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

Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

Submission number: 039

Submitter: Research Australia

Date authorised for publication: 28 April 2026

RESEARCH AUSTRALIA
Championing Australian health & medical research & innovation

Response to the ACT Inquiry into endometriosis and other pelvic pain conditions

Thank you for the opportunity to provide a submission to the Standing Committee on Social Policy's inquiry into endometriosis and other pelvic pain conditions. Across Australia and internationally, there are significant gaps in our understanding of female health and disease, including endometriosis and other pelvic pain conditions, stemming from historical underrepresentation in health and medical research and clinical trials. With close to 1 million Australians affected by endometriosis alone and no current cure for the disease[1], we must centre equitable investment and prioritisation of research as a key enabler of equitable health outcomes.

As the national peak body for the health and medical research and innovation sector, Research Australia has underscored the need for a cohesive, equitable and high-functioning research environment as a prerequisite to improving health outcomes and ensuring social and economic equity, including for women, girls and gender diverse people. Health equity is research equity. Furthermore, the translation of research into ACT-based health services is integral to support improved treatment of endometriosis and other pelvic pain conditions, better health outcomes, and models of care based on the best available evidence. To achieve this, translational research, implementation science, and other disciplines focussed on research translation should be embedded within local health services.

The insights in this submission draw from our previous work - particularly a recent partnership with Besins Healthcare to develop the *Shaping the Future of Australian Women's Health Research - A roadmap for system reform to drive better health outcomes* (Women's Health Research Roadmap) report – released in November 2025.

Recommendations

- Centre equitable investment and prioritisation of research as a key enabler of equitable health outcomes.
- Embed translational research, implementation science, and other disciplines focussed on research translation within local health services.
- Incorporate the findings of the *Shaping the Future of Australian Women's Health Research - A roadmap for system reform to drive better health outcomes* into decision-making relating to women's health, health research and clinical trials.
- Ensure a focus on capturing and addressing lived realities of systemic intersectional discrimination.
- Support measures to embed lived experience perspectives and experiences of endometriosis and other pelvic pain conditions in research processes.
- Undertake a scoping project to understand local research and clinical trials capacity with the view of making ACT a leader in endometriosis and other pelvic pain conditions research.

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

Health equity is research equity. The Women's Health Research Roadmap highlighted the central role that research plays in shaping health outcomes for women. It found that persistent structural inequities within Australia's health and research systems, including systemic bias, narrow definitions of women's health and the underrepresentation of women in research design and leadership, continue to limit the development of a representative evidence base. Stakeholder consultations further identified that these issues are reinforced by fragmented funding models and a lack of diversity in decision-making, reflecting broader gender biases and cultural norms within the health system. These systemic gaps in research not only constrain innovation but directly contribute to poorer health outcomes for women by delaying diagnosis, limiting treatment options, and perpetuating the under-recognition of conditions, such as endometriosis. Accordingly, without addressing inequities in how research is funded, designed and led, efforts to improve health outcomes for women will remain fundamentally constrained. Critically, this must be reinforced by pathways to support translational research in local health services so best practice is embedded in models of care across ACT. The Roadmap outlines a 4 pillared framework to address these foundational issues:

1. **Resourcing an integrated system:** Australia's health research system is fragmented, with siloed efforts, duplication, and limited shared infrastructure. Strengthening national coordination, reforming funding models, and improving workforce equity and leadership are key to building a sustainable system that delivers stronger evidence and better health outcomes.
2. **(Re)defining Women's Health:** Women's health research is too narrow and often fails to reflect lived experiences. Expanding its scope beyond reproductive health, while embedding equity, intersectionality, diverse representation, and stronger data, is essential to improve outcomes for all women, girls and gender diverse people.
3. **(Re)empowering the community:** Community engagement is often tokenistic. Shifting to genuine partnerships – centring lived experience in leadership, building engagement capability, and addressing mistrust will improve research relevance and impact.
4. **Recognising and prioritising areas of need:** Research gaps remain in chronic and noncommunicable conditions. Better aligning priorities with need, investing in under-researched areas, and strengthening data, trials, and interdisciplinary collaboration will enhance translation into policy and practice.

Research Australia recognises that some actions of the 4 pillars fall out of the ACT government's remit – however they could be used as a framework for decision-making processes relating to women's health, health research and clinical trials.

Furthermore, addressing systemic intersectional discrimination in women's health research is critical as individuals can experience overlapping forms of systemic discrimination to accessing healthcare. Discrimination based on gender, ethnicity/race, disability, sexuality, socioeconomic status, and geographic location interact in unique ways to amplify health inequities. Addressing these structural barriers goes beyond just funding alone and requires evidence, engagement and community-informed approaches to capture lived realities.

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

As outlined in the Women's Health Research Roadmap, endometriosis diagnosis is a complex process, often taking significant time and financial resources involving multiple services, health care professionals and diagnostic measures, including pathology and surgeries[2]. A recent study suggests that the median time to diagnose endometriosis in women attending general practice is 2.5 years[3]. Once diagnosed, endometriosis and other pelvic pain conditions can have significant impacts across physical, psychological, social, and financial domains, often leading to reduced quality of life and impaired daily functioning. From a research perspective, the ACT government should support measures to embed lived experience perspectives and experiences of endometriosis and other pelvic pain conditions in the research process to ensure outputs are reflective of the real-world economic and social impacts for people in the ACT.

As well as the individual impacts of these conditions both pre- and post-diagnosis, there are substantial effects of chronic disease (of which endometriosis is included) in terms of lost productivity. For example, people with chronic disease are 60% more likely to not participate in the labour force, are less likely to be employed full-time, and more likely to be unemployed, than those without chronic disease[4]. Chronic disease also represents a significant cost burden to the wider health system (including those services located in the ACT) – with annual national spending on health currently $270.5 billion, an increase of $2.8 billion compared to 2022–23[5]. Taken together, this underscores the case for investing in health and medical research and innovation for improved diagnosis, treatment and prevention of endometriosis and other pelvic conditions, which ultimately powers productivity and cost containment across multiple fronts.

Understanding the different economic and social impacts of endometriosis and pelvic pain conditions through intersectionality is also critical in addressing the different experiences women and gender diverse people experiencing endometriosis and pelvic pain can have and then be compounded on matters such as education, employment and lost productivity due to ethnicity/race, disability, sexuality, socioeconomic status, and geographic location. This is critical in designing policies and programs that recognise diversity, equity and inclusion.

7) research and trials currently being explored in Australia and opportunities for this to take place in the ACT

A desktop scan of the Australian New Zealand Clinical Trials Registry (ANZCTR) lists 106 clinical trials containing the keyword 'endometriosis' and 170 for 'pelvic pain' – of which 29 (27%) and 18 (11%) list ACT as recruitment sites[6]. While these insights suggest a strong clinical trial environment, there is traditionally a concentration of research activity in New South Wales and Victoria – with NHMRC Grant Round data suggesting Victorian institutions made up 38% of applications and received 42% of the total grant funding in 2023[7].

As noted across this submission, there also needs to be a core focus on ensuring our health services are implementing the latest research and evidence relating to endometriosis and other pelvic pain conditions. This includes supporting translational research, implementation science and other disciplines which traditionally are not embedded in the health system. Embedding new models of care emerging from research activity into routine practice may require investment in implementation planning, the development of training materials and guidance, workforce capability uplift and training, and integration into existing workflows and standard operating procedures to ensure accountability and sustained practice change.

At the national level, health and medical research and innovation is highly uncoordinated and fragmented across Commonwealth, state and territory governments, as well as multiple departments and portfolios such as Health, Industry, and Education. This lack of coordination and reliable funding data makes it challenging to comprehensively track where investments are being made, assess their impact and identify critical gaps – particularly in priority areas like women's health. It also limits visibility over where there may be opportunities to expand or better target research activity, including within jurisdictions such as the ACT. Research Australia recommends the ACT government undertake a scoping project to understand local research and clinical trials capacity with the view of making ACT a leader in endometriosis and other pelvic pain condition research.

Conclusion

Thank you for the opportunity to provide a submission to the Standing Committee on Social Policy's inquiry into endometriosis and other pelvic pain conditions. We look forward to continuing partnering with governments, our members and all relevant stakeholders to ensure equitable investment and prioritisation of health and medical research and innovation as a key prerequisite to achieving equitable health outcomes.

For further information regarding this submission please contact [redacted] [redacted],or policy@researchaustralia.org.

Warm regards,

[redacted]

Nadia Levin

CEO & Managing Director
Research Australia

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About Research Australia

Setup by government following a landmark review in 2000, Research Australia is the national peak body for the health and medical research and innovation sector. Our membership is drawn from the whole pipeline of health and medical research and innovation, from universities and medical research institutes to charities and patient groups, and health care providers and companies commercialising new health technologies. Our priorities include a whole of systems approach to health and medical research and innovation, smarter investment, workforce and advancing prevention. Underpinning these priorities are equitable health outcomes; collaboration; AI and digital health, data and data linkage.

References

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