways, care is frequently delivered in silos, with limited communication between practitioners and no centralised model of support.

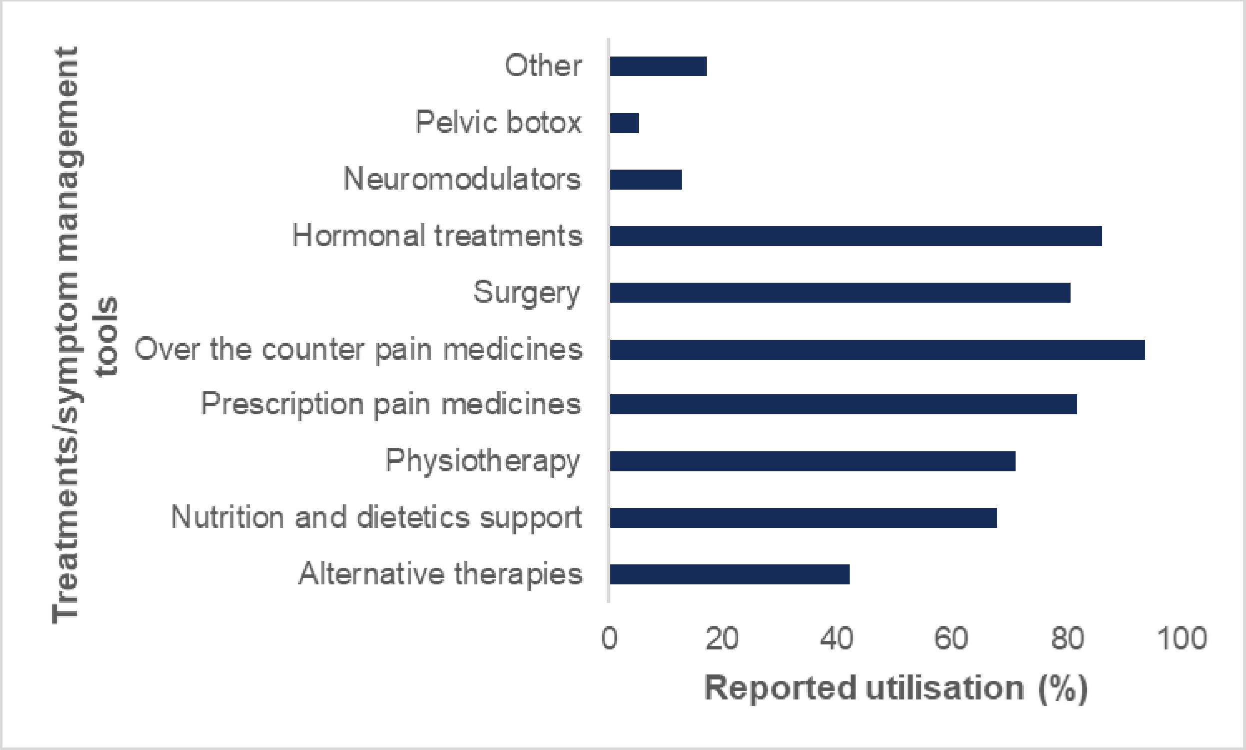

Figure 2. Treatment and management tools utilised by survey respondents. “Alternative therapies” was given the examples of naturopathy or traditional chinese medicine within the question. “Other” includes self-reported tools such as TENS machines, pain psychology and hypnotherapy.

Multiple barriers contribute to this gap between best practice and reality. These include:

- high out-of-pocket costs, which limit access to allied health and specialised services
- insufficient numbers of trained providers, particularly in areas such as pelvic health physiotherapy and pain psychology
- limited awareness among general practitioners regarding available services and appropriate referral pathways
- and a lack of trauma-informed care, which is critical for this patient cohort.

Health professionals working within the ACT have similarly identified structural challenges that constrain the delivery of interdisciplinary care. These include:

- workforce shortages in specialised areas
- limited career pathways and professional support, impacting retention of skilled clinicians
- and insufficient infrastructure to support collaboration across disciplines, particularly outside of hospital-based settings.

As a result, patients are often left to:

- coordinate their own care across multiple providers
- receive fragmented and disconnected treatment
- or default to more readily available interventions, such as surgery or pharmacological management, even where these may not represent optimal or sufficient long-term solutions.

This disconnect between what is known to be best practice and what is accessible in reality highlights a critical gap in the ACT health system. Without targeted investment in workforce, infrastructure, and coordinated care pathways, interdisciplinary care will remain an aspirational model rather than a consistently deliverable standard.

System Reliance on Interstate Care

One of the clearest indicators of system limitation within the ACT is the extent to which patients are required to leave the jurisdiction to access appropriate and timely diagnosis and treatment. This is not an occasional occurrence, but a frequent and, in many cases, clinically directed pathway, reflecting gaps in local capacity and confidence in available services.

Data from our consultation indicates that approximately 52 per cent of respondents travelled interstate to access diagnosis and/or treatment for endometriosis and pelvic pain. Importantly, this was often not a patient-led decision, but one made in consultation with, or directly recommended by, ACT-based healthcare providers. This highlights a concerning reality: even within the local health system, there is recognition that patients may receive more appropriate, timely or specialised care outside of the ACT. This is particularly concerning given Canberra functions as a key service delivery hub supporting a significant area of rural and regional NSW.

Patients report travelling interstate to access:

- specialised surgical expertise, particularly for complex or advanced disease
- advanced diagnostic imaging, including services with greater expertise in identifying endometriosis
- clinicians with specific experience in pelvic pain and multidisciplinary care.

Patients describe being referred to Sydney for surgical intervention due to a perceived lack of local expertise, as well as travelling interstate for imaging after being advised that local services may not have an appointment available in the near future, and may not provide sufficiently accurate or reliable results. These experiences point not only to gaps in service availability, but also to variability in clinical confidence within the ACT system itself.

The requirement to travel interstate introduces a range of additional burdens. These include:
- significant financial costs, such as travel, accommodation, and time away from work
- disruption to continuity of care, particularly where follow-up occurs across jurisdictions
- and emotional and logistical strain for patients and their families, who must navigate care in unfamiliar environments.

Health professionals have also expressed concern regarding this reliance on interstate services. Clinicians report:
- frustration at needing to refer patients outside the ACT to access timely/appropriate care
- recognition of gaps in local capability, particularly in specialised diagnostics and surgery
- and concern that patients are not receiving equitable, locally accessible care.

This pattern of referral reflects a system that is not yet self-sufficient in delivering the full spectrum of care required for endometriosis and pelvic pain. While cross-jurisdictional care can be an important component of a national health system, its routine use as a default pathway highlights a structural limitation within the ACT.

Without targeted investment in local capability, workforce development, and specialised services, this reliance will continue, perpetuating inequity and placing additional burden on individuals who are already navigating complex and chronic health conditions.

Surgery

Endometriosis excision is complex. General gynaecologists are not adequately trained in recognising and removing all presentations of the disease. RANZCOG Guidelines state that surgery on more extensive endometriosis lesions should only be attempted by gynaecologists with additional AGES fellowship training. Complex cases may also involve removal of disease from areas outside the pelvis, often the diaphragm and lungs. There are very few surgeons in the ACT with the requisite skill and experience to manage complete surgical removal of pelvic endometriosis, and to our knowledge none operating on extra-pelvic disease.

Recent media regarding inappropriate surgical procedures being performed on endometriosis patients in another jurisdiction are distressing, but not surprising to members of our community. Credentials are inadequate, and patients have no definitive list or source of information on which surgeons are skilled and experienced in surgical management of endometriosis. A collaborative effort across jurisdictions is needed to address these credentialing inadequacies and to develop a reliable information source to assist patients to choose a suitable surgeon.

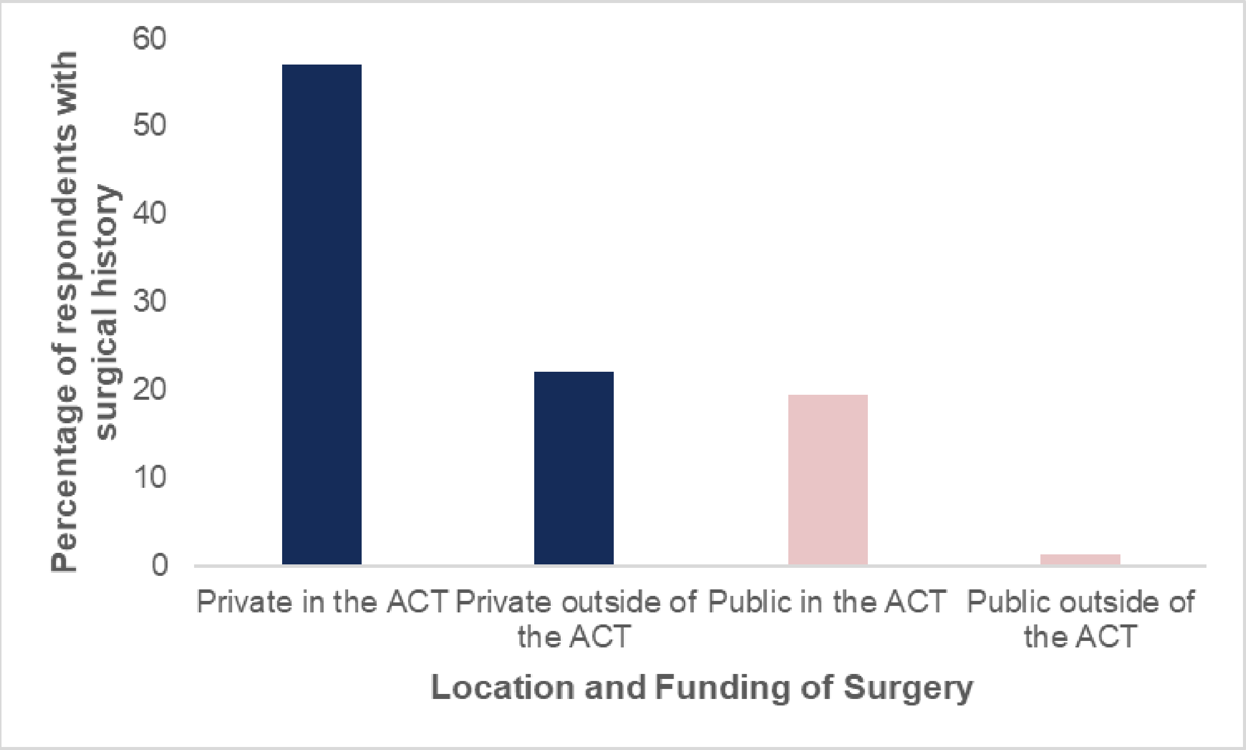

Figure 3. Location and funding source for surgery for survey respondents who have had surgical treatment for endometriosis or pelvic pain.

Efforts are also required to attract suitable surgeons to operate in the ACT public system. Most experienced surgeons in the ACT are pulling back from public work as they are inundated with private patients in their own practices.

Some endometriosis patients are being turned away from ACT public gynaecology clinics because the surgeons do not have the skills to operate on them. Other patients have endured unnecessary surgeries with surgeons who should not be operating on endometriosis patients because they lack the necessary extra training and experience to adequately remove endometriosis. They operate outside their scope of practice, but with no accountability. As endometriosis awareness and education increases, patients are increasingly looking for suitably trained and experienced surgeons, often necessitating looking outside the ACT for surgical care. Patients who cannot afford consultations in the private sector are left with whichever gynaecologists the public system can provide, leading to long waits that result in substandard outcomes.

Endometriosis affects multiple body systems. It is a whole body disease. As long as we continue to approach surgical management through a gynaecological lens, patients will suffer.

Pelvic Botox

QENDO Canberra/ACT recently arranged a petition due to the ceasing of the provision of pelvic botox for persistent pelvic pain in the ACT public system. This service is available in other jurisdictions and has been for years, however Canberra Health Services are refusing to provide this treatment option to patients, citing an inadequate evidence base. This is confusing for patients who are forced into NSW to access this treatment, and for some patients that makes it inaccessible.

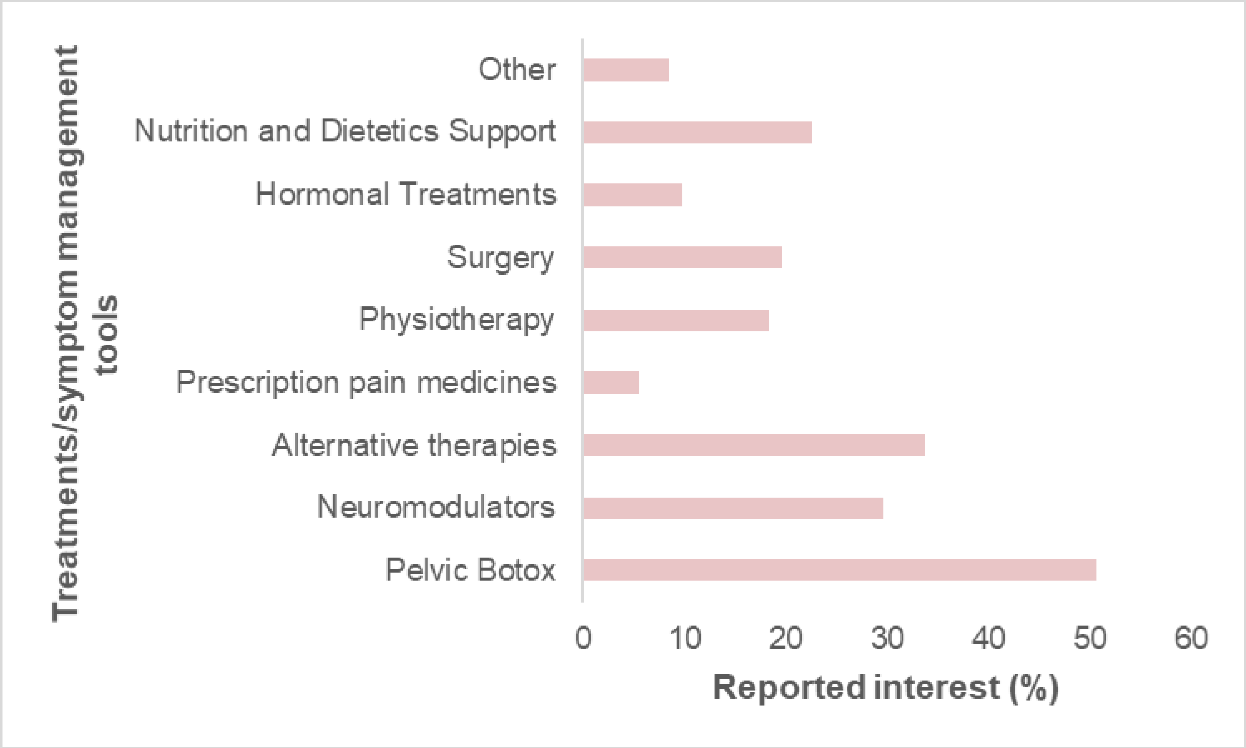

Figure 4. Treatment and management tools survey respondents expressed interest in accessing. Percentages based on total response to question, not overall survey response. “Alternative therapies” was given the examples of naturopathy of traditional chinese medicine within the question. “Other” includes self-reported totals such as hysterectomy, or any new non-hormonal medication not yet developed.

SHFPACT

Services like the Federally funded Pelvic Pain Clinic at Sexual Health and Planning ACT are valuable, but largely inaccessible to those who struggle with the cost. Funding to allow this service to provide bulk-billed GP visits would be advantageous. Expanding this clinic to provide patients with a long-term GP as opposed to the short-term care it currently offers would benefit many patients who do not have a family GP. The decreasing number of bulk-billing GP practices means many patients lack continuity of care in the primary care setting, contributing to diagnostic delay and disease burden.

Widespread Experiences of Dismissal, Bias, and System Distrust

“I was not prescribed birth control initially because of the doctor's ‘personal beliefs’. My surgeon got embarrassed in my consult when I stated that sex was painful, and he quickly moved on. Even when I had surgery, some endometriosis tissue was not excised because the surgeon was certain I would change my mind about not wanting children, so I didn't want to touch my uterus, despite the severity of my pain.” - Mary

Findings from our consultation indicate that experiences of dismissal, bias, and stigma within the healthcare system are not isolated incidents, but pervasive and deeply embedded challenges for people living with endometriosis and pelvic pain in the ACT. These experiences have profound implications not only for individual care, but for trust in the health system as a whole.

Survey data highlights the scale of this issue. An overwhelming 92.47 per cent of respondents reported that their symptoms had been dismissed or minimised by a healthcare professional, while 68.82 per cent reported experiencing gender bias or medical misogyny in the course of seeking care. In addition, more than 62 per cent identified cultural attitudes and stigma surrounding menstruation and pelvic pain as a barrier to accessing appropriate care . These findings are consistent with broader national and international evidence and reflect systemic patterns rather than individual provider behaviour alone.

Patients also described:
- not being believed when reporting the severity of their pain
- having symptoms attributed to psychological or emotional causes without adequate investigation
- being treated differently based on age, gender, or cultural background.

There were also consistent reports of clinical interactions in which fertility was prioritised over current quality of life, with some individuals only receiving appropriate attention when expressing a desire to conceive. Others described a reluctance from clinicians to pursue certain treatments where reproductive outcomes were perceived to be at risk, even when pain and functional impairment were severe.

Additionally, respondents identified experiences of cultural and racial bias, including assumptions about pain tolerance, medication use, and health behaviours. These experiences are particularly concerning for individuals from Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse backgrounds, where intersecting forms of bias may further compound barriers to care.

The consequences of these experiences are significant. Many individuals reported:
- delaying or avoiding seeking care due to previous negative interactions
- actively avoiding Emergency Departments during acute pain episodes

- feeling unsafe, unheard, or unsupported within healthcare settings

Survey question	Respondents with a “yes” response (%)	Respondents with an “unsure” response (%)
Have you ever felt like your symptoms were being dismissed or minimised by a healthcare professional?	92.47	3.23
In your experience, do cultural attitudes or stigma around menstruation and/or pelvic pain negatively impact access to care?	62.37	23.66
Do you personally believe you have experienced medical misogyny or gender bias whilst seeking treatment for endometriosis or another pelvic pain condition in the ACT?	68.82	13.98

Over time, this leads to a progressive erosion of trust in the healthcare system, with individuals disengaging from services even when in significant need of care.

Health professionals themselves have acknowledged these challenges. Clinicians recognise:
- the presence of both implicit and systemic bias within healthcare delivery
- the need for improved education and training, particularly in trauma-informed and patient-centred care
- and the importance of rebuilding trust through more respectful, informed, and collaborative clinical interactions

Addressing these issues requires more than awareness, it necessitates system-wide cultural and practice change, supported by training, accountability, and the embedding of lived experience perspectives into service design and delivery. Without this, improvements in access and service provision alone will not be sufficient to ensure that individuals feel safe and supported when seeking care.

Economic and Social Implications

“I frequently go over the medicare safety net, adding medications and foods it (financial cost of condition) would be more than $8,000 a year at best.” - Ella

The current system in the ACT places a significant, ongoing, and often unsustainable financial burden on individuals living with endometriosis and pelvic pain. Rather than being supported through accessible and coordinated public care pathways, many patients are required to personally absorb the cost of managing a chronic and complex condition in the private sector.

QENDO members consistently report high out-of-pocket expenses, with annual costs frequently exceeding $8,000 to $15,000, driven by ongoing needs such as specialist consultations, diagnostic imaging, medications, allied health services, and, in many cases, surgery. Notably, in our recent survey, respondents reported that more than 79 per cent of surgical interventions were privately funded, reflecting both a lack of accessible public options and a perceived or advised need to seek care outside the public system to obtain timely or appropriate treatment.

Cost was also identified as the primary barrier to accessing further care, with over 78 per cent of respondents indicating that there were treatments or management options they wished to pursue but were unable to access due to financial constraints. This includes not only advanced or specialised interventions, but also essential components of best-practice care such as pelvic physiotherapy, pain psychology, and interdisciplinary support.

The financial strategies reported by the ACT endometriosis sector illustrate the severity of this burden. Individuals described:

- taking out personal loans
- relying on financial support from family members
- accessing superannuation on compassionate grounds
- or delaying and, in some cases, forgoing care entirely.

Importantly, this is not a single or short-term expense. There is currently no cure for endometriosis. Endometriosis and pelvic pain are chronic conditions, and the associated costs accumulate over time, resulting in long-term financial strain. This has broader implications for:

- workforce participation and career progression
- financial independence
- long-term economic security.

The system, as it currently operates, effectively creates a two-tiered model of care. Individuals with the financial means to access private services are more likely to receive timely diagnosis, specialised treatment, and continuity of care. In contrast, those without such means often remain in prolonged pain, navigating delays and limited options within the public system.

Health professionals are acutely aware of these disparities and have expressed significant discomfort in recommending private pathways, despite recognising them as the most viable option for timely and expert care. Clinicians report a lack of accessible alternatives within the public system and increasing distress among patients who are unable to proceed with recommended treatment due to cost.

This dynamic places both patients and providers in a difficult position, where clinical need and financial reality are misaligned, further reinforcing inequity and contributing to poorer long-term health outcomes.

Lack of adequate early intervention and accessible interdisciplinary care also creates unnecessary financial burden on the health system itself. Adequate and timely screening and interdisciplinary care would assist to prevent:

- unnecessary surgical procedures
- unnecessary emergency department presentations
- birth injuries and birth trauma
- other medical trauma
- late diagnosis of life-threatening conditions that cause pelvic pain, e.g. ovarian cancer
- lack of productivity and decreased local workforce participation
- unnecessary engagement with parenting, mental health and disability support services.

Due to the young age at which many people start developing symptoms of endometriosis, persistent pelvic pain and other related conditions, education in schools is absolutely paramount. Programs such as ‘PEPP Talk’ should be routinely offered in all government high schools. Age appropriate education on how to know if symptoms are abnormal and where to seek help should be incorporated into the school health curriculum for all students regardless of gender identity.

Groups like QENDO Canberra/ACT are essential for the provision of community education. Peer support reduces isolation and promotes wellbeing. Provision of funding would allow for such groups to provide more locally focused community education and events.

Improved education for medical professionals is needed throughout the healthcare system, from surgeons to nurses to primary care practitioners. It is acutely needed in Emergency Department settings. Education should also be considered for specialists in gastroenterology and respiratory health, to identify signs of endometriosis and refer patients appropriately.

“We just need a lot more research into these conditions so healthcare professionals can better understand how to treat it.” - Poppy

While research in the area of endometriosis and pelvic pain is increasing, it remains under funded compared to other chronic conditions with similar disease burden. The vast majority of the ACT Endometriosis Sector are interested in innovative research focusing on new diagnostic tools, types of disease and disease mechanisms, as well as treatment effectiveness. It is imperative that any research is informed by consumers, and in a manner where consumers are consulted beyond a box-ticking exercise. Many in the community express that the future of health education and development is dependent on quality research moving forward, not only research that involves consumers, but does well to inform practitioners and patients of findings.

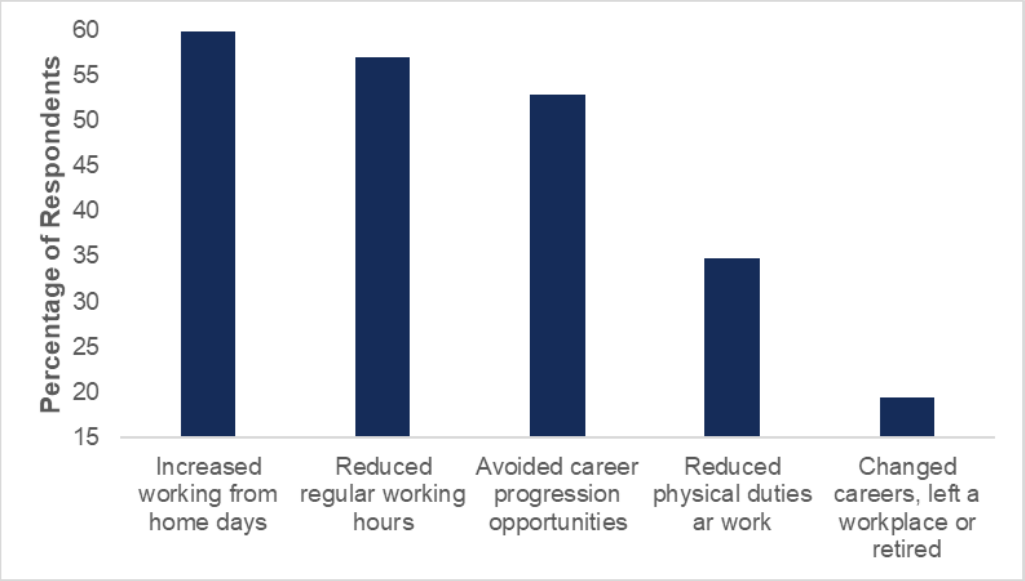

Figure 5. Career adjustments reported by respondents who indicated their careers had been impacted by their condition. Y-axis bounds and intervals adjusted for better data visibility.

Recommendations

1. Develop an ACT Endometriosis and Pelvic Health Strategy

QENDO recommends that the ACT Government develop a dedicated ACT Endometriosis and Pelvic Health Strategy, similar in intent to broader women's health strategies adopted in other jurisdictions, but with specific and measurable focus on endometriosis, adenomyosis, persistent pelvic pain, and related conditions.

This recommendation responds directly to the findings of our community consultation, which show long-standing fragmentation across diagnosis, treatment, referral pathways, workforce development, and community support. At present, patients in the ACT are too often required to navigate the system alone, while clinicians report frustration at the absence of clear pathways, limited referral options, and insufficient specialised services. A jurisdiction-wide strategy would create the policy architecture needed to coordinate reform, align services, and ensure that endometriosis and pelvic pain are treated as ongoing health system priorities rather than isolated clinical issues.

QENDO is well placed to partner in the development of this strategy. Through the QENDO – ACT Branch, the organisation holds deep local community trust and engagement. Through its national structure, QENDO also brings experience in health system navigation, consultation, service design, policy engagement, and lived-experience-led reform. QENDO can support government consultation, assist with stakeholder engagement, contribute community evidence, and help ensure the strategy reflects both local realities and national best practice.

The barrier this addresses is the absence of coordinated ACT-wide planning and policy leadership. The expected outcomes include improved service alignment, more consistent referral pathways, better integration between community and clinical care, and clearer accountability for endometriosis and pelvic pain outcomes. The longer-term impact would be a more efficient and responsive system, reduced duplication, improved patient experience, and a stronger basis for targeted investment. From a health service perspective, coordinated strategy reduces waste associated with fragmented care, repeated presentations, inappropriate referrals, and late-stage intervention.

2. Strengthen and Expand the Canberra Endometriosis Centre as a Multidisciplinary Hub

QENDO recommends bipartisan commitment to sustain and strengthen the Canberra Endometriosis Centre (CEC) as a core part of the ACT response to endometriosis and pelvic pain. The CEC is one of the ACT's strongest existing assets and should be built on, not treated as sufficient in its current form.

Evidence from our consultation shows that community members continue to face major barriers to multidisciplinary care, with strong demand for pelvic physiotherapy, dietetics, pain psychology, and integrated support, but low levels of reported treatment effectiveness and difficulty accessing the care they need. Many respondents also described care pathways that remain hospital-centric, difficult to access, or insufficiently trauma-informed.

QENDO recommends expansion of the CEC to include a dedicated dietitian, pain specialists, increased pelvic physiotherapy capacity, stronger pre and post-surgical support pathways, and outreach-based community education outside hospital settings. It is also recommended that internal education and workforce development be strengthened to support staff retention and sustain specialist expertise over time.

QENDO's role here is as a partner and connector. QENDO can support community consultation, co-design, consumer feedback loops, and the translation of services into community settings. Through its ACT Branch and national programs, QENDO can also assist in linking the CEC to peer support, navigation, app-based care planning, and broader education efforts.

The primary barriers addressed through this recommendation are limited access to multidisciplinary care, insufficient service capacity, poor community accessibility, and weak continuity between hospital-based and community-based care. The likely outcomes include quicker diagnosis, improved symptom management, reduced reliance on surgery as the first or only intervention, earlier access to allied health and supportive care, and a more trauma-informed patient experience. Health service benefits would include reduced repeat presentations, reduced escalation of untreated symptoms, better preparation for surgical care where required, and more effective post-treatment support.

3. Build and Retain a Specialist Pelvic Health Workforce in the ACT

A recurring issue reported during our community consultation is the shortage of adequately trained health professionals in the ACT, particularly in relation to AGES-trained gynaecologists, pelvic health physiotherapists, women's health nurses, and pain-informed clinicians. Both patients and clinicians described the effects of these shortages, including limited access, long wait times, inconsistent quality, and the need to refer patients interstate.

QENDO recommends targeted ACT investment in workforce development, training pathways, and retention strategies to build specialist capability locally. This should include specific focus on trauma-informed care, gender bias, medical misogyny, culturally safe practice, and contemporary multidisciplinary management of endometriosis and pelvic pain.

QENDO can partner in the design and delivery of lived-experience-informed training, clinician education, and sector engagement. Through national partnerships and local networks, QENDO can help bridge the gap between workforce training and community needs.

This recommendation addresses the barrier of insufficient specialist capacity and poor service confidence within the ACT, which contributes to delayed diagnosis, fragmented care, and interstate referral. The likely outcomes include a stronger local workforce, improved quality and consistency of care, and better local access to services that are currently unavailable or hard to access. Over time, this should reduce outward referral pressure, improve continuity of care, and lower the system costs associated with repeated presentations, prolonged diagnostic journeys, and avoidable disease progression.

4. Strengthen GP Education, Referral Pathways, and Primary Care Navigation

The findings show that many patients are still being referred into generalist or inappropriate pathways, or are receiving incomplete or delayed advice regarding the services available to them. Respondents specifically identified the need for better GP awareness of local endometriosis and pelvic pain services, including the Canberra Endometriosis Centre and relevant multidisciplinary supports .

QENDO recommends ACT-wide strengthening of GP education and referral pathways, including practical referral guidance, decision-support tools, and clearer integration between primary care, specialist services, and community support. This should also include better support for GPs to understand that surgery is not always the first or only clinically indicated pathway, and that multidisciplinary care should be embedded earlier in the patient journey.

QENDO can play a direct support role by delivering GP and community education, creating accessible resources, and integrating navigation tools such as the QENDO App and local service information into frontline referral practice.

This recommendation addresses the barrier of poor referral clarity, uneven GP knowledge, and weak connection between primary care and specialist/community pathways. The likely impact includes earlier intervention, improved referral quality, reduced patient self-navigation burden, and shorter time to appropriate care. Cost savings would arise from fewer inappropriate referrals, fewer repeated presentations, and less diagnostic drift across multiple providers.

5. Standardise Emergency Department and Acute Care Responses to Pelvic Pain

A significant concern raised by our community is the number of patients who actively avoid the Emergency Department because of previous negative experiences, including dismissal, stigma, inadequate pain management, and being perceived as drug-seeking or overly emotional. This is one of the clearest indicators of system distrust and system failure.

QENDO recommends development of standardised ACT protocols for Emergency Department and acute pelvic pain presentations, including pain management pathways, trauma-informed care guidance, bias-aware clinical practice, and clear follow-up pathways into community and specialist services.

QENDO can partner by contributing live-experience-informed training content, patient journey mapping, and tools that support continuity of care following acute presentations.

This recommendation addresses the barrier of inconsistent acute care responses and low patient trust in emergency settings. The likely outcomes include safer patient experiences, more consistent treatment, earlier follow-up, and reduced disengagement from care. Health service savings are likely through reduced repeat presentations, reduced escalation caused by delayed care, and more appropriate follow-up rather than recurring crisis-based presentations.

B. Recommendations Where QENDO Can Directly Deliver or Coordinate Support

6. Establish Recurrent Funding for the QENDO – ACT Branch as Core Community Infrastructure

QENDO recommends that the ACT Government establish recurrent funding for the QENDO – ACT Branch as core community health infrastructure.

The QENDO – ACT Branch is already the most established local, lived-experience-led endometriosis and pelvic pain community network in the ACT. It has undertaken the largest ACT consultation of its kind captured in this submission, supports a substantial local community, and has longstanding relationships with patients, families, volunteers, clinicians, and decision-makers . Yet despite this, it remains volunteer-run and unfunded.

QENDO proposes minimum recurrent investment of $400,000 per annum over five years to support delivery of local peer mentor programs, facilitated support groups, education sessions, navigation supports, outreach, and coordination workforce. This would also support stronger integration with ACT Health pathways and ensure local implementation is sustainable rather than reliant on goodwill and unpaid labour.

The barrier this addresses is the absence of funded, local, community-based support infrastructure, despite strong and growing demand. The outcomes would include improved early support, reduced isolation, stronger health literacy, better navigation of services, and increased trust and continuity for people managing chronic conditions. It would also reduce unnecessary pressure on clinical services by ensuring people receive support earlier, closer to home, and outside acute settings.

From a health service perspective, this investment represents preventative spend rather than downstream spend. It has the potential to reduce Emergency Department reliance, improve preparedness for specialist appointments, reduce repeated crisis presentations, improve self-management capacity, and support workforce participation and quality of life.

7. Fund Telehealth Multidisciplinary Support Linked to the National QENDO Network - QENDOare - an established telehealth multidisciplinary service linking with in primary care and tertiary health services to support the patients from health services to community.

www.qendo.org.au/care

QENDO recommends ACT Government investment in a telehealth multidisciplinary support pathway, connected to QENDO's broader national network and designed to support ACT patients who are unable to access timely specialised care locally.

This is particularly important given the inquiry findings regarding long wait times, barriers to multidisciplinary care, financial burden, and the large proportion of people needing to travel interstate for diagnosis and treatment. A telehealth-based model would provide a practical and scalable option for patients who need specialised support but cannot access or afford it through existing local pathways.

QENDO can directly support and coordinate this model by linking ACT patients into a national telehealth multidisciplinary network, including navigation support, non-medical coordination, and free or low-barrier support that does not depend solely on traditional service entry points. This is especially relevant for people who may not have a Medicare card, have had difficulty engaging with mainstream services, or need specialist support while remaining linked to their local GP.

This model would help address barriers including lack of local specialist access, delayed intervention, fragmented care, worsening situational mental health concerns, and missed opportunities for early identification of related issues such as eating disorders, complex pain, and psychosocial deterioration. Outcomes would include earlier specialist support, better coordination with local GPs, reduced deterioration while waiting for treatment, improved quality of life, and reduced need for avoidable acute escalation.

Health service cost benefits include reduced ED use, fewer preventable acute mental health presentations, reduced duplication of assessment across multiple providers, and better use of existing GP relationships to support earlier and more coordinated care.

8. Sustain and Expand the QENDO App as a Digital Front Door to Care

QENDO recommends ACT investment to sustain and expand the QENDO App as a digital front door to care for people living with endometriosis and pelvic pain.

The findings of this inquiry demonstrate that many patients experience a fragmented care journey, poor continuity, repeated retelling of their story, low confidence in services, and substantial self-navigation burden. The QENDO App directly responds to these issues by providing symptom tracking, flare management, education, care planning, support navigation, and a structured way for individuals to prepare for and engage with care.

QENDO proposes an ACT contribution of $350,000 per annum within the national app model, allowing ACT users to continue accessing and benefiting from the platform while strengthening its local integration with ACT services and referral pathways.

The barrier this addresses is the lack of coordinated digital support and the burden placed on patients to manage and communicate their condition without tools or continuity. The outcomes include improved patient preparedness, better symptom documentation, stronger patient-clinician communication, and more effective navigation of both community and clinical services.

For the health service, the app offers a cost-effective way to improve efficiency by reducing information loss, supporting clearer consultations, improving discharge and follow-up, and helping patients self-manage before conditions escalate. As a scalable digital tool, it represents strong value for investment relative to the cost of repeated fragmented care.

9. Embed Consumer Co-Design and Research Partnership Through QENDO

The inquiry findings also highlight strong community interest in research, innovation, and better translation of evidence into practice. QENDO recommends that the ACT Government formalise lived-experience involvement in service design, policy, education, and research relating to endometriosis and pelvic pain.

QENDO can directly support this through structured consumer engagement, consultation, and co-design processes. As both a local and national organisation, QENDO is able to mobilise diverse lived experience voices, facilitate meaningful participation, and ensure that consultation is not tokenistic but genuinely informs design and implementation.

This recommendation addresses the barrier of systems being designed without sufficient consumer input, which contributes to poor fit, low trust, and missed opportunities for improvement. The likely outcomes include more relevant services, stronger uptake, improved patient experience, and better policy and research decisions. In health service terms, well-designed services are more likely to be used appropriately, reduce churn, and achieve intended outcomes more efficiently.

Conclusion to Recommendations

Taken together, these recommendations provide a practical and evidence-informed response to the issues raised through this inquiry and the largest ACT consultation on endometriosis and pelvic pain captured to date through QENDO's local branch and community networks . They are designed not only to improve patient experience, but to address avoidable health system inefficiencies, reduce long-term costs, and create a more coordinated, equitable, and trusted model of care in the ACT.

QENDO is not offering abstract support. QENDO is offering a specific role: to partner where systems need redesign, and to directly deliver where community infrastructure, navigation, digital support, and telehealth coordination are urgently needed. This is the opportunity before the ACT Government: to work with the organisation already embedded in the issue, already embedded in the community, and ready to act.

The ACT has the opportunity to lead nationally in endometriosis care.
But this requires:

- investment in community infrastructure
- education and cultural change across the health system
- recognition of lived experience as central to care design.

People with endometriosis are not just navigating a health system, they are navigating their entire lives within it.

Submission prepared for QENDO by [redacted]
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02 April 2026
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