

Briefing to the Incoming Minister
December 2023



About Endometriosis New Zealand (ENZ)

Endometriosis New Zealand is New Zealand's national endometriosis organisation. As a registered charitable trust, our purpose is to improve the lives of those with endometriosis through providing support, advocacy, research, information, education and awareness.

About Endometriosis

Endometriosis is a common yet frequently under-recognised chronic disease estimated to affect at least 120,000 New Zealanders. It occurs when tissue similar to the lining of the uterus, is found in places outside of the uterus. The cause of endometriosis is unknown and there is no definite cure. Endometriosis is a highly individualised disease. Some people have very little pain or symptoms, while others experience chronic pain that affects their daily life.

The signs and symptoms of endometriosis may include period pain that affects daily life; pain during and/or after sex; pelvic, lower back and leg pain; bladder and/or bowel troubles; abnormal menstrual bleeding; sub-infertility or infertility; tiredness and low energy; immune system issues; premenstrual syndrome (PMS); low mood and depression.

Endometriosis at a glance



Affects at least 1 in 10 girls, women and those assigned female at birth.⁶



8+ years is the average delay between onset of symptoms and diagnosis.⁷



At least **one third** of those with endometriosis experience **fertility problems**.⁸

Endometriosis costs an average **\$30,000** per patient per year in **lost productivity and healthcare costs**.⁹



1 in 6 endo sufferers have **lost their jobs** due to their endometriosis.¹⁰



1 in 3 endo sufferers have been **passed over for promotion** due to their endometriosis.¹¹

6. Endo Warriors Aotearoa believes this figure could be significantly higher due to underreporting, misdiagnosis, and a lack of nonsurgical and non-invasive diagnostic methods and cites J Rowlands et al 'Prevalence and incidence of endometriosis in Australian women: a data linkage cohort study' (2020) <https://obgyn.onlinelibrary.wiley.com/doi/abs/10.1111/1471-0528.16447>

7. Tewhaiti-Smith, J., Semprini, A., Bush, D. et al. An Aotearoa New Zealand survey of the impact and diagnostic delay for endometriosis and chronic pelvic pain. *Sci Rep* 12, 4425 (2022). <https://www.nature.com/articles/s41598-022-08464-x>

8. Endometriosis and Infertility: A Systematic Review - Amani Harris, Jim Tsaltas, 2017 (sagepub.com)

9. The cost of illness & economic burden of endometriosis & chronic pelvic pain in Australia: A national online survey | PLOS ONE

10. <https://www.endometriosisaustralia.org/endo-in-the-workplace>

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Current state

In March 2023 ENZ put in a comprehensive submission to Manatū Hauora Ministry of Health to inform the development of New Zealand's first Women's Health Strategy. We have attached a copy of our submission to this BIM for your reference.

Our submission, which was supported by New Zealand's two other endometriosis charities (Insight Endometriosis and Endo Warriors Aotearoa), outlined many of the issues leading to delayed diagnosis and fragmented quality of care including:

- a lack of endometriosis education in primary healthcare
- patients experiencing long delays to see gynaecologists and other specialists
- limited access to publicly funded ultrasounds, MRIs and hormonal treatment options; and
- no New Zealand network of tertiary referral centres for complex endometriosis surgery.

As a result of our advocacy, and that of our members and the wider sector, we were pleased to see endometriosis specifically referenced in the Women's Health Strategy which was released in July 2023.

This is a promising start but as we learnt from the publication of the Diagnosis and Management of Endometriosis in New Zealand guidelines in 2020, words alone will not improve the lives of individuals with endometriosis, who are still waiting an average of eight years between onset of symptoms and diagnosis.

We provided a comprehensive overview of the issues with implementing the best practice guidance in our submission (page 9-12) and are keen and committed to continuing to work with your officials going forward.

We are aware there is significant work ahead to turn the Strategy into action, and to deliver a with Government Policy Statement on Health as required under the Pae Ora Act by 1 July 2024.

That is why it is critical to develop a national endometriosis action plan, similar to that which was successfully implemented in Australia.

This will provide a clear blueprint to tackle endometriosis through education and awareness, clinical management and care, and research.

This plan can be based off international examples, though adapted for Aotearoa New Zealand's demographics. Such a plan would enable the Government to finally acknowledge that endometriosis causes a substantial health and economic burden on our population and wider society. It will also provide a clear blueprint to tackle endometriosis on all fronts.

Our preference would be for this action plan to be co-designed with endometriosis clinicians, researchers, ENZ, Insight Endometriosis and Endo Warriors Aotearoa to ensure it is fit for purpose.

The action plan should be supported by funding to have endometriosis education and awareness run in the community through our respective organisations.

Priorities

Within the National Action Plan for Endometriosis, we see the following priorities:

Education and awareness

- Improve information and education about endometriosis to increase awareness and understanding.
- Improve access to empowering information about endometriosis, diagnosis and management options at all stages of a sufferer's journey.
- Improve education for health professionals working at every stage of endometriosis in the guidelines for Diagnosis and Management of Endometriosis in New Zealand (2020).
- Improve education for health professionals on the equity principles related to Māori and Pasifika patients with endometriosis.

Clinical Management and care

- Improve early recognition of endometriosis symptoms to reduce diagnostic delay, especially in primary care settings.
- Develop the nationwide health workforce to ensure patients have access to prompt and appropriate care, no matter where they live.
- Rollout appropriately trained multidisciplinary teams to improve health outcomes (eg, gynaecology, pain management, fertility specialists, radiology, psychology, physiotherapy, dietetics, paediatrics/adolescent health).
- Review and update 2020 best practice guidelines: 'Diagnosis and Management of Endometriosis'.
- Adapt the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) endometriosis guidelines for an Aotearoa New Zealand context.

Research

- Build a collaborative network that enables world leading research on endometriosis (for example, biology of the disease, biomarkers and early detection/screening, pain management, and experiences of different population groups).
- Invest in research to understand the causes and impacts of endometriosis, especially to improve equity for Māori.
- Funding to develop a New Zealand National Endometriosis Clinical and Scientific Trials (NECST) Network.

Te Tiriti o Waitangi and equity lens

Implementation of the Women's Health Strategy provides an ideal opportunity for the Government to improve hauora Māori outcomes for wāhine and kotiro Māori and give effect to the health sector principles outlined in s7 of the Pae Ora Act.

We also know there is minimal research on the diagnosis and treatment of endometriosis for wāhine and kotiro Māori. Despite this reality we know from an analysis of other women's health issues and current health inequities suffered by wāhine Māori compared with non-Māori that there are entrenched and systemic inequities.

We are also keen to improve access to and availability of health services for Māori together with the development and delivery of programmes that reflect Māori needs and aspirations.

The Women's Health Strategy needs to be inclusive of the needs of LGBTQIA+, disability and ethnic and migrant communities, including New Zealand's Pasifika populations.

Supporting your work

ENZ is available to provide you and your officials with expertise on any aspect of this BIM.

We would also welcome the opportunity to meet with you at the earliest opportunity to discuss how we can work together to improve the lives of individuals with endometriosis.

If you or your staff have any questions about the information provided in this briefing please contact:



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