

An Audit of Endometriosis of Pre-Menopausal & Menopausal Women in Aotearoa: A 5-year Study of the Hidden Disease

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Abstract

Endometriosis is a chronic inflammatory gynaecological condition affecting women worldwide. In New Zealand, approximately 1 in 10 women is affected, with an average diagnostic delay of 8.7 years. Despite its prevalence, endometriosis remains underdiagnosed and undertreated. Delays in diagnosis are often compounded by inconsistencies in clinical management across age groups, ethnicities, and regions, contributing to inequities in care. This observational cohort study examined diagnostic delay and treatment management patterns among women diagnosed with endometriosis in the Waitematā region between 1 January 2018 and 31 December 2022. Variables analysed included age, ethnicity, geographic region within Waitematā, hospital setting, and treatment type. Routinely collected clinical patient data were used, with cases outside the defined study framework excluded.

A total of 524 women were included in the analysis. The average diagnostic delay was seven months, with 75% of women receiving a diagnosis within nine months. No statistically significant differences in diagnostic delay were observed among Māori, Pacific, Asian, or New Zealand European/Pākehā women; however, women categorised as “Other” experienced longer delays. Age-related analysis showed slightly longer delays among women aged 31–40 years. Combined surgical and hormonal therapy was the most common management approach between 2018 and 2022, with treatment patterns varying by age. Laparoscopic surgery alone was less frequently utilised among older women, while incidental lesion detection increased with age. Standalone non-surgical treatments were not commonly offered. Geographic region and hospital setting had minimal influence on diagnostic timelines.

Overall, the findings indicate relatively timely and consistent diagnosis and management of endometriosis in the Waitematā region, suggesting more timely diagnosis in this region compared with previously reported estimates. Nevertheless, disparities observed among certain ethnic groups and women in their 30s

highlight the ongoing need for early symptom recognition, culturally responsive care, and continued efforts to promote equitable healthcare delivery in New Zealand.

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor used artificial intelligence tools or generative artificial intelligence tools (unless it is clearly stated, and referenced, along with the purpose of use), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

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In New Zealand, healthcare is hindered by practitioner bias, financial and logistical barriers, and limited gynaecological expertise among clinicians (Ellis & Wood, 2022; Shafrir et al., 2018). The Ministry of Health (2002) reports that socially disadvantaged groups experience poorer health outcomes, greater exposure to health risks, and reduced access to services. Māori and Pacific populations are particularly affected, facing differential access that contributes to inequities in health status and mortality. According to Ellis et al. (2025), GPs function as the main gatekeepers to specialist care, meaning access often depends on referrals to public or private services. This has created regional disparities—described as a “postcode lottery”—especially for surgical and specialist treatment. Communication challenges and limited resources further compound access issues for Māori and Pacific communities.

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Chapter One

Introduction

General Introduction

Endometriosis is a chronic, inflammatory gynaecological condition that significantly affects the health and well-being of pre-menopausal women worldwide. It is characterised by the presence of endometrial-like tissue outside the uterine cavity. It is commonly associated with symptoms such as severe pelvic pain, dysmenorrhoea, menstrual irregularities, infertility, and substantial impairment to daily functioning and quality of life (Griffiths et al., 2024; Seckin, 2021). Despite its high prevalence, endometriosis remains widely underdiagnosed and undertreated, with many women experiencing prolonged delays often extending over several years before receiving an accurate diagnosis and appropriate management (Sims et al., 2021). These delays are further exacerbated by inconsistencies in clinical management across geographical regions, age groups, and ethnic populations (Seckin, 2021; Sims et al., 2021).

In Aotearoa New Zealand, the burden of endometriosis is compounded by a lack of comprehensive national data and clearly defined clinical care pathways. This absence contributes to inequities in diagnosis and management, particularly for Māori and Pacific women, who already experience systemic barriers to accessing timely and culturally responsive healthcare services. Consequently, disparities in health outcomes persist, underscoring the need for improved data collection and more equitable models of care (Ellis et al., 2022).

Significant gaps remain in understanding endometriosis, particularly regarding disease progression and diagnostic processes. Persistent diagnostic challenges continue to contribute to delayed, missed, or incorrect diagnoses. Multiple factors, including the heterogeneous and non-specific nature of symptoms, inconsistent referral pathways, and limited access to timely specialist

assessment or laparoscopic confirmation, drive these challenges. Evidence suggests that the interval between symptom onset and a confirmed diagnosis typically ranges from 4 to 11 years (De Corte et al., 2024; Sims et al., 2021; Swift et al., 2024). Such prolonged delays not only hinder effective clinical management but also have profound consequences for physical health, mental well-being, social participation, and overall quality of life. Compounding these challenges is the historical underfunding of endometriosis research, both internationally and within New Zealand, resulting in limited population-specific evidence and restricted understanding of lived experiences.

In Aotearoa New Zealand, approximately one in ten women is affected by endometriosis, with an average diagnostic delay of 8.7 years (Ellis & Wood, 2024; Ministry of Health, 2020; Tewhaiti et al., 2022). These delays reflect broader global challenges, including limited public and professional awareness, insufficient research funding, and restricted access to timely diagnostic tools, all of which contribute to poorer health outcomes and reduced quality of life (Tewhaiti et al., 2022). Several countries have established national or regional databases to monitor endometriosis, such as the Endometriosis Knowledgebase in Mumbai, Endomet in Turkey, and the British Society for Gynaecological Endoscopy (BSGE) Endometriosis Centres Database in the United Kingdom (British Society for Gynaecological Endoscopy, 2025; Dignity, 2023; Endomet, 2025). Endometriosis New Zealand (ENZ) is a national database that actively conducts research to generate NZ-specific data, including a 2025-2026 research project in partnership with the University of Canterbury. This database will comprise a series of national surveys to examine the impact, diagnosis, and treatment of endometriosis (Endometriosis New Zealand,

2026). This will enable a better understanding of the disease in NZ and aim to improve diagnostic times and treatment management plans.

In addition to structural and systemic barriers, the persistent stigma surrounding endometriosis further complicates timely diagnosis and effective management. Women living with the condition frequently report negative psychosocial consequences, including diminished mental health, strained interpersonal relationships, and unsatisfactory interactions with healthcare providers (Agarwal et al., 2019; Sims et al., 2021). Addressing this stigma requires a multifaceted approach that includes improved clinician education, enhanced patient awareness, and clearer, more consistent referral pathways to support earlier diagnosis and intervention (Agarwal et al., 2019; Hudelist et al., 2012).

This study aims to examine the current medical management of endometriosis among premenopausal and menopausal women across age groups in the Waitematā region. It seeks to examine diagnostic timelines, identify patterns of care, and assess how treatment strategies vary according to demographic factors. By analysing factors contributing to diagnostic delay and variations in management, this research aims to inform more equitable and consistent models of care. Ultimately, the findings aim to improve clinical practice, support earlier diagnosis and more effective symptom management, and enhance health outcomes for individuals affected by endometriosis in Aotearoa New Zealand.

1.1 Purpose of this Study

This study employs a retrospective design to analyse five years of routinely collected health data (2018–2022) obtained from the Health New Zealand database. The analysis focuses on women aged 20 to 56 years who have received a diagnosis of endometriosis within the Waitematā region. This region encompasses the North Shore, Waitākere, and Rodney areas, including Warkworth, Huapai, and Whangaparāoa (Figure 1). The selected study period reflects the most recent timeframe for which complete and consistent data were available.

The primary objective of this research is to examine the extent of diagnostic delays and the patterns of clinical management of endometriosis in this population. Existing New Zealand-based research has largely focused on chronic pelvic pain (CPP) associated with endometriosis (Ellis & Wood, 2024; NZEndo, 2024; Tewhaiti-Smith et al., 2022), rather than on diagnostic pathways and delays.

Although endometriosis is not classified as a fatal condition, delayed diagnosis and suboptimal management can result in significant morbidity. Potential complications include infertility, ectopic pregnancy, adverse mental health outcomes, and, in severe cases, small bowel obstruction (Saetta et al., 2019). Women with endometriosis have been reported to experience up to a threefold increased risk of ectopic pregnancy, attributed to impaired tubal and egg transport mechanisms (Kmietowicz, 2015; Saetta et al., 2019; Stoppler, 2024). These outcomes highlight the clinical importance of timely diagnosis and effective intervention, reinforcing the need for a better understanding of diagnostic delays and management practices to reduce the disease burden and improve patient outcomes.

4. The pathogenesis, physiology and risk factors associated with endometriosis
5. Classification and staging systems
6. Clinical features
7. Types of endometriosis
8. Global mortality

1.2 Incidence Rates of Endometriosis

Endometriosis affects approximately 10% of women of reproductive age, with reported incidence estimates ranging from 5% to 15%, according to the Global Burden of Disease (GBD) study (The Lancet, 2025). The GBD is a comprehensive international surveillance initiative that systematically quantifies health loss and disease burden over time across 204 countries and territories, providing robust comparative epidemiological data (Feng et al., 2022; Hatch, 2018).

A population-based study conducted in Spain analysed data collected between 2009 and 2018 and included 16,258 women diagnosed with endometriosis. The median age at diagnosis was 37.0 years (interquartile range [IQR]: 32.0–43.0). Prevalence was highest among women aged 35–44 years in 2018, followed by those aged 45–55 years, with an overall prevalence of 1.24% that year. The study also identified socioeconomic gradients in disease prevalence, with higher rates among women residing in the least socioeconomically deprived quintiles (U1–U3) than in more deprived quintiles (U4–U5) and in rural areas (R). These findings are illustrated in Figures 2A and 2B (Medina-Perucha et al., 2022).

Figure 2

Time trends between 2009 and 2018 related to the prevalence of endometriosis and age (Perucha et al., 2022).

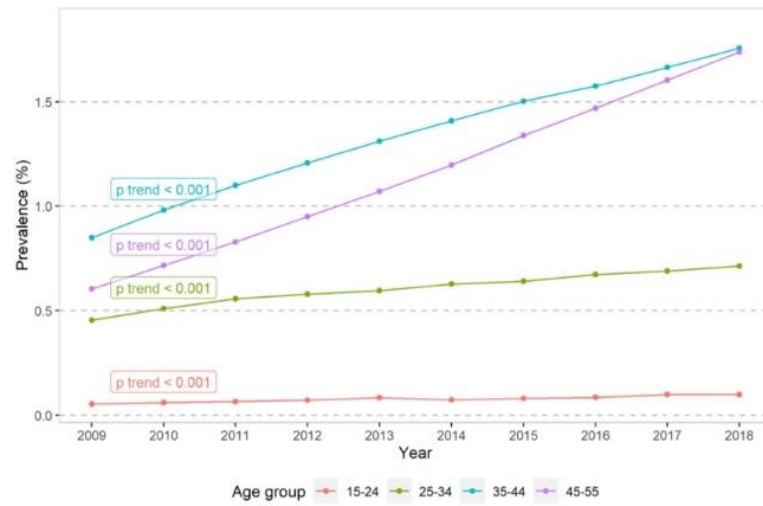
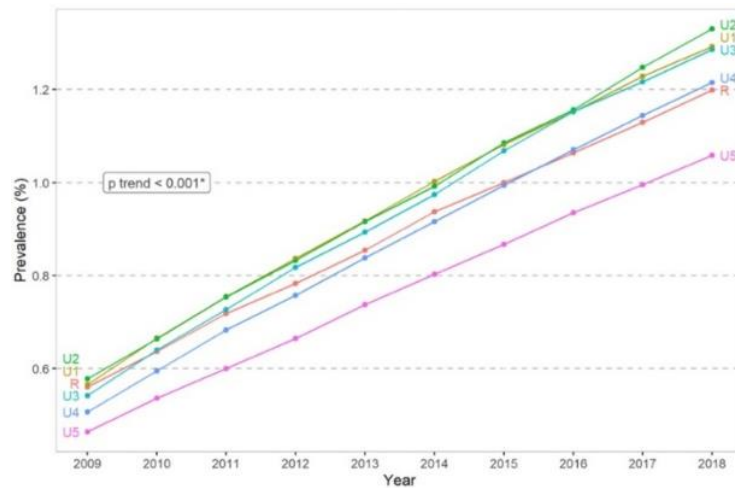


Figure 3

Time trends between 2009 and 2018 related to the prevalence of endometriosis and the deprivation index. (U1: least deprived, U5: most deprived, R: rural areas) (Perucha et al., 2022).



Age-Standardised Incidence Rates (ASIR) are a measure of the rate at which new cases of a disease occur in a population. They are adjusted to eliminate the influence of varying age distributions (Stang & Gianicolo, 2025). Table 1 below presents the trends and ASIR for endometriosis from 1990 to 2019, with incidence estimates of 3,430,094 in 1990 and 3,785,955 in 2019. Therefore, this reflects a 10.37% increase in incidence between 1990 and 2019. A downward trend is evident in the Sociodemographic Index (SDI) regions, with the largest decline observed in low- to middle-income SDI regions (Feng et al., 2022; The Lancet). Additionally, the highest incidence was observed among the 20-24 age group globally and across all SDI regions, as shown in Figure 3 above (Feng et al., 2022).

Table 1

Incidence cases and ASIR of endometriosis in 1990 and 2019, and their trends (Feng et al., 2022).

Characteristics	1990	2019	1990–2019	
	ASIR (per 100,000)	ASIR (per 100,000)	Change in Number No. (%)	EAPC
	No. (95% UI)	No. (95% UI)		No. (95% CI)
Global	60.40 (43.44, 85.62)	48.31 (35.21, 68.15)	0.10 (0.07, 0.14)	−0.81 (−0.86, −0.77)
	-	-	-	-
Sociodemographic index (SDI)	74.28 (52.71, 104.55)	54.55 (38.54, 78.00)	0.70 (0.65, 0.75)	−1.09 (−1.13, −1.05)
Low SDI	70.28 (50.26, 99.25)	50.47 (36.50, 71.14)	0.20 (0.16, 0.24)	−1.19 (−1.21, −1.16)
Low-middle SDI	59.54 (42.55, 83.65)	47.55 (34.36, 66.49)	0.04 (−0.02, 0.10)	−0.78 (−0.84, −0.73)
Middle SDI	53.80 (38.42, 76.06)	44.36 (32.36, 61.84)	−0.08 (−0.14, −0.01)	−0.67 (−0.72, −0.61)
High-middle SDI	49.98 (36.18, 70.09)	40.81 (29.82, 56.83)	−0.14 (−0.19, −0.08)	−0.87 (−0.93, −0.81)
High SDI	-	-	-	-
Region	71.01 (50.71, 99.62)	51.09 (36.73, 71.71)	0.21 (0.11, 0.33)	−1.08 (−1.13, −1.04)
Andean Latin America	64.88 (45.37, 93.42)	57.20 (40.87, 81.22)	0.05 (−0.05, 0.15)	−0.33 (−0.44, −0.22)
Australasia	61.53 (44.01, 87.49)	48.60 (35.24, 68.56)	−0.02 (−0.09, 0.05)	−0.81 (−0.83, −0.80)
Caribbean	69.72 (50.10, 97.74)	60.87 (43.46, 86.37)	0.21 (0.12, 0.29)	−0.30 (−0.43, −0.16)
Central Asia	42.08 (30.23, 58.35)	38.03 (27.23, 53.31)	−0.27 (−0.31, −0.23)	−0.35 (−0.46, −0.24)
Central Europe	63.57 (44.80, 89.85)	40.15 (28.08, 56.56)	−0.04 (−0.15, 0.06)	−1.69 (−1.74, −1.64)
Central Latin America	68.29 (48.40, 97.21)	49.43 (35.17, 70.80)	0.82 (0.66, 1.01)	−1.03 (−1.13, −0.94)

Central sub-Saharan Africa	50.97 (35.82, 70.57)	36.41 (26.13, 49.36)	-0.26 (-0.34, -0.17)	-1.14 (-1.30, -0.98)
Table 1. Incidence cases and ASIR of endometriosis in 1990 and 2019, and their trends (Feng et al., 2022) continued.				
Eastern Europe	67.37 (47.99, 94.47)	48.93 (34.65, 69.94)	0.72 (0.66, 0.78)	0.15 (0.01, 0.29)
Eastern sub-Saharan Africa	60.48 (43.24, 85.79)	52.94 (38.73, 73.01)	-0.26 (-0.33, -0.18)	-1.11 (-1.14, -1.07)
High-income Asia Pacific	46.17 (32.00, 65.47)	31.23 (23.18, 42.66)	-0.27 (-0.38, -0.15)	-0.70 (-0.79, -0.60)
High-income North America	82.18 (58.35, 114.87)	60.28 (43.01, 85.00)	0.37 (0.27, 0.49)	-1.83 (-1.98, -1.68)
North Africa and the Middle East	74.83 (52.93, 103.53)	67.94 (47.69, 95.73)	0.91 (0.77, 1.07)	-1.39 (-1.46, -1.31)
Oceania	70.98 (50.83, 100.61)	51.01 (36.71, 72.27)	0.28 (0.25, 0.32)	-0.33 (-0.35, -0.30)
South Asia	66.43 (48.17, 91.66)	55.06 (39.41, 76.17)	0.20 (0.13, 0.28)	-1.10 (-1.14, -1.05)
Southeast Asia	50.66 (36.37, 73.10)	43.04 (30.74, 60.21)	0.15 (0.06, 0.25)	-0.61 (-0.65, -0.58)
Southern Latin America	58.80 (41.79, 82.62)	42.99 (30.93, 60.97)	0.11 (0.03, 0.20)	-0.49 (-0.54, -0.44)
Southern sub-Saharan Africa	58.14 (40.38, 83.83)	45.51 (32.29, 64.28)	0.11 (0.01, 0.22)	-1.04 (-1.07, -1.02)
Tropical Latin America	40.45 (28.80, 59.20)	38.92 (27.58, 56.29)	-0.12 (-0.17, -0.06)	-0.87 (-0.91, -0.83)
Western Europe	65.56 (46.68, 92.35)	50.04 (35.71, 71.33)	0.91 (0.84, 0.97)	-0.11 (-0.13, -0.08)
Western sub-Saharan Africa				-0.94 (-0.99, -0.89)

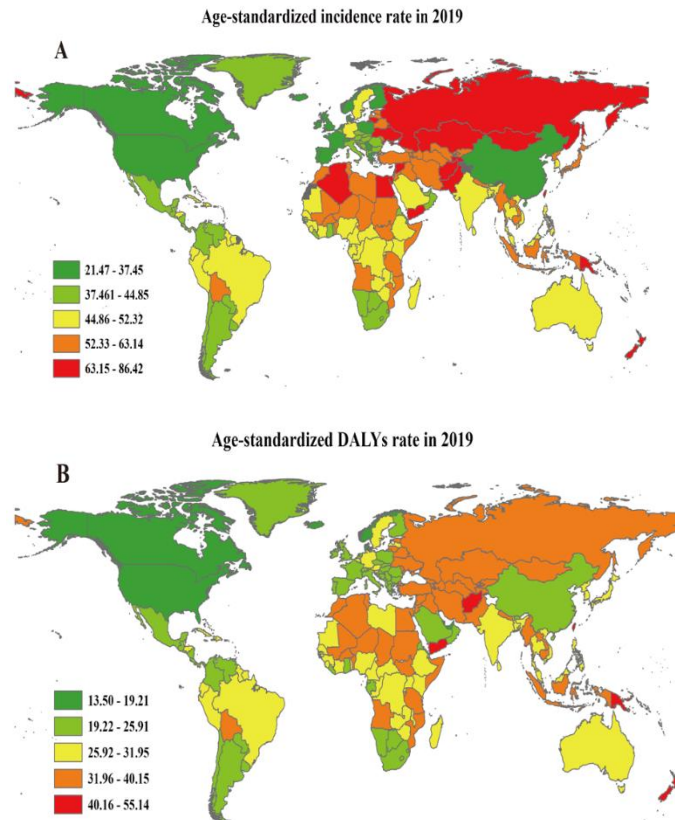
ASIR, age-standardised incidence rate; EAPC, estimated annual percentage change; NA, not available; UI, uncertainty interval.

ASIRs based solely at the country level indicated the following countries with the highest ASIRs in 2019: New Zealand (86.42 per 100,000 population), the Solomon Islands (71.01 per 100,000 population), and Afghanistan (71.83 per 100,000 population) (Feng et al., 2022).

In contrast, the lowest ASIRs were reported in Iceland (21.47 per 100,000 population), Qatar (27.89 per 100,000 population), and Malta (29.42 per 100,000 population), as shown in Figure 3. An upward ASIR trend based on the estimated annual percentage change (EAPC) was noted in eight countries: Austria, Belarus, Iceland, Kazakhstan, Kyrgyzstan, the Russian Federation, Sweden, and the United Kingdom; however, a downward trend was noted in the remaining 196 countries (Feng et al., 2022).

Figure 3

Global ASIRs of endometriosis in 204 countries in 2019. (A) The ASIR. (B) The age-standardised DALY rate (Feng et al., 2022).



The highest ASIR rates for endometriosis were observed in Oceania (67.94 per 100,000 population), Eastern Europe (65.48 per 100,000 population), and Central Asia (60.87 per 100,000 population). The lowest ASIR trends were observed in high-income North America (31.23 per 100,000 population), East Asia (36.41 per 100,000 population) and Central Europe (38.03 per 100,000 population) (Figure 3A) (Feng et al., 2022). These variations likely reflect differences in diagnostic practices, healthcare access and reporting systems across regions.

Based on health insurance data (inpatient vs. outpatient information), in Germany, 0.81% of 62,323 women were affected by endometriosis, with a higher prevalence in women aged 35-44, with a rate of 1.28%. 98%-99% of the Hungarian population is covered by the National Health Insurance Fund Administration (NHIFA), with a prevalence of 10,058 (197.3 per 100,000) in outpatient care vs. 23.5 per 100,000 in inpatient care. In Israel, the prevalence rate is 1.86% in women aged 40-44, and the average annual incidence rate is 7.2 per 10,000. Lower endometriosis prevalence was observed in Korea between 2002 and 2013, with an age-adjusted prevalence of 0.35% among patients aged 15-54 years. American women diagnosed with endometriosis showed prevalence rates of 1.1% for age groups 30-39 and 0.7% for 18-55 years (Harder et al., 2024).

Harder et al. (2024) reported a pooled prevalence of endometriosis in symptomatic patients of 21% (95% CI, 12.30%-28.70%). Study regions included Jordan, the United Kingdom, Taiwan, the USA, Denmark, Sweden, New Zealand, Egypt, Canada, China, and India. The most common symptom among women with endometriosis is chronic pelvic pain (CPP) in the stomach and pelvis. The pooled prevalence of endometriosis based on CPP was 44% (95% CI: 25.00% - 64.00%) (Harder et al., 2024).

1.3 Anatomy and Physiology of the Female Pelvic Cavity Affected by Endometriosis

Endometriosis is a gynaecological condition characterised by the presence of endometrial-like tissue outside the uterine cavity. These ectopic implants are located within the pelvic cavity, particularly involving the ovaries, fallopian tubes, uterosacral ligaments, and peritoneal surfaces, as well as regions of the gastrointestinal tract. Less commonly, extrapelvic endometriosis may occur in

the vagina, vulva, cervix, perineum, urinary tract, thoracic cavity, and, in rare cases, the central nervous system (Charatsi et al., 2018; Tsamantioti & Mahdy, 2023).

The endometrium is a highly specialised, steroid-responsive tissue that plays a critical role in female reproduction. Under the influence of cyclical ovarian hormones, particularly oestrogen and progesterone, the endometrial lining undergoes dynamic structural and functional changes throughout the menstrual cycle. These changes facilitate preparation for potential embryo implantation through endometrial proliferation and vascularisation, followed by shedding during menstruation in the absence of implantation (Pasalic et al., 2023).

In endometriosis, ectopic endometrial-like tissue exhibits hormonal responsiveness similar to that of the eutopic endometrium, resulting in cyclical proliferation and breakdown. However, unlike uterine endometrial tissue, ectopic lesions lack an effective pathway for menstrual shedding. This results in recurrent local tissue injury, chronic inflammation, fibrosis, and adhesion formation within the pelvic cavity. These pathological processes can disrupt normal pelvic anatomy and physiology, contributing to pelvic pain, altered organ function, and reproductive impairment. Inflammatory mediators and adhesions may interfere with ovulatory processes, oocyte release, tubal transport, and fertilisation, thereby increasing the risk of subfertility or infertility (Han & Sadiq, 2023).

The ovaries are among the most frequently affected pelvic organs in endometriosis and play a critical role in both hormonal regulation and reproductive function (Acién & Velsco, 2013).

1.3.1 Physiology

According to John Samson, the theory of retrograde menstruation endometriosis arises from the flow of eutopic endometrium into the peritoneal cavity via the fallopian tubes during menstruation (Yovich et al., 2020). Although this theory is universally accepted, it fails to explain the detection of endometrial tissue outside of the pelvic area. Theories of coelomic metaplasia and Mullerian remnant differentiation may explain the disease's non-uterine origin (Adilbayeva & Kunz, 2024). Coelomic metaplasia involves hormonal and immunologic factors, including epithelial dendritic cells (EDCs), which transform normal peritoneal tissue into ectopic endometrial tissue (Adilbayeva & Kunz, 2024; Burney & Giudice, 2021). The Müllerian theory posits that residual Müllerian duct cells migrate and form endometriotic lesions under the influence of oestrogen. The theory of benign metastasis suggests that the development of ectopic endometriotic lesions results from haematogenous or lymphatic dissemination of endometrial cells (Adilbayeva & Kunz, 2024).

1.3.2 The Ovaries

The peritoneal cavity includes the ovaries found in the lower left and right quadrants of the abdomen, specifically on either side of the uterus within the pelvis and close to the ends of the fallopian tubes, as seen in Figure 4. They are paired, oval-shaped organs that produce elevated levels of oestrogen, testosterone, inhibin, and progesterone in response to increasing secretion of gonadotropin-releasing hormone (GnRH). The increase in oestrogen is responsible for the development of secondary sex characteristics during puberty. The ovary contains oocytes that begin developing in utero and pause until puberty (Gibson & Mahdy, 2023). The oocyte is a highly specialised cell responsible for creating, activating, and

controlling the embryonic genome, as well as supporting cellular homeostasis, metabolism, and cell cycle progression (Gibert, 2000).

Figure 4

The female reproductive system showing the peritoneal cavity (National Cancer Institute, n.d).



Ovarian endometriomas may lead to the formation of endometriomas, commonly referred to as “chocolate cysts”, which are filled with thick, dark fluid resembling a “chocolate” appearance, as seen in Figures 5 and 6. The development of endometriomas can irritate surrounding tissue and create scar tissue and bands of fibrous tissue called “adhesions”, resulting in pelvic tissue and organs sticking to each other. The cysts can cause pelvic pain and fertility issues, and potentially increase the risk of ovarian cancer (Casalechi et al., 2024; Holye & Puckett, 2023; Kitajima et al., 2021).

Figure 5

Endometrioma filled with dark fluid resembling “chocolate cysts” (Nezhat et al. 2024).

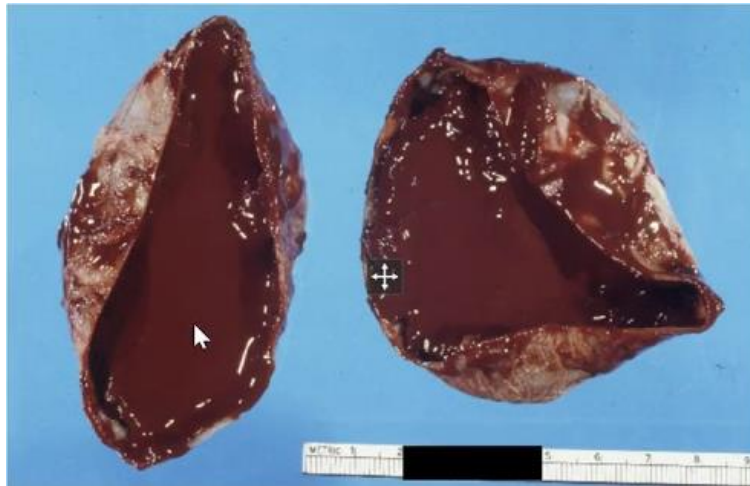


Figure 6:

Endometrioma with dense adhesions (Nezhat et al. 2024).



1.3.3 The Fallopian Tubes

The fallopian tubes are bilateral conduits between the ovaries and the uterus within the female pelvis. They are hollow, seromuscular organs comprised of four anatomical regions: the intramural (uterine) region, the isthmus, the ampulla, and the infundibulum. The ampulla is the most common site for fertilisation and acts as a passageway for the ovum to travel from the ovary to the uterus. Due to this role, the fallopian tubes are a common place for infertility, surgical sterilisation, ascending infections, and neoplasms (Han & Sadiq, 2023).

Tubal endometriosis (TEM) is characterised by the development of ectopic endometrial glands and stroma within the fallopian tubes. This may partly result from ovarian endometriosis (Jiao et al., 2022). There are three histopathological categories of TEM.

The first category includes endometrial implants that invade the tubal serosa, involving the peritoneal surface of the fallopian tubes and resulting in fibrosis after repeated cycles of haemorrhage. Consequently, this leads to tubal retraction and hydrosalpinx formation (Figures 7A and 7B) (Hill et al., 2020).

Hydrosalpinx causes the fallopian tubes to dilate and become filled with inflammatory and alkaline compounds, cytokines, and prostaglandins. This condition is embryotoxic, increasing the risk of pregnancy failure due to poor endometrial receptivity, the abnormal expression of endometrial adhesion molecules (IL-2 and HOXA10), and the activation of toxic inflammatory cytokines (IL-2, IL-8, IL-12) (Wang et al., 2022).

Figure 7A

Haemorrhage developed from tubal endometriosis (Felten et al. 2020).

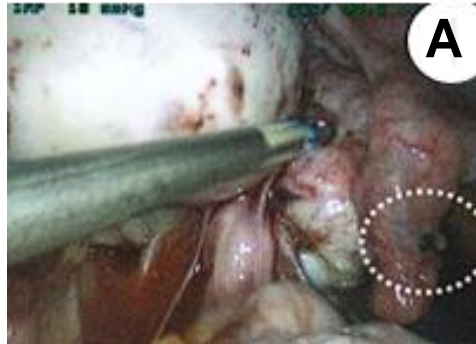


Figure 7B

Endometrial implants developed from tubal endometriosis (Felten et al. 2020).



The second category includes “endometrial colonisation,” in which endometriotic implants invade the tubal mucosa and obstruct the tubal lumen, also known as “intraluminal endometriosis.” Continuous implantation of endometrial tissue during menstrual cycles perpetuates tubal endometriotic lesions, exacerbating obstruction and leading to haematosalpinx formation (Wang et al., 2022). Haematosalpinx, or haemosalpinx formation, refers to the accumulation of blood within the fallopian tubes due to conditions such as ectopic pregnancies, endometriosis,

pelvic inflammatory disease (PID), pelvic trauma, tubal torsion, and tubal carcinoma. This condition may cause individuals abdominal pain, unusual vaginal bleeding, and irregular menstruation (Sulaman et al., 2021).

The third category includes endometrial growth that develops in the proximal residual segment of the fallopian tube after tubal ligation. This is called “post-salpingectomy endometriosis” and is found in 20-50% of fallopian tubes after laparoscopy (Wang et al., 2022).

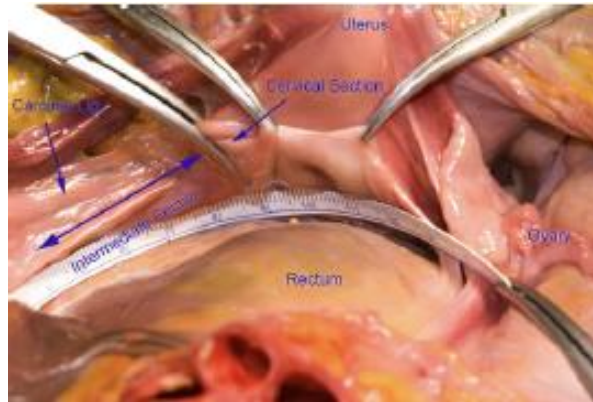
1.3.4 The Ureters

Ureteral endometriosis can be classified into two types: intrinsic, which infiltrates the muscle and mucosal layer of the ureter, and extrinsic, involving the adjacent peritoneum, uterosacral ligaments (USL), and ovaries (Lima et al., 2017).

The uterosacral ligament (USL), or rectouterine, is a paired, fibrous, supportive band of tissue connecting the lower part of the uterus (cervix) to the base of the spine (sacrum) (Figure 8). The dense connective tissue of the ligaments is crucial for maintaining the uterus’s normal position and preventing prolapse. In cases of deep infiltrating endometriosis, the USL is the site with the highest prevalence of 69.2%, followed by the vagina (14.5%), the bladder (6.4%), and the intestine (9.9%) (Lima et al., 2017). Endometriosis of the USL results in deep dyspareunia, chronic pelvic pain, and requires complex surgery upon the involvement of the parametrium and the ureter (Scioscia et al., 2021).

Figure 8:

Uterosacral ligament showing tissue connecting the cervix to the spine (Vu et al. 2010).

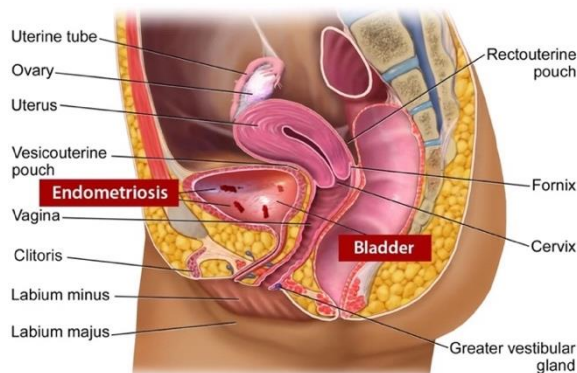


1.3.5 The Bladder

Bladder endometriosis is characterised by the presence of nodular lesions in the bladder's detrusor muscle, either partial or full-thickness infiltration, or bladder epithelium, as shown in Figure 9. It occurs in 70-85% of cases of urinary tract endometriosis (Fleischer et al., 2024; Leonardi et al., 2020). Bladder endometriosis can disrupt urine storage and release if lesions extend to the ureter (Fleischer et al., 2024).

Figure 9

Bladder endometriosis demonstrating infiltration of the bladder wall (New York Gynaecology Endometriosis, n.d.).



1.3.6 Extrapelvic Endometriosis:

Rectovaginal and Gastrointestinal Endometriosis

1.3.6.1 Rectum and Vagina

Rectovaginal endometriosis (RVE) is a form of deep-infiltrating endometriosis in which endometrium infiltrates the rectum, vagina, rectovaginal septum, and the Pouch of Douglas. This form is considered one of the most severe types of endometriosis and causes rectal bleeding, chronic pelvic pain, dysmenorrhoea, dyspareunia, constipation, and dyschezia. Due to its location, the gastrointestinal system and reproductive functions are significantly affected (Moawad & Caplin, 2013).

The deep infiltrative nature of rectovaginal endometriosis often results in significant fibrosis and distortion of pelvic anatomy, making surgical management particularly complex.

1.3.6.2 Gastrointestinal Tract

The most common locations for intestinal endometrium involvement are the sigmoid colon and rectum, followed by the ileum, appendix, and caecum (Jiang et al., 2013). Intestinal endometriosis is less common and involves the extra-mucosal layers of the intestine. Often, patients experience dyschezia, constipation, diarrhoea, bloating and abdominal pain, dyspareunia and rarely, rectal bleeding during menstruation. Misdiagnosis is common in endoscopic biopsies because architectural changes in tissue may be misinterpreted as inflammatory bowel disease (IBD), mucosal prolapse, or ischaemia (Miller et al., 2024).

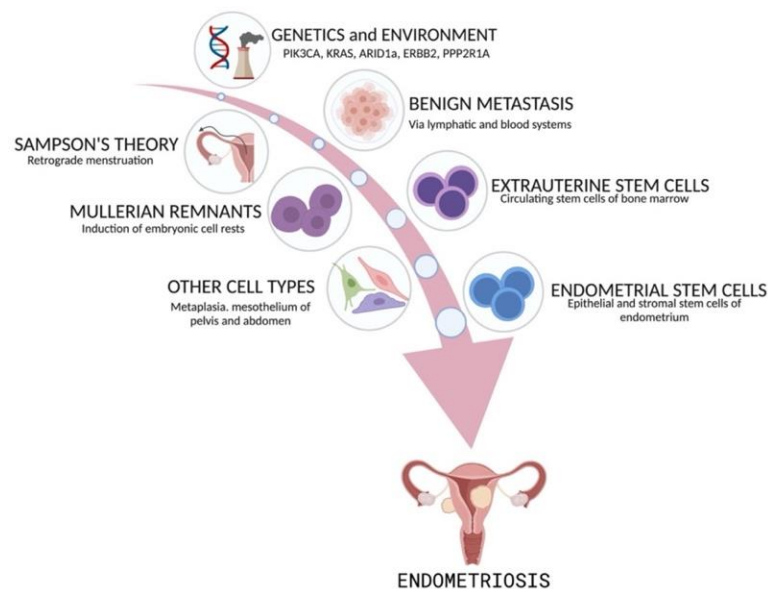
1.4 Pathogenesis and Risk Factors of Endometriosis

1.4.1 Pathogenesis

Understanding the natural history and pathophysiology of endometriosis is essential for assessing factors that influence the condition's prevalence and risk (Koninckx et al., 2021; Miller et al., 2024). Several theories have been proposed to explain the pathogenesis of endometriosis, including retrograde menstruation, stem cell origins, benign metastasis through the haematogenous or lymphatic spread of endometrial cells, coelomic metaplasia, and of Müllerian rest induction, as shown in Figure 10, have been proposed to explain the pathogenesis of endometriosis (Adilbayeva & Kunz, 2024; Burney & Giudice, 2021).

Figure 10

Pathogenesis pathways of endometriosis (Adilbayeva and Kunz, 2024).



1.4.2 Risk Factors

Modifiable risk factors such as diet and lifestyle may significantly impact the risk of developing endometriosis. These factors can also affect the menstrual cycle, oestrogen levels, inflammation, and prostaglandin metabolism. Diets rich in fresh fruits, green vegetables, omega-3, and omega-6 polyunsaturated fatty acids are associated with a lower risk of developing endometriosis. At the same time, diets high in coffee, trans fats, and red meat are associated with an increased risk of endometriosis (Adilbayeva & Kunz, 2024; Hemmert et al., 2018).

Environmental factors, such as smoking, can increase the risk of the disease. (Adilbayeva & Kunz, 2024). Chemicals found in cigarettes not only disrupt gene expression but also disrupt the female reproductive system (Sofa et al., 2015). This finding is relevant to endometriosis because smoking-related toxins may contribute to inflammatory responses, oxidative stress and hormonal dysregulation associated with the pathophysiology of the condition (Vallée & Matos, 2025).

1.5 Classification and Stages of Endometriosis

Several classification systems have been developed to assess the location, severity, and clinical impact of endometriosis, helping to aid in the diagnosis, treatment and fertility management of the condition (Vermeulen et al., 2021). Four commonly referenced staging systems for endometriosis are the revised American Society for Reproductive Medicine (rASRM), ENZIAN, the endometriosis fertility index (EFI), and the American Association of Gynaecologic Laparoscopists (AAGL) (Pasalic et al., 2023).

1.5.1 The rASRM staging system

According to the staging system, endometriosis is classified into four stages based on lesion size, severity, depth, location, and number. There are four stages of the rASRM: stage I (minimal disease) with 1-5 points, stage II (mild disease with 6-15 points, stage III (moderate disease) with 16-40 points, and stage IV (severe disease) with more than 40 points, as shown in Table 2 below. This scoring system relies on visual parameters rather than histological analysis and so has poor reproducibility and a reduced prognostic accuracy for fertility issues in endometriosis patients. In cases of deep-infiltrating endometriosis (DIE), there is no information for the localisation and mapping of ectopic endometriotic lesions (Pasalic et al., 2023).

Table 2

rASRM scoring system used for endometriosis classification (Pasalic et al., 2023).

ENDOMETRIOSIS			<1 cm	1-3 cm	>3 cm
PERITONEUM	SUPERFICIAL		1	2	4
	DEEP		2	4	6
OVARY	R	SUPERFICIAL	1	2	4
		DEEP	4	16	20
	L	SUPERFICIAL	1	2	4
		DEEP	4	16	20
POSTERIOR CUL-DE-SAC OBLITERATION			PARTIAL		COMPLETE
			4		40
ADHESIONS			<1/3 ENCLOSURE	1/3 – 2/3 ENCLOSURE	>2/3 ENCLOSURE
OVARY	R	FILMY	1	2	4
		DENSE	4	8	16
	L	FILMY	1	2	4
		DENSE	4	8	16
TUBE	R	FILMY	1	2	4
		DENSE	4*	8*	16
	L	FILMY	1	2	4
		DENSE	4*	8*	16

*if the fimbriated end of the fallopian tube is completely enclosed, change the point assignment to 16

Figure 11

ENZIAN classification system guide (Pasalic et al. 2023).

P	O	T	A	B	C	F
Peritoneum • Sum of all diameters	Ovary • Sum of all diameters left right	Tubal ovarian condition • Adhesions • Motility • Patency test left right	Rectovaginal space Vagina Retrocervical area • Largest diameter	Sacrouterine ligg. Cardinal ligaments Pelvic sidewall • Largest diameter left right	Rectum • Largest diameter	Adenomyosis
P1 $\Sigma < 3$ cm	O1 $\Sigma < 3$ cm	T1 Pelvic sidewall	A1 < 1 cm	B1 < 1 cm	C1 < 1 cm	F Bladder
P2 $\Sigma 3-7$ cm	O2 $\Sigma 3-7$ cm	T2 Pelvic sidewall, uterus	A2 1 - 3 cm	B2 1 - 3 cm	C2 1 - 3 cm	F Intestinum
P3 $\Sigma > 7$ cm	O3 $\Sigma > 7$ cm	T3 Pelvic sidewall, uterus, bowel, USL	A3 > 3 cm	B3 > 3 cm	C3 > 3 cm	F Ureter
P_	O_/_ m ovary is missing x unknown/not visible	T_/_ m tube is missing x unknown/not visible + or - patency test	A_	B_/_	C_	F(_) • Diaphragm • Lung • Nerve • (Location)

1.5.2 The ENZIAN Scoring System

The ENZIAN scoring staging system was introduced in 2005 to address the lack of clinical adaptability of the rASRM system. The ENZIAN system focuses on DIE and describes the location of deep endometriotic lesions. Values used to classify endometriosis stages include the following: i) the compartment of the organ involved in the observed lesion, represented by P, O, T, A, B, C, F, as a way to correspond to organ structures, and ii) the extent of endometriosis is assigned a value between 1 and 3. This method is precise for surgical planning and has a low false-positive rate; however, it requires integrating complete surgical and imaging data to enable proper implementation, prognostic consultations, and patient treatment (Pasalic et al., 2023). Figure 11 represents the system above.

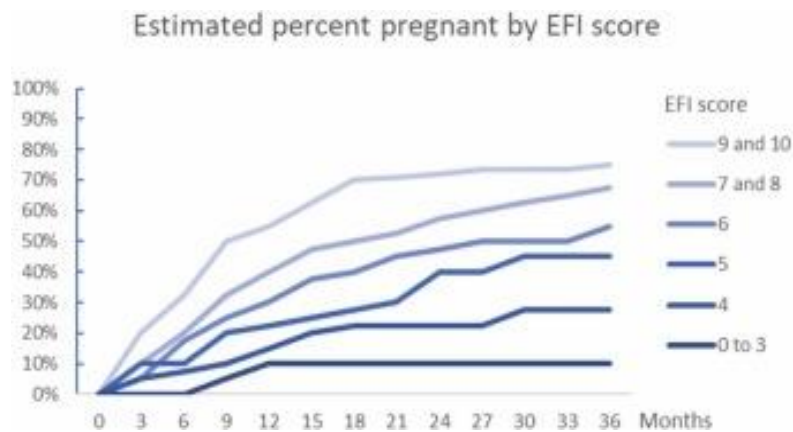
1.5.3 Endometriosis Fertility Index (EFI)

Established in 2010, the EFI system is used for determining pregnancy rates in those with surgically diagnosed endometriosis who attempt non-IVF conception. The EFI is calculated from a statistical

analysis of patient data based on the final surgical assessment of endometriosis. This system assesses the function of reproductive organs, with values ranging from 0 to 4: 0 indicates absence of function, whereas 4 indicates a healthy, functional structure. The fallopian tubes, fimbria and ovaries are scored on both sides, followed by calculating the least function (LF). The LF is the sum of the lowest value out of all the scores from either side. It is used to determine the surgical EFI factor score, which is combined with the historical factor score to derive the final EFI score. EFI values range from 0 to 10, with 0 indicating the worst and 10 the best projected pregnancy outcome. Unlike other systems, the EFI system incorporates additional classification systems to finalise its surgical factors (Pasalic et al., 2023). Figure 12 below shows EFI scores for fertility.

Figure 12

EFI score projects fertility outcomes for patients attempting non-IVF conception (Pasalic et al., 2023).



1.5.4 American Association of Gynaecological Laparoscopists (AAGL)

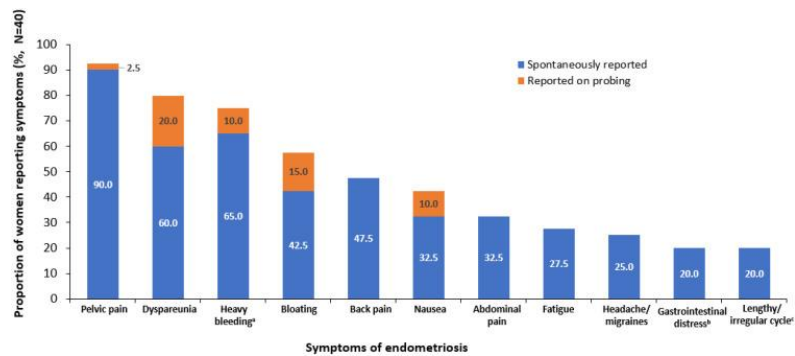
The AAGL is an anatomy-based endometriosis staging system that more accurately reflects surgical complexity, with scores ranging from 0 to 10. Like ASRM, the AAGL system categorises endometriosis into four stages; however, it is more dependable for complex surgical predictions. This staging system provides preoperative assessments for patients, facilitating more comprehensive prognostic discussions and greater insight into postoperative risks and complications. The AAGL is useful for comparative research and for standardising medical records across institutions (Pasalic et al., 2023).

1.6 Clinical Features of Endometriosis (including Etiology, Symptoms and Prevalence)

Endometriosis can be described as a neuro-inflammatory condition that is associated with debilitating chronic pelvic pain and is the most common symptom affecting 6-10% of women of reproductive age. Additionally, women with endometriosis experience dysmenorrhoea, dyspareunia, infertility, gastrointestinal issues (constipation, diarrhoea, bloating, and nausea), dyschezia and dysuria (painful bowel movements or urination), heavy menstrual bleeding or abnormal bleeding and fatigue (Parasar et al., 2018). Figure 13 shows commonly reported symptoms (Hunsche et al., 2023).

Figure 13

Symptoms of endometriosis (Hunsche et al. 2023).



Dysmenorrhoea is a common cause of lower abdominal pain radiating to the inner thighs and back. Defined as “painful monthly bleeding,” dysmenorrhoea is associated with significant psychological, emotional, and functional health impacts. These symptoms have been associated with the following risk factors: women up to the age of 30 years, smoking, high or low body mass index (BMI), family history of dysmenorrhoea, attempts to lose weight, depression/anxiety, and menarche at a younger age.

Dysmenorrhoea can be classified as primary or secondary. Primary dysmenorrhoea occurs in adolescents or young adults within the first two years of menarche and is characterised by recurrent lower abdominal pain. Elevated levels of prostaglandins (PGs) are thought to be the main cause of primary dysmenorrhoea, found in endometrial tissue upon shedding during menstruation. The release of PGs is positively correlated with the intensity of uterine contractions and can cause tissue hypoxia and ischaemia, resulting in pain, diarrhoea, and nausea (Nagy et al., 2023).

Secondary dysmenorrhoea is presented as painful cramps associated with an underlying disorder, structural abnormality, or disease within or outside the uterus. Females in their 30s and 40s are commonly affected by

this symptom. These women show varying levels of pain, dyspareunia, menorrhagia, intermenstrual bleeding, and postcoital bleeding. Common causes of secondary dysmenorrhoea include endometriosis (found in 29% of women with dysmenorrhoea), fibroids, large caesarean scars, adenomyosis, interstitial cystitis, endometrial polyps, and pelvic inflammatory disease (Nagy et al., 2023).

Dyspareunia can be defined as genital pain before, during, or after intercourse. Dyspareunia affects 3-18% of the global population, and 10-28% of the population. The symptom can be categorised as superficial or deep and primary or secondary. Superficial dyspareunia occurs in the vulva or vaginal entrance, while deep dyspareunia is associated with deep penetration and so affects the deeper parts of the vagina. Primary dyspareunia refers to the beginning of sexual intercourse, while secondary dyspareunia occurs after intercourse and lasts for some time. In some cases, patients experience a combination of dyspareunia and vulvodynia, which refers to genital pain lasting for more than three months with or without intercourse. Women experiencing dyspareunia feel a significant impact on their sexual relationships, mental and physical health, leading to hypervigilance to pain, anxiety, low self-esteem, and negative body image (Tayyeb & Gupta, 2023).

Endometriosis is strongly associated with infertility, affecting 25–50% of infertile women, while 30–50% of women with endometriosis experience infertility. Its prevalence has remained relatively stable over the past three decades, affecting approximately 6–8% of women of reproductive age (World Health Organisation, 2025). The presence of endometrial-like tissue outside the uterus may distort a woman's pelvic anatomy from chronic

inflammatory reactions, the formation of scar tissue and adhesions. Other issues include endocrine and ovulatory disorders involving impaired folliculogenesis, luteinised unruptured follicle syndrome, luteal phase defect, and premature luteinising hormone (LH) surges. The influx of peritoneal fluid, as seen in endometriosis, results in elevated levels of macrophages, prostaglandins, interleukin-1 (IL-1), tumour necrosis factor (TNF), and proteases, leading to adverse effects on the embryo, sperm, oocyte, and fallopian tube. Endometriosis is also associated with lower live birth rates, as women with endometriosis have a fertility rate of 2-10% per month. Normally, fertile women have fecundity rates of 15-20% per month, with a steady decline with age (Bulletti et al., 2010; Puscheck, 2024; Somigliana et al., 2016).

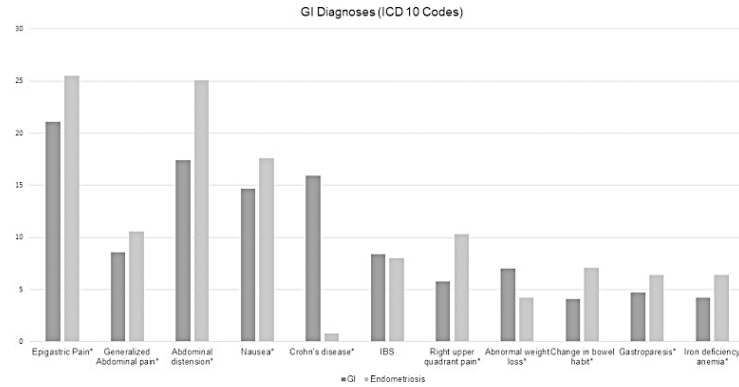
90% of women with endometriosis experience gastrointestinal (GI) symptoms, including bloating, nausea, vomiting, and constipation and are at 3-5 times greater risk of experiencing irritable bowel syndrome (IBS) symptoms. Women with both endometriosis and IBS experience more painful menstrual cycles and lower pain thresholds, amplifying their pain levels and decreasing their quality of life (QoL).

Figure 14 below illustrates differences in the prevalence of gastrointestinal (GI) disorders and symptoms among women with and without a diagnosis of endometriosis.

Women with endometriosis demonstrated higher rates of GI-related conditions, including abdominal distention, altered bowel movements, epigastric pain, nausea, and iron deficiency anaemia. This highlights the strong association between endometriosis and gastrointestinal symptom burden (Simons et al., 2024).

Figure 14

Comparison of GI diagnosis and endometriosis (Simons et al. 2024).



Dysuria is the painful sensation felt during urination. This is a common symptom, affecting 3% of adults aged 40 years and older. In some cases, endometrial tissue in the urinary tract, particularly the bladder, can cause inflammation and scarring, leading to dysuria (Leonardi et al., 2020).

In cases of deep-infiltrating endometriosis (DIS), dyschezia or painful bowel movements can be a symptom once endometrial-like tissue invades the rectum or bowel, causing pain and inflammation during bowel movements. Affecting 47% of women with endometriosis, dyschezia is influenced by the location and size of the endometriotic lesions in the bowel or rectum (Saetta et al., 2019).

1.7 Types of Endometrioses

There are three types of endometriosis based on the pathophysiology and localisation of ectopic endometrial lesions. These include: superficial peritoneal endometriosis (SPE), ovarian endometrioma (OMA), and deep infiltrating endometriosis (DIE) (Imperiale et al., 2023).

1.7.1 Superficial peritoneal endometriosis (SPE)

SPE, or superficial endometriosis, is the least severe form of endometriosis and is found on the surface of the peritoneum, located superficially on the pelvic peritoneum, extending up to less than 5mm in depth. This type of endometriosis is found in 15-50% of women diagnosed with endometriosis (Pedrassani et al., 2023). Red, black, and white peritoneal lesions are said to indicate the evolutionary steps of endometriosis. Red, active, highly vascularised lesions represent the first step. These lesions are often associated with an inflammatory reaction and result in haemorrhagic lesions (Figure 15). The second step is represented by black or brown lesions (Figure 16). These microcysts indicate old haemorrhage and therefore advanced endometriosis (Bailey et al., 2023; Franco-European Multidisciplinary Endometriosis Institute, 2021; Imperiale et al., 2023, p. 5). Figure 17 shows white lesions representing the last step, indicating healed or latent endometriosis (Franco-European Multidisciplinary Endometriosis Institute, 2021; Nisolle & Donnez, 1997; Pedrassani et al., 2023).

Figure 15:

Red lesions seen in superficial peritoneal endometriosis (Franco-European Multidisciplinary Endometriosis Institute, 2021).

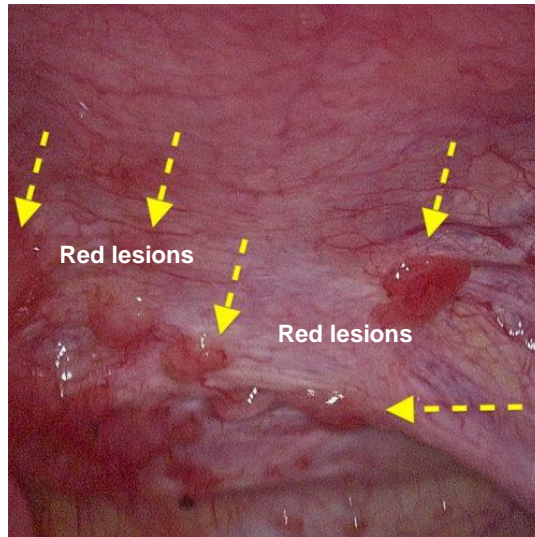


Figure 16:

Black/brown microcysts indicating old haemorrhage (Franco-European Multidisciplinary Endometriosis Institute, 2021).

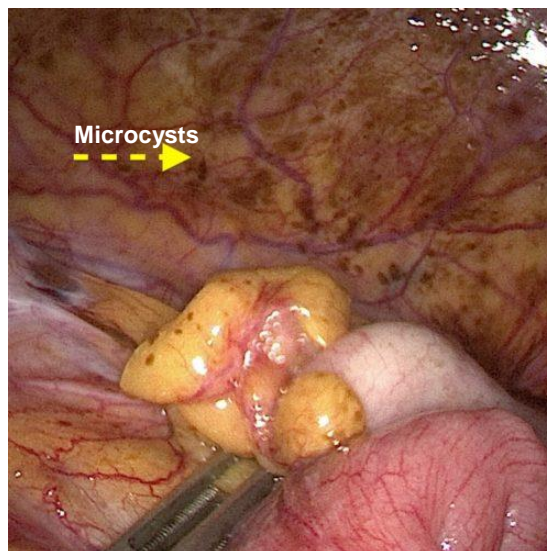
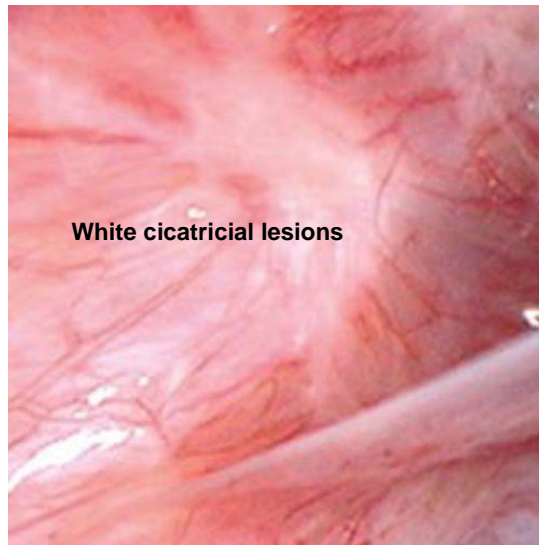


Figure 17:

White cicatricial lesions indicating the healing process of SPE (Franco-European Multidisciplinary Endometriosis Institute, 2021).



1.7.2 Ovarian endometrioma (OMA)

Ovarian endometrioma (OMA) affects 50% of women with infertility issues, and 2-10% of women within childbearing age (Imperiale et al., 2023). Endometriomas are cystic lesions filled with dark brown endometrial fluid, commonly found in the ovaries, as shown in Figure 18. These cysts, often called “chocolate cysts,” are indicative of the most severe stages of the condition (Hoyle & Puckett, 2023). There are two types of chocolate cysts, indicative of the origin of the endometriomas. Type 1 (primary endometriomas) have the same origin as peritoneal endometriomas, while type 2 (secondary endometriomas) arise from follicular ovarian cysts that become infiltrated by endometriotic tissue, distinguishing them from primary endometriomas. Secondary endometriomas are classified into three types: IIA, IIB, and IIC, and range in size from 3 to 20 cm (Eugonia, 2025).

Figure 18

Laparoscopic image of an endometriotic cyst of the left ovary (Eugonia, n.d.).



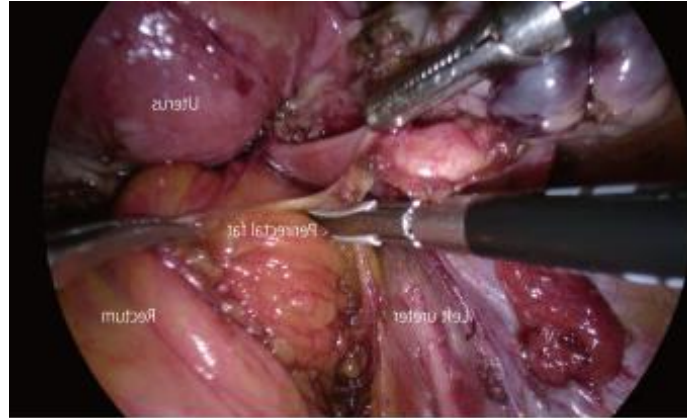
1.7.3 Deep infiltrating endometriosis (DIE)

Deeply infiltrating endometriosis (DIE) is the most severe and advanced form of endometriosis, characterised by endometriomas deeply embedded in the abdomen that invade the pelvis and surrounding structures, including the bowel, bladder, nerves, and blood vessels. This occurs when ovarian endometriomas begin to invade and rupture into the wall of the ovaries, causing the cysts to leak and spill into the abdominal and pelvic cavity—a combination of inflammatory enzymes, thickened blood, and debris aids in the leak of the endometriomas, resulting in the formation of nodules and scar tissue (Figure 19) (& Park, 2023; D’Alterio et al., 2021).

More than 95% of women with DIE experience severe pain, as lesions infiltrate the peritoneum by >5mm, increasing the risk of infertility (Cho & Park, 2024).

Figure 19

Surgical procedure of DIE showing haemorrhagic lesions and rectovaginal nodules infiltrating the uterus, ureter, and rectum (Cho & Park, 2024).



1.8 Global Mortality of Endometriosis

Endometriosis is a non-communicable disease (NCD) that cannot be spread from one person to another. In the case of women diagnosed with endometriosis (with or without laparoscopy), the death rates are 2.01 and 1.40 per 1000 person-years, respectively (Wang et al., 2024). Women with a history of endometriosis have been reported to have an approximately 31% higher risk of premature mortality. These women are at an elevated risk of developing neurological conditions, gynaecological cancers, and respiratory diseases. (Duboust, 2024; Zurowska, 2024).

1.9 Knowledge Gap and Contribution of this Study

Despite growing recognition of the impact of endometriosis, a knowledge gap remains regarding region-specific data in NZ. While initiatives and advocacy have highlighted the challenges of diagnostic delays and inequitable access to care, no other regional audit has systematically examined these issues. The absence of these analyses limits understanding of how diagnostic and management patterns vary across our health services and

reduces opportunities for targeted improvement and policy development.

This study addresses this gap by providing the first region-based evaluation of diagnostic delays and clinical management pathways in the Waitematā region. Using five years of routinely collected patient data, this study offers new insights into diagnostic patterns across demographic groups. The findings aim to support more equitable and evidence-based clinical management by investigating diagnostic delays and variations in endometriosis management across different demographic and age groups, while contributing to culturally responsive models of care that promote consistent and timely diagnosis. This aligns with the research questions below.

1.10 Research Questions

1. What clinical predictions, patterns and variations exist in the medical management of endometriosis among pre-menopausal and menopausal women in New Zealand over the study period?
2. Which demographic and clinical factors predict longer diagnostic delays for endometriosis among women in the Waitematā region during the study period?
3. What age-related differences exist in treatment approaches for endometriosis, and how is age associated with clinical management patterns among premenopausal and menopausal women in the Waitematā region?



Chapter Two

Literature Review

Overview of Chapter Two

This chapter reviews the national and international literature, as well as other relevant sources, on the prevalence of endometriosis across all age groups. It also examines diagnostic delays and the clinical symptoms experienced by patients.

2.1 Introduction

To examine the prevalence of endometriosis, its clinical characteristics, and available treatment options in relation to diagnostic practices, a comprehensive literature review was conducted. Peer-reviewed journal articles were identified through systematic searches of major scholarly databases, including PubMed, MEDLINE, EBSCO Health, Google Scholar, the Cochrane Library (via Ovid and Wiley), and Scopus, in addition to other relevant academic and professional websites. Searches were conducted using a range of relevant keywords and combinations, including *endometriosis, epidemiology, race/ethnicity, young women, pre-menopausal, age at diagnosis, diagnostic delays, international studies, regions, treatment types and management, ethnic disparities, and New Zealand*. Reference lists of key articles and expert recommendations were also reviewed to identify additional relevant studies. All retrieved and relevant publications are cited in the reference list.

The literature review primarily focused on articles published between 2018 and 2022 to ensure the inclusion of contemporary evidence. Earlier or later publications were selectively included, as necessary, to provide historical context or support foundational concepts related to the disease.

Analysis of the literature involved identifying recurring and significant themes, including: (i) patterns and prevalence of endometriosis across different geographical regions, (ii) variations observed across diverse ethnic groups, (iii) key clinical characteristics of the disease, (iv) available treatment options, and (v) delays in diagnosis and treatment.

Overall, the literature search strategy incorporated both systematic and organic elements, enabling a structured yet flexible approach to capturing a broad, relevant body of evidence.

A total of 164 articles were identified using the above search parameters, with emphasis on endometriosis diagnosis and treatment delays, as shown in Figure 21. The selection criteria were further refined by variable-specific details, as shown in Table 8 and in Chapter 4: Results.

2.2. Diagnostic Pathway

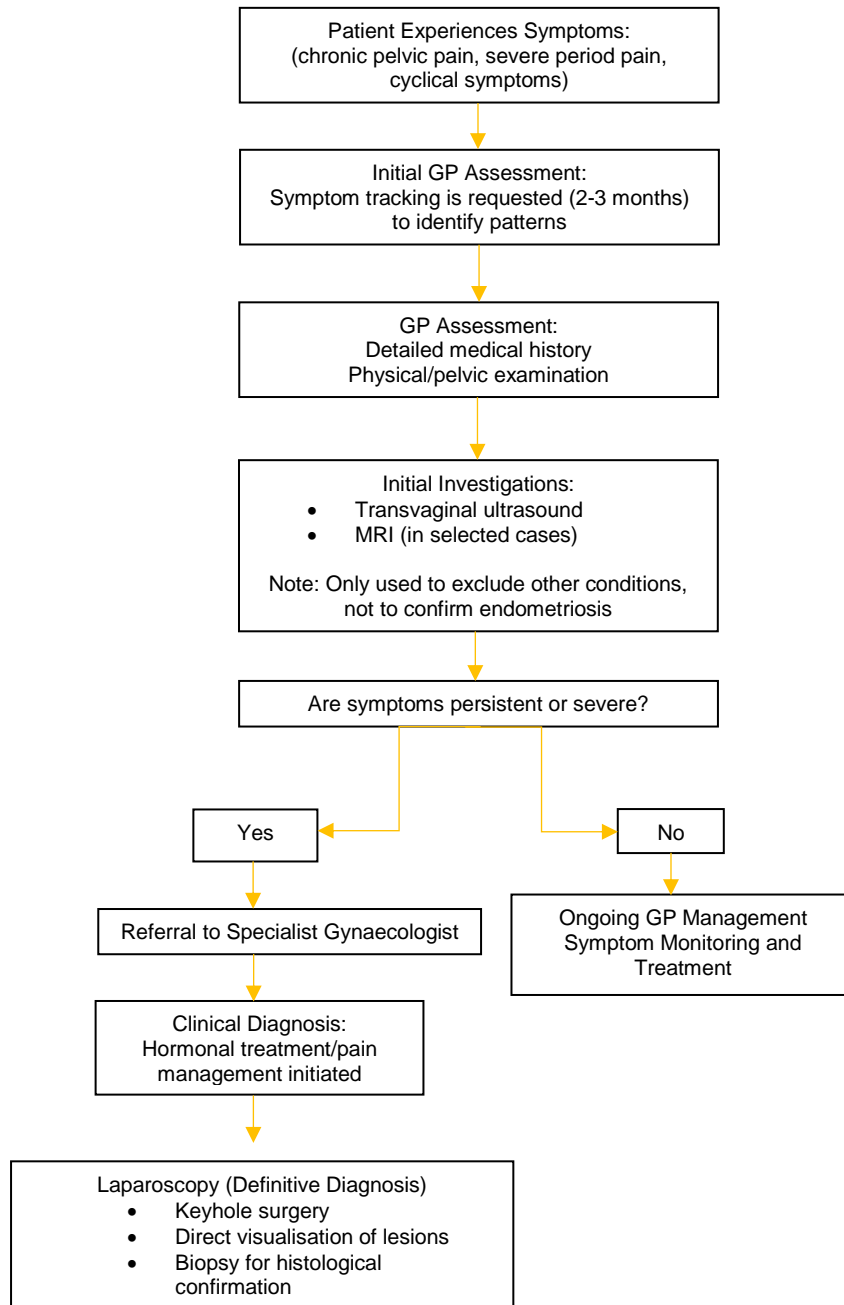
In New Zealand, the diagnostic pathway for endometriosis typically commences in primary care with consultation with a general practitioner (GP). Initial assessment focuses on characteristic symptoms such as chronic pelvic pain, dysmenorrhoea, and dyspareunia. Patients may be advised to maintain a symptom diary to document patterns and severity, thereby supporting clinical evaluation. The GP undertakes a comprehensive medical history and may request further investigations, including physical and pelvic examination, to exclude alternative diagnoses.

Where clinically indicated, imaging modalities such as transvaginal ultrasound or magnetic resonance imaging (MRI) may be utilised to identify features suggestive of deep infiltrating endometriosis or endometriomas. Patients presenting with severe or persistent symptoms are typically referred to a specialist gynaecologist for further

evaluation. Although a definitive diagnosis of endometriosis requires laparoscopic surgery, early management may be initiated in primary care and can include hormonal therapy and/or analgesia. Laparoscopy enables direct visualisation of endometriotic lesions and allows histological confirmation through biopsy (Ministry of Health, 2020) (Figure 20A).

Figure 20A

Flow Diagram of NZ's Diagnostic Pathway for Endometriosis (Ministry of Health, 2020).



Globally, the diagnostic approach to endometriosis has evolved from reliance on delayed surgical confirmation toward earlier, non-invasive identification using imaging modalities (Allaire et al., 2023; Bedaiwy et al., 2017). In most clinical settings, the diagnostic process begins with a detailed clinical history and assessment of symptoms, with particular attention to cyclical and non-cyclical pelvic pain, dysmenorrhoea, and infertility. Contemporary guidance emphasises the importance of symptom recognition, often prioritising clinical assessment over routine physical examination in the initial evaluation (Allaire et al., 2023). Imaging techniques, particularly transvaginal ultrasound and magnetic resonance imaging (MRI), are increasingly regarded as first-line investigative tools, although their use is influenced by the severity and complexity of the presentation (Bedaiwy et al., 2017). Laparoscopy is now generally reserved for cases in which imaging findings are inconclusive, symptoms persist despite empirical treatment, or diagnostic uncertainty remains. This shift reflects a broader move toward earlier, less invasive diagnostic pathways in endometriosis care (Allaire et al., 2023; Bedaiwy et al., 2017) (Figure 20B).

Figure 20B:

Flow Diagram of Global Diagnostic Pathways for Endometriosis (Allaire et al. 2023).

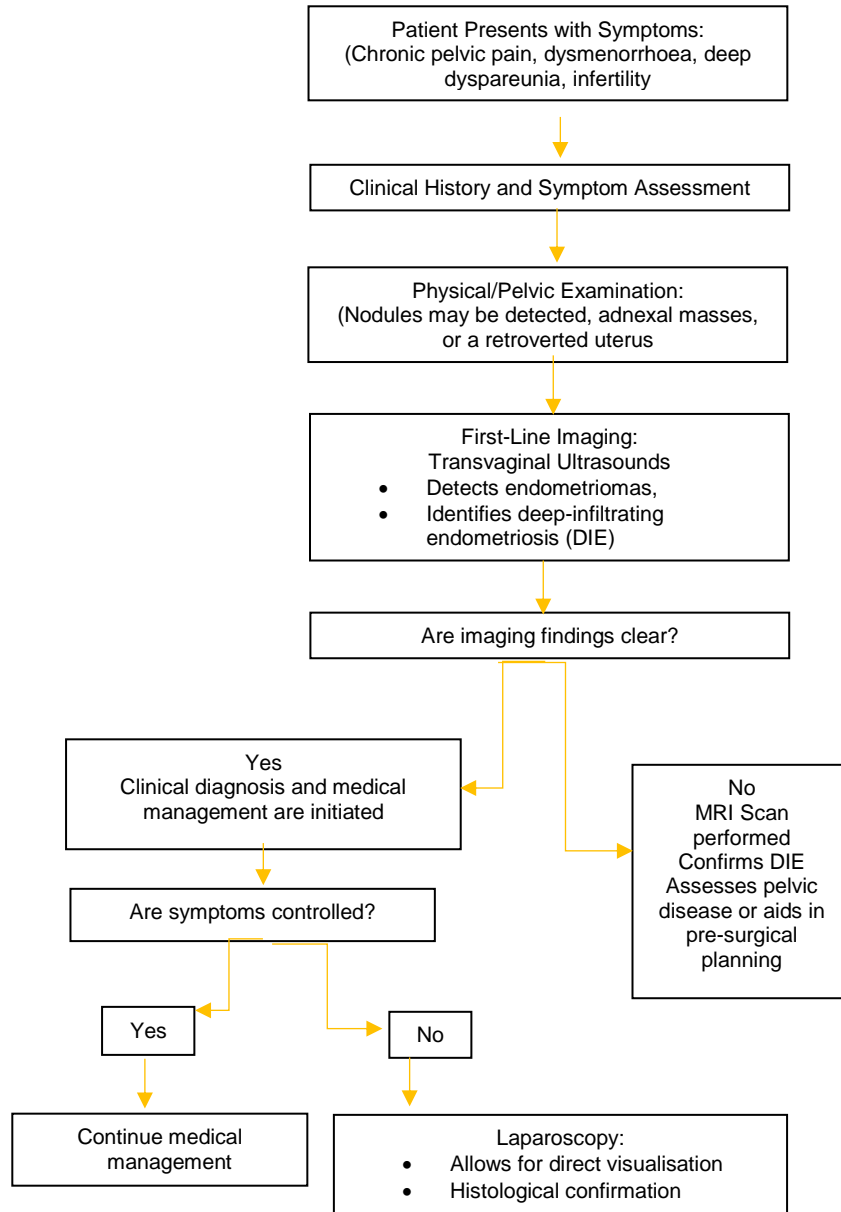
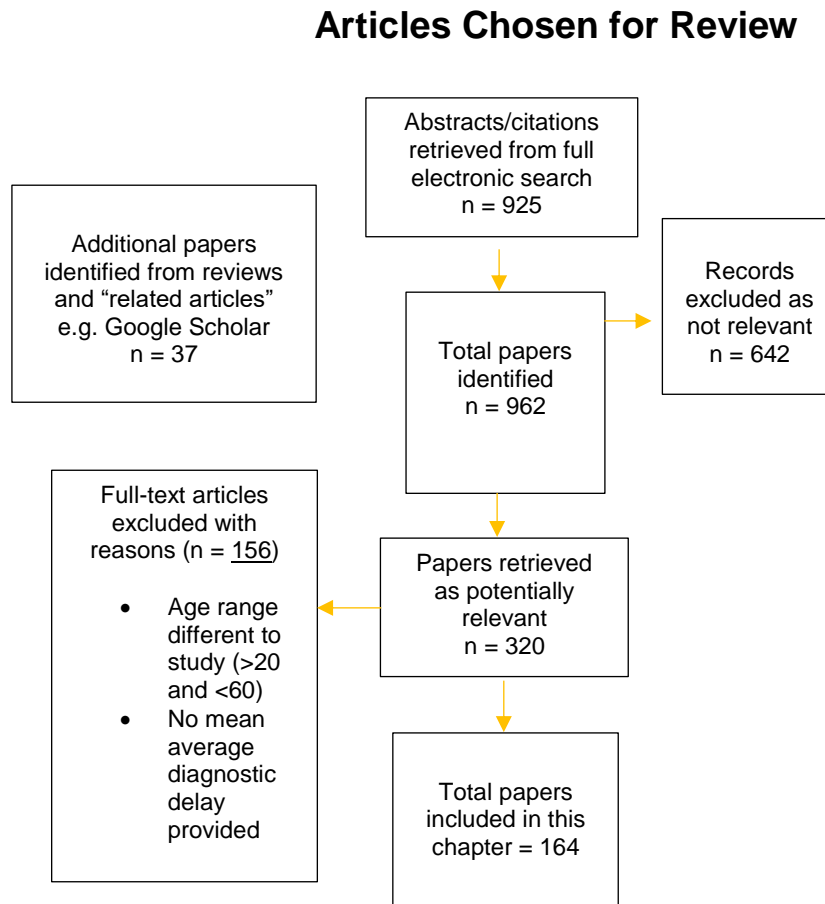


Figure 21

Flow diagram showing the selection of papers to be included in the literature review.



2.3 Prevalence of Endometriosis

A total of seven studies were reviewed to summarise the condition.

Endometriosis is a chronic, debilitating, oestrogen - dependent condition that significantly affects the quality of life (QoL) of women worldwide, including both premenopausal and postmenopausal populations (Chapron et al., 2019; Muyldermans et al., 1995; Signorile et al., 2022). Globally, endometriosis is estimated to affect approximately 10–15% of women of reproductive age and up to 30–50% of women who present with symptoms suggestive of the condition. The condition is characterised by the presence of endometrial-like tissue outside the uterine cavity and is commonly associated with chronic pelvic pain, dyspareunia, dysuria, menstrual irregularities, and infertility (Dunselman et al., 2014; Ellis et al., 2022; Eisenberg et al., 2017; Parasar et al., 2017).

2.3.1 Prevalence at the Country Level

A total of five studies were reviewed to assess the prevalence of endometriosis, specifically using age-standardised incidence rates (ASIR) (Bontempo et al., 2020; Feng et al., 2022; Kristjansdottir et al., 2023; Shen et al., 2024; Soliman et al., 2017). A large global study by Feng et al. (2022) was cited to provide in-depth insight into the prevalence of endometriosis across 204 countries.

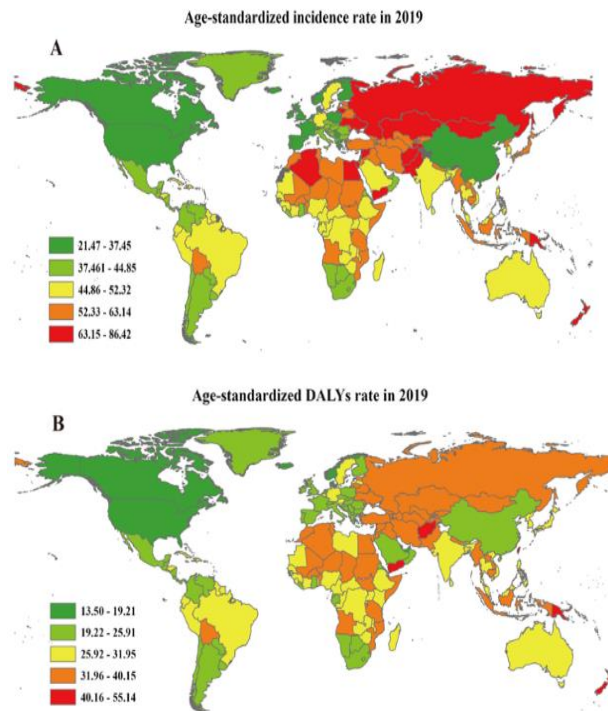
The difference in endometriosis prevalence may be due to misdiagnosis (Bontempo & Mikesell, 2020). A global study by Feng et al. (2022) between 1990 and 2019 reported a 10.37% increase in the global incidence of endometriosis and a 0.72% rise in age-standardised incidence rates (ASIR) in Eastern Europe, with an annual percentage change of 0.15%. The ASIR incidence rate in the Icelandic population ranged from 0.6% to 3.6% between 2001 and 2015, based on confirmed endometriosis diagnoses over

5-30 years (Kristjansdottir et al., 2023). The study reported by Kristjansdottir et al. (2023) found that the crude incidence of all diagnosed endometriosis among women aged 15-49 was 13.1/10,000 person-years, and the incidence of histologically verified endometriosis was 7.0/10,000 person-years. Within the same age group, the age-standardised annual incidence was 12.5/10,000 person-years, whereas the incidence of histologically verified endometriosis was 6.6/10,000 person-years. For women aged 15-69 years, Kristjansdottir et al. (2023) reported a crude incidence of all diagnoses of 10.2/10,000 person-years, and an incidence of histologically verified endometriosis of 5.8/10,000 person-years. The age-standardised annual incidence for this age group was 10.2/10,000 and 5.7/10,000 person-years, respectively.

Another study by Shen et al. (2024) reported that the prevalence change (PC) in age-standardised rates (ASR) of endometriosis declined globally by 20.47%, and the age-standardised prevalence rate (ASPR) decreased to 610.57 per 100,000 population in 2019, from 767.75 (Shen et al., 2024). The study by Feng et al. (2022) did not examine changes in prevalence or age-standardised prevalence rates, despite the underlying foundation of both studies remaining the same. At the country level, 200 of 209 countries (Figures 22A and B) showed a downward trend in PC of ASPR for endometriosis between 1990 and 2019. The Russian Federation (0.22%), Iceland (12.30%), Austria (7.33%), and Sweden (45.14%) showed increases in PC of ASPR.

Figure 22

A) The global ASIR of endometriosis in 204 countries in 2019; (B) The age-standardised DALY rates in 204 countries in 2019 (Feng et al. 2022).



Similarly, Feng et al. (2022) reported that the highest ASIR rate in 2019 was in New Zealand (NZ) at 86.42 per 100,000 population, followed by Afghanistan (71.83 per 100,000) and the Solomon Islands (71.01 per 100,000), as shown in Figure 21A. The largest decreases in ASIR for endometriosis were observed in Qatar (27.89 per 100,000) and Iceland (21.47 per 100,000) (Feng et al., 2022; Soliman et al., 2017), whereas incidence rates increased by approximately 11% in New Zealand. These numbers are reflected in Figure 21B. However, the literature on this disease in New Zealand is limited, underscoring the importance of this study. The data collected in this study will provide the basis for estimating the prevalence of endometriosis in New Zealand.

2.3.2 Prevalence in Different Ages

A total of 7 studies were reviewed to present that the highest burden of endometriosis was on those of reproductive age (25-39). Rozati et al. (2023) and 6 additional studies reported similar findings (Abbas et al., 2012; Ballard et al., 2008; Eisenberg et al., 2018; Kim et al., 2021; Morassutto et al., 2016; von Theobald et al., 2016).

A study performed by Rozati et al. (2023), based in South India, examined 60 women diagnosed with endometriosis, stages I and II (n=33) and stages III and IV (n=27). The prevalence of endometriosis was 2.5%, highest among women aged 25 to 34 years and 35 to 39 years (15.2 ± 3.5 years), as shown in Figure 23 (Rozati et al., 2023). This prevalence rate aligns with other studies by Morassutto et al. (2016) with 2% in Italy, Christ et al. (2021) with 1.9% in the United States, Ballard et al. (2008) with 1.5% in the United Kingdom, von Theobald et al. (2016) with 1.5% of women at reproductive age in France, Eisenberg et al. (2018) with 1.08% in Israel, Abbas et al. (2012) with 0.1% in Germany, and Kim et al. (2021) with 2.12 to 3.56 per 1000 South Korean women.

2.3.3 Prevalence of Infertility and Endometriosis

A total of 18 studies were reviewed. The findings from this literature reported the prevalence of infertility among women with endometriosis (Bablok et al., 2011; Camilleri et al., 2011; Chen et al., 2025; Eisenberg et al., 2022; Jabeen et al., 2018; Khawaja et al., 2009; Maggiore et al., 2024; Matorras et al. 2001; Meuleman et al., 2009; Mishra et al., 2015; Ozkan et al., 2008; Reid et al., 2019; Singh et al., 2020; Sinha et al., 2003; Strathy et al., 1982; Sule et al., 2008; Yamamoto et al., 2017).

A study conducted by Meuleman et al. (2009) examined

the prevalence of endometriosis in infertile Belgian women and reported an overall prevalence of stage I and II endometriosis of 47% in the population. Infertility was found to be significantly higher in younger women with endometriosis, (similar to results reported by Chen et al., 2025, who reported women in the 25–29-year age group to be at a higher risk of infertility due to endometriosis) compared to women without the condition; 60% of women aged 25-30 with endometriosis, compared with 42% of women older than 35 years (Meuleman et al., 2009). Similarly, Ozkan et al. (2008) reported results of the prevalence of endometriosis in infertile women between 25% and 40%, while only 2% of the 100 infertile participants had been found to have endometriosis in a study by Strathy et al. (1982); however, the data reported similar findings in terms of endometriosis being more prevalent among infertile patients. Similarly, Mishra et al. (2015) reported a prevalence rate of 48.38% among infertile women diagnosed with endometriosis.

In 2016, Prescott et al. reported that women with endometriosis experienced more than a twofold increase in infertility risk compared with women without the condition (Prescott et al., 2016). Similarly, in 2024, Maggiore et al. conducted a large prospective cohort study in the United States involving 90,625 participants and reported an infertility incidence rate of 1,380 per 100,000 person-years among women with endometriosis (Maggiore et al. 2024).

In Canada, Singh et al. (2020) analysed data from a cross-sectional online survey of 28,532 participants and observed markedly higher odds of infertility among women with endometriosis (OR = 4.1). Likewise, Eisenberg et al. (2022) conducted a retrospective case–control study in Israel involving 30,718 participants and reported elevated odds of infertility in women diagnosed with endometriosis

(OR = 3.3). Overall, evidence across varied populations and study designs consistently indicated an increased likelihood of infertility among women with endometriosis. In Spain, Matorras et al. (2001) undertook a prospective study of 750 patients and identified endometriosis in 34.5% of cases. By contrast, Sinha et al. (2003) reported a substantially lower frequency of 2.5% in a retrospective study conducted in Nepal.

In South Asia, Khawaja et al. (2009) reported a frequency of 16.8% in a retrospective study from Pakistan involving 796 participants, while Sule et al. (2008) documented a higher prevalence of 23.4% in a retrospective Nigerian cohort. European studies reported comparatively higher frequencies, with Meuleman et al. (2009) identifying endometriosis in 47.1% of patients in Belgium, and Bablok et al. (2011) reporting a prevalence of 9.6% in a multicentre prospective study in Poland. Similarly, Camilleri et al. (2011) observed a frequency of 16.9% in a retrospective study from Malta.

More recent prospective studies demonstrated considerable variability. Reid et al. (2019) identified a lower prevalence of 6.6% in an Australian cross-sectional survey. Jabeen et al. (2025), conducted in Pakistan, reported frequencies of 16.4%. In the United States, Yamamoto et al. (2017) reported a prevalence of 9.5% based on a retrospective review of clinical charts. In contrast, Mishra et al. (2017) reported the highest frequency at 55.0% in a prospective cohort.

2.4 Age and Endometriosis

2.4.1 Disability-adjusted Life Years and Death Trends Associated with Endometriosis

Disability-adjusted life years (DALYs), calculated as the sum of years of life lost due to premature mortality (YLLs) and years lived with disability (YLDs) in a population. The World Health Organisation (WHO) refers to one DALY as the loss of one year of full health (Australian Institute of Health and Welfare, 2023; Feng et al., 2022; WHO, 2025). In 2022, Feng et al. examined disability-adjusted life years (DALYs) and their association with endometriosis and found a decline among individuals aged 25–29 between 1990 and 2019 (Feng et al., 2022).

Globally, the age-standardised DALY was reported to have declined in the 25–29-year age group between 1990 and 2019. Between 1990 and 2019, New Zealand had the highest age-standardised DALY rate (55.14 per 100,000 population), followed by Taiwan (47.76 per 100,000 population) and Afghanistan (44.68 per 100,000 population). The lowest trends were reported in Iceland (13.50 per 100,000 population), followed by Qatar (14.44 per 100,000 population) and the United States of America (17.04 per 100,000 population). The largest increase in age-standardised DALY was observed in Sweden (EAPC, 1.54), whilst the lowest was observed in Oman (EAPC, -2.81). Globally, DALYs attributable to endometriosis increased by 16.36%, from 1,882,003 in 1990 to 2,250,033 in 2019. At the same time, the age-standardised DALY rates decreased from 35.08/100,000 persons in 1990 to 28.05/100,000 persons in 2019, with an EAPC of -0.80. Table 3 below shows DALY trends from 1990 to 2019 (Feng et al., 2022).

Table 3

The DALY cases and age-standardised DALY rates of endometriosis in 1990 and 2019, and their trends (Feng et al., 2022).

Characteristic	1990	2019	1990-2019	
	age-standardised DALY rate (per 100,000)	age-standardised DALY rate (per 100,000)	Change in Number No. (%)	EAPC No. (95% CI)
	No. (95% UI)	No. (95% UI)		
Global	35.08 (20.98, 55.56)	28.05 (16.87, 44.42)	0.20 (0.15, 0.24)	-0.80 (-0.83, -0.76)

A study by the Australian Institute of Health and Welfare (AIHW) (2023) found that endometriosis does not have a higher burden of premature death. Only the non-fatal burden (YLD) was reported, unlike the study by Feng et al. (2022). A rate of 0.61 per 1,000 females and 8,213 YLD from endometriosis were reported in the Australian Burden of Disease Study in 2023, ranking reproductive and maternal conditions third-highest, as shown in Figure 23. Among women aged 30-34 years, 1,676 YLD were reported, corresponding to 1.71 YLD per 1000 females and representing 0.51% of all non-fatal burdens among women in Australia (Australian Institute of Health and Welfare, 2023).

Figure 24 below shows that in 2003, the prevalence of endometriosis in females peaked between ages 25 and 34, with the highest number of cases observed in the 30–34 age group. Both the number of cases and the crude rate per 1,000 population were very low among females under 15 and over 55, resulting in a bell-shaped distribution, with the highest rates among women of reproductive age. In comparison, Figure 23 shows endometriosis YLD rates in

2003 and 2023; the 40% increase may be attributable to community awareness, disease prevalence, or earlier diagnosis (Australian Institute of Health and Welfare, 2023).

Figure 23

Endometriosis YLD in Females by age, 2003 (Rate of 0.00 per 1000 population (Australian Institute of Health and Welfare [AIHW], 2023).

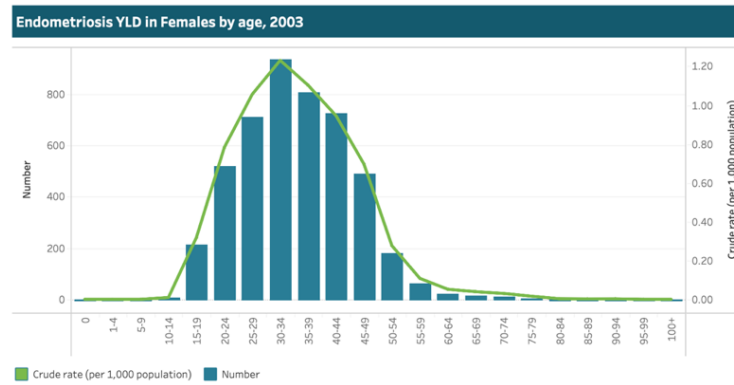
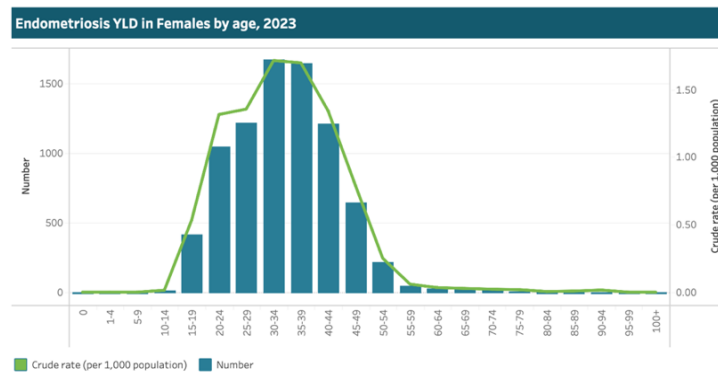


Figure 24

Endometriosis YLD in Females by age, 2023 (Rate of 0.00 per 1000 population (Australian Institute of Health and Welfare [AIHW], 2023).



2.4.2 Age Standardised Disability-adjusted Life Years Associated with Endometriosis

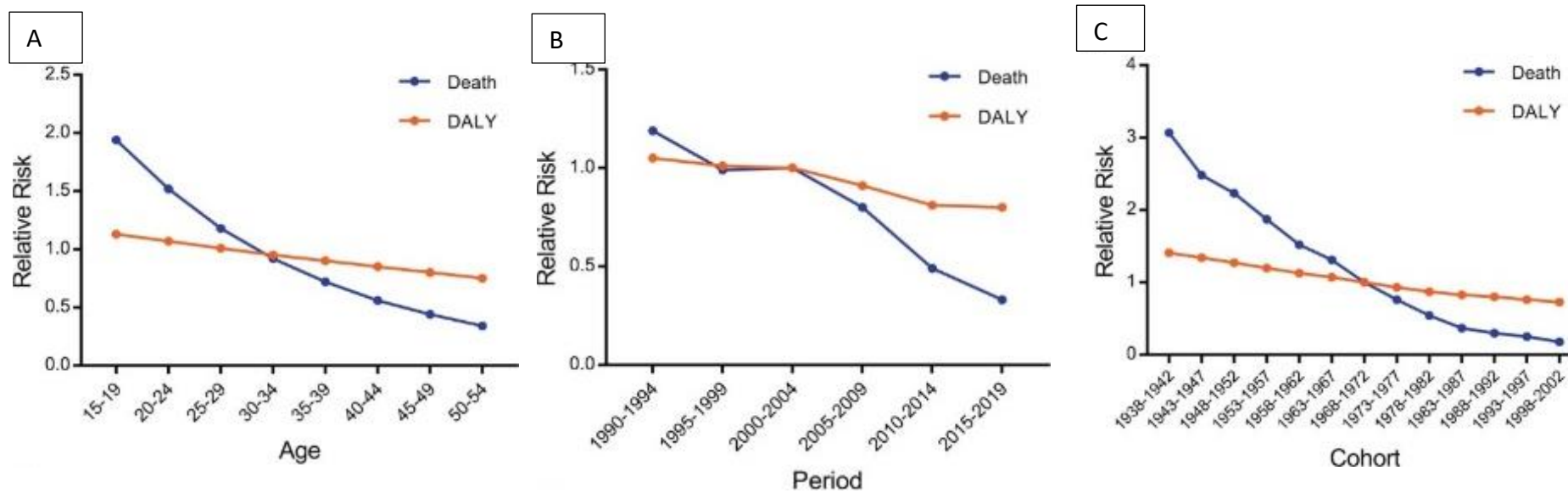
Two studies were reviewed. One was based in China and the other in Central America. Both studies reported a decline in age-standardised DALY estimates, ultimately suggesting a reduction in the number of endometriosis cases. However, it was also reported that sociodemographic disparities are still present and persistent across Central America (Shen et al., 2024; Wang et al., 2022)

Like the global study by Feng et al. (2022), Wang et al. (2022) examined trends in age-standardised disability-adjusted life years (DALYs) for women with endometriosis in China between 1990 and 2019. Overall, age-standardised DALY rates declined, with average annual per cent changes (AAPCs) of -4.7 and -1.2 . Age-standardised death rates (ASDR) decreased from 1990 to 1996 and from 2004 to 2019, with a slight increase observed between 1996 and 2004. The largest decline in DALYs occurred between 2005 and 2010 (APC = -4.3), while a modest increase was noted from 2010 to 2017 (APC = 0.4).

Relative risk (RR) analyses indicated a decline in the association between age and mortality and DALYs, with ages 15–19 and 50–54 years showing reductions of 82.5% and 33.6%, respectively. Period effects similarly demonstrated an overall downward trend, with DALY RR decreasing by 23.8% and death RR by 72.3% between 1992 and 2017, particularly in 2002. Cohort effects revealed declines in RR from 1938–1942 and 1998–2002, corresponding to decreases of 94.1% and 48.2% for both death and DALY, as shown in Figures 25 A, B and C. (Wang et al., 2022).

Figure 25

Death and DALY relative risks (RR) of Endometriosis due to (A) age, (B) period, and (C) cohort effects (Wang et al., 2022).



A more recent study by Shen et al. (2024) reported regional variations in the burden of endometriosis from 1990 to 2019, as shown in Figure 26 below. Central Latin America experienced the largest reduction (-36.44%), followed by South Asia (-31.56%) and North America (-29.58%). Globally, age-standardised DALY rates decreased from 71.08 per 100,000 population in 1990 to 56.61 per 100,000 in 2019.

Figure 26

Trends of endometriosis DALYs by sociodemographic index from 1990 to 2019 (Shen et al., 2024).

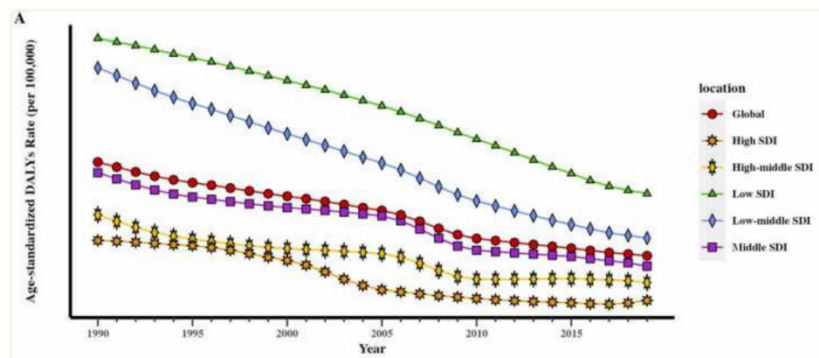
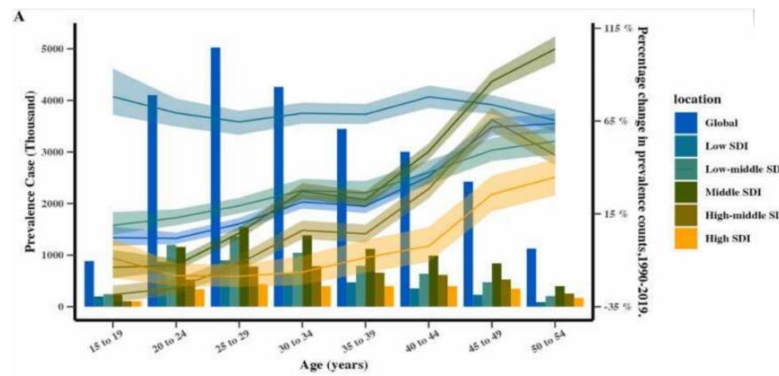


Figure 27 illustrates the global, regional, and national prevalence and disability-adjusted life years (DALYs) associated with endometriosis across 204 countries and territories. The figure also presents data according to sociodemographic index (SDI) levels, highlighting that the largest reduction in prevalence occurred in low- to middle-income countries, with a decline of 31.03%. Despite this decrease, low SDI countries reported the highest age-standardised prevalence rate at 718.35 cases per 100,000 population, whereas high SDI countries had the lowest rate at 538.61 cases per 100,000 population (Shen et al., 2024).

Figure 27

Age-SDI prevalence counts in 2019 and percentage counts of endometriosis in 1990 to 2019 (Shen et al., 2024).



2.5 Ethnicity and Endometriosis

A total of ten studies were reviewed regarding the influence of ethnicity on endometriosis prevalence, diagnosis, and access to care. Six studies reported that ethnicity may affect disease prevalence, clinical presentation, and healthcare access, with Asian and non-White populations showing higher prevalence compared to White populations (Bougie et al., 2019, 2022; Christ et al., 2021; Thrift et al., 2025; Treffers & Jung, 2025; Yamamoto et al., 2017; Williams et al., 2019). Four New Zealand-based studies highlighted systemic inequities and delayed recognition of endometriosis among Māori and Pacific populations (Dunning et al., 2025; Ellis et al., 2024; Li et al., 2021; Rahmioglu & Zondervan, 2024).

Despite growing attention, research on ethnicity and endometriosis remains limited and methodologically inconsistent (Bougie et al., 2022). Ethnicity may influence the clinical presentation of endometriosis among minority groups, contributing to delays in diagnosis and management. Cultural factors also affect healthcare experiences, including cultural safety, access to care, and recognition of cultural bias (Bougie et al., 2019; Treffers &

Jung, 2025).

In a 10-year retrospective cohort study in Washington, Christ et al. (2021) reported that 70% of patients diagnosed with endometriosis were White, while 4.7% were non-Hispanic, 6% Hispanic, and 9% Asian. Similarly, Yamamoto et al. (2017) found a higher prevalence among Asian women (15.7%) compared to Caucasians (5.8%). Canadian research indicated that East and Southeast Asian women were 8.3 times more likely to receive a diagnosis compared to White women (Williams et al., 2019), with Thrift et al. (2025) reporting analogous trends in non-White populations.

In contrast, Li et al. (2021) stated that lower prevalence rates in non-White groups may reflect healthcare inequities driven by socioeconomic and racial disparities, with prevalence estimates of 11.1% in non-Hispanic White, 6.4% in combined ethnic groups, 5.8% in non-Hispanic Black, and 2.7% in Hispanic populations. Broader global health disparities—including limited non-invasive diagnostic markers, symptom normalisation, inadequate public health programs, outdated policies, and insufficient research have contributed to delayed diagnosis in minority groups (Rahmioglu & Zondervan, 2024).

New Zealand studies similarly highlight inequities. Dunning et al. (2025) reported lower referral rates among Māori, Pacific, and Asian women in both the North and South Islands compared to European women. Ellis et al. (2024) noted that Māori and Pacific women experienced poorer health outcomes, lower life expectancy, and reduced access to healthcare, with symptoms often normalised or downplayed when seeking care. Collectively, these studies underscore the need for culturally responsive healthcare and targeted research to address ethnic disparities in endometriosis diagnosis and management.

2.5.1 Ethnicity and Disparities in Treatment

Options

A total of three studies were reviewed regarding the ethnic disparities faced by minority groups internationally and in NZ (Ellis et al., 2024; Kashyap et al., 2025; Sutaria et al., 2005).

Ethnic disparities in endometriosis treatment have been well-documented. In the United States, Black women experience inequities in both pain management and treatment access. Kashyap et al. (2025) reported that 28 drug classes were prescribed significantly more often to White patients (61%) compared to only four classes for Black patients (14%), indicating systemic inequities and potential biases in prescribing practices. Similarly, Sutaria et al. (2005) reported that White patients were four times more likely to be offered non-hysterectomy surgical options than Black patients. Among those living above the federal poverty line who underwent hysterectomy, survival outcomes were lower, highlighting the impact of both treatment disparities and socioeconomic factors (Kashyap et al., 2025; Sutaria et al., 2005).

Comparable inequities have been observed in New Zealand. Ellis et al. (2024) reported that Māori and Pacific women experience racial disparities in endometriosis care like those documented in the US, highlighting delayed diagnosis, reduced access to specialist referral pathways, and inequitable access to timely surgical and fertility-related interventions. These disparities are shaped by broader structural determinants of health within the New Zealand health system, including barriers to accessing primary care, differences in referral patterns, and the under-recognition of endometriosis symptoms in Māori and Pacific patients. This underscores the global relevance of ethnic and systemic inequities in patient

prognosis, treatment selection, and outcomes.

2.6 Etiology and Risk Factors of Endometriosis

A total of 18 studies were reviewed on the aetiology, risk factors, and outcomes associated with endometriosis. Research by Chantalat et al. (2020), Guo, 2009; Maksym et al. (2021), and Zubrzycka et al. (2020) reported findings on hormonal, immunological, and epigenetic dysfunctions, while eight studies focused on the environmental factors associated with higher chances of developing endometriosis (Cramer et al., 1986; Koninckx et al., 1991; Matalliotakis et al., 2008; Peterson et al., 2013; Shafrir et al., 2018; Tang et al., 2020). Three studies reported findings on the genetic predisposition of endometriosis (Barlow & Kennedy, 2005; Bischoff & Simpson, 2004; Hansen & Eyster, 2015), and three studies related endometriosis to the chances of developing endometrial cancers (Bhyan et al., 2019; Meredith et al., 2012; Yu et al., 2015)

Hormonal imbalances are a consistent feature of endometriosis. Elevated oestrogen production and overexpression of oestrogen receptors (ER α and ER β , encoded by ESR1 and ESR2) contribute to disease progression. ESR2 mRNA levels in endometriotic tissue are up to 34-fold higher than in normal endometrium, with persistent nuclear and cytoplasmic ER β expression. Endometriotic tissue can also locally synthesise 17 β -estradiol (E2) from cholesterol via aromatase (CYP19A1) and steroidogenic acute regulatory protein (StAR), enzymes absent in normal endometrium (Chantalat et al., 2020).

Immunological dysfunction further contributes to the pathophysiology of the disease. Maksym et al. (2021) reported impaired natural killer (NK) cell activity and

chronic inflammation, characterised by cytokine release (TNF, IL-1, IL-6, IL-8, IL-10), metalloproteinase activation, lymphocytic infiltration, and elevated systemic markers, including CA-125 and CRP. Endometriosis is thus considered a chronic inflammatory and immune-mediated disorder.

Epigenetic modifications, including histone changes, DNA methylation, and microRNA regulation, mediate interactions between hormonal and immune pathways, influencing gene expression in response to environmental stimuli (Guo, 2009; Zubrzycka et al., 2020).

Common risk factors identified include increasing age, early menarche, low body mass index (BMI), family history, prolonged menstrual flow, infertility, alcohol and caffeine intake, smoking, and intense physical activity (Cramer et al., 1986; Koninckx et al., 1991; Matalliotakis et al., 2008; Peterson et al., 2013; Shafrir et al., 2018; Tang et al., 2020). Prolonged oestrogen exposure and lean body composition have been associated with higher disease risk, while higher BMI has been linked to reduced risk, though findings are inconsistent (Chantalat et al., 2020; Hong & Yi, 2022; Rowlands et al., 2022).

Endometriosis demonstrates a familial and polygenic predisposition, with women 5 to 7 times more likely to develop severe disease if family history is present (Hansen & Eyster, 2015). Genetic aberrations, including loss of heterozygosity at 5q, 6q, 9p, 11q, and 22q, have been linked to both endometriosis and ovarian cancer (Barlow & Kennedy, 2005; Bischoff & Simpson, 2004).

In New Zealand, Pacific women exhibit higher rates of endometrial cancer, with physical inactivity, obesity, and diabetes identified as contributing factors (Meredith et al., 2012). Globally, endometriosis has been associated with an increased risk of endometrial cancer, although local New Zealand literature on this association remains limited

(Bhyan et al., 2019; Yu et al., 2015).

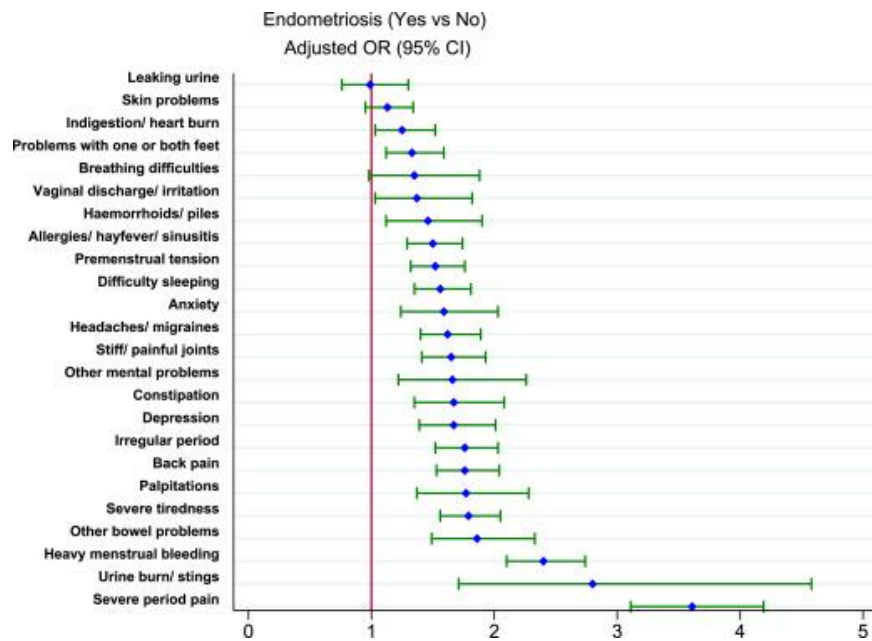
2.7 Symptoms of Endometriosis

A total of 16 studies were reviewed regarding the symptom profile and impact of endometriosis. Becker et al. (2021) conducted a European study including over 27,000 women and confirmed that pelvic pain is the most reported symptom. Similar findings were reported by Soliman et al. (2017), who also identified anxiety and stress as common experiences among patients. A French study by Fruchart et al. (2023) identified additional, previously underreported symptoms, including limb oedema, neuralgia, muscle pain, vaginal itch, haematuria, hot flushes, and generalised symptoms such as nausea, dizziness, and fatigue. Neuroinflammatory processes related to endometriosis were highlighted in earlier studies by Bajaj et al. (2003) and Veenstra van Nieuwenhoven et al. (2003). Furthermore, three studies explored the impact of endometriosis on infertility and quality of life (Martins et al., 2021; Nnoaham et al., 2021; Signorile et al., 2022; Soliman et al., 2020). Two New Zealand studies by Ellis et al. (2022) and Tewhaiti-Smith et al. (2022) reported findings consistent with international research, including chronic pelvic pain that begins before age 20.

Becker et al. (2021) reported that over 68% of women across six European countries experienced pain, with the highest prevalence in Poland (91%) and the lowest in Hungary (68%). Pain types included dysmenorrhoea, dyspareunia, and pelvic pain during or after sexual intercourse, while 8.5% of participants reported general pain. Additional common experiences included heavy or irregular bleeding (50.8%), depressive symptoms (49.9–69.9%), and feelings of failure (38.1–59.3%). Similarly, Soliman et al. (2017) found that 75% of over 1,260 U.S. participants reported pain, anxiety, stress, and lower back

In 2023, the Australian study by Gete et al. highlighted severe period pain, dysuria, and heavy menstrual bleeding as the most significant symptoms of endometriosis, while no associations were found with skin conditions, urinary incontinence, or respiratory difficulties (Gete et al., 2023). This is shown in Figure 29 below.

Figure 29
Association between endometriosis and each symptom (Gete et al., 2023).



Global studies indicate that endometriosis is associated with infertility and reduced health-related quality of life (QoL) in affected women compared with women without the condition (Martins et al., 2021; Nnoaham et al., 2011; Signorile et al., 2022; Soliman et al., 2017). Two cross-sectional studies reported that symptoms and treatment of endometriosis contributed to a loss of productivity of 7.41–10.8 hours per week and approximately 19.3 days per year (Fourquet et al., 2011; Nnoaham et al., 2011). Additionally, affected women experienced moderate to severe anxiety, depressive episodes, difficulties with self-care, and challenges in maintaining daily activities (Fourquet et al.,

2011; Simoens et al., 2012).

In New Zealand, literature has primarily focused on commonly reported symptoms such as dysmenorrhoea, mid-cycle pain, chronic pelvic pain (CPP), fatigue, brain fog, and migraines (Ellis et al., 2022; Tewhaiti-Smith et al., 2022). Tewhaiti-Smith et al. (2022) further highlighted the impact of endometriosis on health-related quality of life, particularly in friendships and relationships, and noted a high prevalence of CPP before age 20. Ellis et al. (2022), in a study of 50 participants diagnosed with endometriosis, reported additional symptoms including insomnia (6%), sensitive skin (6%), depression (6%), vomiting (4%), rectal bleeding (2%), and blacking out from pain (2%).

Overall, literature in New Zealand remains limited regarding the broader impacts of endometriosis on QoL and daily functioning. Consequently, findings from this study aim to contribute to the existing body of knowledge and provide context-specific insights to address the research questions.

2.8 Malignant Transformation of Endometriosis

A total of five studies were reviewed examining the association between endometriosis and ovarian malignancy. Five studies reported on *endometriosis-associated ovarian cancer* (EAOC), while four studies discussed atypical endometriosis and the prevalence of endometrioid ovarian cancer subtypes (Aris, 2010; Capozzi et al., 2024; Chiaffarino et al., 2024; Sampson, 1925; Scott, 1953).

Although endometriosis is generally considered benign, malignant transformation, particularly in the ovaries, has been documented (Chiaffarino et al., 2024). The association between endometriosis and ovarian cancer was first described by Sampson (1925), who introduced

the term *endometriosis-associated ovarian cancer* (EAOC). Sampson outlined three diagnostic criteria for EAOC: (a) clear histological evidence of endometriosis in proximity to the tumour, (b) exclusion of metastatic disease to the ovary, and (c) the presence of endometrial-type stroma surrounding epithelial glands. Subsequently, Scott (1953) proposed the term *ovarian cancer arising in endometriosis*, which requires histological evidence demonstrating a direct transition from benign endometriotic tissue to malignant ovarian tissue.

Atypical endometriosis, characterised by endometriotic glands exhibiting cytological atypia, is considered a potential precursor lesion and has been identified in approximately 60%–80% of ovarian cancers associated with endometriosis (Capozzi et al., 2024; Chiaffarino et al., 2024).

Figures 30 and 31 below show the relationship between endometriosis and EAOC development, as well as their prevalence (Aris, 2010; Chiaffarino et al., 2024). These findings support the hypothesis of a continuum between benign endometriosis, atypical endometriosis, and ovarian malignancy, underscoring the clinical relevance of recognising atypical histological features in patients with endometriosis.

Figure 30

The relationship between endometriosis-associated ovarian cancer and ovarian cancer arising in endometriosis (Chiaffarino et al., 2024).

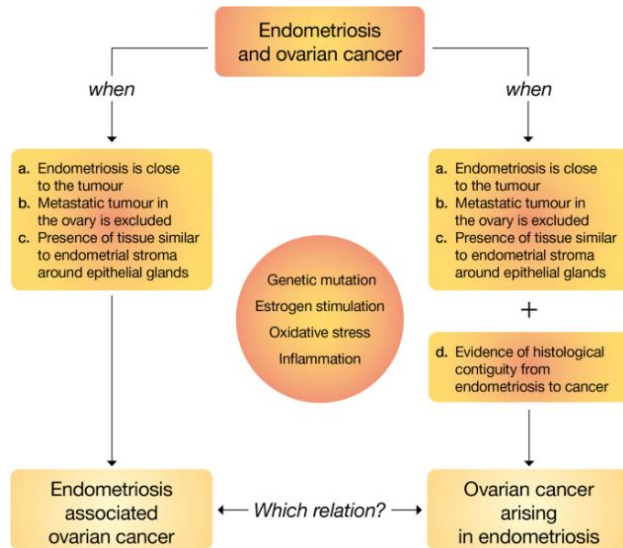
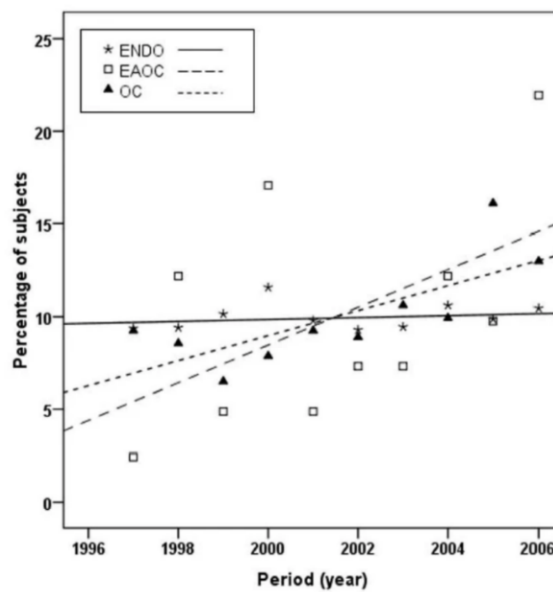


Figure 31

Analysis showing variation of percentage of endometriosis, EAOC, and ovarian cancer between 1997 and 2006 (Aris, 2010).



2.9 Significance of Immunohistochemistry Markers in Endometriosis

A total of 10 studies were reviewed examining the roles of phosphatase and tensin homolog (PTEN) and Ki-67 expression in endometriosis and ovarian malignancy. Five studies highlighted the significance of PTEN expression in endometriosis, ovarian cancer, and clear cell carcinoma (Dorigo & Berek, 2006; Ma et al., 2016; Martini et al., 2002; Obata et al., 1998; Sato et al., 2000). Additionally, four studies reported the utility of Ki-67 as a marker for assessing cellular proliferative activity (Kumar et al., 2023; Schlüter et al., 1993; Sun & Kaufman, 2019; Yalcin et al., 2017), while one study identified an association between Ki-67 expression and progression from endometriosis to ovarian cancer (Akbarzadeh-Jahromi et al., 2020).

The *PTEN* tumour suppressor gene, located on chromosome 10q23, encodes a dual-specificity phosphatase that regulates both protein and lipid substrates. *PTEN* is a key negative regulator of the phosphatidylinositol 3-kinase (PI3K)/Akt signalling pathway, which governs cellular proliferation, survival, metabolism, and tumour progression. Activation of PI3K signalling occurs through growth factor stimulation, including platelet-derived growth factor (PDGF) and insulin-like growth factor (IGF), which increase intracellular levels of PIP2 and PIP3. These phospholipids activate downstream kinases (PDK1/PDK2), thereby phosphorylating and activating Akt. Activated Akt promotes cell proliferation, resistance to apoptosis, angiogenesis, and invasive capacity. *PTEN* counteracts this process by dephosphorylating PIP3, thereby suppressing PI3K/Akt pathway activation and maintaining cellular homeostasis.

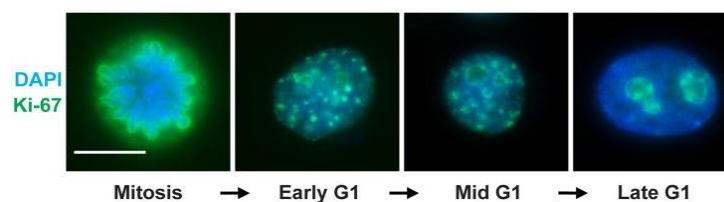
Loss or reduced *PTEN* expression disrupts this regulatory balance, contributing to malignant transformation. *PTEN*

inactivation has been reported in endometrial and ovarian pathologies, including ovarian endometriotic cysts, clear cell carcinomas, and endometrioid ovarian carcinomas. (Chiaffarino et al., 2024). Mutations are identified in approximately 7–21% of ovarian cancers, with higher prevalence in endometrioid subtypes (Kuo et al., 2009). In endometrial carcinoma, *PTEN* is among the most frequently altered genes, with mutation rates approaching 50% (Martini et al., 2016). Collectively, these findings highlight *PTEN* as a critical molecular driver in gynaecological carcinogenesis and a key component of PI3K pathway dysregulation (Vivanco & Sawyers, 2002).

Ki-67 is a nuclear protein encoded by the *MKI67* gene on chromosome 10 and is widely used as a marker of cellular proliferation. It is expressed during all active phases of the cell cycle (G1, S, G2, and M) but is absent in quiescent cells (G0), as seen in Figure 32 below (Sun & Kaufman, 2019; Yalcin et al., 2017). Due to its short half-life, Ki-67 provides a reliable index of proliferative activity and is commonly utilised in cancer diagnosis and prognosis (Kumar et al., 2023). Structurally, the Ki-67 protein contains multiple functional domains, including an N-terminal forkhead-associated (FHA) domain, a C-terminal leucine/arginine-rich chromatin-binding domain, a protein phosphatase 1 (PP1) binding domain, and a large region of tandem repeats (Schlüter et al., 1993; Sun & Kaufman, 2019).

Figure 32

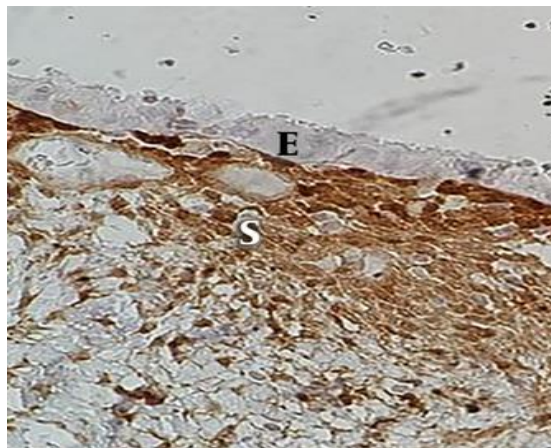
Localisation of Ki-67 throughout the cell cycle (Sun & Kaufman, 2019).



An Iranian study by Akbarzadeh-Jahromi et al. (2020) investigated *PTEN* and Ki-67 expression across typical endometriosis, atypical endometriosis, and endometriosis-associated ovarian cancer (EAOC). In typical endometriosis (n = 25), all epithelial cells demonstrated preserved *PTEN* expression with strong immunoreactivity (3+). In contrast, loss of *PTEN* expression was observed in 8% (2/25) of atypical endometriosis cases and in 50% (12/24) of EAOC cases (Figure 33) (Akbarzadeh-Jahromi et al., 2020).

Figure 33

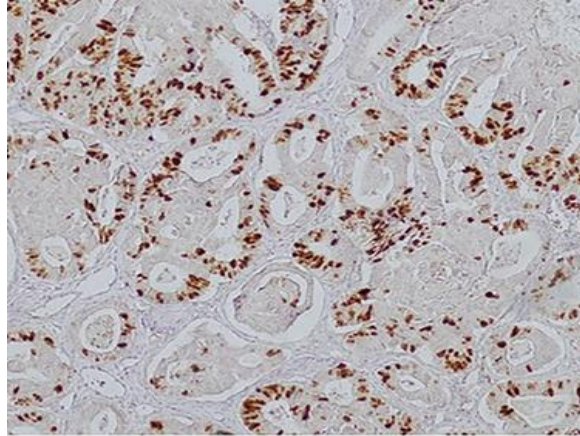
PTEN loss in epithelial cells (E) and stromal staining (S) in atypical endometriosis (Akbarzadeh-Jahromi et al., 2020).



The pattern of *PTEN* loss in endometriosis-associated ovarian cancer closely resembled that observed in ovarian carcinoma, indicating progressive molecular alteration during malignant transformation, as reflected in Figure 34 below.

Figure 34

Endometrioid carcinoma with squamous metaplasia highlighted by Ki67 staining (Akbarzadeh-Jahromi et al., 2020).



Stromal PTEN expression further supported this trend, with more than 50% of typical and atypical endometriosis cases exhibiting strong (3+) staining intensity, compared to moderate (2+) intensity in EAOc cases. Ki-67 immunoreactivity, reflecting proliferative activity, was detected in more than 50% of epithelial tissue components across all groups. Quantitatively, Ki-67 positivity was reported in 7.3% of typical endometriosis cases, 8.0% of atypical endometriosis cases, and 33.3% of EAOc cases. The marked increase in Ki-67 expression in EAOc suggests enhanced cellular proliferation associated with disease progression (Akbarzadeh-Jahromi et al., 2020).

2.10 Diagnostic Delays of Endometriosis

A total of 19 studies were reviewed across Sections 2.9 to 2.9.1, with 11 studies reporting diagnostic delays for endometriosis ranging from 3.3 to 12.3 years. Geographic variation in diagnostic delay was evident. Studies conducted in European countries generally reported

longer delays, whereas North American data indicated more moderate delays, with an average of 5.4 years reported in Canada. In the Oceanic region, diagnostic delays have been shown to increase over time, with Australian studies reporting delays of 6.1-12.3 years and New Zealand studies reporting delays of 8.7-9.0 years. Across regions, women of reproductive age were consistently identified as the most affected group, experiencing prolonged intervals between initial symptom onset and formal diagnosis (Ellis & Clarke, 2022; Ellis et al., 2022; Ghai et al., 2019; Horne & Missmer, 2022; Hudelist et al., 2012; Nnoaham et al., 2011; Pino et al., 2023; Singh et al., 2020; Staal et al., 2016; Tewhaiti-Smith et al., 2022).

Four studies specifically examined factors contributing to diagnostic delay. A recurrent theme across these studies was insufficient knowledge and awareness of endometriosis among healthcare professionals, which was identified as a significant contributor to delayed diagnosis (Bontempo & Mikesell, 2020; Hudelist et al., 2012; Staal et al., 2016; Wrobel et al., 2022). In addition, the normalisation of symptoms - particularly dysmenorrhoea and abnormal menstruation—was frequently reported, with symptoms often misattributed to other conditions, further compounding diagnostic delays (Chapron et al., 2019; Ellis et al., 2022; Fung & Montgomery, 2018; Kiesel & Sourouni, 2019).

Overall, the literature indicates that diagnostic delays for endometriosis remain substantial worldwide, typically ranging from 4 to 12 years (Ellis & Clarke, 2022; Kiesel & Sourouni, 2019).

Table 4 below shows that diagnostic delays for endometriosis remain substantial worldwide, ranging from a mean of 3.3 years in China to over 12 years in Australia. European countries consistently report longer delays (>10

years), while moderate delays are observed in North America; however, Oceanic countries, including Australia and New Zealand, demonstrate persistently prolonged delays of approximately 6-12 years. Younger age groups experience longer delays, indicating age-related inequities in diagnosis.

Table 4

Global Diagnostic Delays of Endometriosis (Ellis & Clarke, 2022; Ellis & Wood, 2024; Ghai et al., 2020; Horne & Missmer, 2022; Hudelist et al., 2012; Husby et al., 2003; Nnoaham et al., 2011; Pino et al., 2023; Singh et al., 2020; Staalet al., 2016; Tewhaiti-Smith et al., 2022).

Year of Study	Country	Number of years of delay (mean)	Spread of age groups (y)
2011	China	3.3	18-45
2011	Italy	10.7	18-45
2023	Italy	11.4	9-19 (<i>m</i> = 14.8), 20-30 (<i>m</i> = 6.9), 31-45 (<i>m</i> = 2.9)
2020	Canada	5.4	18-49
2022	Great Britain	6.8	18-49
2022	Australia	6.1	15-19 (<i>m</i> = 8.3), 30-34 (<i>m</i> = 1.3)
2003	Norway	6.7 ± 6.2	N/A
2016	Netherlands	7.4	N/A
2019	United Kingdom	8	N/A
2012	Austria and Germany	10.4	N/A
2022	New Zealand	8.7	N/A
2023	New Zealand	9.0 ± 5.2	18-48
2022	New Zealand	8.7 ± 2.9	N/A
2025	Australia	12.3 (range = 0-38, SD = 7.5)	18-63

There is limited evidence examining diagnostic delays for endometriosis in New Zealand compared with international studies. This research is therefore significant, as it offers a contemporary overview of endometriosis diagnostic timelines in New Zealand and has the potential to identify

systemic delays and inform targeted health system interventions to reduce inequities in diagnosis.

2.10.1 Cause of Diagnostic Delay

Misdiagnosis and prolonged diagnostic delays in endometriosis have been attributed to multiple systemic and clinical factors, including limited disease-specific knowledge among healthcare professionals, difficulties in symptom recognition by general practitioners (GPs), inadequate consultation and referral practices, and ineffective or inappropriate treatment approaches (Wróbel et al., 2022). Swedish research indicates that more than three-quarters of patients were initially misdiagnosed with either a mental health condition or an alternative physical disorder by GPs or gynaecologists, highlighting the pervasive nature of diagnostic error in endometriosis care (Bontempo & Mikesell, 2020). Similar findings were reported by Staal et al. (2016), who identified alternative diagnoses proposed by GPs as a major contributor to delayed diagnosis.

A multicentre Austrian and German study involving 171 patients found that misdiagnosis, the normalisation of dysmenorrhoea by patients, and the societal perception of menstruation as inherently negative significantly contributed to diagnostic delays, with an average delay of 10.4 years. Notably, 74% of participants had been misdiagnosed or incorrectly diagnosed before receiving a definitive endometriosis diagnosis (Hudelist et al., 2012).

In New Zealand, laparoscopy remains the gold standard for definitive diagnosis of endometriosis; however, diagnostic delays persist, partly due to the limited use and diagnostic value of non-invasive assessment methods (Ellis & Clarke, 2022). Physical examination and abdominal ultrasound alone are insufficient for diagnosis, and transvaginal ultrasound may be inappropriate for

some individuals due to sexual inactivity, personal preference, or cultural considerations. Furthermore, early-stage endometriosis (stages I and II) is often not detectable on ultrasound, while only more advanced disease may be visualised (Chapron et al., 2019; Fung & Montgomery, 2018; Kiesel & Sourouni, 2019). Although magnetic resonance imaging (MRI) may assist in evaluation, it is not recommended as a primary diagnostic tool for endometriosis (Chapron et al., 2019).

New Zealand-based research has emphasised the role of structural and funding-related barriers in prolonging diagnostic timelines. Ellis et al. (2022), in a study of 50 participants with confirmed endometriosis, identified subsidised care, increased research funding, and improved access to reliable information as key strategies to reduce diagnostic delays.

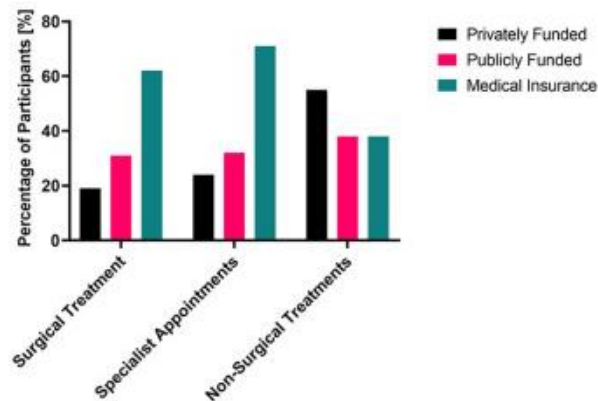
Figure 35 below shows differences among private, publicly funded, and insured patients, as well as the time spent waiting for treatment. Further work by Ellis et al. (2023) demonstrated a significant disparity in diagnostic timelines based on patient experiences of dismissal. Participants who reported that their symptoms were dismissed experienced a mean diagnostic delay of 9.0 ± 5.2 years, compared with 4.6 ± 3.4 years among those whose concerns were taken seriously, a difference of 4.4 years.

Financial barriers also influenced access to timely diagnosis and treatment. Approximately 19% of participants sought private healthcare due to delays within the public system, while 62% of patients with a confirmed diagnosis were ultimately able to access surgical treatment through public healthcare. Regarding specialist care, 24% paid out of pocket for private services, 71% used medical insurance, and 32% relied exclusively on publicly funded care. Participants who transitioned from public to private healthcare reported more timely

diagnoses, greater clinician empathy, and improved overall care experiences, underscoring inequities between healthcare sectors (Ellis et al., 2023).

Figure 35:

Comparison of funding participants who chose to pay for treatments and consultations after the length of waiting for diagnosis (Ellis et al., 2022).



2.10.2 Reducing Diagnostic Delays

A total of 13 studies were reviewed regarding the use of non-invasive biomarkers for diagnosing endometriosis.

Early studies investigating non-invasive and tissue-based diagnostic approaches for endometriosis focused on neural and hormonal biomarkers that reflected the disease's inflammatory and oestrogen-dependent nature. Neural markers such as protein gene product (*PGP 9.5*) were explored because endometriotic lesions are associated with increased nerve fibre density and neuroangiogenesis. *PGP 9.5* expressed was identified in eutopic and ectopic endometrial tissue from individuals with endometriosis (Tokushige et al., 2006). Zhang et al. (2009) reported that the density of *PGP 9.5* nerve fibres correlated with pelvic pain severity, linking endometriosis-associated pain to abnormal peripheral nerve growth and

inflammatory sensitisation.

Hormonal markers such as cytochrome P450 aromatase (CYP19) were also investigated due to their role in local oestrogen biosynthesis. Aromatase is typically absent in healthy endometrial tissue but has been shown to be expressed in endometriotic lesions (Noble et al., 1996). This enzyme converts androgens into oestrogen, contributing to hyperestrogenic microenvironments that promote lesion survival, inflammation and proliferation (Simpson, 2003). Increased CYP19 expression reinforced the understanding of endometriosis as an oestrogen-dependent inflammatory disorder and contributed to the later development of aromatase inhibitor therapies for disease management (Pavone & Bulun, 2012).

Gupta et al. (2016) evaluated 54 studies encompassing 2,729 participants. They assessed multiple biomarker categories, including angiogenesis and growth factors (PROK-1), cell-adhesion molecules (integrins $\alpha3\beta1$, $\alpha4\beta1$, $\beta1$, $\alpha6$), DNA-repair molecules (hTERT), hormonal markers (CYP19, 17 β HSD2, ER- α , ER- β), inflammatory markers (IL-1R2), myogenic markers (CALD-1), neural markers (PGP 9.5, VIP, CGRP, SP, NPY, NF), and tumour markers (CA-125). Of these, only PGP 9.5 (mean sensitivity = 0.96, mean specificity = 0.86) and CYP19 (mean sensitivity = 0.77, mean specificity = 0.74) demonstrated promising diagnostic accuracy; however, the evidence was insufficient or of low quality to support clinical recommendations.

Subsequent studies increasingly focused on cancer antigen 125 (CA125) as a reliable biomarker. CA125 is a glycoprotein expressed by the endometrium and other tissues derived from the coelomic epithelium, with serum levels elevated in women with advanced or ovarian endometriosis (McCausland & McCausland, 1998). However, its diagnostic utility is limited by low sensitivity

for early-stage disease and poor specificity, as elevated levels may occur in other benign and malignant gynaecological conditions (Nisenblat et al., 2016).

Nisenblat et al. (2016) systematically reviewed 141 studies involving 15,141 participants and 122 biomarkers, identifying CA-125 as the only marker demonstrating significant diagnostic heterogeneity. Additional studies confirmed the utility of CA-125 for differentiating endometriomas from other benign ovarian cysts and as an adjunctive tool in patients with chronic pelvic pain (Berker & Seval, 2015; Hornstein et al., 1995; Koninckx et al., 1991; Muyldermans & Koninckx, 1995). Consequently, CA125 is not recommended as a standalone diagnostic marker but may contribute to multimodal diagnostic approaches when combined with other clinical and imaging findings (Nisenblat et al., 2016).

More recent research has explored microRNAs (miRNAs) as potential non-invasive biomarkers for early detection of endometriosis (Bendifallah et al., 2022; Ghasemi et al., 2022; Karkia et al., 2011; Moustafa et al., 2020; Zafari et al., 2022). miRNAs are highly conserved, noncoding RNA molecules approximately 25 nucleotides long that regulate gene expression by binding to messenger RNA, thereby modulating mRNA degradation and translation. Plasma-based studies have identified thousands of miRNAs associated with endometriosis; Bendifallah et al. (2022) selected 86 miRNAs that demonstrated high diagnostic performance, with a sensitivity of 96.8%, specificity of 100%, and overall accuracy of 98.4%. Similarly, Moustafa et al. (2020) validated miRNA panels that can differentiate endometriosis from other gynaecological conditions. These findings suggest that miRNA biomarkers have significant potential to facilitate early, non-invasive diagnosis of endometriosis, thereby reducing prolonged patient discomfort, surgical risk, disease progression,

healthcare costs, and associated comorbidities (Bendifallah et al., 2022; Moustafa et al., 2020).

2.10.3 Barriers to Diagnosis

A total of 12 studies were reviewed regarding barriers to the timely diagnosis of endometriosis. Findings from four studies included limited clinical experience and education among healthcare providers, cultural stigma, and the resulting difficulty patients face in expressing symptoms (Ellis et al., 2024; Ellis et al., 2025; Frayne et al., 2023; Langmann et al., 2024). Two studies further identified disparities between public and private healthcare systems and the lack of subsidised treatment options as contributing factors to diagnostic delays (Ellis et al., 2025; Mosterd et al., 2025). Specific attention has been drawn to the racial and cultural inequities experienced by Māori and Pacific communities in New Zealand, which contribute to emotional and psychosocial distress and may further hinder timely diagnosis and treatment (Ellis et al., 2024; Ellis & Wood, 2025).

Diagnostic delays in endometriosis are of considerable concern, as they may result in suboptimal or postponed management, negatively impacting fertility, quality of life, work productivity, and, in severe cases, contributing to organ damage and disability.

Table 5 summarises the barriers to diagnosing endometriosis, with semi-structured focus groups consisting of 43 general practitioners from the Netherlands (Van der Zanden et al., 2020).

Table 5

Barriers to the diagnostic process for endometriosis, as reported by GPs (Van der Zanden et al., 2020).

Barriers	
Professional experience and competence	<ul style="list-style-type: none">• Low sense of urgency for timely diagnosis• Limited experience with endometriosis• Limited knowledge and skills related to endometriosis• Reluctance for referral due to a lack of understanding of the condition.• Insufficient training and literature
Patient characteristics	<ul style="list-style-type: none">• Patients not returning to their GP after initiated treatment fail.• Young women are less likely to be considered for a pathological condition.• Lack of patient engagement
Guidelines factors	<ul style="list-style-type: none">• Lack of GP guidelines on endometriosis
Collaboration	<ul style="list-style-type: none">• Lack of patient understanding of diagnostic/treatment options• Lack of communication between GPs and gynaecologists

Several studies have explored barriers to the timely diagnosis of endometriosis, highlighting systemic, cultural, and individual factors. In Western Australia, Frayne et al. (2023) identified barriers including clinician inexperience and limited awareness, time constraints, and a lack of screening opportunities. Cultural factors, perceived gender biases, and women's personal choices and priorities were

also identified as contributing to delayed diagnosis. The normalisation of pelvic pain, along with economic and geographic barriers to care, has further exacerbated diagnostic delays (Horne & Missmer, 2022).

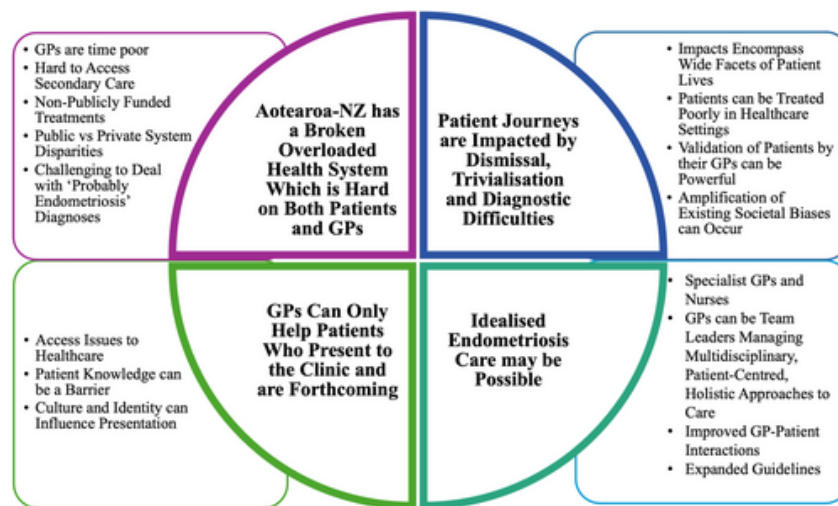
Mosterd et al. (2025) reported that diagnostic delays increased with the number of general practitioners (GPs) a patient consulted before receiving a diagnosis, due to practitioners' disbelief or dismissal of symptoms. The phenomenon of 'doctor shopping' was highlighted, reflecting the additional time and effort patients must expend to find a clinician who takes their concerns seriously. Access to healthcare funding also affected diagnostic times, with public-sector patients experiencing longer waits than those using private healthcare. Interestingly, contrasting findings from the United Kingdom indicated that privately funded healthcare could take longer than publicly funded services (Nnoaham et al., 2011).

In New Zealand, access to healthcare is hindered by practitioner bias, financial and logistical barriers, and limited gynaecological expertise among clinicians (Ellis & Wood, 2022; Shafrir et al., 2018). The Ministry of Health (2002) reports that socially disadvantaged groups experience poorer health outcomes, greater exposure to health risks, and reduced access to services. Māori and Pacific populations are particularly affected, facing differential access that contributes to inequities in health status and mortality. According to Ellis et al. (2025), GPs serve as the primary gatekeepers to specialist care, so access often depends on referrals to public or private services. This has created regional disparities—described as a “postcode lottery”—especially for surgical and specialist treatment. Communication challenges and limited resources further compound access issues for Māori and Pacific communities. Ellis and Wood (2025)

examined 87 patients with confirmed endometriosis. They reported that 46% used the public healthcare system for specialist appointments, 60.9% utilised private medical insurance, and 25.3% paid for appointments directly, highlighting the multifaceted impact of funding structures on patient access to care. Figure 36 below shows the GP perspective on the delays patients face after an endometriosis diagnosis (Ellis et al., 2025).

Figure 36:

A theme map presenting perspectives on endometriosis care and delay in NZ from GPs (Ellis et al., 2025).



Ellis et al. (2025) report that general practitioners (GPs) in New Zealand often lack the capacity to provide adequate care, treatment, and support for patients with endometriosis, contributing to systemic issues such as insufficient treatment subsidisation, extended waiting times, and overburdened specialist pathways. Primary care challenges included limited consultation time, which hindered the development of strong patient-practitioner relationships. GPs indicated that allocating more time for consultations would foster trust and improve patient understanding. Financial barriers were also highlighted, as some of the most effective treatments available were

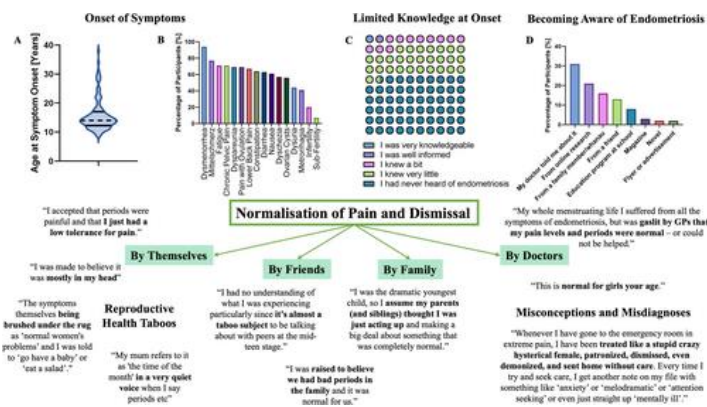
unfunded or not subsidised, creating frustration for both practitioners and patients. Referral processes from public care to specialist services, including diagnostic testing and ultrasounds, were reported to be time-consuming and resource-intensive, particularly when patients were declined multiple times. Figure 36 summarises the GP perspective on delays in endometriosis care (Ellis et al., 2025).

Consistent with findings by Mosterd et al. (2025), Ellis et al. (2025) noted that patients accessing private healthcare—either through out-of-pocket payments or medical insurance—were more likely to receive faster, more effective care than those navigating the public system. Consequently, patients' financial capacity significantly influences access to timely diagnosis. GPs also identified resource shortages, extended waiting times, and variability in specialist availability as barriers to optimal care, with quality often dependent on geographic location. Additional barriers included the normalisation, dismissal, and trivialisation of symptoms, as reported by GPs in New Zealand. Patients frequently felt judged, invalidated, or minimised when specialists or healthcare professionals advised them to “toughen up” or “live with it.” Ellis et al. (2025) noted that such attitudes from specialists reinforced the invalidation of patients' experiences. Cultural taboos, racial biases, and low health literacy further compounded these challenges. Patients with limited knowledge or the ability to articulate endometriosis-related symptoms often normalised their pain and delayed seeking medical attention (Ellis et al., 2025). Cultural taboos, shaped by historical, social, and collective experiences, contribute to shame surrounding menstrual cycles, particularly among young women, reinforcing the perception that painful symptoms are normal (Langmann et al., 2024). Ellis et al. (2025) observed a lower representation of Māori, Pacific,

and Asian patients in their study, likely reflecting the effects of cultural taboos and reduced discussion of reproductive health within these communities. GPs highlighted that difficulty in expressing reproductive health concerns can adversely affect patients' quality of life and overall well-being (Ellis et al., 2025).

Ellis and Wood (2025) identified the strongest themes in diagnostic barriers in New Zealand as dismissal and the normalisation of pain. Figure 37 below presents a summary of patient quotations illustrating these themes (Ellis & Wood, 2025).

Figure 37:
Summary of the theme “Normalisation of Pain and Dismissal” with quotations (Ellis & Wood, 2025).



An average diagnostic delay of 9.9 ± 6.3 years has been reported in New Zealand, with authors suggesting that the absence of a confirmed source for symptoms often leads patients to independently research endometriosis and its associated manifestations (Ellis & Wood, 2025). Common misconceptions identified in this context include beliefs such as “menstrual distress is normal,” “all endometriosis patients have severe symptoms,” “treatment only matters when trying to conceive,” and “if a patient does not have

certain symptoms, endometriosis can be ruled out.” Dismissal of symptoms was not limited to healthcare professionals; it also occurred within patients’ social networks, with family, friends, and even other endometriosis patients minimising experiences, labelling patients as dramatic or hysterical, and suggesting relaxation or therapy rather than medical consultation (Ellis & Wood, 2025).

Ellis et al. (2024) examined the experiences of Māori and Pacific patients and highlighted additional barriers to timely diagnosis. Māori patients experienced an average delay of 11.6 ± 7.8 years, while Pacific patients experienced longer delays of 12.4 ± 6.2 years. These delays were attributed to systemic racial discrimination and health inequities, resulting in poorer health outcomes, reduced life satisfaction, negative mental health impacts, and a higher prevalence of advanced cervical cancers, particularly in Pacific communities. A lack of awareness of endometriosis was prevalent, with 63% of Māori and 90% of Pacific participants reporting that they had never heard of the condition before diagnosis. Following initial consultation, patients often experienced diminished confidence in their symptom reporting, resulting in self-doubt and the perception that they were overemphasising their health concerns. Approximately 40.7% of Māori patients were accused of “drug seeking” when trialling multiple pain medications due to ineffective treatment options (Ellis et al., 2024). Cultural barriers, including shame (whakama) associated with discussing symptoms with GPs, family, and friends, further compounded delays (Ellis et al., 2024). Patients reported a 22% reduction in GP support over the course of symptom progression, whereas specialist support increased by 36%. Specifically, 70.4% of Māori and 70% of Pacific patients relied on GP care during early symptom development, which declined to 55.6% of Māori

and 60% of Pacific in specialist care. Participants also noted that the New Zealand healthcare system was primarily designed for the “Western world” and lacked relational practices such as *whakawhanaungatanga*, which are vital to culturally sensitive care. Discrimination and discomfort with male GPs contributed to patient unease when discussing reproductive health, highlighting the need for longer consultations to facilitate trust and openness (Ellis et al., 2024).

Ellis et al. (2024) noted that patient autonomy and focus on symptom management were often overshadowed by discussions of fertility, with the emphasis placed on the potential for conception rather than alleviating pain. Within this cohort, 33.3% of Māori and 40% of Pacific women experienced infertility related to endometriosis, exacerbating emotional and spiritual distress. Regarding treatment accessibility, 66.7% of Māori and 60% of Pacific participants disagreed that endometriosis treatment was readily available, and private funding was identified as a facilitating factor for only a minority of patients (Ellis et al., 2024).

Internationally, BMI has been found to correlate with endometriosis symptom intensity and infertility, though not necessarily with anatomical disease distribution (Piriyev et al., 2025). Within Māori and Pacific populations, higher BMI prevalence and weight-based discrimination by healthcare providers have been identified as additional barriers to timely diagnosis (Ellis et al., 2024).

Recent New Zealand studies have expanded the international literature on diagnostic delays and barriers in endometriosis. This audit aims to provide updated evidence on the length of delay experienced by New Zealand women, contributing to the current body of knowledge and informing strategies to improve timely diagnosis and care.

2.10.4 The Importance of Diagnosis

A total of two studies were reviewed, highlighting the sense of validation and empowerment that patients experience upon receiving a confirmed diagnosis of endometriosis. Additional reported benefits included pain relief, improved quality of life (QoL), and fertility preservation (Dantkale & Agrawal, 2024; Mosterd et al., 2025).

Mosterd et al. (2025) conducted a study in Australia on the perceived importance of receiving an endometriosis diagnosis. Of 506 participants, over 96% viewed diagnosis as important, with only 0.8% reporting no relief. A confirmed diagnosis offered self-validation, reassurance, and relief from psychological distress, particularly after experiences of being dismissed by healthcare practitioners. It also fostered empowerment and self-advocacy, especially around infertility, enabling women to better understand and manage their condition. Additional validation came through support groups, empathetic healthcare professionals, and assistance in securing a diagnosis (Mosterd et al., 2025).

Similarly, Dantkale and Agrawal (2024) emphasised the importance of prompt and early diagnosis to improve fertility preservation, achieve faster pain relief, enable effective disease monitoring, and enhance overall QoL. Early diagnosis was suggested to reduce patient suffering and minimise healthcare costs.

2.11 Treatment and Management of Endometriosis

A total of 11 studies were reviewed regarding the treatment and management of endometriosis. Surgical and hormonal interventions were the most reported approaches, including laparoscopy, oral contraceptives, and oestrogen-suppressing medications (Barbara et al., 2021; Bedaiwy et al., 2017; Donnez & Dolmans, 2021; Kalaitzopoulos et al.,

2021). Laparoscopy is both a diagnostic and therapeutic procedure for endometriosis, enabling the visualisation and treatment of lesions during the same operation. (Dunselman et al., 2014; Becker et al., 2022). Three New Zealand-based studies highlighted the use of cannabis as an effective management option, providing pain relief and reducing nausea and vomiting (Armour et al., 2021; Chapron et al., 2019; Sinclair et al., 2022). Age-specific treatment considerations were also reported: women over 40 years focused on fertility goals, menopausal symptom management, and symptomatic relief (Witt & Barad, 1993), whereas adolescents (<20 years) were initially offered hormonal contraceptives, primarily progestins, with surgical or advanced interventions considered only if first-line treatments were ineffective (Hare et al., 2023).

Current treatment strategies for endometriosis combine surgical and hormonal approaches. Suppression of oestrogen production and induction of amenorrhoea have been recommended as effective strategies for disease management (Bedaiwy et al., 2017). Oral contraceptives, particularly progestins such as dienogest, medroxyprogesterone, or ethinylestradiol, are considered first-line therapy, often combined with the surgical excision of endometrial implants and endometriomas (Barbara et al., 2021; Donnez & Dolmans, 2021; Kalaitzopoulos et al., 2021).

New Zealand literature indicates that cannabis may offer significant symptomatic relief, especially for pain and nausea, with some patients reporting it as the most effective management strategy alongside laparoscopic surgery and hormonal therapy (Armour et al., 2021; Chapron et al., 2019; Sinclair et al., 2022).

Women over 40 years with endometriosis require consideration of reproductive goals, symptomatic relief, and strategies to delay or prevent recurrence, alongside

management of perimenopausal symptoms and declining fertility. Therapeutic approaches may include surgery, assisted reproductive technologies, and oestrogen replacement therapy (Witt & Barad, 1993). In adolescents, GPs commonly recommend hormonal contraceptives, progesterone, or non-steroidal anti-inflammatory drugs as first-line management, with escalation to gonadotropin-releasing hormone (GnRH) therapy, ultrasound monitoring, laparoscopy, or surgery if initial treatments are unsuccessful (Hare et al., 2023).

In 2024, a study by Ellis et al. summarised the first-line treatments recommended by New Zealand GPs (Ellis et al., 2024), as shown in Table 6 below. Table 6 shows the different types of treatments recommended by GPs. Other interventions, such as dietary changes and physiotherapy, were offered based on varying gynaecology results. Differences in treatment recommendations were noted across GP age groups: those aged 40–49 years were less likely to recommend pregnancy as a first-line treatment, while GPs aged 30-39 suggested to patients that weight loss, chronic pain clinics, and getting pregnant would be the best solution to those diagnosed with endometriosis. GPs aged over 60 years recommended getting pregnant to patients to help with their symptoms (Ellis et al., 2024).

Table 6

First-line and alternative treatments recommended by NZ GPs based on the Diagnosis and Management of Endometriosis in New Guidelines 2020 (Ellis et al., 2024).

TABLE 2 | Perception of first-line treatments, alternative treatments to recommend and reasons for referral for male and female GPs, GPs who had (FGT+) and had not (FGT-) completed further gynaecology training and GPs who had (RG+) and had not (RG-) read the 2020 Diagnosis and Management of Endometriosis in New Zealand guidelines.^a

	See footnote ^b	Total (N = 185)	Male (N = 48)	Female (N = 134)	FGT+ (N = 135)	FGT- (N = 50)	RG+ (N = 65)	RG- (N = 120)
<i>What are the first-line treatments for symptomatic endometriosis?</i>								
Intrauterine contraceptive devices	+	177 (95.7%)	45 (93.8%)	129 (96.3%)	129 (95.6%)	47 (94.0%)	63 (96.9%)	113 (94.2%)
Combined oral contraceptive pills	+	160 (86.5%)	42 (87.5%)	116 (86.6%)	115 (85.2%)	44 (88.0%)	54 (83.1%)	105 (87.5%)
Progesterone injections	+	133 (71.9%)	36 (75.0%)	97 (72.4%)	102 (75.6%)	30 (60.0%)	47 (72.3%)	85 (70.8%)
Progestin-only contraceptive pills	+	129 (69.7%)	34 (70.8%)	93 (69.4%)	94 (69.6%)	35 (70.0%)	54 (83.1%)**	75 (62.5%)
Implant with etonogestrel	+	92 (49.7%)	29 (60.4%)	63 (47.0%)	69 (51.1%)	22 (44.0%)	35 (53.8%)	56 (46.7%)
Non-contraceptive progestins	+	86 (46.5%)	27 (56.3%)	57 (42.5%)	66 (48.9%)*	20 (40.0%)	33 (50.8%)	53 (44.2%)
Long-term treatment with NSAIDs	+	85 (45.9%)	27 (56.3%)	61 (45.5%)	62 (45.9%)	23 (46.0%)	30 (46.2%)	55 (45.8%)
Surgery	—	74 (40.0%)	22 (45.8%)**	45 (33.6%)	52 (38.5%)	22 (44.0%)	19 (29.2%)*	55 (45.8%)
Gonadotrophin-releasing hormone treatment	—	45 (24.3%)	14 (29.2%)	30 (22.4%)	38 (28.1%)*	7 (14.0%)	13 (20.0%)	32 (26.7%)
Long-term treatment with prescription-only pain relief	—	12 (6.5%)	5 (10.4%)	6 (4.5%)	8 (5.9%)	4 (8.0%)	3 (4.6%)	9 (7.5%)
<i>Which of the following do you recommend to patients who present with endometriosis symptoms?</i>								
Exercise	+	128 (69.2%)	28 (58.3%)	98 (73.1%)	96 (71.1%)	32 (64.0%)	53 (81.5%)**	75 (62.5%)
Counselling/talk-based therapy		72 (38.9%)	12 (25.0%)*	59 (44.0%)	56 (41.5%)	16 (32.0%)	28 (43.1%)	44 (36.7%)
Chronic pain clinic	+	70 (37.8%)	13 (27.1%)	56 (41.8%)	51 (37.8%)	19 (38.0%)	27 (41.5%)	43 (35.8%)
Physiotherapy	+	67 (36.2%)	14 (29.2%)	52 (38.8%)	48 (35.6%)	19 (38.0%)	27 (41.5%)	40 (33.3%)
Diet changes	+	48 (25.9%)	7 (14.6%)*	39 (29.1%)	36 (26.7%)	12 (24.0%)	24 (36.9%)*	24 (20.0%)
Meditation		45 (24.3%)	16 (33.3%)	28 (20.9%)	32 (23.7%)	13 (26.0%)	18 (27.7%)	27 (22.5%)
Weight loss		33 (17.8%)	11 (22.9%)	21 (15.7%)	23 (17.0%)	10 (20.0%)	13 (20.0%)	20 (16.7%)
Transcutaneous electrical nerve stimulation machine	+	33 (14.6%)	3 (6.3%)	23 (17.2%)	19 (14.1%)	8 (16.0%)	13 (20.0%)	14 (11.7%)
Acupuncture		25 (13.5%)	8 (16.7%)	17 (12.7%)	20 (14.8%)	5 (10.0%)	8 (12.3%)	17 (14.2%)
Pregnancy		12 (6.5%)	6 (12.5%)	6 (4.5%)	10 (7.4%)	2 (4.0%)	4 (6.2%)	8 (6.7%)
Medicinal cannabis		11 (5.9%)	5 (10.4%)	6 (4.5%)	9 (6.7%)	2 (4.0%)	3 (4.6%)	8 (6.7%)
Supplements		9 (4.9%)	2 (4.2%)	6 (4.5%)	7 (5.2%)	2 (4.0%)	2 (3.1%)	7 (5.8%)
Botox		3 (1.7%)	1 (2.1%)	1 (0.7%)	1 (0.7%)	2 (4.0%)	1 (1.5%)	2 (1.7%)

(Continues)

Table 6 continued:

First-line and alternative treatments recommended by NZ GPs based on the Diagnosis and Management of Endometriosis in New Guidelines 2020 (Ellis et al., 2024).

	See footnote ^b	Total (N = 185)	Male (N = 48)	Female (N = 134)	FGT+ (N = 135)	FGT- (N = 50)	RG+ (N = 65)	RG- (N = 120)
<i>When do you refer a patient to a specialist gynaecologist?</i>								
If all attempted first-line treatments for endometriosis symptoms have failed	+	155 (83.8%)	36 (75.0%)*	117 (87.3%)	114 (84.4%)	41 (82.0%)	55 (84.6%)	100 (83.3%)
For treatment of a fertility issue	+	152 (82.2%)	38 (79.2%)	112 (83.6%)	117 (86.7%)**	35 (70.0%)	57 (87.7%)	95 (79.2%)
If initial treatment for endometriosis symptoms fails	+	127 (68.6%)	37 (77.1%)	87 (64.9%)	89 (65.9%)	38 (76.0%)	36 (55.4%)**	91 (75.8%)
If the results of a clinical examination are abnormal		94 (50.8%)	22 (45.8%)	71 (53.0%)	70 (51.9%)	24 (48.0%)	34 (52.3%)	60 (50.0%)
If the patient is having to miss study and/or work because of symptoms		85 (45.9%)	28 (58.3%)*	54 (40.3%)	57 (42.2%)	28 (56.0%)	27 (41.5%)	58 (48.3%)
Patient has a confirmed diagnosis of endometriosis and presents with symptoms		69 (37.3%)	22 (45.8%)	44 (32.8%)	51 (37.8%)	18 (36.0%)	25 (38.5%)	44 (36.7%)
Immediately upon request by the patient		48 (25.9%)	15 (31.3%)	30 (22.4%)	34 (25.2%)	14 (28.0%)	16 (24.6%)	32 (26.7%)
As soon as you suspect endometriosis is likely		22 (11.9%)	10 (20.8%)*	12 (9.0%)	16 (11.9%)	6 (12.0%)	8 (12.3%)	14 (11.7%)
When treatment has to be initiated for endometriosis symptoms		12 (6.5%)	4 (8.3%)	8 (6.0%)	10 (7.4%)	2 (4.0%)	2 (3.1%)	10 (8.3%)
Following blood tests		6 (3.2%)	3 (6.3%)	3 (2.2%)	5 (3.7%)	1 (2.0%)	2 (3.1%)	4 (3.3%)

^aComparisons were done between groups (male and female, FGT+ and FGT- and RG+ and RG-), and significance is shown by * for $p < 0.05$ and ** for $p < 0.01$ in the left column of the comparison group.

^bSuggestions by GPs accompanied by a '+' indicate that these are indicated in the 2020 Diagnosis and Management of Endometriosis in New Zealand guidelines as a first-line approach, potential non-pharmacological strategy or reason for referral for specialist attention. Suggestions with a '-' indicate that this strategy is dissuaded as the first line in primary care in the 2020 guidelines. Suggestions without a '+' or '-' are not explicitly referred to within the guidelines as a non-pharmacological strategy or reason for referral.

Building on the existing literature, this study will provide a more up-to-date overview of the disease affecting premenopausal New Zealand women across age groups, with a focus on management and diagnosis in the Waitematā region. Identifying these categories aims to bridge gaps in New Zealand's current management and diagnosis relative to international studies.

2.12 Endometriosis in Different Regions of New Zealand

Findings indicated that women residing in the North Island experienced longer waiting times for the diagnosis of endometriosis compared to those in the South Island. Studies highlighted that improving education and awareness surrounding endometriosis among healthcare professionals and the public could help reduce current barriers to timely diagnosis (Bush et al., 2017; Ellis & Wood, 2024).

Ellis and Wood (2024) reported significantly longer diagnostic delays in the North Island relative to the South Island. Table 7 illustrates the regional demographics of patients in New Zealand with a confirmed diagnosis of endometriosis. The study also noted underrepresentation reflected by the percentages in Northland (2%), Auckland (2.1%), and Bay of Plenty (5.1%), whereas Wellington (14%) and Canterbury (20.7%) were overrepresented, suggesting regional disparities in both diagnosis rates and healthcare access (Ellis & Wood, 2024).

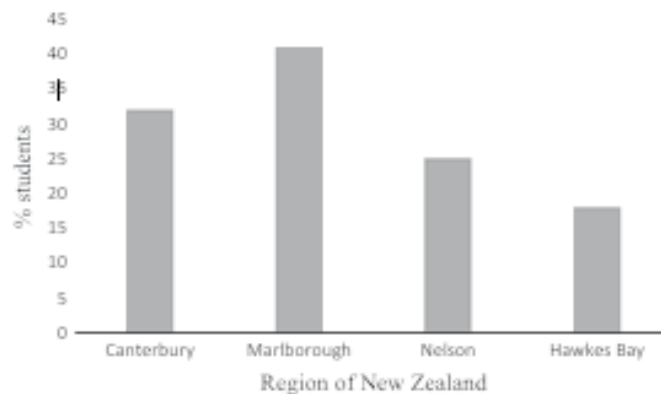
Table 7: Region of Residence of Endometriosis Patients reported with a confirmed diagnosis n = 1024 (Ellis & Wood, 2024)

Region of Residence	Surgically confirmed n = 955	Radiologically confirmed n = 69
Northland/Te Tai Tokerau	19 (2.0%)	1 (1.4%)
Auckland/Tamaki-Makau-Rau	229 (24.0%)	27 (39.1%)
Bay of Plenty/Te Moana-a-Toi	45 (4.7%)	7 (10.1%)
Waikato	96 (10.1%)	6 (8.7%)
Taranaki	16 (1.7%)	
Gisborne/Te Tairāwhiti	4 (0.4%)	1 (1.4%)
Hawke's Bay/Te Matau-a-Māui	39 (4.1%)	2 (2.9%)
Manawatu-Wanganui	43 (4.5%)	1 (1.4%)
Wellington/Te Whanganui-a-Tara	139 (14.6%)	4 (5.8%)
Tasman/Te Tai-o-Aorere	14 (1.5%)	
Nelson/Whakatu	17 (1.8%)	3 (4.3%)
Marlborough/Te Tau Ihu-o-te-Waka	5 (0.5%)	
West Coast/Te Tai Poutini	7 (0.7%)	
Canterbury/Waitaha	200 (20.9%)	11 (15.9%)
Otago/Otakou	51 (5.3%)	5 (7.2%)
Southland/Murihiku	26 (2.7%)	1 (1.4%)

Underrepresentation and overrepresentation in endometriosis diagnoses across New Zealand may be influenced by the level of education provided regarding the condition. Education programs in secondary schools play a crucial role in delivering essential information to young girls who may be experiencing early symptoms of endometriosis. The Endometriosis New Zealand (ENZ) organisation developed the Menstrual Health and Endometriosis (me) programme in 1996, which was implemented in 1997. This program is offered in regions

where independent schools provide funding and aims to reduce the social stigma surrounding menstruation and its irregularities, improve physical and social well-being, protect future fertility, and raise awareness of endometriosis (Bush et al., 2017). Figure 38 below shows the awareness of endometriosis among students across the South Island (Canterbury 32%, Marlborough 41%, Nelson) and the North Island (Hawkes Bay) (Bush et al., 2017).

Figure 38: Student Awareness of Endometriosis with the *me* Programme (Bush et al., 2017)



In the regions shown in Figure 38, a consistent increase in awareness of endometriosis has been observed among women aged under 25. This trend highlights the importance of education provided by health professionals, researchers, and individuals experiencing early symptoms, as it facilitates the recognition of abnormal menstrual symptoms and encourages timely health-seeking behaviours. However, the study noted that the Menstrual Health and Endometriosis (*me*) programme relies on external funding, which limits access to this education and awareness initiative to certain communities. To improve health and diagnostic outcomes for New Zealand women with endometriosis, public health policies

should prioritise increased funding for endometriosis education and support programs (Bush et al., 2017). Building on this, the current study aims to identify diagnostic delays in specific regions of Waitematā, NZ, and to provide insight into the duration patients typically wait for a confirmed diagnosis.

2.13 Identified Research Gaps

Collectively, the global literature presents inconsistent estimates of diagnostic delay, differing methods for surgical confirmation and clinical diagnosis, and various demographic factors associated with diagnostic delays. These inconsistencies reflect differences in healthcare systems and processes, access to specialist care and imaging techniques, patients' help-seeking behaviours, and cultural variations in symptom recognition. This highlights how international literature cannot be directly applied to NZ healthcare settings. As a result, the need for region-specific modelling is underscored to aid better referral pathways, specialist service availability, and equity considerations. This research allows for a glimpse into our current Waitematā healthcare processes.



Chapter Three Methodology

Methodology

3.1 Introduction

This chapter outlines the methodological approach and underlying rationale employed in this thesis. The primary aim of the study is to develop a framework that characterises patterns and variations in medical management, diagnostic delay, and treatment modalities among women diagnosed with endometriosis in the Waitematā region of New Zealand.

3.2 Study Design

This study uses an observational cohort design to examine selected variables, including age group, ethnicity, geographic location within the Waitematā region, and types of clinical interventions or treatments received. The analysis is based on routinely collected clinical data from women diagnosed with endometriosis in the Waitematā region between 1 January 2018 and 31 December 2022. Data outside this timeframe were excluded from the analysis.

3.3. Clinical Portal Access

Clinical Portal 8 is an online, patient-centric clinical dashboard that provides healthcare professionals with a consolidated view of patients' medical histories, including clinical documentation, medical alerts, radiology, and laboratory results. The system was developed in collaboration with Orion Health, the four former Northern Region District Health Boards (Auckland, Northland, Waitematā, and Counties Manukau), and their digital service provider, healthAlliance (Health Informatics New Zealand, 2021).

The Northern Region Clinical Portal supports

approximately 33,000 registered users and 1.9 million patients, making it the largest integrated healthcare information system in New Zealand. In 2022, the District Health Boards were disestablished and merged into a single national entity, now known as Health New Zealand | Te Whatu Ora.

The transition from the Concerto system (previously used clinical dashboard) to Clinical Portal 8 occurred as follows (Health Informatics New Zealand, 2021):

- Auckland: 2020
- Waitematā and Counties Manukau: 2018
- Northland: 2021

3.4 Data Extraction and Clinical Portal Query

A targeted electronic search was conducted within the Clinical Portal 8 system at North Shore Hospital (Waitematā) using the keyword “*endometriosis*”. Clinical concepts were mapped to the SNOMED CT code **129103003**, which uniquely identifies endometriosis, as confirmed through Health New Zealand’s terminology browser.

Manual verification of patient records was undertaken when a SNOMED CT code was absent to ensure diagnostic accuracy and the completeness of case identification.

3.5 Inclusion Criteria and Study Population

Eligible patient records for the period 1 January 2018 to 31 December 2022 were identified and reviewed to confirm inclusion. Patients were categorised into four age groups based on age at diagnosis:

- Group 1: 20–30 years
- Group 2: 31–40 years
- Group 3: 41–50 years
- Group 4: 51–60 years

The selected age groups align with the known prevalence of endometriosis among pre-menopausal women (Groups 1 and 2) and post-menopausal women (Groups 3 and 4).

Ethnicity data were categorised into five groups: Māori, Pacific, NZ European/Pākehā, Asian, and Other. Individuals identifying as Māori were categorised as Māori; those identifying with any Pacific nation as Pacific Peoples; individuals identifying as European or Pākehā as NZ European/Pākehā; individuals identifying with any Asian country as Asian; and all remaining ethnicities were classified as Other.

The Waitematā region, which includes North Shore, Waitākere, and Rodney (Warkworth, Huapai, and Whangaparāoa), was selected due to the researcher's professional affiliation with the region and the intent to prioritise it as an initial focus (Figure 39).

Figure 39

Map of the Waitematā Health NZ | Te Whatu Ora regions (Newman, 2025).



Treatment and intervention modalities included in this study comprised:

- Laparoscopic surgery alone or in combination with a levonorgestrel-releasing intrauterine device (Mirena)
- Subcutaneous injections (e.g., Zoladex^R)
- Depot medroxyprogesterone acetate (Depo-Provera^R)
- Major surgical procedures (e.g., hysterectomy, appendectomy, colectomy)
- Oral hormonal therapies (e.g., Noriday^R, norethisterone)
- Non-pharmacological or complementary pain management approaches (e.g., magnesium supplementation)

These interventions were the most frequently documented management options in the study cohort.

Data spanning five years were extracted to allow sufficient time to identify trends in diagnostic delay, medical management, and treatment practices, while minimising anomalies and capturing recent developments within the Waitematā healthcare system. Patients diagnosed before 1 January 2018 were excluded.

3.6 Data Management

At the point of extraction, each patient's National Health Index (NHI) number and a unique laboratory identifier were recorded for auditability and traceability. A comprehensive review of patient records was conducted, including general practitioner referrals, specialist correspondence, and surgical reports.

Variables extracted included:

- Age at initial symptom onset
- Age at confirmed diagnosis
- Type of diagnostic intervention (e.g., imaging, laparoscopy)
- Treatment modalities pre- and post-diagnosis (e.g. surgical, hormonal therapy, or pharmacologic)

3.7 De-Identification Protocol

To maintain patient confidentiality, all NHI numbers were replaced with anonymised identifiers reflecting hospital location (e.g., *NSH1* for the first patient identified at North Shore Hospital). This approach enabled secure data linkage while preserving anonymity.

3.8 Statistical Analysis

Data analysis was conducted using R (The R Project for Statistical Computing) on macOS. Initial univariate analyses were performed to assess patterns of diagnostic

delay.

One-way analysis of variance (linear regression) was conducted to compare mean delay durations between categorical variables. Where assumptions of normality were not met, appropriate non-parametric alternatives were applied.

Multivariate analysis of variance (MANOVA) was used to examine multiple predictor variables simultaneously in relation to the outcome measures.

Outcome/Indicator Variables

- Duration of delay between the first onset of symptoms and the final diagnosis
- Indicator of delay
- Types of treatment offered to individuals

Diagnostic and treatment delay was calculated using:

- Date of initial symptom presentation (e.g., chronic pelvic pain, dysmenorrhoea, dyspareunia)
- Date of surgical intervention and/or initiation of medical treatment from initial symptom presentation
- Date of confirmed diagnosis via clinical or histology results

Descriptive statistics were reported using means, medians, standard deviations, and interquartile ranges. Linear and multiple regression analyses were used to examine predictors of diagnostic delay and associations between clinical variables and demographics. Linear regression allows us to test whether a predictor variable (e.g., age) is significantly associated with a continuous outcome (the time to final diagnosis, measured in months). Multiple regression was used to examine the effects of

several predictors (e.g., age, ethnicity, hospital setting, region) on the time to final diagnosis.

Comparative analyses included:

- Age groups vs. delay of diagnosis
- Ethnicity groups vs. delay of diagnosis
- Location vs. delay of diagnosis
- Location and delay of diagnosis vs. ethnicity groups
- Location and delay of diagnosis vs. age groups
- Treatment options provided vs. age groups
- Treatment options offered vs. ethnic groups

Diagnostic confirmation was based on:

- Surgical evidence (e.g., laparoscopy or combined surgical procedures)
- Non-surgical clinical diagnosis supported by documented symptoms

Patient data was checked for accuracy and outliers prior to analysis. Cases with missing key variables, patterns of missingness, and missing data that reflected variability were excluded from relevant analysis. Potential confounders (e.g., age, ethnicity, healthcare setting, region) were identified, and multiple regression models were used to account for these factors and identify independent associations. Bias considerations include the retrospective design, possible misclassification of symptom onset, selection bias from a single regional cohort, and possible residual confounding from unmeasured factors, including socioeconomic status and healthcare-seeking behaviours.

3.9 Ethics

- Ethical approval for this study was obtained from the Auckland University of Technology Research Ethics Committee (AUTEC), reference number 25/57
- Locality authorisation was granted by the Research and Knowledge Centre, North Shore Hospital, under registration number RM15532.
- Submission to the Health and Disability Ethics Committee (HDEC) was not required.
- This observational cohort study aimed to examine diagnostic delay, patterns of medical management, and treatment interventions among women diagnosed with endometriosis in the Waitematā region of New Zealand.



Chapter Four Results

Results

4.1 Introduction

This chapter presents the results of a quantitative analysis examining the prevalence of endometriosis among premenopausal women in the Waitematā region. Results are organised according to the study's research questions, and a concise summary of key findings is presented for each.

Table 8 below shows a cohort predominantly aged 20-40 years, reflecting the typical age distribution of individuals affected by endometriosis (Ellis & Wood, 2024). The majority are NZ European/Pakeha with a smaller representation from Māori, Pacific, and Asian groups. Variance in ethnic groups highlights equity considerations in access to diagnosis and care. Most patients were managed in inpatient settings, indicating that most management involved treatments and procedures beyond routine care.

Table 8

Patient Demographics Table showing Age, Ethnicity, Region and Hospital Setting.

VARIABLES	2018	2019	2020	2021	2022	TOTAL
AGE						
20-30	24	40	39	38	60	201
31-40	24	48	42	45	53	212
41-56	21	18	20	30	22	111
TOTAL						524
ETHNICITY						
NZ EUROPEAN/PAKEHA	38	60	51	57	71	277
MĀORI	7	11	4	10	22	54
PACIFIC	2	5	7	7	7	28
ASIAN	12	14	23	20	20	89
OTHER	10	16	15	20	15	76
TOTAL						524
REGION						
NORTH SHORE	34	54	57	58	62	265
WAITĀKERE	28	37	31	44	53	193
RODNEY	7	15	12	12	20	66
TOTAL						524
HOSPITAL SETTING						
OUTPATIENT	18	43	32	25	34	152
INPATIENT	51	63	67	90	101	372
TOTAL						524

N.B: Due to low numbers in Groups 3 (41-50 years) and 4 (51-60 years), they have been combined (41-56). The oldest patient in this cohort was a 56-year-old.

4.2 Research Question One: What clinical predictions, patterns and variations exist in the medical management of endometriosis among pre-menopausal and menopausal women in New Zealand over the study period?

Data were summarised in R using the 'table()' function, with years and treatment groups analysed independently across ethnicity, age, and regional classifications (Table 9).

A total of 524 endometriosis treatment cases (Table 9) were recorded in the Waitemata region between 1 January 2018 and 31 December 2022, encompassing the North Shore, Waitakere, and Rodney areas.

Over the five-year study period, laparoscopic surgery (28.6%), combined surgical and hormonal management (contraceptive pill and intrauterine device) (56.0%), and incidental diagnostic findings (8.6%) showed a consistent increase. Overall, the number of treatment cases doubled, increasing from 68 in 2018 to 135 in 2022.

One case was excluded from the analysis because it was an extreme outlier, with a diagnostic delay of 120 months (5 years). This accounts for the difference between Table 8, showing 69 cases in 2018, and Table 9, showing 68 cases in 2018.

All subsequent analyses were conducted with this outlier removed.

Table 9*Treatment Types ranging from 2018 to 2022 in Waitemata.*

Treatment Code & Treatment Type	2018	2019	2020	2021	2022	Total (2018–2022)	Overall Trend & Notes
1 Laparoscopic Surgery only	25 (36.7%)	34 (31.2%)	31 (31.0%)	22 (19.6%)	39 (28.9%)	150	2nd most common; slight rise in total but % share declines post-2019
2 Subcutaneous injections + contraceptive + surgery	2 (3.0%)	1 (0.9%)	1 (1.0%)	2 (1.8%)	0 (0.0%)	6	Rare; minimal cases, no clear trend
3 Only oral contraceptives	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0	Not used at all
4 Surgery (laparoscopy, appendectomy, colectomy) + D&C +contraceptives + Copper IUD/Mirena)	30 (44.8%)	61 (56.0%)	51 (51.0%)	72 (64.3%)	79 (58.5%)	293	Most frequent; strong upward trend (30→79)
5 Combination of surgery + oral contraceptive	3 (4.5%)	7 (6.4%)	4 (4.0%)	3 (2.7%)	3 (2.2%)	20	Moderate and stable; slight decline in recent years
6 Incidental findings, surgery + removal	7 (10.4%)	5 (4.6%)	12 (12.0%)	12 (10.7%)	9 (6.7%)	45	Fluctuating but steady secondary option
7 Natural (e.g., low-FODMAP diet)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0	Not used
8 Natural (diet) + supplements + surgery	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (0.7%)	1	Very rare; single case in 2022

9 Natural + surgery + IUD insertion	0 (0.0%)	1 (0.9%)	0 (0.0%)	1 (0.9%)	3 (2.0%)	5	Rare but slowly emerging trend
10 Surgery + painkillers + IUD + contraceptive pills	1 (1.5%)	0 (0.0%)	1 (1.0%)	0 (0.0%)	0 (0.0%)	2	Very uncommon; no recent cases
Total Cases per Year	68	109	100	112	134	523	Steady growth - roughly doubled from 2018→2022

4.2.1 Overall Treatment Trends (2018-2022)

As illustrated in Table 9, surgical management remained the predominant treatment modality for endometriosis between 2018 and 2022. The treatment category “*Surgery (laparoscopy, appendectomy, colectomy) combined with dilation and curettage (D&C), hormonal contraception, and copper or levonorgestrel-releasing intrauterine devices (Mirena)*” was the most frequently utilised approach across the study period, accounting for 293 cases (56.0% of all treatments). The number of cases managed with this combined approach increased from 30 in 2018 to 79 in 2022.

“Laparoscopic surgery only” was the second most common treatment modality, comprising 150 cases (28.7%). While an overall increase in absolute case numbers was observed over the study period, the proportion of cases using this modality declined after 2019, falling from 36.7% in 2018 to 28.9% in 2022.

4.2.2 Combination and Alternative Treatments

Combination treatment modalities, including *“incidental findings with surgical intervention and lesion removal”*, ranked third most frequently utilised (n = 45, 8.6%), followed by *“surgery combined with oral contraceptives”* (n = 20, 3.8%). The proportion of cases classified as *“incidental findings with surgery and removal”* remained relatively stable across the study period, ranging from 4.6% to 12.0%.

Less frequently utilised treatment modalities included *“natural (dietary) interventions with supplements and surgery”* and *“natural approaches combined with surgery and intrauterine device insertion”*, which together accounted for seven cases (1.3% of total treatments).

No cases were recorded for treatment with oral contraceptives alone. Surgical intervention, either alone or in combination with adjunct therapies, accounted for many of the observed treatment approaches.

4.2.3 Temporal Patterns and Growth in Personalised Combined Treatments

Surgical management was the predominant approach to care across the study period. By 2022, the proportion of cases managed with combined treatment approaches that included hormonal contraceptives, intrauterine devices, and natural supplements increased.

The number of recorded cases increased from 67 in 2018 to 135 in 2022.

The above addresses Research Question One.

4.3 Research Question Two: What is the duration of waiting for the diagnosis of endometriosis among women in Waitematā, and which demographic groups are most affected?

A series of linear and multiple regression analyses was performed to compare predictor variables.

Table 10

A summary expanding on the boxplot (Figure 40).

Statistic	Value (months)	Interpretation
Mean	7.35	On average, women waited approximately 7 months for a diagnosis.
Median	5	Half of the women were diagnosed within 5 months of symptom onset.
Standard Deviation	7.89	Most women's experiences clustered near the mean, but a few had much longer delays.
25th Percentile (Q1)	3	25% of women were diagnosed within 3 months.
75th Percentile (Q3)	9	75% of women were diagnosed within 9 months.
Interquartile Range (IQR)	6	The middle 50% of the group experienced delays of 3-9 months.

Figure 40:

Boxplot representing the duration of delay of each patient in this cohort (n = 523, n = 1 excluded).

Length of Delay from 2018 to 2022 in Waitematā

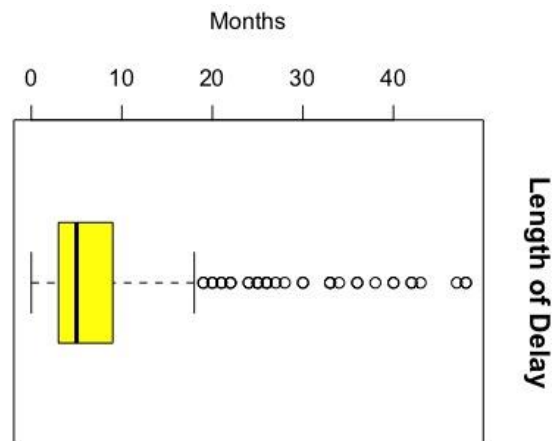


Table 10 and Figure 40 show that the average diagnostic delay was 7.35 months, with a median of 5 months, indicating that half of the patients in this cohort were seen and diagnosed within 5 months. However, the standard deviation of 7.89 months and the presence of outliers suggest variability, with some women experiencing longer delays. The interquartile range (IQR) of 6 months (3-6 months) shows that the middle 50% of women experienced delays within this timeframe.

4.3.1 Diagnostic Waiting Times Amongst Various Demographics

Logistic regression was conducted to examine demographic differences in diagnostic waiting times, using the tenth decile (top 10%) of cases as the outcome variable.

Ethnicity

A logistic regression model (`glm(length_deciles ~ ETH, family = binomial, data = DEIDENTIFIED_DATA_4R2)`) was fitted in R. Model fit statistics were: AIC = 338.8, Residual Deviance = 324.9. The reference group was NZ European/Pākehā.

- **Other ethnicities:** $\beta = 1.03$, SE = 0.37, $z = 2.76$, $p = 0.0059$; OR = 2.80, 95% CI [1.35, 5.82]
- **Māori and Pacific (combined):** $\beta = 0.04$, $p = 0.937$; OR not calculated
- **Asian:** $\beta = 0.55$, $p = 0.159$; OR = 1.74

Māori and Pacific participants were combined due to small sample sizes.

Region

A logistic regression model (`glm(length_deciles ~ Region, family = binomial, data = DEIDENTIFIED_DATA_4R2)`) was fitted with region as the categorical predictor and North Shore as the reference group. Model fit statistics: AIC = 338.7.

- **Rodney:** $\beta = 0.38$, $p = 0.341$, OR = 1.46, 95% CI [0.67, 3.16]
- **Waitākere:** $\beta = -0.65$, $p = 0.069$, OR = 0.52, 95% CI [0.26, 1.05]

Age (20-56)

A logistic regression model was fitted with age group as the predictor and the 20–30 years group as the reference category. Model fit: AIC = 340.23.

- **31–40 years:** $\beta = 0.58$, $p = 0.094$, OR = 1.78, 95% CI [0.91, 3.50]
- **41–56 years (combined 41–50 and 51–56):** $\beta = 0.0174$, $p = 0.94$, OR not calculated

Hospital Setting

Hospital setting (outpatient vs. inpatient) was included as a predictor, with outpatient as the reference group. Model fit: AIC = 342.1.

- **Inpatient:** $\beta = -0.20$, SE = 0.34, OR = 0.82, 95% CI [0.42, 1.58], $p > 0.05$

4.3.2 Multiple Regression Analysis

Multiple regression analysis was used to examine how the predictor variables (ethnicity, age, hospital setting, and region) influenced the outcome variable (diagnostic delay).

A multiple logistic regression model (glm(length_deciles ~ ETH + Age + Hospital Setting + Region, family = binomial, data = DEIDENTIFIED_DATA_4R2)) was fitted, including ethnicity, age group, hospital setting, and region as predictors.

Table 11

Single-Predictor Logistic Regression Models (Ethnicity, Age, Region, Hospital Setting).

Predictor	Reference Group	Comparison Group	β	SE / z	P-value	OR	95% CI
Ethnicity	NZ European/Pākehā	Other	1.0288	0.37 / 2.76	0.006	2.80	[1.35, 5.82]
		Māori + Pacific	0.04	0.481/0/08	0.937	1.04	[0.40, 2.67]
		Asian	0.55	0.394/1.41	0.159	1.74	[0.80, 3.77]
Region	North Shore	Rodney	0.38	0.395/0.95	0.341	1.46	[0.67, 3.16]
		Waitākere	-0.65	0.356/-1.82	0.069	0.52	[0.26, 1.05]
Age Group	20–30 years	31–40 years	0.58	0.345/+1.68	0.094	1.78	[0.91, 3.50]
		41–56 years	1.74	0.367/-0.07	<0.001	5.71	[2.78, 11.71]
Hospital Setting	Outpatient	Inpatient	-0.20	0.34	>0.050	0.82	[0.42, 1.58]

Model fit statistics (single predictor models): AIC (Ethnicity) = 338.8, AIC (Region) = 338.7, AIC (Age) = 340.23, AIC (Hospital Setting) = 342.1

Table 11 shows that women in the “Other” group had significantly higher odds of diagnostic delay than NZ European/Pakeha (OR = 2.80, $p = 0.006$). This suggests potential inequities in access to timely care. No significant differences were found among the Māori, Pacific, and Asian groups. No significant impacts were seen in Region or Hospital Settings, although Waitākere showed shorter delays ($p = 0.069$). Age groups did not predict delay; a non-significant trend was observed for those aged 31-40 years ($p = 0.094$). This highlights the need to address factors in specific populations that delay diagnosis.

Table 12: Multiple Logistic Regression Model for Treatment Delay (Ethnicity, Age, Region, Hospital Setting)

Predictor	Reference Group	Comparison Group	β	SE / z	p-value	OR	95% CI
Ethnicity	NZ European/Pakehā	Other	1.25	0.39 / 3.20	0.001	3.50	[1.63, 7.53]
		Māori + Pacific	0.06	0.489/0.13	0.890	1.07	[0.41, 2.78]
		Asian	0.76	0.424/1.81	0.070	2.15	[0.94, 4.93]
Age Group	20–30 years	31–40 years	-0.79	0.36/-2.18	0.030	0.45	[0.22, 0.92]
		41–56 years	-0.19	0.38/1.92	0.616	0.83	[0.39, 1.74]
Region	North Shore	Rodney	0.48	0.411/1.18	0.239	1.62	[0.72, 3.63]
		Waitākere	-0.68	0.37/-1.85	0.064	0.51	[0.25, 1.04]
Hospital Setting	Outpatient	Inpatient	-0.084	0.35/-0.24	0.811	0.92	[0.46, 1.83]

Model fit statistics (multiple predictor model): AIC = 335.34, Residual Deviance = 315.8

Table 12 shows that women in the “Other” ethnic group experienced significantly longer treatment delays (OR =

3.50, $p = 0.001$), which suggests potential inequities in timely care. Women aged 31-40 had lower odds of having the longest diagnostic delay compared with women aged 20-30 years (OR = 0.45, $p = 0.030$), indicating barriers to prompt treatment. No significant differences were identified by region or hospital setting, although Waitākere showed a trend towards shorter delays. These findings highlight systemic and age-related factors contributing to treatment delays.

The above addresses Research Question Two.

Table 13: Linear and Multiple Regression Analysis (Ethnicity, Region, Age, Hospital Setting).

Model	Predictors	Reference Group	Estimate (β)	Std. Error	Odds ratio	lower boundary	Upper boundary	z value	p-value	Significance	Direction / Interpretation	AIC
Ethnicity (Linear Model)	ETHAsian	NZ European / Pākehā	0.5547	0.3942	1.74	0.80	3.77	1.407	0.159	—	Weak positive - slightly higher than the reference group but not statistically significant	338.8
	ETHMāori & Pacific Islander		0.0383	0.481	1.04	0.40	2.67	0.08	0.937	—	Not significant	
	ETHOther		1.0288	0.3733	2.80	1.35	5.82	2.756	0.00585	**	Positive association ↑	
Region	RegionRodney	North Shore	0.3762	0.3951	1.46	0.67	3.16	0.952	0.341	—	Not significant	338.7
	RegionWaitakere		-0.6454	0.3556	0.52	0.26	1.05	-1.815	0.069	.	Weak negative trend ↓	
Age (20–56)	Age when Reported	20-30								**	Not significant	340.23
		31-40	0.57763	0.34513	1.78	0.91	3.50	-1.674	0.0942			
		41-56	1.74	0.36671	5.71	2.78	11.71	-0.075	0.94			
Hospital Setting	Outpatient	Inpatient	-0.2001	0.336	0.82	0.42	1.58	—	—	—	Not significant	342.1
Multiple Regression (Full Model)	ETHAsian	NZ European / Pākehā	0.76431	0.4235	2.15	0.94	4.93	1.805	0.07111	.	Not significant	335.34
	ETHMāori & Pacific Islander		0.06414	0.48898	1.07	0.41	2.78	0.131	0.89564	—	Not significant - no difference in odds compared with reference ethnicity	
	ETHOther		1.25247	0.39107	3.50	1.63	7.53	3.203	0.00136	**	Strong positive ↑ (3.4x higher of being in a higher length decile)	
			31-40	-0.78767	0.36197	0.45	0.22	0.92	-2.176	0.02955		
	Age when Reported	41-56	-0.19039	0.37935	0.83	0.39	1.74	1.923	0.61576	.	Borderline significant, as age increases, odds slightly decreases	
	Hospital Setting – Outpatient	Inpatient	-0.08372	0.35083	0.92	0.46	1.83	-0.239	0.81139	—	Not significant	
	RegionRodney	North Shore	0.48407	0.41129	1.62	0.72	3.63	1.177	0.23921	—	Not significant	
	RegionWaitakere		-0.67643	0.3653	0.51	0.25	1.04	-1.852	0.06407	.	Weak negative trend ↓	

Table 13 shows that women in the “Other” ethnic group had 3.5 times higher odds of experiencing longer treatment delays compared to NZ European/Pakeha ($p = 0.001$), indicating a strong disparity in timely care. A non-significant trend towards longer delays was observed in the Asian group ($OR = 2.15, p = 0.071$), whereas the Māori and Pacific groups did not differ from the reference group. Age was a significant predictor, with women aged 31-40 years having lower odds of delays than 20–30-year-olds ($R = 0.45, p = 0.030$), suggesting that younger women experience longer delays. Region and hospital settings were not significant predictors impacting treatment delay in this cohort. These findings highlight ethnic disparities and age-related differences in treatment timelines and pathways.

4.4 Research Question Three: Is there a difference in the distribution of treatment approaches for endometriosis across different age groups within the pre-menopausal population?

To address Research Question 3, a two-way table was constructed in R to examine the distribution of endometriosis treatment approaches by age group in the premenopausal population. The independent variable was age group (20-30, 31-40, 41-56), and the dependent variable was the treatment approach (10 categories).

Below is a summary of the findings.

Table 14: Endometriosis Treatment Types across Pre-Menopausal Age Groups (20-30, 31-40, 41-56).

Treatment Types	20-30 (years)	31-40 (years)	41-56 (years)	Total % of all patients
1. Laparoscopic Surgery only	61 (30.35%)	64 (30.19%)	25 (22.52%)	150 (28.63%)
2. Subcutaneous injections + contraceptive + surgery	1 (0.50%)	1 (0.47%)	4 (3.60%)	6 (1.15%)
3. Only oral contraceptives	0	0	0	0 (0.00%)
4. Surgery (laparoscopy, appendectomy, colectomy) + D&C + contraceptives + Copper IUD/Mirena	112 (55.72%)	117 (55.19%)	65 (58.56%)	294 (56.1%)
5. Combination of surgery + oral contraceptive	10 (4.98%)	9 (4.25%)	1 (0.90%)	20 (3.82%)
6. Incidental findings, surgery + removal	10 (4.98%)	20 (9.43%)	15 (13.51%)	45 (8.59%)
7. Natural (e.g., low-FODMAP diet)	0	0	0	0 (0.00%)
8. Natural (diet) + supplements + surgery	1 (0.50%)	0	0	1 (0.19%)
9. 9 – Natural + surgery + IUD insertion	4 (1.99%)	1 (0.47%)	1 (0.90%)	6 (1.15%)
10. 10 – Surgery + painkillers + IUD + contraceptive pills	2 (1.00%)	0	0	2 (0.38)
TOTAL	201	212	111	524

4.4.1.Descriptive Results

Table 14 shows that 524 patients were distributed across the following treatment approaches and age groups: 20-30, 31-40, and 41-56.

The most offered treatment was the combined surgical and hormonal management (Surgery (laparoscopy, appendectomy, colectomy) + D&C +contraceptives + Copper IUD/Mirena):

- 55.7% (n = 112) of patients aged 20-30 years
- 55.2% (n = 117) for patients aged 31-40
- 58.6% (n = 65) of patients aged 41-56 years

“Laparoscopic surgery” was the second most reported treatment offered across all age groups:

- 30.4% (n =61) of patients aged 20-30 years
- 30.2% (n =64) of patients aged 31-40
- 22.5% (n = 25) in patients aged 41-56

“Incidental findings, with surgery and removal” was less common, but an age-related increase was observed with this treatment option:

- 5.0% (n = 10) in patients aged 20-30
- 9.4% (n = 20) in patients aged 31-40
- 13.5% (n = 15) in patients aged 41-56

In contrast, “Combination of surgery + oral contraceptives” was observed in the younger age group:

- 5.0% (n= 10) in patients aged 20-30
- 4.3% (n = 9) of patients aged 31-40
- 0.9% (n = 1) of patients aged 41-56

All other treatment options, including natural or diet-based treatments, subcutaneous injection-based regimens, and

multimodal strategies involving pain management or intrauterine device insertion, together accounted for less than 2% of cases across all age groups. No patients were exclusively managed with oral contraceptives or non-surgical natural therapies.

The above addresses Research Question Three.



Chapter Five

Final Discussion

Overview of Chapter 5

This chapter discusses the findings of the present study in relation to the research questions and situates them within the context of existing literature. The results are critically analysed to identify areas of alignment and divergence with previous research and to highlight the contribution of this study to the understanding of endometriosis diagnosis and management in Aotearoa New Zealand. The discussion is organised according to the study's research questions, with each section providing a concise synthesis of key findings and their implications for prior research.

5.1 Introduction

Endometriosis remains a complex and underrecognised condition that continues to challenge diagnostic pathways and management for women globally (Simancas-Racines et al., 2025). Despite advances in medical knowledge and clinical awareness, many women continue to experience prolonged delays between the onset of symptoms and a confirmed diagnosis. Such delays are associated with persistent physical pain, psychological distress, reduced quality of life, and delayed access to appropriate and effective treatment (Saunders & Horne, 2025; Tewhaiti-Smith et al., 2022).

Understanding the factors contributing to diagnostic delay is critical to improving the management of endometriosis and patient outcomes after diagnosis. Identifying how demographic, clinical, and system-level factors influence time to diagnosis enables more targeted approaches to care and supports the development of equitable and responsive health services.

This chapter presents the key findings of the present study, which examined variations in treatment management and diagnostic waiting times among premenopausal women

diagnosed with endometriosis in the Waitematā region between 2018 and 2022. The findings are interpreted in relation to existing national and international literature, with particular attention given to the influence of demographic characteristics, age, geographic region, and hospital setting on diagnostic pathways and treatment approaches. Finally, this chapter considers the broader clinical/policy/education implications, service delivery, and future research implications.

5.2 Summary of Key Findings

This study sought to examine the extent of diagnostic delays and patterns of clinical management for endometriosis within the Waitematā population. The findings indicate that, on average, women experienced a diagnostic delay of approximately seven months from the initial onset of symptoms, with 75% of women receiving a diagnosis within nine months. These findings contrast with the broader body of national and international literature, which consistently reports diagnostic delays of several years between symptom onset and confirmed diagnosis (Beloshevski et al., 2024; Dmowski et al., 1997; Ellis & Wood, 2024; Mosterd et al., 2025; Nishimata & Sato, 2025; Othman et al., 2024; Pino et al., 2023; Soliman et al., 2017; Tewhaiti et al., 2022). As such, the diagnostic timeframes observed in the present study are inconsistent with previously reported trends and suggest potential regional, systemic, or methodological factors that may contribute to shorter diagnostic pathways in the Waitematā setting.

No statistically significant differences in diagnostic waiting times were observed for Māori, Pacific, or Asian women when compared with the New Zealand European/Pākehā reference group. However, participants classified as “Other” experienced significantly longer diagnostic delays. New Zealand-based literature has primarily examined

diagnostic delays among Māori, Pacific, New Zealand European, and Asian populations, consistently reporting disproportionately prolonged diagnostic pathways for Māori and Pacific women (Ellis et al., 2024; Ellis & Wood, 2024). However, these findings should be interpreted in the context of the underlying data sources. Ellis et al. (2024) utilised qualitative data from 27 Māori and 10 Pacific participants, via online anonymous discussions, providing rich insight into patient experiences but limiting broader generalisability. Ellis and Wood (2024) employed an online survey of 1,262 respondents recruited through Endometriosis New Zealand's social media platforms and mailing lists, which may be susceptible to self-selection bias. In contrast, the present study analysed clinical data from 524 patients identified through the Waitematā regional clinical portal database, providing a retrospective population-based perspective that is less reliant on voluntary participation and may better reflect diagnostic patterns within the regional healthcare setting.

In contrast, international studies have identified substantial diagnostic delays among minority populations, particularly Black, Asian, and Hispanic women, often attributed to structural inequities, cultural barriers, and differential access to care (Imbroane et al., 2024; Imbroane et al., 2025; Li et al., 2021). While the present study did not demonstrate extended diagnostic delays among Māori or Pacific, the significantly longer waiting times observed among women in the "Other" ethnic group align with international evidence indicating that women from less clearly defined or aggregated ethnic categories may experience greater barriers to timely diagnosis. Overall, these findings partially align with both national and international literature and suggest that ethnic categorisation and population heterogeneity may influence

observed diagnostic patterns within regional health services.

Analysis of diagnostic waiting times by age group indicated that women aged 41–56 years did not differ significantly from the reference group aged 20–30 years. A higher likelihood of longer diagnostic delays was observed among women aged 31–40 years; however, this increase was not statistically significant. These findings are consistent with both national and international research, which reports similar patterns of age-related diagnostic timing in endometriosis, suggesting that while some variation exists across age groups, no age group consistently experiences prolonged delays (Dinu et al., 2024; Endometriosis New Zealand, 2024; Moradi et al., 2017; Raheem et al., 2025; Shukri et al., 2023).

Analysis of diagnostic waiting times by region indicated no statistically significant differences for women residing in the Rodney or Waitākere areas compared with the North Shore reference group. Although the Waitākere group demonstrated slightly shorter waiting times, this difference was not statistically significant. Similarly, no significant differences were observed between outpatient and inpatient settings in diagnostic delays or in treatment pathway variation. These findings align with existing New Zealand literature suggesting that regional location and hospital setting may have limited influence on the timeliness of endometriosis diagnosis and management within publicly funded health services (Ellis & Wood, 2024).

The present study identified that between 2018 and 2022, the most common treatment approach for pre-menopausal women with endometriosis was a combination of surgical intervention, including laparoscopy, appendectomy, or colectomy, with dilation and curettage, the use of contraceptives, and intrauterine device (IUD) insertion

(copper or Mirena). This was followed by laparoscopic surgery alone and incidental findings, where endometriosis lesions were detected during unrelated surgical procedures. While the distribution of treatment approaches varied across age groups, combined surgical and hormonal management remained the predominant strategy in all groups. Laparoscopic surgery alone was less frequently offered to patients aged 41–56 years, whereas incidental lesion detection and removal increased among women in this older age group. In contrast, younger patients (20–30 years) were more likely to receive surgery in combination with oral contraceptives. Natural or non-surgical treatments were not employed as a standalone management strategy in any age group. These patterns are consistent with international literature, which demonstrates that combined surgical and hormonal approaches constitute the mainstay of endometriosis management, with treatment strategies adjusted according to patient age and reproductive considerations (Alkatout et al., 2013; Farzizadeh et al., 2026; Piriyeve et al., 2025; Raheem et al., 2025; RANZCOG, 2025). This study aims to identify patterns in the medical management of endometriosis among premenopausal and menopausal women in the Waitematā region, assess diagnostic delays from symptom onset to diagnosis, and examine variations in treatment approaches across age groups.

5.3 Interpretation of Findings

This study examined diagnostic delays and treatment patterns for endometriosis in the Waitematā region to understand current clinical practices and identify opportunities for improvement. On average, women waited approximately seven months from the onset of symptoms to receiving a confirmed diagnosis. While this is considerably shorter than international reports, which

frequently document delays of several years, it nonetheless indicates that women in the Waitematā region experience meaningful delays. Notably, 25% of participants waited nine months for a diagnosis, highlighting opportunities to improve earlier symptom recognition and timely clinical intervention.

Analysis by ethnicity revealed no statistically significant differences in diagnostic waiting times among Māori, Pacific, Asian, or New Zealand European/Pākehā participants. This suggests that diagnosis is relatively consistent and that progress towards equitable access to care across these groups is underway. This aligns with NZ's commitment to uphold the principles of Te Tiriti o Waitangi, aiming to reduce health inequities through culturally responsive care models, improved by Māori and Pacific healthcare representation and community initiatives (Ministry of Health, 2020). However, equitable access to care does not automatically result in the equity of outcomes or experiences in care, as women classified within the "Other" ethnic category experienced significantly longer waiting times. This finding may reflect barriers related to cultural differences, language challenges, limited access to healthcare services, or the unfamiliarity with navigating the healthcare system (Ellis et al., 2024), suggesting potential equity concerns warranting further investigation.

Regarding age, women aged 31–40 years were more likely to experience longer diagnostic delays than those aged 20–30 years, although this difference was not statistically significant. This trend may reflect the overlapping presentation of endometriosis symptoms with hormonal changes and fertility-related conditions in this age range, potentially complicating timely diagnosis (Ellis et al., 2023). Women aged 41–56 years showed no significant differences in diagnostic timing compared with

younger groups, suggesting that overall diagnostic efficiency remains relatively stable across age categories. The regional analysis indicated no statistically significant differences among the North Shore, Waitākere, and Rodney populations. Women in the Waitākere area experienced slightly shorter waiting times, which may reflect minor variations in referral pathways or local healthcare accessibility (van der Zanden et al., 2020). Overall, the results suggest a consistent standard of care across the region. Similarly, no significant differences were observed between inpatient and outpatient settings, indicating that treatment decisions and timelines are applied consistently across care locations.

Treatment patterns between 2018 and 2022 demonstrated that the most common approach involved a combination of surgical intervention, typically laparoscopy, alongside hormonal management, including oral contraceptives or intrauterine devices (IUDs). This combined approach aligns with international best-practice recommendations for endometriosis management (Mick et al., 2024; Piriyeve et al., 2025) and is consistent with NZ clinical guidance, which recommends hormonal suppression therapies and laparoscopic surgery as key management strategies depending on symptom severity, fertility goals, and treatment response (Health New Zealand | Te Whatu Ora, 2026). Laparoscopic surgery alone was the next most frequent treatment modality, followed by incidental lesion findings during unrelated surgical procedures. These patterns confirm the continued centrality of surgical intervention in the management of endometriosis within both international and NZ clinical practice (Health New Zealand | Te Whatu Ora, 2026; Mick et al., 2024; Piriyeve et al., 2025).

Age-related variations in treatment were also observed. Younger women (20–30 years) were more likely to receive

combined surgical and hormonal management, reflecting a proactive approach for symptom control and fertility preservation (Alkatout et al., 2013; Farzizadeh et al., 2026; RANZCOG, 2025). In contrast, older women (41–56 years) underwent fewer surgical interventions and were more likely to have incidental lesion detection. These differences may relate to the reproductive stage and clinical priorities. Notably, no natural or non-surgical treatments were reported as stand-alone options, indicating that medical and surgical interventions remain the preferred standard of care.

The findings from this study underscore several opportunities to strengthen service planning within the NZ healthcare system, including a streamlined referral pathway from primary to specialist care. Clearer, evidence-based referral guidelines are necessary and should be disseminated to GPs to enhance education and awareness of various endometriosis symptoms, facilitating earlier recognition and quicker referrals.

In summary, the findings indicate that the diagnosis and treatment of endometriosis in the Waitematā region are generally consistent and relatively efficient, particularly when compared with international data. Although equitable access appears to be achieved for most ethnic and regional groups, disparities remain for women in the “Other” ethnic category and for those in their 30s. These findings underscore the importance of ongoing efforts to enhance early symptom recognition, ensure culturally responsive care in partnership with Māori and Pacific communities, and continue refining management strategies to close the gaps for women living with endometriosis in Aotearoa New Zealand.

5.4 Comparison of Study Findings to Existing Literature

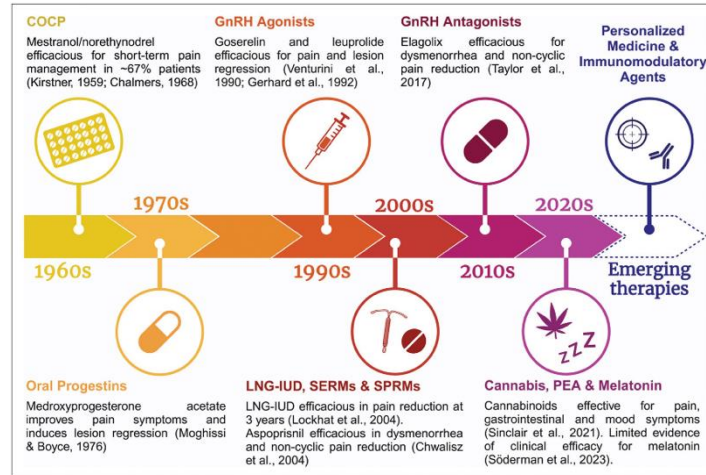
5.4.1 Medical Management

Hormonal management for endometriosis was first introduced in the 1940s, with patients initially offered androgens, followed by oestrogen, oestrogen–progestin combinations, antigonadotropic agents, and antiprogestin therapies in sequence. In parallel, pelvic endoscopic techniques were developed to assist in differentiating endometriosis from other intra-abdominal conditions, including appendicitis, intra-abdominal bleeding, and salpingitis. The 1970s marked a significant advancement with the widespread adoption of laparoscopic techniques, which subsequently became the gold standard for diagnosis and treatment. In the 1980s, intraperitoneal adjuncts were introduced to reduce postoperative adhesion formation, further enhancing the effectiveness of surgical management (Brosens & Benagiano, 2011).

In recent years, the medical management of endometriosis has attracted considerable interest, reflecting increasing awareness and recognition of the condition (Rafique & DeCherney, 2018). While advances in research have expanded knowledge of endometriosis and its treatment, the basic treatment strategies have remained largely unchanged since the condition was first described in 1921 (Jones, 2015). Figure 41 shows key milestones in the development of endometriosis treatments from the 1960s to the present day (Anais et al., 2024).

Figure 41

Timeline of milestones in the development of historical and emerging developments for endometriosis (Anaïs et al., 2024).



5.4.2 Hormonal Management of Endometriosis

The primary goal of endometriosis management is to control pain and suppress hormonally active endometriotic tissue. First-line interventions commonly include non-steroidal anti-inflammatory drugs (NSAIDs) to alleviate dysmenorrhoea-associated pain, alongside hormone therapies aimed at suppressing endometriotic lesions. Hormonal options include combined oral contraceptives (COCP), progesterone-only contraceptives, aromatase inhibitors, and gonadotropin-releasing hormone (GnRH) agonists (Dogan et al., 2004; Zorbas et al., 2015). Evidence suggests that COCPs effectively reduce symptoms such as severe dysmenorrhoea and pelvic pain (Torres et al., 2023). These findings are supported by international studies demonstrating significant improvements in pelvic pain, dysmenorrhoea, and dyspareunia after 12 months of COCP use (Alcade et al., 2022).

Dienogest (DNG), a progestin and norethisterone derivative, has been widely studied internationally, with

evidence demonstrating improvements in endometriosis-related symptoms and quality of life across diverse populations (Chen et al., 2024; Dick et al., 2025; Park et al., 2025). In contrast, patients in the present study were not offered combined oral contraceptives (COCPs) as a standalone first-line treatment, differing from some international treatment approaches.

Expert opinion from Professor Neil Johnson, Medical Director of Fertility at Auckland District Health Board, notes that while COCP effectively manages symptoms, it does not halt disease progression (NZendo, 2018). Similarly, a New Zealand study by Ellis et al. (2022) reported that although COCP was provided to 80% of patients, only 25% considered it effective, whereas 67% rated laparoscopic surgery positively. These findings suggest that patients often prefer additional interventions beyond COCP for symptom relief, aligning with the present study's observations.

Hormonal intrauterine devices (IUDs), particularly levonorgestrel-releasing IUDs (LNG-IUDs, Mirena), are frequently used post-surgically as maintenance therapy for endometriosis (Gibbons et al., 2021; Healthify, 2026). The LNG-IUD exerts antiestrogenic and androgenic effects on the endometrium, leading to downregulation of endometrial cell proliferation, atrophy, and increased apoptosis, which supports symptomatic relief (Vigano et al., 2007; Maruo et al., 2001; Silverberg et al., 1986). Multiple studies have demonstrated that LNG-IUD reduces the recurrence of dysmenorrhoea and chronic pelvic pain (CPP) and is considered an acceptable long-term management option (Fedele et al., 2001; Lockhat et al., 2005; Petta et al., 2005; Vercellini et al., 2003; Yucel et al., 2018). Recent research evaluating adolescents has shown high rates of continuation at one year for menstrual management, contraception, or abnormal uterine bleeding

(Shim et al., 2025; Parks et al., 2020). A New Zealand study by Paterson et al. (2009) reported LNG-IUD use primarily for menorrhagia, though off-label use in adolescents was noted in 29% of patients. In the present cohort, 56.6% of patients were offered an IUD as part of a combination treatment strategy, alongside surgery, pain management, or other interventions.

Subcutaneous (SC) hormonal injections, including GnRH agonists (e.g., Zoladex) and Depo-Provera (medroxyprogesterone acetate), provide long-acting suppression of endometriotic tissue by inhibiting oestrogen signalling (Zhu et al., 2025; Depo-Provera, 2024; Zoladex, 2025). Zoladex induces temporary chemical menopause by signalling the pituitary to halt oestrogen production, while Depo-Provera suppresses ectopic endometrial growth and reduces bleeding and pain. Side effects include weight gain, mood changes, bloating, irregular bleeding, bone mineral density loss, hot flashes, vaginal dryness, and headaches (Depo-Provera, 2024; Zoladex, 2025). Evidence supporting efficacy is limited; however, depot injections have been reported to relieve symptoms with minimal side effects when used appropriately (Gezer & Oral, 2015; Fedele et al., 2008; Rock et al., 1986; Shaw, 1992; Venturini et al., 1990). In the present study, 57.25% of patients were offered either Mirena or Zoladex as part of combined therapy, with usage slightly higher among the 41–56-year group (62.16%) compared with younger cohorts (20–30 years: 56.22%; 31–40 years: 55.66%), consistent with recommendations to tailor treatment based on reproductive priorities (Gezer & Oral, 2015).

Endometriosis is a chronic condition predominantly affecting reproductive-aged women, and many therapeutic agents interfere with fertility. Consequently, the ongoing development of effective, safe, and fertility-sparing medical management is essential. In New Zealand, a

recently introduced pharmaceutical, RyeqoR—a combination of norethisterone acetate, relugolix, GnRH, and estradiol in a single once-daily tablet—is available for the treatment of moderate-to-severe symptoms. However, it is not subsidised and requires a private prescription (NZendo, 2025), highlighting ongoing barriers to equitable access to treatment.

Natural approaches to endometriosis aim to relieve pain and improve pelvic floor function both pre- and post-surgery (Mazur-Bialy et al., 2024; Smolarz et al., 2021). A prominent theme in the literature is the use of cannabis as a self-management strategy, consistently reported across multiple international studies (Armour et al., 2021; Armour et al., 2022; Cummings et al., 2024; Jasinski et al., 2024; Sinclair et al., 2021; Sinclair et al., 2022; Sinclair et al., 2023). In countries such as Germany (Jasinski et al., 2024) and Australia (Sinclair et al., 2021; Sinclair et al., 2022), where medicinal cannabis requires a prescription, participants often accessed cannabis illicitly to reduce pain intensity, improve sleep, reduce reliance on pharmaceutical pain medications, and manage menstrual pain. In the United States, where medical cannabis is legal in 40 states and recreational use is legal in 24 states, Cummings et al. (2024) surveyed over 1,800 participants using cannabis for endometriosis symptom management. Their findings indicated that cannabis use helped modulate pain, reduce inflammation, relax muscles, and alleviate neuropathic discomfort. The authors suggested that medicinal cannabis could be considered a first-line option for endometriosis symptom management.

In New Zealand, access to cannabis is restricted to medicinal use through prescription under the Ministry of Health's Medicinal Cannabis Scheme (Ministry of Health, 2023). Like international findings, patients using medicinal cannabis reported reduced symptoms, improved sleep,

decreased reliance on conventional medications, and alleviation of nausea and vomiting (Armour et al., 2021). However, societal stigma and judgment were reported as barriers to access, despite patients reporting significant symptomatic relief and the ability to substitute conventional pharmaceuticals with cannabis (Sinclair et al., 2023).

Dietary interventions have also been explored for symptom management. Several studies suggest that the consumption of dairy, citrus fruits, vitamin D, and omega-3 fatty acids is associated with a lower risk of developing endometriosis, whereas high intake of caffeine, red meat, trans-unsaturated fats, and alcohol is associated with a higher risk (Grodstein et al., 1993; Harris et al., 2018; Matalliotakis et al., 2007; Missmer et al., 2010; Nodler et al., 2020; Yamamoto et al., 2018). However, these associations remain inconclusive, and no studies have definitively confirmed links between citrus fruits, red meat, alcohol, or caffeine and the risk of endometriosis (Nap & de Roos, 2022).

In the present study, only 1.34% of patients were offered a natural approach, including dietary changes and medicinal cannabis. The low FODMAP diet was specifically recommended based on recent Monash University research demonstrating improvements in gastrointestinal symptoms in endometriosis, analogous to those observed in irritable bowel syndrome (Varney et al., 2025). Data regarding medicinal cannabis use were not consistently recorded, representing a limitation in this analysis.

Laparoscopy, often referred to as “keyhole” surgery, is widely regarded as the gold standard for both diagnosing and managing endometriotic lesions. This minimally invasive approach has been associated with reduced postoperative recovery times, lower infection rates, and improved pain management (Zanelotti & DeCherney,

2018). During laparoscopy, a small camera is inserted through abdominal incisions, allowing the surgeon to visualise endometriotic lesions and to excise or ablate (burn) scar tissue and fibroids. This approach not only provides symptom relief and may improve fertility but also enables simultaneous diagnosis and treatment, reducing the need for multiple procedures (Fazel & Boitard, 2024). Comparative studies examining laparoscopy (LS) versus laparotomy (LT) indicate clear clinical advantages for LS. Laparotomy, a more invasive procedure, is typically reserved for emergencies, such as obstruction or trauma, where direct access to the abdominal cavity is required to remove organs, obtain biopsies, or repair complications. LT often necessitates longer hospital stays and extended recovery periods and is associated with an increased risk of adhesion formation (Rajaretnam et al., 2023). Chinese studies have demonstrated that LS is safer, more effective, and associated with better postoperative outcomes, while simultaneously serving as both a diagnostic and therapeutic tool (Li et al., 2023; Li et al., 2024). Earlier research from 1990 also supported the use of LS in moderate-to-severe endometriosis (Fayez & Collazo, 1990).

However, some studies have suggested that LS and LT may be equally effective in managing endometriosis, its associated symptoms, and infertility concerns (Busacca et al., 1998; Crosignani et al., 1996). Notably, Crosignani et al. (1996) reported higher pregnancy rates and lower rates of dyspareunia among patients undergoing LT, suggesting that patient-specific factors may influence the choice of surgical approach.

Within a New Zealand context, Joseph (2021) questioned the clinical value of repeated laparoscopies, finding that although they are considered “low-value, high-cost care,” laparoscopy remains the most effective treatment for

women experiencing persistent pelvic pain. Research on the surgical management of endometriosis in New Zealand remains limited.

In the present study, laparoscopic surgery featured in eight of the ten identified treatment types, either as a standalone intervention, combined with hormonal therapy, or alongside natural and holistic approaches (refer to Table 10). Laparoscopy alone accounted for 28.63% of treatments across the cohort (20–30 years: 30.35%; 31–40 years: 30.19%; 41–56 years: 22.52%), while a combination of surgery (laparoscopy, appendectomy, colectomy), dilation and curettage (D&C), contraceptives, and IUD insertion (copper or Mirena) represented 56.1% of the total cohort (20–30 years: 55.72%; 31–40 years: 55.19%; 41–56 years: 58.56%). These findings are consistent with international and national literature, confirming that laparoscopic surgery—alone or in combination with adjunct therapies- remains the primary and most effective intervention for managing endometriosis.

5.5 Delays at Country Level

Delays in diagnosing endometriosis are a consistent theme across the international and national literature. Findings from the present study indicate a substantially shorter diagnostic delay, measured in months, compared to the several years reported internationally and nationally. Internationally, the duration of diagnostic delays varies considerably. In Japan, the median delay was reported as 1.5 years (Nishimata & Sato, 2025), whereas in Egypt, the average delay was 3 years (Othman et al., 2024). Australian studies have reported delays of more than 12 years in some cohorts (Mosterd et al., 2025). New Zealand, Italy, and the United States reported delays of 6 to 11 years (Ellis & Wood, 2024; Tewhaiti-Smith et al.,

2022; Pino et al., 2023; Soliman et al., 2017; Dmowski et al., 1997). In contrast, younger populations, such as in Israel (Beloshevski et al., 2024) and Belgium (Klein et al., 2014), reported shorter delays of under five years. Sample sizes in these studies ranged from small cohorts of 32 participants in England (Ballard et al., 2006) to large multi-country studies including over 7,600 participants (Swift et al., 2024). More recent literature indicates a trend toward shorter delays compared with older cohorts (Armour et al., 2020; Nishimata & Sato, 2025), although multi-year delays remain prevalent.

Australian data indicate an improvement in diagnostic timeliness. Armour et al. (2020) reported mean delays of 9.9 ± 6.6 years before 2005, 4.8 ± 2.6 years between 2005 and 2012, and 1.5 ± 0.7 years after 2012, reflecting increased awareness among clinicians and the public. Similarly, Mazza et al. (2025) reported a median diagnostic time of 2.5 years in Australia, alongside increases in the proportion of women diagnosed through guideline-driven pelvic ultrasound and the establishment of dedicated endometriosis clinics (RANZCOG, 2025; Mazza et al., 2025; NZendo, 2025).

In New Zealand, Ellis and Wood (2024) reported a mean diagnostic delay of 9.7 ± 7.1 years, with slightly longer delays observed in the North Island (10.0 ± 7.1) than the South Island (8.8 ± 6.9). Previous estimates for 2003–2012 suggested slightly shorter delays of 8.6–8.7 years (Tewhaiti-Smith et al., 2022). The persistence of lengthy diagnostic delays has prompted calls for updated clinical pathways and improved implementation of existing guidance to facilitate earlier recognition and referral of patients with suspected endometriosis (NZendo, 2025).

European studies reported average delays of 7.9 years (5–11.4 years) from symptom onset to diagnosis (Ballard et al., 2006; Brandes & Bettina, 2020; de Kok et al., 2025;

Hudelist et al., 2012; Husby et al., 2003; Madsen et al., 2025; Pino et al., 2023), with notable variations. For example, Klein et al. (2014) reported a median delay of 2 years in Belgium. Prolonged delays were often attributed to symptom normalisation, misdiagnoses, the prescription of symptom-suppressing medications by GPs, and insufficient awareness among healthcare providers and patients (Ballard et al., 2006; Hudelist et al., 2012; Pino et al., 2023). Patients with advanced endometriosis in sites such as the rectovaginal septum or bladder (eVIRB) experienced longer delays, up to nine years, compared to two years for non-eVIRB cases (Madsen et al., 2025). Prolonged delays were associated with extended use of hormone therapy and painkillers, and increased risk of disease progression (Madsen et al., 2025). Economic analyses in Belgium revealed significant societal and healthcare costs associated with delayed diagnosis (€9,872 per patient annually; Klein et al., 2025).

Middle Eastern studies report an average delay of 4.7 years (3–7 years) (Beloshevski et al., 2024; Othman et al., 2024; Swift et al., 2024), with similar contributing factors including symptom normalisation, low awareness, and limited access to invasive diagnostics in adolescents (Beloshevski et al., 2024). Subsidised laparoscopies in Egypt and high infertility rates may have contributed to shorter delays (Othman et al., 2024). Brazilian studies report an average delay of 6.9 years, attributable to cultural, social, and healthcare access factors (Arruda et al., 2003; Breton et al., 2025; Flores-Caldera et al., 2021; Santos et al., 2012).

Asian and Asia-Pacific literature reports diagnostic delays ranging from 1.5 years in Japan (Nishimata & Sato, 2025) to 2–5 years across multiple Asia-Pacific countries (APEX panel, 2023). North American studies indicate an average delay of 5.4 years (Dmowski et al., 1997; Singh et al.,

2020; Soliman et al., 2017), with younger patients experiencing longer delays compared to older cohorts, reflecting underrecognition of symptoms in adolescents (Soliman et al., 2017; Singh et al., 2020).

Collectively, international and national evidence demonstrates that diagnostic delays remain a significant barrier to the timely management of endometriosis, despite recent improvements in awareness and guideline-directed practice. The findings from the present study, showing considerably shorter delays, indicate potential regional efficiencies but highlight the continued need for early recognition, education, and equitable access to care.

5.5.1 Ethnicity & Delayed Endometriosis

Diagnosis

5.5.1.1 The Impact of Ethnicity in International Countries

Historically, endometriosis has been predominantly associated with Caucasian women of higher socioeconomic status, often linked to delayed childbearing and elevated stress levels (Bougie et al., 2019; Hayden, 1956). There is limited literature examining the prevalence and diagnostic delays in Black, Indigenous, and People of Colour (BIPOC) populations (Barnes et al., 2021).

International studies consistently demonstrate significant racial and ethnic disparities in access to treatment, laparoscopy, and emergency surgical care (Capra et al., 2025; Imbroane et al., 2025; Li et al., 2021; Orlando et al., 2022; Williams et al., 2019). In the United States, Black patients were significantly less likely to receive laparoscopy or other surgical interventions, while Asian and Hispanic women were also less likely to undergo laparoscopy (Capra et al., 2025). Non-White patients

consistently experienced longer diagnostic delays, with Black patients waiting an average of 1.34 years compared to 0.67 years for White patients, and Hispanic patients experiencing delays of 1.11 years (Imbroane et al., 2025). Another study reported that Asian patients experienced the longest delays at 48.1 months, followed by Latina patients at 39.4 months, Black patients at 15.2 months, and White patients at 13.6 months (Li et al., 2021). Similarly, Imbroane et al. (2024) observed mean delays of 501 days for Black women, 210 days for Asian women, and 390 days for Hispanic women, compared to 226.7 days for White patients.

A Canadian study highlighted that East and South East Asian patients were 8.3 times more likely to present with stage III/IV endometriosis prior to referral, 2.7 times more likely to have a palpable nodule, 4.1 times more likely to present with an endometrioma on ultrasound, and 10.9 times more likely to have advanced disease at surgery, relative to White patients (Williams et al., 2019). Interestingly, one US study reported that Black women received more hormonal, pain, and surgical management compared to non-Black women, yet experienced lower specialist referral rates (Zaritsky et al., 2025).

Disparities in care are influenced by structural inequities, including financial barriers, clinician bias, and limited access to specialist services (Imbroane et al., 2025; Raffone et al., 2025). Historical misconceptions about the prevalence of endometriosis in middle-to-upper-class White women have shaped healthcare provider perceptions, leading to underrecognition of symptoms in Black patients. Additionally, pervasive myths that Black women are less sensitive to pain contribute to dismissal or misidentification of symptoms, fostering medical mistrust and cultural expectations to endure pain silently (Katon et al., 2023; Jackman et al., 2025). These inequities are

reflected in treatment outcomes, with Black women experiencing higher rates of perioperative complications, inappropriate hysterectomies, and morbidity compared to White patients (Jacoby et al., 2010; Orlando et al., 2022). Similar disparities have been observed among Latin American women, including symptom invalidation, restricted access to specialists, high out-of-pocket costs, and systemic healthcare limitations (Flores-Caldera et al., 2025; Sutaria et al., 2025). Provider bias stemming from the perception of endometriosis as a “disease of White women” further contributes to delayed diagnostic testing and less aggressive management in Hispanic patients (Bougie et al., 2022).

Cultural norms and taboos also influence symptom reporting among populations in the Asia-Pacific region. In Bangladesh, menstrual blood is viewed as unclean and associated with misfortune or disease, while in Malaysia, menstrual cycles are sometimes linked to spiritual influences, leading women to isolate themselves during menstruation (Castro & Czura, 2025; The Lancet Regional Health – Western Pacific, 2025). Such cultural interpretations may lead women to self-blame and avoid reporting abnormal symptoms, delaying diagnosis (The Lancet Regional Health – Western Pacific, 2025). Additionally, genetic predispositions, dietary factors, and environmental contaminants have been suggested as contributors to the higher prevalence and risk of endometriosis in Asian women (Velarde et al., 2023). Despite this, limited research has been conducted in this population, underscoring the need for further investigation.

5.5.1.2 The Influence of Ethnicity in New Zealand

Two New Zealand studies reported significant delays in the diagnosis of endometriosis among Māori and Pacific patients. Māori participants experienced an average delay of 10.65 ± 7.5 years, and Pacific women 11.25 ± 6.4 years, compared to 9.4 ± 6.8 years in New Zealand European/Pākehā women (Ellis et al., 2024; Ellis & Wood, 2024). Asian women were reported to have an average delay of 8.1 ± 5.4 years.

Racial and cultural barriers in New Zealand extend beyond diagnostic delays to treatment access and pain management. Despite limited literature, Ellis et al. (2024) highlight key challenges experienced by minority groups, including a lack of knowledge regarding endometriosis. Among participants, 63% of Māori and 90% of Pacific women reported minimal or no awareness of the condition. For most, the primary sources of information were general practitioners (GPs) or online research, although Māori patients are known to under-utilise primary care services (Crengle et al., 2005).

Perceptions of “normalcy” also contributed to delayed diagnosis, as patients compared their symptoms to social norms and downplayed their severity, particularly when healthcare providers normalised their experiences. Additionally, 40.7% of Māori participants reported being accused of “drug seeking,” reflecting stereotypes and mistrust based on ethnicity. Menstrual-related pain and endometriosis were often associated with shame and silence in Māori and Pacific communities, further limiting discussion and timely care-seeking.

Reliance on specialist care increased among these groups, with 36% of patients depending on specialist services while GP consultations declined to 22%, indicating gaps in primary care awareness and education

(Ellis et al., 2024). Participants also reported discomfort in healthcare spaces perceived as Western, White, and male-dominated, with tokenistic approaches and limited attention to culturally informed, holistic care. Symptoms were frequently dismissed unless linked to fertility concerns, undermining patient autonomy and the legitimacy of reported pain. Fertility-related anxiety was prevalent, affecting 33% of Māori and 40% of Pacific participants, often compounded by multiple surgeries, financial burden, and long public waitlists. Barriers related to private health insurance, missed family or work commitments, cultural obligations, and weight-based discrimination were also noted, highlighting systemic inequities and the need for culturally safe, equitable, and holistic care (Ellis et al., 2024).

In the present study, no significant differences in diagnostic delays were observed among Māori, Pacific, and Asian groups compared to New Zealand European/Pākehā patients. However, the “Other” ethnic group experienced significantly longer waiting times. These findings align with both international and New Zealand literature, which consistently report prolonged diagnostic pathways among ethnic minority populations (Li et al., 2021; Imbroane et al., 2024; Imbroane et al., 2025). International studies indicate that Black, Asian, and Hispanic women face longer delays due to reduced access to care, symptom dismissal, limited specialist availability, and structural inequities embedded within healthcare systems (Bougie et al., 2019; Barnes et al., 2021; Katon et al., 2023).

In New Zealand, Māori, Pacific, and Asian women demonstrate similar patterns of delayed diagnosis compared to NZ European women (Ellis et al., 2024; Ellis & Wood, 2024). The “Other” ethnic group often represents populations that are underrepresented in research and are

more likely to encounter cultural and systemic barriers. Delays in this group likely reflect mechanisms identified in prior studies, including symptom normalisation, limited awareness of endometriosis, reduced access to culturally responsive care, and clinician bias.

5.6 Age and Diagnostic Delay

Endometriosis is typically described as a progressive condition that can present from the onset of menstruation and persist until menopause (Comptour et al., 2024). Several international studies report that adolescents and women in their early 20s experience longer diagnostic delays, particularly when symptoms present during adolescence (Ballard et al., 2006; Breton et al., 2025; de Kok et al., 2025; Fryer et al., 2024; Li et al., 2025; Mathias et al., 2025; Soliman et al., 2017; University of York, 2024). These delays are attributed to a combination of patient and clinician factors, including pain normalisation, limited awareness of the condition, and reluctance to perform invasive procedures in young patients (Mathias et al., 2025; Breton et al., 2026). Reviews of adolescent populations report diagnostic delays ranging from six to fourteen years, with earlier symptom onset consistently associated with longer diagnostic timelines (Moradi et al., 2017; University of York, 2024).

In contrast, a New Zealand study observed that diagnostic delays increased with age (Ellis et al., 2024). Younger adults (18–24 years) experienced shorter delays of 5.7 ± 2.8 years, whereas adults aged 25–34, 35–44, 45–54, and over 55 experienced delays of 8.5 ± 5.3 , 10.8 ± 7.8 , 13.6 ± 9.5 , and 12.0 ± 9.1 years, respectively. Interestingly, the youngest participants were less likely to have surgically confirmed endometriosis and more likely to report a clinically suspected diagnosis than older participants (Ellis et al., 2024). This pattern may reflect historical changes in

the recognition and diagnosis of endometriosis. Older women were more likely to experience symptoms when awareness was lower, diagnosis relied heavily on surgical confirmation, and symptoms were often normalised or dismissed (Hudelist et al.; Zondervan et al., 2020). In contrast, younger women may have benefited from greater awareness, improved diagnostic pathways, and increased acceptance of clinical diagnosis without laparoscopy (Chapron et al., 2019; Ministry of Health, 2020). Therefore, differences in diagnostic delay may reflect generational changes in healthcare rather than age alone.

This contrasts with the international literature, which suggests that earlier symptom onset generally corresponds to longer delays due to symptom dismissal and under-recognition among adolescents (Breton et al., 2026).

While literature predominantly focuses on reproductive-aged women, endometriosis can persist during and after menopause, either due to residual oestrogen production or systemic hormonal activity (de Almeida Ascencio et al., 2019; Dinu et al., 2024; Matalliotakis et al., 2019; Raheem et al., 2025). Older patients often experience undiagnosed or misdiagnosed disease for extended periods, owing to the normalisation of pelvic pain, symptom overlap with other conditions, and limited early, non-invasive diagnostic options. Women aged 30–40 years commonly experience delays of three to eight years from symptom onset, which can be further prolonged if symptoms began in adolescence, adversely affecting fertility and quality of life (Endometriosis New Zealand, 2024; Shukri et al., 2023).

In the present study, no statistically significant differences in diagnostic delays were observed across the 20–30, 31–40, and 41–56-year age groups. Nevertheless, there was a trend toward longer waiting times among women aged 31–40 years. This aligns with prior evidence suggesting

that women of reproductive age face considerable delays in diagnosis, influenced by symptom normalisation, hormonal treatment masking, and delayed healthcare-seeking behaviour (Dinu et al., 2024; Endometriosis New Zealand, 2024; Moradi et al., 2017; Raheem et al., 2025; Shukri et al., 2023).

5.7 Region/Hospital Setting and Endometriosis

There is very limited literature examining diagnostic delays in endometriosis by geographic region. Ellis and Wood (2024) reported no significant differences in delay across the 16 regions included in their study, which encompassed Northland, Auckland, Bay of Plenty, Waikato, Taranaki, and Gisborne. However, when aggregated into larger geographic categories, the North Island showed a significantly longer average diagnostic delay of 10.0 ± 7.1 years, compared with 8.8 ± 6.9 years in the South Island. The authors noted that temporal variation in diagnostic delay across regions was not captured, which represents a limitation of their study (Ellis & Wood, 2024).

The present study similarly found no significant differences in diagnostic delay among the Waitematā sub-regions of North Shore, Waitākere, and Rodney. This suggests that within these local areas, diagnostic timelines are relatively uniform.

These findings should be interpreted cautiously due to methodological differences across studies, particularly in data sources and cohort selection. Much of the literature relies on self-reported surveys, which are susceptible to recall bias and may overrepresent individuals with persistent symptoms or greater healthcare engagement, potentially inflating estimates of diagnostic delay (Moradi et al., 2017; Agarwal et al., 2019). In contrast, the present study uses clinically verified hospital records, reducing

recall bias but reflecting a narrower population who have accessed specialist services. This may exclude undiagnosed individuals or those managed in primary care, thereby limiting variability in observed diagnostic timelines (Nnoaham et al., 2011). Overall, these findings highlight that regional variation in the diagnosis of endometriosis in New Zealand remains understudied. Further research into geographic disparities may reveal additional structural, social, or healthcare-system factors that contribute to diagnostic delays.

5.8 Distribution of Treatment and Age

Treatment strategies for endometriosis vary across age groups, reflecting differences in clinical presentation, fertility goals, and risk considerations. In adolescents and young women, management prioritises symptom relief and disease suppression while minimising invasive procedures such as laparoscopy. First-line options typically include combined oral contraceptives, progestin-only medications, and non-steroidal anti-inflammatory drugs (NSAIDs), which reduce pelvic pain and dysmenorrhoea while preserving future fertility potential (Li et al., 2024). Clinical guidelines emphasise that there is no single optimal treatment for adolescents, and hormone therapy should be tailored to each patient. The American College of Obstetricians and Gynecologists (ACOG, 2025) recognise hormonal suppression as the first-line treatment in this population, whereas this approach is not uniformly applied to adult women. Concerns regarding the long-term effects of laparoscopy and the need for ongoing suppressive therapy are often cited when considering surgical intervention in younger patients (Shim et al., 2024).

For reproductive-aged women (late 20s to late 30s), treatment typically involves a combination of medical and surgical interventions. Hormonal options include combined

oral contraceptives, progestins, and advanced therapies such as GnRH agonists or antagonists for severe pain (Othman et al., 2024). Progestins are suitable for long-term management, whereas GnRH-based therapies are generally reserved as second-line options due to their side effect profiles (Piriyev et al., 2025). Laparoscopic excision is frequently employed when symptoms persist despite medical therapy or when fertility concerns exist. Postoperative hormone therapy may be utilised to reduce the risk of recurrence (Becker et al., 2022).

In late reproductive and perimenopausal women, treatment focuses on long-term symptom control. Management decisions consider menopausal status and balance hormone therapy against potential surgical interventions. Hysterectomy, with or without oophorectomy, may be indicated for patients with severe symptoms who no longer desire fertility. Across all age groups, the literature consistently emphasises that treatment should be individualised based on age, symptom severity, fertility goals, and patient preferences (Becker et al., 2022; Dr Praveen De Silva, n.d.).

Although the literature directly comparing treatment approaches across the age groups used in the present study is limited, existing evidence aligns with the observed trends. The study found that younger women (20–40 years) were more likely to receive a combination of surgery and hormonal management, reflecting a proactive approach to symptom control and fertility preservation (Alkatout et al., 2013; Farzizadeh et al., 2026; RANZCOG, 2025). In contrast, older women (41–56 years) were offered fewer surgical interventions and were more likely to have incidental lesion findings. This pattern may be explained by changes in reproductive priorities, increased surgical complexity, and comorbidities that influence clinical decision-making (Piriyev et al., 2025; Raheem et

al., 2025). Overall, although age-specific treatment comparisons remain underreported, the present study's findings are consistent with the broader literature and highlight a research gap. This gap is noteworthy because current evidence predominantly assesses overall treatment effectiveness, with limited investigation of age-specific management strategies, despite age being a key factor influencing symptom burden, fertility goals, and surgical risk. (Becket et al., 2017; Dunselman et al., 2014; RANZCOG, 2025).

5.9 Clinical / Policy / Educational implications

This subchapter examines the clinical, policy, and educational issues arising from the findings of the present study on endometriosis in the Waitematā population. While this study reported diagnostic delays that were comparatively shorter than those reported in the international and national literature, significant variation was observed across age groups, ethnicities, and treatment approaches. These findings highlight persistent challenges in achieving equitable care, optimising management strategies, and promoting early recognition of endometriosis symptoms. The following discussion considers how these insights can inform clinical practice, policy development, and educational initiatives to improve outcomes for individuals affected by endometriosis in New Zealand.

5.9.1 Clinical Implications of Key Findings

The findings of this study carry several important clinical implications for the management of women with endometriosis in the Waitematā population. On average, women were diagnosed within seven months of symptom onset, with 75% receiving a diagnosis within nine months.

These timelines are substantially shorter than those reported in national and international literature, where delays often span several years (Beloshevski et al., 2024; Dmowski et al., 1997; Ellis & Wood, 2024; Tewhaiti-Smith et al., 2022; Mosterd et al., 2025; Nishimata & Sato, 2025; Othman et al., 2024; Pino et al., 2023; Soliman et al., 2017). This suggests that early recognition and continued vigilance by clinicians in this region are effective. Contributing factors may include established referral pathways, primary care education, and ongoing awareness campaigns (Endometriosis New Zealand, 2026).

While Māori, Pacific, and Asian women did not experience longer diagnostic delays, the “Other” minority ethnic group did, indicating the need for targeted outreach and monitoring for underrepresented populations (Manohar et al., 2026). Age-related patterns were also observed, with women aged 31–40 more likely to experience delays, highlighting the importance of age-specific education for both patients and providers (Roullier et al., 2021).

Regarding treatment approaches, combined surgical and hormonal therapy was the most frequently used, particularly among younger women. In contrast, the use of laparoscopic surgery alone declined with age, and incidental findings increased. Standalone non-surgical approaches were rarely offered, suggesting a potential care gap for individuals unwilling or unable to undergo surgery (Ellis et al., 2022). No significant differences were observed between the inpatient and outpatient settings, supporting the flexibility of service delivery without compromising care quality.

Overall, these findings emphasise the need for age- and ethnicity-sensitive care, enhanced patient awareness, ongoing clinician education, and accessible referral pathways to reduce diagnostic delays further and improve

treatment outcomes (Ellis et al., 2022; Manohar et al., 2026; Roullier et al., 2021). The findings of this study will help identify gaps and strengthen service planning and endometriosis management in Aotearoa NZ.

5.9.2 Policy Implications

The findings of this study carry several important policy implications for the management of endometriosis in Waitematā and across New Zealand. The relatively short diagnostic delays observed in this study contrast sharply with existing NZ literature, which reports average delays of 8.7–9.7 years from initial symptom onset to final diagnosis following consultations with multiple clinicians (Ellis & Wood, 2024; Endometriosis New Zealand, 2024). Prolonged delays have been linked to limited recognition of symptoms by primary care clinicians, inconsistent referral pathways, and inadequate clinician education. National reports and advocacy campaigns continue to highlight these gaps, calling for improved care and updated guidelines to support earlier diagnosis (Endometriosis New Zealand, 2025; Ministry of Health, 2020).

Although this study did not find significant diagnostic disparities among Māori, Pacific, and Asian women, other NZ research has documented longer delays and dissatisfaction with care in Māori and Pacific populations. This underscores the need for national policy to address ongoing inequities by engaging priority communities and implementing culturally responsive strategies (Ellis & Wood, 2024; Ellis et al., 2024).

Age-related variations in diagnostic and treatment patterns further suggest that targeted educational campaigns could be beneficial, particularly for women in their early 20s and 30s, to promote timely symptom recognition and early

presentation to healthcare services. The absence of significant differences in outcomes between outpatient and inpatient settings supports flexible service delivery models that may improve accessibility and efficiency.

Finally, the predominance of combined surgical and hormonal management, coupled with the limited availability of standalone treatment options, highlights the need for updated treatment guidelines that accommodate diverse management strategies and individual patient preferences (Ministry of Health, 2020). Policy efforts should therefore prioritise equitable access, clinician education, and the integration of flexible, patient-centred care pathways to improve outcomes for all women with endometriosis in New Zealand

5.9.3 Educational Implications

The findings of the present study underscore several important educational implications for improving the early recognition, diagnosis, and management of endometriosis. Although diagnostic delays in the Waitemātā population were shorter than reported in national and international literature, the persistence of delays following symptom onset indicates ongoing gaps in public and patient awareness regarding endometriosis. Previous research highlights that individuals experiencing chronic pelvic pain, dysmenorrhoea, and gastrointestinal symptoms often normalise or conceal their experiences, which prolongs diagnostic delays (Davenport et al., 2023; Li et al., 2025). This underscores the need for comprehensive public education initiatives, including community health programs and school-based curricula, to increase awareness of abnormal menstrual symptoms and encourage timely healthcare-seeking behaviours (EndoNews, 2021).

Clinician education is a critical priority. While this study found no statistically significant diagnostic delays across

ethnic or regional groups, other NZ studies report longer delays among Māori and Pacific populations (Ellis et al., 2024; Ellis & Wood, 2024). These disparities reflect variations in access to specialist care, clinical recognition, and referral pathways. Key contributors to prolonged delays include the normalisation of menstrual pain by both patients and clinicians, limited professional training, and insufficient awareness of age-specific symptom presentation (Davenport et al., 2023; Penzer & Schweikart, 2025). Targeted clinician education focused on endometriosis symptomatology, age-specific presentations, and culturally responsive care may reduce diagnostic delays and improve outcomes, particularly for underrepresented populations, such as the “Other” ethnic group identified in this study.

The predominance of combined surgical and hormonal management as the primary treatment approach across all age groups highlights the importance of integrating educational strategies for both clinicians and patients. The observed reduction in laparoscopic interventions and the increased incidence of incidental findings among older patients align with current guidelines emphasising tailored management based on age, disease progression, symptom severity, and fertility considerations (BPAC NZ, 2021). Educating patients to participate in treatment decisions actively may enhance satisfaction, adherence, and long-term outcomes.

Educational implications also extend into broader social, educational, and occupational contexts. Evidence indicates that poorly managed symptoms and delayed diagnoses negatively affect school and workplace participation, reduce quality of life, and impair productivity (Li et al., 2025; Tewhaiti-Smith et al., 2022). Educational interventions that challenge menstrual stigma, de-normalise chronic pelvic pain, and increase awareness

among adolescents and young adults may contribute to earlier diagnosis, improved symptom management, and better long-term health outcomes (EndoNews, 2022).

5.10 Strengths and Limitations

5.10.1 Strengths

A key strength of this study is its use of real-world clinical patient data to examine diagnostic delays and treatment patterns for endometriosis within the Waitematā region. By analysing patient data collected between 2018 and 2022, the study provides current, region-specific insights into diagnostic timelines and treatment modalities. Another strength is considering multiple factors that influence diagnosis and management, including age, ethnicity, geographic region, treatment type, and hospital setting. Examining these variables allowed for a more comprehensive understanding of access, equity, and clinical practice patterns. Additionally, the comparative approach, which contextualises findings against national and international literature, highlights the notably shorter diagnostic delays in Waitematā. This suggests that effective referral pathways and clinician education may contribute to earlier diagnosis and offer potential guidance for future care strategies. Finally, the analysis of age in relation to treatment types provides valuable insights into how management approaches evolve across the lifespan, enhancing the study's clinical relevance and supporting evidence-informed recommendations for policy and practice.

A major strength across the literature used in this study was the diverse methodological approaches, including narrative reviews (Bougie et al., 2022), retrospective clinical cohorts (Treffers & Jung, 2025), large database

studies (Christ et al., 2021), reproductive medicine outcome studies (Yamamoto et al., 2017), and clinical analyses (Thrift et al., 2025; Williams et al., 2019), which strengthens these studies by addressing endometriosis from multiple populations within a region. Additionally, cross-sectional surveys (Singh et al., 2020) and multicentre studies (Hudelist et al., 2012; Pino et al., 2023) strengthened the reliability of the reports. Studies by Christ et al. (2021) and Thrift et al. (2025) utilised large registry-based datasets, thereby improving statistical power and increasing the observed prevalence of endometriosis over time.

NZ-based research by Ellis et al. (2022) and Ellis and Wood (2024) provided patient perspectives that addressed patient-defined concerns and underrepresented areas in endometriosis research. Research focused on the public health system and provided insights beyond symptom- and survey-based research, as well as insights from public health and biology (Horne & Missmer, 2022; Staal et al., 2016; Tewhaiti-Smith et al., 2022; Wrobel et al., 2022).

5.10.2 Limitations

Several limitations should be acknowledged. First, the study relied on retrospective data, which are dependent on the quality, accuracy, and completeness of clinical records. The estimation of diagnostic delay depends on accurate recording of symptom onset and diagnosis dates; missing or inconsistently documented information may have influenced the results. The sample size of 524 patients, while sufficient to examine diagnostic delays and treatment patterns within the Waitematā population, may have limited statistical power to detect smaller differences between subgroups. This could explain why some trends observed among women aged 31–40 years or across ethnic groups did not reach statistical significance. The

study's focus on a single region limits the generalisability of findings to other areas of New Zealand, as diagnostic practices in Waitematā may not reflect those elsewhere. Grouping diverse populations into the "Other" category further limited the ability to explore systemic, linguistic, and cultural barriers these patients face. Additionally, the study did not include patient-reported outcomes, such as quality of life, symptom severity, or satisfaction with care. Finally, while treatment types were recorded, the study did not assess their effectiveness or long-term outcomes, as individual responses to management approaches may vary.

Limitations of international data included reliance on tertiary-care studies, which would overrepresent severe cases of endometriosis and exclude less severe cases in the general population (Hudelist et al., 2012; Nnoaham et al., 2011; Treffers & Jung, 2025; Williams et al., 2019). A few studies employed retrospective designs, which limited the specific outcomes examined in relation to variables of interest and introduced recall bias (Hudelist et al., 2012; Singh et al., 2020; Pino et al., 2023). Large studies relied on self-reported diagnoses, which may be subject to misclassification (Singh et al., 2020), and were not confirmed by surgical means. Smaller samples were used in qualitative studies, limiting the applicability across broader healthcare and cultural settings (Ellis et al., 2022; Ellis & Wood, 2024). Lastly, laboratory-based findings can strengthen pathophysiology but limit diversity in study populations and cannot confirm improvements in diagnostic timelines or patient outcomes (Staal et al., 2016; Tewhaiti-Smith et al., 2022; Wrobel et al., 2022).

5.11 Recommendations for future research

Future research should build on the present study by incorporating larger, multi-regional samples across New Zealand, including missing data to enhance statistical power, validity, and generalisability. While the current study of 524 patients provided valuable insights into diagnostic timelines and treatment patterns, larger datasets would enable more robust analyses and facilitate the identification of trends within minority groups and age categories. Previous New Zealand research (Ellis & Wood, 2024; Ellis et al., 2024; Tewhaiti-Smith et al., 2022) has demonstrated that larger sample sizes are essential for a more nuanced understanding of inequities in endometriosis.

Further investigation is warranted to explore the experiences of women classified in the “Other” ethnicity group, who experienced significantly longer diagnostic delays. Future studies should adopt culturally specific analyses to identify barriers to accessing culturally responsive care, including language differences, health literacy, and systemic service limitations. International literature highlights structural and communication barriers faced by minority populations, which contribute to prolonged diagnostic timelines (Othman et al., 2024; Pino et al., 2023).

Incorporating patient-reported outcomes represents another critical research direction. Capturing lived experiences, including quality of life, symptom burden, and satisfaction with care, would provide a more comprehensive understanding of how diagnostic delays and treatment approaches impact well-being. International studies have consistently highlighted experiences of symptom dismissal, pain normalisation, and delayed validation, which exacerbate diagnostic delays (Davenport et al., 2023; Nishimata & Sato, 2025).

Future research should also evaluate the long-term effectiveness of treatment strategies, particularly the combined surgical and hormonal management approach identified in this study. Assessments of quality of life, symptom recurrence, fertility outcomes, and healthcare utilisation would provide insight into whether current management approaches meet patient expectations. Given that endometriosis is a chronic condition, international evidence underscores the importance of evaluating outcomes well beyond initial treatment (Alkatout et al., 2013; Mick et al., 2024).

Finally, despite shorter diagnostic delays observed in this study than in international and national data, further research should continue to assess the impact of patient and clinician education. Evidence from both New Zealand and international studies emphasises that education is central to reducing diagnostic delays and improving equity of care (Bush et al., 2017; Sims et al., 2021). This study examined diagnostic delays and treatment management patterns for women with endometriosis within the Waitematā population. Findings indicated that, on average, women received a diagnosis within seven months of symptom onset, with the majority achieving a final diagnosis within nine months. Compared to national and international literature, this represents a substantially shorter delay, suggesting that clinician awareness, referral pathways, and healthcare delivery in the region may be functioning effectively. Nevertheless, the persistence of diagnostic delays for some patients underscores the need for continued improvement in early recognition and intervention.

No significant differences in diagnostic waiting times were observed among Māori, Pacific, Asian, or NZ European/Pākehā women, suggesting consistent diagnostic practices across these groups within

Waitematā. However, women categorised as “Other” experienced significantly longer delays, highlighting a potential equity gap that warrants further investigation. Age-related patterns were observed, with women aged 31–40 years experiencing longer delays, although these differences did not reach statistical significance. Minimal regional differences were observed across the North Shore, Waitākere, and Rodney, indicating consistent care provision across these areas.

Strengths of this study include the use of real-world clinical patient data, detailed age- and ethnicity-specific analyses, and robust comparisons with both national and international literature. Limitations include the retrospective design, regional focus, moderate sample size, and the absence of patient-reported outcomes, which may have constrained the ability to detect subgroup differences and to capture the lived experiences of women with endometriosis.



Chapter Six

Conclusion

6.1 Conclusion

This study provides contemporary evidence on the diagnosis and management of endometriosis in New Zealand, showing that care is generally timely and equitable across age, ethnicity, and regions. It highlights the need for earlier symptom recognition, culturally responsive care, and patient-centred approaches to further improve outcomes. By establishing a benchmark for clinical practice and health service planning, these findings guide future research using larger, multi-regional datasets to enhance care for women across Aotearoa New Zealand.

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Glossary

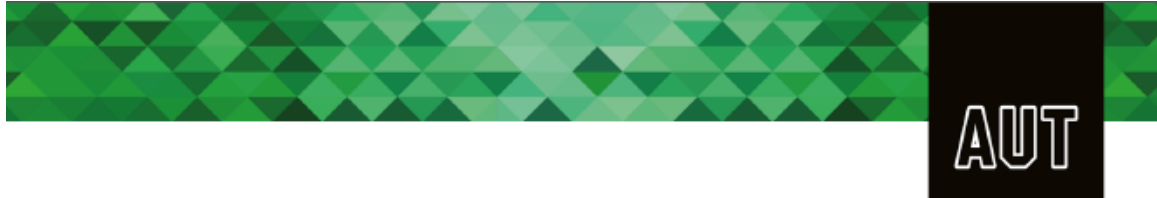
Age-Standardised Incidence Rates (ASIRs)		weighted average of age-specific rates calculated per 100,000 people to adjust for differing age structures across populations or over time.
Amenorrhoea		the absence of menstruation.
Angiogenesis		a physiological process of forming new blood vessels from pre-existing ones.
Biomarker (or biological marker)		a measurable and quantifiable characteristic of a biological or pathological process, or response to a therapeutic intervention.
Chronic Pelvic Pain (CPP)		persistent pain in the pelvic region lasting at least 6 months.
Disability-Adjusted Years (DALYs)	Life	a measure of the total burden of disease.
Dysmenorrhoea		a medical term for painful menstruation.
Dyspareunia		persistent or recurrent genital pain occurring before, during, or after sexual intercourse.
Dyschezia		a condition characterised by straining before the successful or unsuccessful passage of stool.
Dysuria		pain, burning, or discomfort during urination.
Oestrogen		a group of primary sex hormones essential for reproductive development, the menstrual cycle, and pregnancy.

Endometriosis	a condition in which tissue like the uterine lining is inside the pelvis or abdomen.
Gonadotropin-Releasing Hormone (GnRH)	a hormone produced in the hypothalamus that regulates puberty, sexual development, and reproduction (menstrual and sperm production).
Growth Factors	naturally occurring signalling proteins that regulate cellular growth, proliferation, differentiation, and tissue repair.
Hematogenous	originating or carried by the blood.
Heterogeneous	a term used to describe a condition, tissue, or cell population made up of diverse components.
Hydrosalpinx	a condition where a fallopian tube is blocked and fills with fluid.
Laparoscopic	a minimally invasive technique for abdominal or pelvic procedures.
Menopause	natural cessation of menstruation.
Morbidity	suffering from a disease or medical condition.
Müllerian Rest	embryological remnants of the primitive Müllerian ducts that persist into adulthood.
Non-Communicable Disease (NCDs)	a term used to refer to chronic, non-infectious conditions.
Premenopausal	refers to the entire reproductive stage from the

	first menstrual cycle until the onset of menopause.
Prevalence Change	measures the proportion of a population with a specific condition, fluctuating over time and driven by shifts in new cases, cures, or deaths.
Progesterone	a steroid hormone that regulates the menstrual cycle, supports early pregnancy and aids in breast development.
Vascularisation	a biological process that develops new blood vessels within tissues, enabling oxygen/nutrient delivery and waste removal.

Appendices

Appendix A: PGR1 Approval from Faculty of Health and Environmental Sciences, AUT



26 March 2025

Rukshar Sharina Saheed
9 Archibald Road
Kelston
Auckland 0602

Dear Rukshar,

Thank you for submitting your Research Proposal for the Master of Medical Laboratory Science programme.

Your proposal has been reviewed and approved by the Faculty of Health and Environmental Sciences, at the Postgraduate Research Committee March 2025 meeting.

Your research details are:

Programme:	Master of Medical Laboratory Science
Paper enrolment:	MELS999 Thesis
Student ID:	15924147
Working title:	An Audit of Endometriosis of Pre-Menopausal Women in Aotearoa: A 5-year study of the Hidden Disease
Primary supervisor:	Sharita Meharry
Secondary supervisor:	Wee Leong (Joe) Chang
Start date:	31 March 2025
Expected completion date:	20 March 2026

For more information about the programme of study, please refer to the [Postgraduate Handbook](#).

Yours sincerely

A handwritten signature in blue ink, appearing to read 'Nada Signal', on a light blue background.

Associate Professor Nada Signal
Associate Dean Postgraduate Research · Hoa Mautaki Taura Rangahau
Faculty of Health and Environmental Sciences · Te Ara Hauora A Pūtaiao
Auckland University of Technology · Te Wānanga Aronui o Tāmaki Makau Rau
09 921 9666 extension 7062

Cc Primary supervisor: Sharita Meharry
Secondary supervisor/mentor: Wee Leong (Joe) Chang

Appendix B: AUTECH Approval, AUT



Auckland University of Technology Ethics Committee (AUTECH)

10 April 2025

Sharita Meharry
Faculty of Health and Environmental Sciences

Dear Sharita

Re Ethics Application: **25/57 An Observational Research of Endometriosis of Pre-Menopausal Women in Aotearoa: A 5-year Study of the Hidden Disease**

Thank you for your responses to AUTECH's conditions.

Your ethics application has been approved for three years until 10 April 2028.

It is noted that an external peer review of the study was not supplied to support the use of a limited number of variables in the research.

Standard Conditions of Approval

1. The research is to be undertaken in accordance with the [Auckland University of Technology Code of Conduct for Research](#) and as approved by AUTECH.
2. All public facing documents must have the AUTECH approval number and be of a high standard of spelling and grammar. Dates on the Information Sheet(s) and Consent Form(s) must be consistent.
3. Any amendments to the project must be approved by AUTECH prior to being implemented.
4. A progress report is due annually on the anniversary of the approval date.
5. A final report is due at the expiration of the approval period, or, upon completion of project.
6. Any serious or adverse events must be reported to AUTECH, this includes unforeseen issues that might affect continued ethical acceptability of the project.
7. AUTECH grants ethical approval only. You are responsible for obtaining management permission for access from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken.

The application number and title need to be referenced on all correspondence related to this project.

All forms are available online <http://www.aut.ac.nz/research/researchethics>

For any enquiries, please contact the Secretariat at ethics@aut.ac.nz
(This is a computer-generated letter for which no signature is required)

The AUTECH Secretariat
Auckland University of Technology Ethics Committee

Cc: ruksharsaheed@gmail.com

Appendix C: Research and Knowledge Centre (WDHB) Locality Authorisation

RM15532 - An Overview of Endometriosis Affecting Pre-Menopausal Women in New Zealand in The Last Five Years: An Audit of The Hidden Disease - Locality Authorisation ✕ 🖨
🗉 Inbox x



Research & Knowledge Centre (WDHB) <research@waitematadhb.govt.nz>
to me ▾

Thu, Apr 10, 2025, 12:31PM ☆ 😊 ↶ ⋮

Dear Rukshar,

The Research & Knowledge Centre has now received the relevant approvals for the following study:

Project Title: An Overview of Endometriosis Affecting Pre-Menopausal Women in New Zealand in The Last Five Years: An Audit of The Hidden Disease

Registration #: RM15532

This study now has Waitematā Locality Authorisation. Please continue to forward to us copies of all correspondence regarding ongoing ethics approval for this study (if any). All amendments to your study must be submitted to the Research & Knowledge Centre for review. Any substantial amendment (as defined in the Standard Operating Procedures for AUT) must also be submitted to your ethics committee for approval.

Research, audit and related activity must meet Health **NZ** Te Whatu Ora policy and ethical standards in relation to the safe storage, retention, transfer and disposal of research data.
Important:

- Identifiable data must not be emailed or uploaded to a USB even if password protected. Refer to the National Ethical Standards for Health and Disability Research and Quality Improvement Table 12.1 (page 164) for definition of identifiable data.
- Remove identifiers including NHIs as soon as possible after data collection, and if re-identification may be needed replace NHI with a Unique Study ID. Keep the list matching IDs and NHIs securely within the Health **NZ** district network and separate from the de-identified data collection.
- Where data is to be transferred, the use of safe transferal technology such as ShareFile is preferred. Ensure the access instructions / password are sent to the intended recipient in a separate communication (eg. text or TEAMS).

Note: Access to ShareFile can be requested from the national IT service desk - Service Now Portal

At the conclusion of this study a copy of any outputs, reports or publications should be forwarded to research@waitematadhb.govt.nz

Good luck with your study.

Kind regards

Research & Knowledge Centre
Te Whatu Ora - Waitematā
research@waitematadhb.govt.nz

Appendix D: HDEC-Out-of-Scope Letter

From: donotreply@infonetica.net
Subject: An Overview of Endometriosis Affecting Pre-Menopausal Women in New Zealand In The Last Five Years: An Audit of The Hidden Disease is out of scope
Date: 18 June 2023 at 4:39 PM
To: ruksharsaheed@gmail.com

D



Health and Disability Ethics Committees
 Ministry of Health
 133 Malesworth Street
 PO Box 5013
 Wellington
 6011
 hdec@health.govt.nz

18 June 2023

Ms Rukshar Saheed

9 Archibald Road, Kelston
 Auckland
 New Zealand
 0602
 New Zealand

Tēnā koe Rukshar

This is an automated message to inform you that, based on your answers in the HDEC screening form, your study *An Overview of Endometriosis Affecting Pre-Menopausal Women in New Zealand in The Last Five Years: An Audit of The Hidden Disease* is out of scope and does not require HDEC approval. This does not mean the project does not require ethics review, only that it is out of scope for HDEC review. This scope is described in section three of the [Standard Operating Procedures for Health and Disability Ethics Committees](#).

Please note, your locality may have additional ethical review policies, please check with your locality. **If your study involves a DHB, you must contact the DHB's research office before you begin. If your study involves a university or polytechnic, you must contact its institutional ethics committee before you begin.**

If you consider that our advice on your project being out of scope is incorrect please contact us as soon as possible giving reasons for this.

This letter does not constitute ethical approval or endorsement for the activity described in your application, but may be used as evidence that HDEC review is not required for it.

This form was generated by:

Ms Rukshar Saheed

The out of scope determination was made due to the following answers received:

S1 - value	S2 - value	Screen.StudyType - value	Screen.ActiveParticipants - value	Screen.VulnerableParticipants - value
Yes	No	Observational Study	No active human participants	

Screen.IdentifiedDisclosure - value	Screen.IdentifiedHealthInfo - value	Screen.ConsentHealthInfo - value	Screen.UseofTissue - value	Screen.TissueUseWithoutConsent - value
Yes, all information will be received by researchers previously deidentified	Yes	No, participants have not consented to this	No	

Screen.TissueConsent - value	Screen.TissueExemption - value	Screen.TissueFUR - value	Screen.Features.FullPathway - value	Screen.ClassDevice - value
			None of the above	No

Screen.MastersExempt - value	Screen.Guthrie - value	Screen.Disclaimer - value
Yes	No	Yes