Submission cover sheet

Inquiry into endometriosis and other pelvic pain conditions

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Additional data findings supplementing Women's Health Matters submission to the Legislative Assembly Inquiry into Endometriosis and Pelvic Pain Conditions

Updated 21 May 2026

Endometriosis/adenomyosis: Prevalence by key variables

This additional material was requested by the Social Policy Committee during the hearing on 14 May 2026 when Women's Health Matters and Women With Disabilities ACT gave evidence.

The original submission and our oral evidence highlighted findings from our 2025 Survey of Women's Health that showed some relationships between the rates of Persistent Pelvic Pain (one cause of which might be endometriosis/adenomyosis) and a range of demographic and other variables.

We noted in our submission and in the hearing that we found similar patterns when we looked at rates of endometriosis/adenomyosis in relation to these same variables (and again when looking at PCOS). The Committee asked whether we could provide more detail documenting these patterns with specific reference to rates of endometriosis/adenomyosis rather than PPP. The current document provides these details.

Among the 1,319 survey respondents as a whole, 18.7% reported that they had ever been diagnosed with or treated for endometriosis/adenomyosis. This is the measure used for comparison in the current document.

As noted in our original submission, it is important to understand that we cannot be sure of the nature of any relationships we are seeing in the data. For example, being under stress financially might make it harder to access healthcare and other resources that could prevent or alleviate pelvic pain conditions. At the same time, having pelvic pain conditions often interferes with people's work and study, with impacts on income and financial stress, as well as imposing costs from having to pay for healthcare.

Regardless of causation, these findings can help guide health system responses to be appropriate for people who are more likely to be among those experiencing endometriosis/adenomyosis and other pelvic pain conditions.

Migration, visa, country of birth and language background

Our survey data indicates little difference in prevalence when comparing on the basis of **country of birth**, **migrant background**, **preferred language** or **main language spoken at home**.

In relation to **visa status**, Australian citizens and permanent residents had rates of endometriosis/adenomyosis that were similar the average, but temporary visa holders reported lower rates (7.4% compared with 18.7% among the survey respondents as a whole). The reason for this difference is not clear and may need further investigation.

Other research and WHM's experience delivering multilingual health education makes it clear that temporary visa holders, together with recent migrants and people whose preferred or usual language is other than English, experience barriers and difficulties accessing health services generally (AIHW 2024; AIHW 2023).

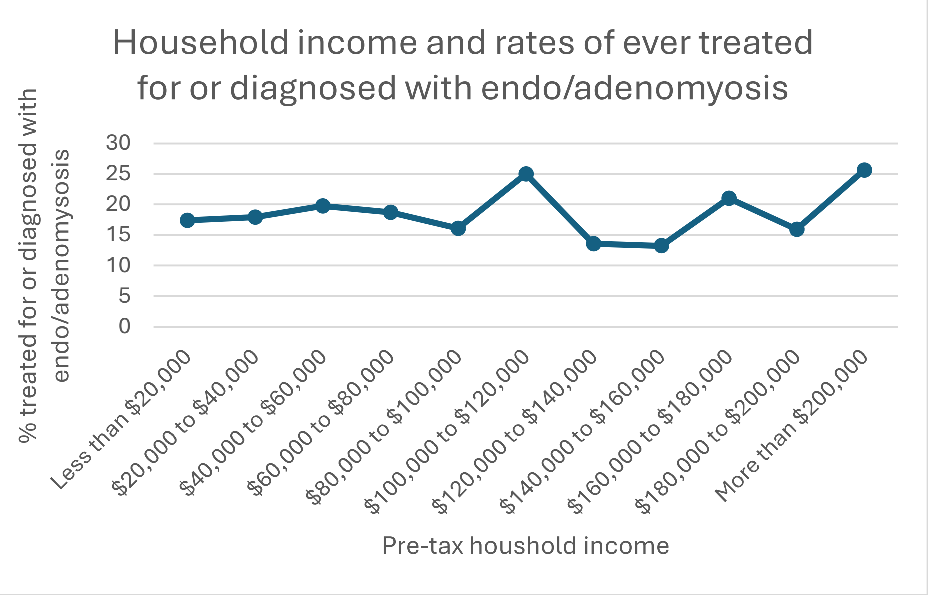
Financial stress

There were significant differences depending on **financial stress**:

- Among people who experienced at least one form of financial stress in the last year, 24% had experienced endometriosis/adenomyosis in the last two years, compared with 15% of those who had not experienced any financial stress.
- Among people who experienced four or more forms of financial stress, over 30% had experienced endometriosis/adenomyosis.
- People with endometriosis/adenomyosis were much more likely to have gone without medical care or medication in the last year due to not having enough money (31% of those with endometriosis/adenomyosis compared with 18% of the full sample).

Household income

In our data there appears to be a less clear relationship between household income and endometriosis/adenomyosis than between financial stress and endometriosis/adenomyosis, as shown by the following chart.



Note: 18% of respondents reported having household incomes more than $200,000, while every other income range was reported by fewer than 9% of respondents. This indicates a need to disaggregate higher incomes further in future surveys. As differences in income above $200,000 were not recorded in our 2025 survey, we cannot discern how those differences might relate to rates of endometriosis/adenomyosis (e.g. we cannot compare rates of endometriosis/adenomyosis among people with a household income of $400,000 with rates among people who have a household income of $200,000).

While we cannot be certain, the difference between financial stress and household income in terms of their relationship with endometriosis/adenomyosis might be partly explained by the different reference unit: while financial stress refers to experiences of the individual person, household income refers to the family or household unit and does not necessarily reflect the individual's own financial situation (e.g. their ability to mobilise resources for their own healthcare or other preventative factors).

Age

In terms of age, people in our survey who were aged 25-34 and 35-44 reported endometriosis/adenomyosis at higher than average rates, with 22% and 26% respectively who had ever been diagnosed with or treated for endometriosis/adenomyosis.

Gender

In our 2025 survey sample of 1319 people, just over 1% (15) identified their gender in a free-text response as non-binary, trans, agender and/or genderqueer, while 2.3% of respondents selected 'Prefer not to answer'. These results are broadly consistent with the ABS's finding that around 0.9% of people in Australia who are aged 16 years and over are trans and gender diverse, but these responses in our survey do not constitute a large enough dataset to analyse experiences of endometriosis/adenomyosis among trans and gender diverse people in the ACT.

Drawing on input from consumer advocates, Health Care Consumers Association's submission includes discussion of the challenges faced by trans and gender diverse people in accessing healthcare for pelvic pain, which we encourage the Committee to consider. Women's Health Matters' key principle is that health services need to be made inclusive of all people who need them. For services often considered to be "women's health services" (such as services assisting with endometriosis or PCOS) this means working with community members and relevant organisations to make sure services are welcoming, safe and well-informed about the needs of trans men and non-binary people.

Sexuality

While people who told us their sexuality was straight (heterosexual) reported close to average rates of endometriosis/adenomyosis (18%), people who told us they were bisexual, pansexual or queer had somewhat higher rates of endometriosis/adenomyosis (26%, 24% and 32% respectively). This might be related to poorer access to healthcare for some people who are not straight. For example, 36% of queer people who had consulted a GP in the ACT told us they had only fair or poor access to a GP, compared with 20% of survey respondents overall. Only 10% of gay/lesbian people in the survey reported endometriosis/adenomyosis, although it is unclear why this difference in the data exists and it should be noted that overall numbers are relatively low (e.g. 48 respondents who were gay/lesbian), so strong conclusions should not be drawn from this finding.

Neurodivergence

People who told us they were neurodivergent reported significantly higher rates of endometriosis/adenomyosis: 29% of neurodivergent people in our survey reported endometriosis/adenomyosis compared with 17% of those who were neurotypical.

Disabilities

People with disabilities experienced endometriosis/adenomyosis at a much higher rate (38%) compared with people who did not have disabilities (23%). The exact nature of this relationship is not clear, for example whether people's reporting of their disabilities includes their pelvic pain condition or refers to other conditions/impairments.

As noted in our original submission, WHM endorses the submission provided to this inquiry made by Women With Disabilities ACT and urges the Committee to consider its recommendations.

Mental health

Looking at mental health, among people who reported high levels of psychological distress (measured as scores of 19 or more on the Kessler 6 scale), 25% reported having endometriosis/adenomyosis, compared with only 17% of those with lower levels of psychological distress.

People who had ever been diagnosed or treated for a mental health condition reported endometriosis/adenomyosis at twice the rate (22%) compared with those who had never been diagnosed or treated for a mental health condition (11%). Among all of those who reported endometriosis/adenomyosis, 80% had been diagnosed or treated for a mental health condition at some point (compared with 66% of the sample as a whole).

Note: In our original submission we cited rates of mental health conditions among people with Persistent Pelvic Pain compared with rates among the survey sample as a whole. However, we gave an incorrect figure of 45% for the rate of ever having been diagnosed or treated for a mental health condition among the sample as a whole. The rate should have been given as 66% (as above). Apologies for the error.

Experiences of violence

People who had experienced some form of violence also had higher rates of endometriosis/adenomyosis, with 23% reporting endometriosis/adenomyosis compared with 14% of those who did not indicate having experienced any form of violence. Among people who had experienced sexual violence specifically, 24% of these respondents also reporting endometriosis/adenomyosis, compared with 17% who told us they had not experienced sexual violence. These findings are consistent with research indicating that people who have experienced violence are more likely to have chronic pain in general (Uvelli et al 2024).

References

Australian Institute of Health and Welfare. (2024) *Social determinants of health among culturally and linguistically diverse people in Australia*, AIHW, Australian Government, accessed 16 April 2026.

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Uvelli A, Ribaudo C, Gualtieri G, Coluccia A, Ferretti F. The association between violence against women and chronic pain: a systematic review and meta-analysis. *BMC Womens Health*. 2024 Jun 4;24(1):321. doi: 10.1186/s12905-024-03097-w. PMID: 38834977; PMCID: PMC11149284.