



New Zealand House of Representatives
Te Whare Māngai o Aotearoa

Health Committee

Komiti Whiriwhiri Take Hauora

54th Parliament

September 2026

Briefing on endometriosis

**Petition of Endo Warriors Aotearoa:
Independent review and rewrite of
endometriosis guidelines**

Presented to the House of Representatives
by Sam Uffindell, Chairperson

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Briefing on endometriosis

Recommendation

The Health Committee has considered a briefing on endometriosis and the petition of Endo Warriors Aotearoa: Independent review and rewrite of endometriosis guidelines, and recommends that the House take note of its report.

Background about this report and the condition

This report first discusses a briefing we have carried out about endometriosis, and then a petition calling for updated endometriosis guidelines in New Zealand. We have combined them in one report given the close affinity in subject matter.

We initiated a briefing on this subject in response to a letter from Endometriosis New Zealand, which asked to meet with us to discuss the challenges some New Zealanders face with diagnosis, care, and treatment of endometriosis. Endometriosis NZ is a charity that provides education, advocacy, and support about endometriosis across communities, schools, and workplaces.

Endometriosis is among the most common gynaecological conditions. It occurs when tissue similar to the lining of the womb grows in other parts of the body, such as the ovaries, bladder, or bowel.¹ It is described as an “inflammatory disease”. Symptoms may include painful periods (dysmenorrhoea), pelvic pain, dyspareunia, bloating and irritable bowel syndrome, and infertility. Some people with endometriosis may be asymptomatic.²

We held a hearing with Endometriosis NZ on this briefing on 19 November 2025. We also sought written and oral evidence from Health New Zealand—Te Whatu Ora, and met with Health NZ on 19 August 2026.

Comments from Endometriosis New Zealand

Endometriosis NZ told us that the condition affects about 120,000 New Zealanders. The organisation said that people with endometriosis wait, on average, close to 10 years for a diagnosis. During that time, they may experience ongoing pain, with effects on their relationships, wellbeing, education, employment, and careers.

Endometriosis NZ highlighted that the condition has significant economic effects. It referred to ongoing research in New Zealand, which assessed endometriosis as a national “economic burden” that is costing the country billions of dollars annually. Australian modelling has also estimated that endometriosis costs New Zealand’s health system and wider economy

¹ Further information on endometriosis can be found on the [Health New Zealand website](#).

² Ministry of Health, *Diagnosis and Management of Endometriosis*, 3.

between \$1.3 billion and \$1.5 billion each year.³ It said that around two-thirds of this cost is likely to result from lost productivity.

The organisation is also concerned about inequitable access to endometriosis care. Māori, Pasifika, and rural communities are disproportionately affected, because care is fragmented and variable around New Zealand, and access to specialist services and publicly funded diagnosis and treatment is limited, it said. Endometriosis NZ estimates that the average delay to diagnosis is 11.6 years for Māori, and 12.4 years for Pasifika. According to research it cited, 67 percent of both Māori and Pasifika respondents felt that endometriosis treatment was not readily available to them.⁴

Need for updated guidelines

Despite endometriosis being included in the Women's Health Strategy 2023, Endometriosis NZ told us that patients have not experienced material improvements. There is limited support and training for primary care practitioners, access to specialist care is slow, and diagnosis and treatment pathways are inconsistent.

Endometriosis NZ also suggested that the Ministry of Health's 2020 publication on diagnosing and managing endometriosis was outdated and does not reflect current best practice.⁵ It supported adopting the guideline being used in Australia, developed by The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG).⁶ That guideline is a "living document", designed to be updated as evidence on endometriosis evolves. Its features include using ultrasound or pelvic MRI early in the diagnostic process, and starting treatment while diagnosis is under way. This approach aims to reduce reliance on diagnostic laparoscopic surgery (an operation used to look at pelvic organs) and support earlier diagnosis and treatment.

Requests from Endometriosis New Zealand

Endometriosis NZ set out its requests to improve care for people living with endometriosis. It wants:

- greater recognition of endometriosis as a major health, productivity, and quality of life issue for New Zealanders
- adoption of the Australian endometriosis guideline as New Zealand's national clinical standard, with appropriate training and resources such as imaging capacity and support for primary care to put it into practice
- a national action plan for endometriosis in New Zealand, aimed at providing earlier diagnosis, equitable access to treatment, and consistent and integrated care.

³ *The Cost of Endometriosis and Chronic Pelvic Pain Burden in New Zealand (Aotearoa): Results from a Nationwide Survey.*

⁴ *The Perspectives of Māori and Pasifika Mate Kirikōpū (Endometriosis) Patients in Aotearoa New Zealand.*

⁵ *Diagnosis and Management of Endometriosis in New Zealand*, Ministry of Health.

⁶ *Australian Living Evidence Guideline: Endometriosis*, RANZCOG.

Comments from Health New Zealand

We sought written evidence from Health NZ to learn about endometriosis services. In February 2026, Health NZ provided written information and said it was exploring options to update endometriosis guidance. One option included either adapting or adopting the guidelines from Australia, but at that time Health NZ said further work was needed to assess the capacity and resource implications of doing so. New guidance was subsequently announced by the Minister of Health and Minister for Women on 18 August 2026, and our hearing with Health NZ took place the following day.⁷ We summarise below Health NZ's written evidence and our hearing with the agency.

Management and diagnosis of endometriosis

Endometriosis is generally first treated by a GP in primary care, and can be managed through hormonal treatment, pain relief, and lifestyle changes. Health NZ told us that patients may be referred to a gynaecologist if symptoms continue, and that secondary care can include both medical and surgical treatment. As endometriosis requires long-term management, treatment may be shared between primary and secondary care.

Health NZ agreed that people can wait a long time between first having endometriosis symptoms and receiving diagnosis and treatment, and this can have psychological effects. It estimates the delay to be 8 to 12 years. Diagnosis has traditionally relied on laparoscopic surgery, which is considered the "gold standard". However, surgery can be costly and difficult to access through publicly funded hospitals, which delays diagnosis for many. Health NZ told us there is an opportunity to reduce psychological harm by no longer requiring laparoscopic diagnosis before beginning endometriosis care. Instead, a presumptive diagnosis based on symptoms, medical examination, and family history could be used, allowing hormonal treatment to begin earlier.

The information available about endometriosis services is limited. Health NZ said it does not have a national endometriosis-specific dataset that would enable it to assess regional differences in access or quality of services. It also does not collect data about endometriosis from primary care services around the country, nor data on waiting-times for referrals.

Hearing with Health New Zealand

We met with Health New Zealand on 19 August 2026 and discussed the clinical guidelines for diagnosing endometriosis that were announced the day before our hearing. Dame Helen Stokes-Lampard, National Chief Medical Officer, and Astuti Balram, Director Primary and Community Health attended our hearing on behalf of Health NZ. They were joined by Dr Rebekah Doran, a GP with a special interest in women's health.

New clinical guidelines

We heard that Health NZ has been working with RANZCOG to adapt the Australian endometriosis guidelines for the New Zealand context. The Australian Government is supporting this work. Health NZ is also engaging with bodies such as the colleges of anaesthetists and of general practitioners, and Endometriosis NZ to make sure the

⁷ The announcement of these new guidelines is [available on the Beehive website](#).

guidelines are fit for purpose. The guidelines will be reviewed by Health New Zealand's clinical governance group to ensure they work for local communities and consider the needs of Māori and Pasifika.

We were told that the new guidance would support GPs and nurse practitioners to make a clinical diagnosis of endometriosis. This would help people begin hormonal treatment sooner, which Health NZ noted can alleviate symptoms for up to 60 percent of women. Earlier clinical diagnosis and treatment would also enable laparoscopic surgery to be reserved for people who need it, rather than relying on surgery to establish a diagnosis. Training will be developed for GPs and frontline practitioners to help them put the guidelines into practice.

We asked why Health NZ is adapting the Australian guideline rather than developing a new guideline here in New Zealand. Health NZ told us that it is expensive to develop a "living" document, where evidence is updated often, and that the Australian Government has already invested substantially in this work. New Zealand clinicians and researchers have been contributing their expertise to the Australian guideline too, and RANZCOG has agreed in principle to its adaptation for New Zealand. The adapted version would take into consideration the differences between the two health systems, and cultural practices in New Zealand.

During our hearing, Health NZ thanked Endometriosis NZ for its advocacy in this area, and RANZCOG for its collaborative and constructive partnership in adapting the guidance so far.

Developments from 2020

We asked how the new guidelines would differ from the Ministry of Health's 2020 publication on diagnosing and managing endometriosis in New Zealand. Health NZ told us that the earlier publication was progressive for its time and much of its approach would be carried forward. However, it relied heavily on "lower-grade" evidence and expert opinion, whereas the new guidelines will be based on robust, stronger, and "higher-grade" evidence.

The new guidelines would be accompanied by better education packages for GPs and frontline clinicians. Although the earlier guidance also emphasised frontline clinicians' ability to diagnose endometriosis, Health NZ said it was not accompanied by widespread education. Despite improvements in diagnosis rates, therefore, some GPs still lack confidence in making a clinical diagnosis of endometriosis.

We asked how education and implementation would differ this time. Health NZ said it intends to run a national series of webinars and engage "clinical champions" through RANZCOG to undertake local training. Some of us recall that similar measures accompanied the previous guidance. We consider that educational initiatives should include more detail about the operational differences between the guidelines published in 2020 and those announced this year.

The announcement and new guidelines will improve public awareness about GPs diagnosing endometriosis, Health NZ told us. If people can be diagnosed earlier, this will help them feel more validated and heard by their GP. Additionally, Health NZ raised that having a narrative in the public domain about women and their health problems is "a good thing". Evidence about ultrasounds and MRI scanning has also changed between the 2020

publication and the upcoming one. Substantial expertise is needed to use ultrasounds effectively in diagnosing endometriosis, and we heard that it is “still not a great diagnostic tool”. For this reason, a person’s clinical history will be more important. Although we acknowledge the difficulties with using an ultrasound to diagnose endometriosis, we note that an ultrasound is less invasive than surgery. We therefore asked how much it would cost a person with endometriosis symptoms to get one. Health NZ told us there are national criteria for accessing funded pelvic ultrasounds, although capacity and resources in providing them varies across the country. For people accessing ultrasounds privately, Health NZ said the cost varies by location but estimated that, generally, the cost could be between \$250 and \$350.

Our comments

We thank Endometriosis NZ and Health NZ for their work. We acknowledge the significant effects that endometriosis can have on people’s health and quality of life, and remain concerned about how long people wait to be diagnosed and treated.

We welcome the work under way to adapt the Australian endometriosis guidelines for use in New Zealand. In particular, we are encouraged by the greater emphasis for people to be diagnosed early on, enabling them to begin treatment to manage symptoms without requiring diagnostic laparoscopic surgery. We consider that this will improve wait times for diagnosis and reduce the psychological harm that some people experience while waiting many years to be diagnosed.

In saying that, we also recognise that new clinical guidance will only improve patients’ experiences if practitioners are appropriately supported to implement it. We note Health NZ’s intention to provide an education package for GPs and other frontline practitioners. We encourage the next Health Committee to follow the publication and implementation of the new guidelines when they are released in the new Parliament.

Petition of Endo Warriors Aotearoa

Request to review and rewrite endometriosis guidelines

This petition was signed by 2 people. It was presented to the House by Kahurangi Carter on 22 April 2026 and was transferred to us on 21 May 2026. It requests:

That the House of Representatives urge the Government to commission an independent review and rewrite of the Ministry of Health's 2020 endometriosis guidelines, led by Endo Warriors Aotearoa alongside a panel of experts and patients, and make the new guidelines enforceable; and note that 5,964 people have signed a similar petition.

This petition was presented before new endometriosis guidelines were announced.

Comments from Endo Warriors Aotearoa

Endo Warriors Aotearoa provides education about endometriosis, advocacy, practical support, and community connection, and works to improve understanding about endometriosis and menstrual health. It provided written evidence to the Petitions Committee before the petition was transferred to us. We have used that evidence in our consideration of the petition and summarise it below.

Endometriosis care is inadequate

Endo Warriors Aotearoa believes the Ministry of Health's 2020 endometriosis guidance is not fit for purpose. For example, the petitioner stated that the guidance is neither mandatory nor enforceable, it lacks clear diagnostic pathways and timeframes, does not include accountability mechanisms, and does not reflect adequate equitable practices or inclusion.

The petitioner highlighted lengthy delays in diagnosis and accessing treatment. It said that New Zealanders could wait between 7 and 10 years for a diagnosis. These delays are partly due to restricted or declined referrals to gynaecology services, long waiting lists, and limited access to clinicians with expertise in endometriosis. It considers that this creates significant regional variation in accessing care and can leave people reliant on private treatment, where they can afford it.

Improving endometriosis care

Endo Warriors wants a health system where people with endometriosis are believed and their symptoms are taken seriously, and where they receive timely diagnosis, referral, and appropriate investigation. It wants people to have access to a full range of treatment options, be supported to make informed decisions about their care, and receive multidisciplinary care regardless of their income or location. Also, care should be consistent across regions, culturally safe, inclusive, and trauma-informed, and should not depend on people having to advocate for themselves or pay privately. To make this happen, Endo Warriors believes national standards are needed.

Alongside several other proposals, the organisation's submission called for:

- a full, independent review and rewrite of the 2020 endometriosis guidelines

- new guidelines that are enforceable as clinical standards, ensuring consistent and equitable care for people with endometriosis
- the establishment of a national panel of endometriosis experts
- appropriate funding and monitoring for implementation of the new guidelines
- clear leadership for the review, development, and implementation of new guidelines, with Endo Warriors playing a key role, to provide accountability when the guidelines are put into practice.

Hearing with Endo Warriors Aotearoa

We met with Yessenia Sandoval from Endo Warriors Aotearoa on 2 September 2026, after the Government announced that Health NZ would adapt the Australian endometriosis guideline for New Zealand. Yessenia was joined by endometriosis advocates Lucy Smith and Cleaver Athame, who also shared their experiences of the condition.

Concerns about implementation of new clinical guidelines

Endo Warriors stressed that “a political announcement is not implementation”. Although it welcomed the development of new guidelines, it said that that alone would not address the problems experienced by people with endometriosis. The failure of the 2020 publication has never been in its wording, but rather in how it has been put into practice, where accountability lies, and a lack of funding, Endo Warriors told us. For example, it contended that the publication already supports clinical diagnosis in primary care and recognises that an ultrasound or medical examination with a “normal” result does not rule out someone having endometriosis.

Endo Warriors remains concerned about what would happen after a person receives a clinical diagnosis from their GP. It questioned whether they would then be able to access imaging, pain care, specialist care, fertility support, or surgery, or whether they will be diagnosed and left waiting. Specialist ultrasound treatment, Endo Warriors observed, is limited in New Zealand. We were cautioned that people might simply move from “waiting for a diagnosis to waiting with a diagnosis”.

It is also concerned about hormonal medication being positioned in the new guidelines as a first-line treatment. Although it acknowledges that hormonal treatment helps many people, Endo Warriors considers that it should not become an automatic response. It stressed that informed choice and regular reviews of medication are important. It advocated publicly funded access to pelvic health physiotherapy, pain care, fertility support, and evidence-informed holistic and complementary endometriosis care.

Endo Warriors Aotearoa calls for a funded national endometriosis action plan. It identified five areas that it considers a minimum starting point for improving care. They are:

- national pathways for diagnosis and treatment, with timelines for review and referral
- national standards for imaging
- genuine treatment choice
- youth-specific, culturally safe, and inclusive care
- greater accountability, with stronger data about endometriosis across the health system.

Lived experiences of endometriosis

We heard about first-hand experiences from people living with endometriosis. The founder of Endo Warriors, Yessenia Sandoval detailed her own experience living with endometriosis. She described experiencing nine pregnancy losses, surgeries that caused lasting damage, a hysterectomy that did not cure her endometriosis, and losing the ability to work full time.

Cleaver Athame described experiencing severe symptoms from the onset of menstruation. Cleaver repeatedly sought help from the school nurse yet was not believed as nothing was visibly wrong. As a gender-fluid trans man, Cleaver's identity has "added another layer to an already difficult illness". We heard that Cleaver has been intentionally misgendered during treatment, encountered medical staff who have struggled to understand that a man could have endometriosis, and been dismissed. Cleaver emphasised that endometriosis can also affect trans, gender-diverse, and non-binary people, and that the health system needs to recognise this.

We also heard from Lucy Smith, a 20-year-old woman, who told us about her experience seeking endometriosis treatment. She described being passed between doctors and having to wait for appointments, including about a year and a half to see a gynaecologist. Over the last five years, Lucy has repeatedly been prescribed different forms of birth control or pain medication. These provide only temporary relief and sometimes make her symptoms worse. Lucy said she is fatigued from pain medications and does not feel heard when she explains to practitioners that her symptoms are worsening. She continues to study, work, and participate in activities despite dealing with pain nearly every day.

We asked about the barriers that a young person might experience when seeking help from a GP. They include symptoms not being believed, or practitioners lacking knowledge about endometriosis. We heard that, in Lucy's case, her symptoms were attributed to anxiety and ADHD. She believes her symptoms were not recognised as endometriosis because of her age, healthy appearance, the absence of findings on scans, and the fact that she had not experienced pregnancy loss.

Endo Warriors continues to hear about childhood symptoms, people missing school or losing employment, being rejected for referrals, having normal scans despite symptoms, and having surgery without follow-up. These experiences, the petitioner said, demonstrate a continuing pattern of "dismissal, delay, and inadequate treatment". A responsive health system, we were told, would track a person's endometriosis care from the beginning. Different health professionals involved in their treatment would communicate with one another to develop a coordinated plan.

Following our hearing, Endo Warriors provided further information about what it considered good endometriosis care could look like. It emphasised the importance of providing care earlier and closer to where people live, with clear pathways between primary care, allied health services, specialist care, and surgery (when required).

Endo Warriors emphasised that endometriosis can require care from a range of health professionals and should not be treated solely as a gynaecological condition. Multidisciplinary care could involve pain specialists, pelvic health physiotherapists, psychologists, dietitians, colorectal and urology specialists, and sexual health services. We

were urged to consider aspects of Australia's model of specialist endometriosis and pelvic pain clinics based in primary and community care. Endo Warriors told us that Australia has 33 such clinics, which aim to provide multidisciplinary care closer to home, improve referral pathways, increase access to allied health services, and build workforce expertise. It suggested that a similar approach in New Zealand could involve regional endometriosis and pelvic pain clinics where GPs, pelvic health physiotherapists, pain specialists, nurses, and other clinicians work together.

Endo Warriors considers that information about fertility should form part of the care pathway from an early stage. Those who want to have children should receive early information about how endometriosis may affect their fertility. Equally, the organisation stressed that people who do not want children should not have their pain or treatment given less priority because fertility is not one of their goals.

Our comments

We thank Yessenia Sandoval from Endo Warriors Aotearoa for speaking to us about this petition, and for Endo Warriors' advocacy on behalf of those living with endometriosis. We are grateful to Yessenia, Lucy, and Cleaver, who shared deeply personal experiences with us. Their lived experience helped us understand the effects of endometriosis, including the distress and frustration caused when symptoms are not taken seriously or care is difficult to access.

We recognise the effort that Endo Warriors Aotearoa and its supporters have put into drawing attention to these experiences. We were particularly concerned to hear about people experiencing symptoms from a young age, waiting years for specialist care, and continuing to encounter barriers after seeking medical help. We appreciate hearing about the experiences of trans and gender-diverse people with endometriosis and the additional difficulties they can encounter when accessing care.

The petition was presented before the announcement that new endometriosis guidance would be developed for New Zealand. We are pleased that Endo Warriors Aotearoa welcomed this development, while continuing to emphasise the importance of ensuring that the guidance is properly implemented. We agree that earlier diagnosis needs to be accompanied by appropriate treatment and support.

We consider that the petition has raised important issues about access to services, continuity and coordination of care, and ensuring that people with endometriosis are listened to and treated with dignity. We hope that the new guidance will result in meaningful improvements for people living with endometriosis, including young people and those whose communities may face additional barriers to care.

Appendix

Committee procedure

We met between 10 September 2025 and 23 September 2026 to consider this briefing, and heard evidence from Endometriosis New Zealand (19 November 2025) and Health New Zealand (19 August 2026).

The petition was signed by two people on the Parliament website. It was presented to the House by Kahurangi Carter on 22 April 2026 and was referred to us on 21 May 2026. We met with the petitioner and advocates on 2 September 2026.

Committee members

Sam Uffindell (Chairperson)
Dr Hamish Campbell
Dr Carlos Cheung
Ingrid Leary
Cameron Luxton
Hūhana Lyndon
Jenny Marcroft
Debbie Ngarewa-Packer
Hon Dr Ayesha Verrall

Related resources

The documents we received as advice and evidence for this briefing are available on the [Parliament website](#), along with the recordings of our meetings on [19 November 2025](#) and [19 August 2026](#).

The documents we received as evidence for this petition are available on the [Parliament website](#), along with the recording of our meeting on [2 September 2026](#).