Submission to Manatū Hauora Ministry of Health on the Aotearoa New Zealand Women's Health Strategy

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Executive Summary

1. As a national endometriosis organisation, Endometriosis New Zealand (ENZ) welcomes the opportunity to make a submission on Aotearoa New Zealand's first Women's Health Strategy (the Strategy).[1]

2. This submission is also supported by Aotearoa New Zealand's two other endometriosis charities - Insight Endometriosis[2] and Endo Warriors Aotearoa.[3] Together, we see the transformation of the health system and the development of the Aotearoa New Zealand's Women's Health Strategy as a once-in-a-lifetime opportunity to improve health outcomes for women, girls and those assigned female at birth.

3. Our submission is focussed on endometriosis which is a common yet frequently under-recognised and chronic disease estimated to affect at least 120,000 New Zealanders. It is well established that endometriosis affects at least 1 in 10 girls, women and those assigned female at birth.

4. Despite a lack of Aotearoa New Zealand specific research into endometriosis, we know from the work we do in our communities that the health system is failing those with endometriosis. This is illustrated by the fact that the average delay between onset of symptoms and diagnosis is five doctor's visits over 8+ years. This delayed diagnosis can have a significant impact on quality of life, mental health, and fertility.

5. Many issues contribute to delayed diagnosis including a lack of education for primary health care providers about the condition, its symptoms and when to refer patients to a gynaecologist. There are also long delays to see gynaecologists, coupled with limited access to publicly funded ultrasounds, MRIs and hormonal treatments such as Cerazette and Mirena. The cost of pursuing these options privately is also prohibitive for those with endometriosis.

6. When medical management is not effective in controlling symptoms and patients are referred to secondary care, they face barriers in accessing specialty clinics, and experience long waiting times to see specialists, especially in provincial and rural areas. This delayed diagnosis and fragmented care means many patients are not receiving adequate treatment and management until they have had the condition for many years.

7. ENZ notes that as an attempt to address this unacceptable situation, the Ministry of Health published its first ever best practice guidance: 'Diagnosis and Management of Endometriosis in New Zealand' ('the guidelines') in 2020.[4] The document (which ENZ was on the taskforce to develop) aimed to improve the diagnosis and management of endometriosis in primary and secondary health care.

8. While we welcomed the intent behind the document, three years on it is clear that this guidance alone is not enough to deal with the complex issues related to endometriosis care. Critically, the guidelines were also released with no consideration given to resource and cost implications. Consequently, little progress has been made in implementing them.

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1. ENZ approved the submission via a Board resolution on 15th March 2023. Board members are Felicity Evans, Dr Michael Wynn-Williams, Dr Nicola Ngawati, Sandra Matthews and Glenda Harding. https://nzendo.org.nz/people/

2. Insight Endometriosis is a registered charity working towards an Aotearoa New Zealand where lives are not limited nor defined by endometriosis and where there are equitable outcomes for all. They aspire to empower and support those with endometriosis through community support and evidence-based information, and through strong partnerships. As well as raising awareness to reduce diagnostic delays, their services enable those affected by endometriosis to make their own decisions about the treatment and management of their endometriosis by helping them navigate the health system, connecting them with appropriate services and building self-advocacy skills.

3. Endo Warriors Aotearoa is aimed at promoting education and awareness about endometriosis and menstruation.

4. https://www.health.govt.nz/publication/diagnosis-and-management-endometriosis-new-zealand

Key Recommendations

1. We recommend that Aotearoa New Zealand follows the lead of England and Scotland and specifically includes endometriosis in the Women's Health Strategy to ensure that the Strategy includes a comprehensive portrayal of women's health issues in order to improve health outcomes for everyone.
2. While the inclusion of endometriosis in the Strategy is important, we note the Strategy is not an operational level plan where the real changes to benefit the lives of those with endometriosis need to be made. We therefore recommend that Te Whatu Ora commits as part of the development of a New Zealand Health Plan to develop an Aotearoa New Zealand specific National Action Plan for Endometriosis.
3. This plan can be based off international examples (though adapted for Aotearoa New Zealand's indigenous Māori and Pasifika communities). Having this Plan is a way for the Government to finally acknowledge that endometriosis causes a substantial health and economic burden for Aotearoa New Zealand. It will also provide a clear blueprint to tackle endometriosis on all fronts, prioritising action in the three pillars of education and awareness, clinical management and care, and research.

Endometriosis in Aotearoa New Zealand

About Endometriosis New Zealand (ENZ)

ENZ is a 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.

This submission is based on 30 years of work in the field of endometriosis and is informed by the views and lived experiences of our more than 10,000 members. We have also included the views of our Clinical Advisory Committee, which is a multi-disciplinary group of clinical practitioners with a special interest in endometriosis.[5]

We have also encouraged individuals affected by endometriosis to make their own personal submissions to Manatū Hauora Ministry of Health.

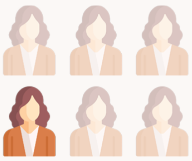
Endometriosis at a glance

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]

5. Members of ENZ's Clinical Advisory Committee can be found here: https://nzendo.org.nz/people/#CAC
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
11. https://www.endometriosisaustralia.org/endo-in-the-workplace

About endometriosis

Endometriosis is a common yet frequently under-recognised chronic disease which occurs when tissue similar to the lining of the uterus, is found in places outside of the uterus. It is commonly found in the pelvic region on the thin pelvic lining called the peritoneum. It may also be found on the pelvic ligaments, ovaries and bowel. It is occasionally also found in places outside the pelvis such as in the appendix, diaphragm, the belly button or lungs.

The disease can affect women, girls, transgender, non-binary and gender-diverse people assigned female at birth, regardless of their background or lifestyle. It is generally considered to affect people in their reproductive years. For some, it can be as early as their first menstrual period, whereas others may develop symptoms later in life. The cause of endometriosis is unknown and there is no definite cure.

Endometriosis is a highly individualised disease, with the symptoms ranging significantly from person to person. 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.

A key issue regarding endometriosis is the delay between onset of symptoms and diagnosis which averages five doctor's visits across more than 8 years[12] This is influenced by the fact there are no existing markers that can detect the presence of endometriosis and the wide variation of symptoms. This makes clear assessment difficult, with definitive diagnosis only able to be made via an invasive laparoscopic surgery including biopsy of the pelvis.

This delayed diagnosis can have a significant impact on endometriosis patients' quality of life including on their education, career, sex life, whānau relationships and mental health, as illustrated in the findings of a 2022 study: An Aotearoa New Zealand survey of the impact and diagnostic delay for endometriosis and chronic pelvic pain.

Earlier diagnosis can be life-changing because once there is a positive diagnosis, different treatment and management options can be explored. However, in many cases, even with treatment and management endometriosis can still lead to debilitating long-term chronic pain and compromised fertility, particularly where the endometriosis is severe due to diagnostic delays.

With regards to fertility, between 30 to 50 per cent of individuals with endometriosis may experience infertility. Endometriosis can influence fertility in many ways including distorted anatomy of the pelvis, adhesions, scarred fallopian tubes, inflammation of the pelvic structures, altered immune system functioning, changes in the hormonal environment of the eggs, impaired implantation of a pregnancy and altered egg quality. Studies have shown that the amount of endometriosis that is seen at the time of laparoscopy is linked to future infertility. Individuals with severe endometriosis, which causes considerable scarring, blocked fallopian tubes and damaged ovaries, experience the most difficulty becoming pregnant and often require advanced fertility treatment. These issues make the need for prompt diagnosis crucial.

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12. 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://doi.org/10.1038/s41598-022-08464-x

Te Tiriti o Waitangi

Endometriosis New Zealand welcomes the Pae Ora (Healthy Futures) Act 2022 ('the Act') providing specific reference in section 6a to Te Tiriti o Waitangi and the Crown's intention to give effect to the principles of Te Tiriti. ENZ considers that the development of this Strategy provides an ideal opportunity to improve hauora Māori outcomes for wāhine and kotiro Māori.

There is very little research on the diagnosis and treatment of endometriosis for wāhine and kotiro Māori. This should be a priority:

- as a Crown agency and Te Tiriti partner with resulting obligations, and
- in order to build an accurate picture and baseline of how the health system is performing for wāhine and kotiro Māori endometriosis patients.

This was identified as a priority in the 2020 best practice guidelines. However, we are not aware of any work being undertaken to act on this priority or rectify this information gap.

The guidelines also outlined as one of their key principles:

> *Services must be available, accessible and acceptable to Māori. They should respect and acknowledge cultural identity and, where possible, incorporate tikanga Māori protocol. He Korowai Oranga, the Māori Health Strategy, sets the overarching framework that guides the Government and health and disability sector to achieve the best outcomes for Māori.*

We hope the Manatū Hauora Ministry of Health together with Te Whatu Ora and Te Aka Whai Ora Māori Health Authority are now able to help progress this work as an immediate priority.

Despite a lack of research, we know from an analysis of other women's health issues, current health statistics for wāhine Māori compared with non-Māori reflect entrenched and systemic inequities. Information from Manatu Hauora Ministry of Health statistical sources which were referred to by former Director-General of Health Sir Ashley Bloomfield during the Stage One hearings of the Health Services and Outcomes Kaupapa Inquiry[13] (WAI 2575), note for example that:

> *"Māori females were around 1.5 times as likely to die from breast cancer as non-Māori females – have a mortality rate about 2.5 times that of non-Māori females …and a lung cancer registration rate over four times that of non-Māori females… Māori female lung cancer mortality was over 4 times that of non-Māori females".*[14]

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13. Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry (justice.govt.nz)
14. Ministry of Health, Tatau Kahukura: Māori Health Chart Book 2015, 3rd ed (Wellington : Ministry of Health, 2015)

Equity Lens

A further purpose of the Act is to “achieve equity in health outcomes among New Zealand’s population groups, including by striving to eliminate health disparities, in particular for Māori (Section 3 (b).”

We would propose that as diverse a range as possible of Aotearoa New Zealand’s population are considered when section 3(b) is being applied towards the creation of the Strategy (including being inclusive of the needs of LGBTQIA+, disability and ethnic and migrant communities).

In addition to the lack of research on endometriosis in relation to wāhine Māori, we note there is also very little research on the diagnosis and treatment of endometriosis for other groups including Pasifika populations. Likewise, we know from other women’s health issues including breast and cervical cancer that these populations are also less likely to access screening and more likely to be diagnosed with these diseases.[15]

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[15] For example, National Screening Unit reports including: https://www.nsu.govt.nz/system/files/page/bsa_monitoring_report_for_women_screened_to_june_2016.pdf and https://www.nsu.govt.nz/health-professionals/national-cervical-screening-programme/cervical-screening-coverage/monthly-6

Current situation

Endometriosis in the Aotearoa New Zealand health system

On average individuals with endometriosis experience a protracted journey of five doctor's visits over a period of 8+ years between onset of symptoms and diagnosis. As already outlined, this is influenced by the fact that symptoms can vary significantly from person to person, making clear assessment difficult, while definitive diagnosis can only be made by invasive laparoscopic surgery and biopsy of the pelvis. We note there will also be many who never receive a diagnosis, or who may only be diagnosed after a long struggle with fertility.

Many issues contribute to these delays including the fact that GPs are regularly not referring suspected endometriosis patients to gynaecologists. This could also be influenced by the fact there are long delays to see gynaecologists. This issue has been exacerbated by Covid-19. This could be improved by specialist triaging processes in secondary care to recognise pelvic pain as a significant symptom of endometriosis. This will also help to remove pressure on Emergency Departments where endometriosis patients often present when suffering chronic pain. Providing education and training programmes for general practitioners, nurses and other clinicians involved in primary health care can help them better identify the symptoms of endometriosis, which will work to address these issues.

There is also limited access to publicly funded ultrasounds, MRIs and hormonal treatment options including Cerazette and Mirena. We welcome the fact the Mirena device is now funded, however we note insertion costs are not. Meanwhile, Cerazette is an effective progesterone-only contraceptive pill that is useful in supressing menstrual cycles of those with endometriosis. The drug is currently unfunded by Pharmac and costs patients $50-80 per month to use. The cost of pursuing these options privately is also prohibitive for many individuals.

When medical management is not effective in controlling symptoms and individuals are referred to secondary care, they also face delays and barriers to accessing specialty clinics and are placed on oversubscribed operating lists with appropriate specialists. We note not all regions can provide this service and Aotearoa New Zealand has no network of tertiary referral centres for complex endometriosis surgery.

As already stated, this delayed diagnosis and fragmented care means many individuals are not receiving adequate treatment and management until they have had the condition for many years, significantly affecting their quality of life, relationships, mental health, work life and fertility.

We note there is also very little Aotearoa New Zealand specific research into endometriosis as illustrated in the 2022 study of the impact of diagnostic delay for endometriosis and chronic pelvic pain.[16] This needs to be prioritised to build an accurate baseline of how the health system is performing for endometriosis patients.

However, we know from the anecdotal evidence of our members that the health system is failing endometriosis patients.

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[16] An Aotearoa New Zealand survey of the impact & diagnostic delay for endometriosis & chronic pelvic pain (springer.com)

Below are several real-life case studies of New Zealanders endometriosis journeys.

Maddison

Maddison is 25-years-old. Her endometriosis symptoms began at the same time she began menstruating at age 14. From that time, she experienced extremely heavy and painful periods which left her bedridden for up to three days each cycle. Despite relaying these issues many times to several different doctors over a number of years, including emergency ED doctors, she was wrongly suspected to have PCOS, IBS, Crohns and even Ulcerative Colitis.

Maddison feels she was robbed of her quality of life for seven years without a diagnosis and has found the disease has severely impacted her mental health, as well as her career as she has had to take a lot of sick leave.

Maddison's journey to a diagnosis included two exploratory laparoscopy surgeries, two colonoscopies, one gastroscopy, one camera endoscopy and countless stays in hospital. None of these surgeries found what was causing her extreme pain and heavy periods. It was only after Maddison went to see a private specialist that she was officially diagnosed with endometriosis.

Aroha

Aroha's endometriosis journey began when she was 10-years-old. She is now 40 and it took half of her lifetime to be correctly diagnosed.

During this time, she was given many different types of antidepressants and was on the sickness benefit for 12 years as she couldn't work because of her chronic pain, anxiety and depression. Over the years Aroha has also seen multiple GPs, counsellors and psychologists but struggled to be referred to a specialist. She was also incorrectly diagnosed on many occasions.

She now fears she is too late to have children and doctors have suggested she have a hysterectomy unless she is able to get pregnant soon due to her age and endometriosis.

Jessica

Jessica was diagnosed with endometriosis at the age of 15 and underwent multiple surgeries over the following decade which destroyed her chances of conceiving a baby naturally.

With the help of her sister, she pursued egg donation IVF when she decided she wanted to start a family with her husband. Her sister was able to produce three viable embryos for her. Unfortunately, she suffered a miscarriage at 16 weeks with the first embryo. She tried again six months later but one embryo perished and the final one did not take when it was implanted.

Jessica's endometriosis robbed her of the chance of having children of her own. She describes her endometriosis journey as long, hard, and emotional draining.

Diagnosis and Management of Endometriosis in New Zealand 2020

In 2020 the Ministry of Health published its first ever best practice guidance: Diagnosis and Management of Endometriosis in New Zealand.[17]

The document aimed to improve the diagnosis and management of endometriosis in Aotearoa New Zealand in primary and secondary health care through:

- early recognition of symptoms
- empowering primary health care providers to make a suspected diagnosis and commence management
- an appropriately trained, multidisciplinary workforce in secondary and tertiary care
- improved equity of access and health outcomes for patients.

While we welcome the intent behind the document, it alone is not enough to deal with the complex issue impacting those with endometriosis. The document needs to be revised to reflect the specific health needs of of wāhine Māori and Aotearoa New Zealand's Pasifika populations. It also needs to include more detailed information around how people may present, including a flow chart for steps taken to investigate and treat suspected endometriosis cases in the primary setting, and when to refer to gynaecology. This could be modelled off what is done in the United Kingdom and Australia. It also needs to provide more holistic information for primary healthcare providers to advise patients around diet, exercise, physiotherapy, complementary treatments and support networks to connect to.[18]

We note the guidelines also included the following disclaimer on page two under the purpose and context section:

> *Given current variability in services across New Zealand, resource and cost implications of implementing the principles in this document have not been considered. The intention is that it will help health services and providers to identify and address barriers to best practice.*

Without additional funding allocated to adequately implement the guidelines, for the most part they cannot be progressed.

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17. https://www.health.govt.nz/publication/diagnosis-and-management-endometriosis-new-zealand

18. https://www.nice.org.uk/guidance/ng73/resources/endometriosis-diagnosis-and-management-pdf-1837632548293 and http://ranzcog.edu.au/wp-content/uploads/2022/02/Endometriosis-clinical-practice-guideline.pdf

The following table illustrates the current lack of implementation of the key principles in the guidelines as observed by our endometriosis specialist on ENZ's Clinical Advisory Committee.

Principle	Issues preventing implementation	ENZ recommendations
A clinical diagnosis and appropriate management of endometriosis can be initiated in primary health care.	No new funding for GP education on endometriosis. However, Australian GP education modules (RANZCOG) can be accessed by NZ GPs. The modules were funded by the Australian Government's Endometriosis Action Plan.	Develop and rollout NZ specific education and training programmes to general practitioners, nurses and other clinicians involved in primary health care, which include achieving equity for wahine Māori.
A physical examination and ultrasound assessment can help in forming a diagnosis. However, a normal physical examination and/or ultrasound does not exclude a diagnosis of endometriosis and, likewise, an abnormal examination or ultrasound does not confirm a diagnosis.	Obtaining access to a pelvic ultrasound or MRI remains difficult for patients with suspected endometriosis, and is not available in many provincial areas. Many hospitals won't accept patient referrals without a positive finding on ultrasound. Due to the limited experience in advanced endometriosis pelvic ultrasound with radiologists and gynaecologists, more expensive MRIs are performed.	Fund specialist training for radiologists and gynaecologists in advanced transvaginal ultrasound techniques. Fund bedside ultrasound units for Gynaecology Clinics.
Hormonal treatments may be successful at managing symptoms and achieving amenorrhoea is appropriate for those with troubling primary dysmenorrhoea, even if it is not due to endometriosis.	Desogestrel (Cerazette), one of the more effective progestin-only contraceptive pills, remains unfunded and too expensive for many patients. Dinogest (Visanne) as recommended in the document is not available in NZ. It is available in Australia.	Funding for hormonal treatments (including insertion of Mirena) to manage the symptoms of endometriosis. Funding of Desogestrel as a treatment for endometriosis related pain (currently costs $50/month as a contraceptive).
Discuss and take into account fertility aspirations with the patient when developing a management plan for endometriosis.	Oocyte freezing is not publicly funded for patients with severe endometriosis and low ovarian reserve. This is in contrast to patients with a malignancy who are to be treated with chemotherapy or radiotherapy and receive urgent publicly funded egg or embryo freezing.	Fund oocyte freezing for patients with severe (stage 4) endometriosis and low ovarian reserve.
Do not perform a laparoscopy for diagnosis only; it should only occur if there is to be surgical treatment.	Diagnostic laparoscopy as a means of diagnosis of endometriosis remains the norm.	Develop regional endometriosis networks (Christchurch, Wellington, Hamilton, Auckland) that provide leadership, education and support to gynaecologists in smaller hospitals. Aim to reduce diagnostic laparoscopy. Increase preoperative diagnosis based on history, symptoms, examination and radiological investigations.

Principle	Issues preventing implementation	ENZ recommendations
Laparoscopy should be performed by gynaecologists with surgical skills in excising endometriosis lesions.	Many hospitals are currently not accepting GP referrals for possible endometriosis or pelvic pain. Even in NZ tertiary centres laparoscopy for endometriosis is performed by general gynaecologists with limited training in endometriosis surgery. As a result, two laparoscopies may be required, the first for diagnosis and the second for treatment.	Develop regional endometriosis networks (Christchurch, Wellington, Hamilton, Auckland) that provide leadership, education and support for gynaecologists in smaller hospitals.
There must be a robust informed surgical consent process, with comprehensive discussion with the patient on management and treatment options, and their respective benefits and risks.	There is an absence of procedure specific surgical consent and patient information forms for endometriosis patients. While endometriosis patient information is provided by RANZCOG it is not tailored to a NZ audience.	Develop NZ procedure specific surgical consent and patient information forms.
There is very little research on the diagnosis and treatment of endometriosis in Māori. This should be a priority. Services must be available, accessible and acceptable to Māori. They should respect and acknowledge cultural identity and, where possible, incorporate tikanga Māori protocol. He Korowai Oranga, the Māori Health Strategy, sets the overarching framework that guides the Government and health and disability sector to achieve the best outcomes for Māori.	There are a number of small projects underway with minimal funding.	Provide funding for New Zealand National Endometriosis Clinical and Scientific Trials (NECST) Network. These have already been developed in Australia and there needs to be significant funding to adapt and run in NZ. We note that NECST have committed to expanding into NZ.
Secondary care services should aim to incorporate a multidisciplinary team (MDT) approach (eg, gynaecology, pain management, fertility specialists, radiology, psychology, physiotherapy, dietetics, paediatrics/adolescent health) with expertise in endometriosis where possible.	There are very few endometriosis clinics throughout NZ.	Define and establish centres of expertise in specialised treatment and management for endometriosis. Develop regional endometriosis networks (Christchurch, Wellington, Hamilton, Auckland).
Only a minority of people with persistent pelvic pain will have endometriosis as the sole cause of their pain and surgery alone is unlikely to be sufficient to relieve their symptoms. In these cases, a multidisciplinary approach is recommended.	As above, there are very few MDT pain teams in NZ.	Develop and fund public women's health pain services in the main centres (Christchurch, Wellington, Hamilton, Auckland) with out-reach services to smaller centres.

Insight Endometriosis have also identified additional issues with the Guidelines and current health system approaches to endometriosis.

They believe the lived experiences of those affected by endometriosis should inform policy development, health system change, as well as help to shape support and information services. This needs to be integrated with researched best practice in a genuine co-design approach.

They also note there has been very little research into endometriosis treatments, which has led to difficulties in developing international consensus on best practice. This has affected the Guidelines and has led to a patient perception that the Guidelines are based more on resource constraints than research. A patient-centred approach is also lacking.

Further, they believe the Guidelines are leading to inequity for women, girls and those assigned female at birth as their health and quality of life is not prioritised. For example, this was the advice provided by Waikato DHB at their Community Health Forum in November 2021:

> *"The DHB advice is that there was a national guideline published last year which is quite clear that medical (or hormonal management) which should be the first line of treatment – and this is what the DHB recommends as well and will not accept a referral unless that patient has had medical management for six months."*

Insight Endometriosis note they see many patients who feel under duress to accept a treatment which they do not want in order to be referred to appropriate care. They also note that this treatment needs to fail before they will be referred for a full assessment and best care treatment. Insight Endometriosis believes this unacceptable situation needs urgent review.

They believe best practice would involve prompt referral to a gynaecologist for full assessment including an ultrasound, and if warranted a surgery for both diagnosis and treatment in the same procedure. The fact that this doesn't routinely happen appears to be based on resource constraints more than best practice.

The need for change at a system level

The health system reforms and development of Aotearoa New Zealand's Women's Health Strategy is a once in a generation opportunity to improve health outcomes for all girls, women and those assigned female at birth including those with endometriosis.

Given the prevalence of endometriosis in Aotearoa New Zealand with more than 120,000 individuals (at least 1 in 10 women, girls and those assigned female at birth) and the fact these patients wait an average of 8+ years for a diagnosis, we know the system is failing those with endometriosis.

To inform our recommendations, we have looked to comparable jurisdictions to see what we could adapt for an Aotearoa New Zealand context. The following is a summary of how comparable countries are tackling endometriosis at a system/Government level.

International examples

Australia

In July 2018, Australia launched a National Action Plan for Endometriosis.[19] The Plan was launched by their Minister of Health and included a formal apology in the Australian Parliament for historic failures that endometriosis patients endured. The Plan is a coordinated and structured strategy which aims to tackle endometriosis on all fronts – through awareness and education, clinical management and care and medical research. It aims to improve understanding and awareness of endometriosis, speed up diagnosis, develop better treatment options and ultimately find a cure.

The Plan was also supported by an initial government investment to improve diagnosis and treatment options for better patient outcomes, and a further investment to increase awareness of endometriosis among GPs and other frontline health professionals. State and territory governments can use the plan to make their own funding and service commitments.

England

England's Women's Health Strategy published in August 2022 specifically includes endometriosis with a number of 10-year ambitions articulated.[20] These include improving education and awareness for individuals, education institutions, workplaces and healthcare professionals especially in primary health; improving timely access to management and treatment options; and more research into endometriosis to better understand causes, treatments and impacts on wider health and quality of life.

The English Strategy also has specific actions in relation to endometriosis. This includes the National Health Service updating the service specification for severe endometriosis to ensure specialist endometriosis services have access to the most up-to-date evidence and advice to improve standards of care for individuals with severe endometriosis.[21]

[19] National Action Plan for Endometriosis | Australian Government Department of Health and Aged Care

[20] Women's Health Strategy for England - GOV.UK (www.gov.uk)

[21] NHS commissioning » E09. Specialised women's services (england.nhs.uk)

Scotland

Scotland's Women's Health Plan (2021-2024) makes specific commitments on endometriosis. The Plan includes improving awareness of endometriosis in young people and in GPs, hospital consultants and A&E doctors; greater support for endometriosis research and fully implementing national guidance on endometriosis care.[22] This was adopted in 2018 to ensure those with suspected or confirmed endometriosis receive the care and support they need including referrals to one of the three endometriosis specialist centres in Scotland, where necessary. Scotland is also developing new care pathways for endometriosis occurring outside the pelvic cavity.

France

In January 2022 President Macron announced that France is launching a new national strategy to combat endometriosis. The national plan will address awareness and education, encourage early diagnosis, and advance treatment on the disease by allocating designated centres of treatment in each region of France. The plan will also focus on forming research teams to study the etiology of the disease.[23]

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22. This useful summary was prepared by Endometriosis UK and can be referred to here: Endometriosis UK welcomes the Scottish Government's Women's Health Plan | Endometriosis UK (endometriosis-uk.org)

23. The Endometriosis Foundation of America Applauds France's New Na | EndoFound

Recommendations for change at a system level

Include endometriosis in the Aotearoa New Zealand Women's Health Strategy

Given the prevalence of endometriosis in Aotearoa New Zealand, we recommend that the Manatū Hauora Ministry of Health specifically includes endometriosis in the Strategy to ensure it includes a comprehensive portrayal of women's health issues to improve outcomes for those with endometriosis. As we have outlined above, this would be consistent with the English and Scottish Women's Health Strategies.

Develop a National Action Plan for Endometriosis

We note the Women's Health Strategy is not an operational level plan where the real changes that will benefit the lives of endometriosis patients need to be made. We therefore recommend that Te Whatu Ora as part of the development of a New Zealand Health Plan, commit to developing an Aoteoroa New Zealand specific National Action Plan for Endometriosis.

This plan can be based off international examples, though adapted for Aoteoroa 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.

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 of endometriosis. We note Endo Warriors Aotearoa would specifically like to see education in schools.
- Improve access to empowering information about endometriosis, diagnosis and management options at all stages of an individual'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 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.

Thank you for considering the submission of ENZ. We would welcome the opportunity to discuss our submission with you further and we can be contacted using the information below.

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