QTON No. 02

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

Inquiry into endometriosis and other pelvic pain conditions

Answer to question taken on notice

Asked by: Mr Thomas Emerson MLA

Addressed to: Dr Rachelle Warner

In relation to: Data on who gets diagnosed and who doesn't

Hearing: 14 May 2026
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Answer Due: 1 June 2026

Dr Warner took on notice the following question(s):

Dr Warner: Are you after data on the cost of endometriosis treatment?

THE CHAIR: The cost and then who—I mean, it is hard to track who is not getting treatment, but is it the case that people who are getting diagnoses and treatment generally tend to be in middle-income and above groups?

Dr Warner: Yes. The Women's Health Matters ACT survey data would have given you quite a bit. The difficulty with the current data is that it collects data on people who are already diagnosed, and the people who are already diagnosed tend to be the ones who can afford it, particularly in the ACT. The ACT has both the benefit and the disadvantage of being very small, very concentrated, but there are only a couple of specialists who deal with endometriosis. If you have a bad experience with one, you may or may not try again. We are limited in pathways and we are limited in other options, whereas in New South Wales, if you go to Sydney, if you go to one specialist and you do not like them, there are 20 other options. In the ACT, there are two or three and they might have a 12- or 24-month waiting period.

I would suggest that the current data reflects the better economic status, because people can afford to get a diagnosis, they can afford to keep going to specialists, and they can afford to go interstate to get a diagnosis; whereas the ones who actually need the most help, which is those who cannot afford it—those who are Indigenous people of colour, those who are disabled, those who are LGBTIQ—do not have those options and therefore do not pursue the diagnosis; they just live with the pain. I can certainly take it on notice and will come back to you if I can find any.

THE CHAIR: That would be great. Thank you. I imagine people in those categories are often also unaware of the existence of this potential diagnosis, so I am wondering if you have views. You spoke earlier about education. How do we help address that entire pathway, not just for clinicians but also for the general population?

Dr Warner: The answer to the Member's question is as follows:

Cost of endometriosis treatment

The economic burden of endometriosis in Australia is substantial, falling on both individuals and the health system.

At the individual level, a 2019 Australian study estimated the cost of endometriosis at AUD$30,900 per person per year. Lost productivity accounted for 84% of these costs, and costs increased with pain severity, with costs for people reporting severe pain six times higher than those reporting minimal pain [1].

At the system level, an estimated $247.2 million was spent on endometriosis in the Australian health system in 2020–21, with around 86% of that expenditure attributed to hospitals. Around 83% of total expenditure was attributed to people assigned female at birth / females of reproductive age (aged 15–44 years). These estimates include payments from all sources of funds: Australian and State and Territory Governments, private health insurance, and out-of-pocket patient payments, but are likely to underestimate total spending where data are lacking on endometriosis-related services, such as primary care and medicines [2].

The total economic burden of endometriosis has been estimated at between $7.4 billion and $9.7 billion per year, with most of the burden driven by lost productivity and reduced workforce participation [2–4].

Who is accessing diagnosis and treatment

The available data can only partially answer this question – those who fall through the gap are, by definition, largely absent from datasets. However, the evidence that does exist points clearly to a socioeconomic gradient in access.

Australian Institute of Health and Welfare data on endometriosis-related hospitalisations provides the most direct evidence. The age-standardised rate of endometriosis-related hospitalisation in the highest 20% of socioeconomic areas was 1.3 times the rate in the lowest 20% of socioeconomic areas. Most endometriosis-related hospitalisations were partly or fully funded by private health insurance (57%), and almost two-thirds (65%) took place in a private hospital. The rate of endometriosis-related hospitalisation in major cities was 1.5 times the rate in remote and very remote areas – a pattern that contrasts sharply with all female hospitalisations, for which the rate in remote and very remote areas is twice the rate in major cities [5].

This pattern is consistent with the structural barriers to access. Definitive diagnosis has historically required laparoscopic surgery (although contemporary clinical practice increasingly supports symptom- and imaging-based diagnosis pathways), which is primarily accessed through the private system. The community has consistently identified that the combination of surgery costs, specialist and GP appointments, allied and complementary health appointments, medications, private health insurance, and lifestyle health costs compounds the overall financial burden of living with endometriosis, and that inhibited employment and earning potential creates a vicious cycle of affordability [4].

The current Chronic Disease Management Plan model provides only five allied health sessions, with the subsidy often covering 50% or less of the total cost, limiting the ability of those with financial constraints to access regular, effective management. Public gynaecology clinics have historically focused on investigations, hormones, and surgery, rather than interdisciplinary care [4].

Taken together, these indicators suggest that those receiving diagnosis and treatment are more likely to be people with greater financial resources, private health insurance, and geographic proximity to specialist services. Those most likely to be missing from the data are people in lower socioeconomic groups, rural and remote communities, and First Nations women, who face

additional barriers that are well-documented in the broader literature on First Nations women's healthcare access [6].

The establishment of the National Endometriosis Clinical and Scientific Trials (NECST) Registry – a longitudinal, population-based data collection on diagnosis, treatment, and patient-reported outcomes has the potential to address important evidence gaps, and its findings will be important for understanding the full equity picture over time [7].

Robinson Research Institute is currently undertaking a study on adolescents who are at the start of their diagnosis which will look at costs prior to surgical diagnosis, along with a survey on accessibility of a diagnosis. This data has not yet been analysed or published but will also contribute to the knowledge base in the future.

References

1. 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. doi:10.1371/journal.pone.0223316 PubMed PMID: 31600241.
2. Australian Institute of Health and Welfare. Endometriosis in Australia 2023 - Economic Burden [Internet]. Canberra; 2023. Available from: https://www.aihw.gov.au/reports/chronic-disease/endometriosis-in-australia-2023/contents/impact/economic-burden
3. Ernst & Young. The cost of endometriosis in Australia: a report for EndoActive. [Internet]. 2019. Available from: https://endoactive.org.au/wp-content/uploads/29May2019-FINAL-The-Cost-of-Endometriosis-in-Australia-EY-EndoActive-Report.pdf
4. Armour M, Avery J, Leonardi M, Van Niekerk L, Druitt ML, Parker MA, et al. Lessons from implementing the Australian National Action Plan for Endometriosis. Reproduction and Fertility. 2022 Jul 1;3(3):C29–39. doi:10.1530/RAF-22-0003
5. Australian Institute of Health and Welfare. Endometriosis in Australia 2023 - Treatment & management of endometriosis [Internet]. Canberra; 2023. Available from: https://www.aihw.gov.au/reports/chronic-disease/endometriosis/contents/treatment-management-endometriosis
6. Ciccia D, Doyle AK, Ng CHM, Armour M. Indigenous Peoples' Experience and Understanding of Menstrual and Gynecological Health in Australia, Canada and New Zealand: A Scoping Review. Int J Environ Res Public Health. 2023 Jul 7;20(13):6321. doi:10.3390/ijerph20136321
7. Ng CHM, Michelmore AG, Mishra GD, Montgomery GW, Rogers PA, Abbott JA. Establishing the Australian National Endometriosis Clinical and Scientific Trials (NECST) Registry: a protocol paper. Reproduction and Fertility. 2023 May 23;4(2):e230014. doi:10.1530/RAF-23-0014

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Signature: 

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By Dr Warner