



Eleven Years of Cyclical Pain Before a Diagnosis of Endometriosis: A Narrative Review of Where the Delay Accrues and Whether It Is Shortening

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Abstract

Endometriosis takes years to name, and the figure most often quoted for how many years is unstable. Reported averages range from under two to over twelve, and the range is not noise: it reflects who was asked, how the interval was defined, and when the study was done.

Objectives: *To review the published evidence on diagnostic delay in endometriosis: how long it is, which segment of the pathway accounts for most of it, why estimates differ so widely between studies, and whether the delay is shortening.*

Material and Methods: *Narrative review of systematic reviews, scoping reviews, multicentre chart-and-questionnaire studies, national surveys and multi-country cohorts indexed in PubMed and the major obstetric, gynaecology and pain journals. No new patient data were generated; every estimate quoted is one published by the original investigators.*

Results: *A systematic review found overall mean time to diagnosis ranging from 5.4 to 11.4 years and median from 5 to 12 years. A scoping review reported an average of 6.6 years with a range of 1.5 to 11.3, and located the longest single segment between gynaecology referral and diagnosis (2.8 years), followed by primary care presentation to diagnosis (2.5 years) and symptom onset to primary care presentation (2.0 years). In a Dutch multicentre study of 837 respondents, median total delay was 7 years, of which patient delay was 1 year, general practitioner delay 1 year and gynaecologist delay under 1 year.*

Conclusion: *Most of the delay accrues after the patient has presented, and the largest single segment sits after specialist referral, which locates the problem inside secondary care rather than in women failing to seek help. There is evidence the interval is shortening, and quoting the largest published figure without its denominator misrepresents current practice.*

Abbreviations: *CPP – Chronic Pelvic Pain, DALY – Disability-Adjusted Life Year, GP – General Practitioner, IQR – Interquartile Range, SD – Standard Deviation, WERF – World Endometriosis Research Foundation.*

Keywords: *Endometriosis; Diagnostic Delay; Chronic Pelvic Pain; Referral Pathways; Evidence Heterogeneity*

Introduction

Endometriosis is the presence of tissue resembling endometrium outside the uterus, and is the commonest cause of chronic pelvic pain, accounting for a substantial share of such diagnoses [1,2,3]. Prevalence estimates vary widely, from 4 to 50 per cent depending on the population and the method of ascertainment, with the most consistent estimates falling between 6 and 10 per cent of women of reproductive age [4,5].

The presenting features are well described: dysmenorrhoea, dyspareunia, non-cyclical pelvic pain and subfertility, though a proportion of women are asymptomatic [2,6]. Symptoms overlap with bladder and bowel conditions, which is one recognised source of diagnostic difficulty [7,8].

Gynaecological conditions are among the leading contributors to years lived with disability in women aged 15 to 49, and diagnostic delay is consistently cited as a reason [9,10,28,29]. Delay itself carries measurable cost in healthcare utilisation [35]. This review examines how long that delay is, where it occurs, and why published estimates disagree so markedly.

Material and Methods

Search strategy: PubMed and the archives of the major obstetric, gynaecology and pain journals were searched for studies of diagnostic delay in endometriosis. Search terms combined endometriosis with diagnostic delay, time to diagnosis, referral, chronic pelvic pain and laparoscopy. Reference lists of systematic and scoping reviews [11,12] were screened by hand for primary sources.

Eligibility: Studies were included if they quantified an interval from symptom onset or presentation to diagnosis, disaggregated that interval by segment, or examined determinants of delay. Prevalence studies are cited for context and identified as such.

Data extraction and handling: Design, recruitment method, sample size, how the interval was defined and the reported estimate were extracted as published. Recruitment method is reported alongside every delay figure, because self-selected survey samples recruited under a banner of diagnostic delay produce systematically longer estimates than chart-based cohorts, and this accounts for much of the disagreement in the literature. No pooling or re-analysis was performed. Figures 1 to 4 and Tables 1 and 2 reproduce published values only. This is a narrative synthesis and was not registered as a systematic review.

Results

How long is the delay: A systematic literature review reported overall mean time to diagnosis ranging from 5.4 to 11.4 years, with median times between 5 and 12 years [11]. A scoping review across a different set of studies found an average of 6.6 years with a range from 1.5 to 11.3 years [12]. The frequently cited figure of 6.7 years derives from a ten-country study of women undergoing first laparoscopy for symptoms suggestive of endometriosis, in which average delay ranged from 3 to 10 years across the participating countries (Figure 4) [13,14].

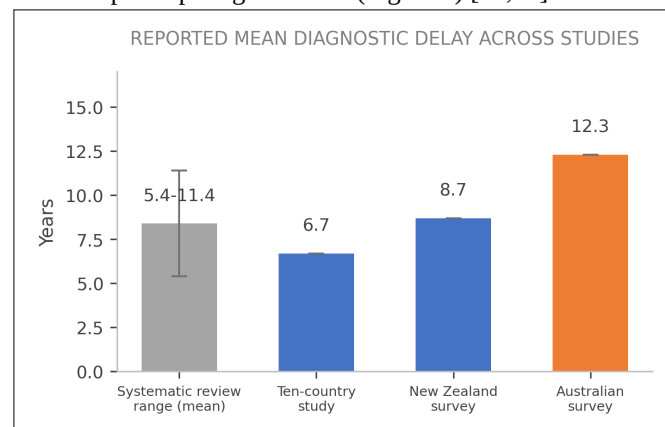


Figure 4: Reported mean diagnostic delay across studies and populations [11,12,13,15,16]

Where the delay occurs: The scoping review disaggregated the pathway and found the longest average segment to be the time from gynaecology referral to diagnosis, at 2.8 years, followed by primary care presentation to diagnosis at 2.5 years, and finally symptom onset to primary care presentation at 2.0 years (Figure 1) [12]. Delays were identified at every stage, but the largest single component sits after specialist referral has already been made.

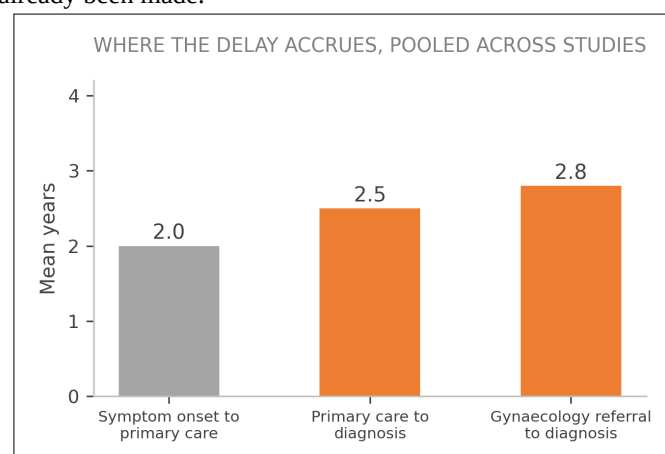


Figure 1: Mean length of each segment of the diagnostic pathway, pooled across studies [12]

A chart-based comparison: A retrospective study across 11 Dutch hospitals screened 9551 medical charts and included 2289 patients with confirmed endometriosis diagnosed between 2018 and 2020; 837 returned questionnaires. Median total diagnostic delay was 7 years (IQR 2 to 15). Median patient delay was 1

year (IQR 0 to 2), median general practitioner delay 1 year (IQR 0 to 9) and median gynaecologist delay under 1 year (IQR 0 to 1) (Figure 2) [15]. The very wide interquartile range on the general practitioner component is itself informative: for some women that step is immediate and for others it takes most of a decade.

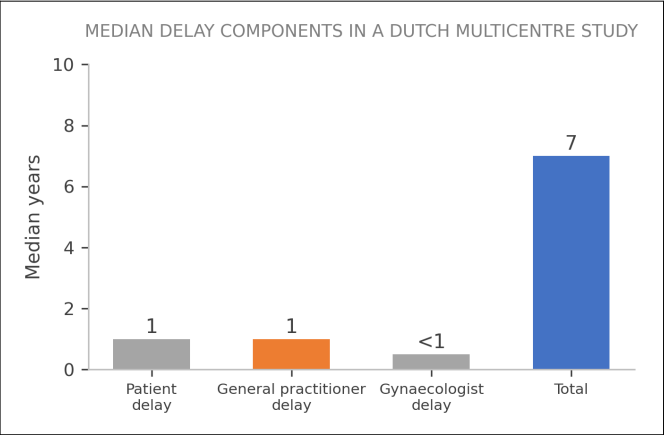


Figure 2: Median delay by segment in a Dutch multicentre chart and questionnaire study [15]

Is it shortening: A New Zealand survey reported a mean delay of 8.7 years, comprising 2.9 years from symptom onset to first presentation and 5.8 years from first presentation to diagnosis, with an average of five doctors seen. Critically, it also reported a fall over time in the interval from first presentation to diagnosis, from 8.4 years among those presenting before 2005 to 2 years among those presenting after 2012 (Figure 3) [16]. An Australian survey reached a similar conclusion that time to diagnosis is decreasing [17].

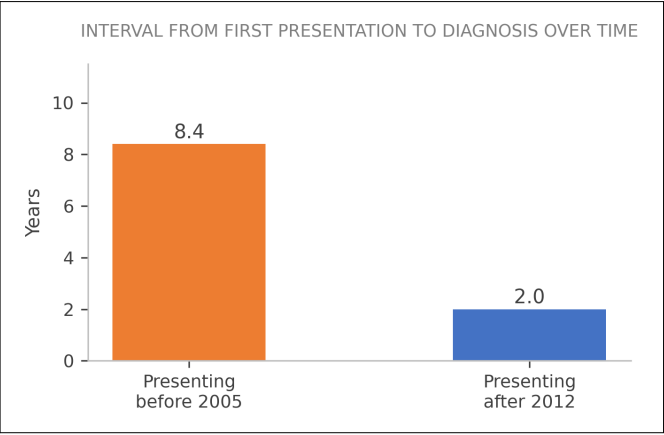


Figure 3: Interval from first presentation to diagnosis by era of presentation [16]

Study	Design and recruitment	Principal reported finding
De Corte et al. 2025 [11]	Systematic literature review	Mean time to diagnosis 5.4 to 11.4 years
Fryer et al. 2024 [12]	Scoping review, social-ecological framework	Average 6.6 years; longest segment after gynaecology referral
Nnoaham et al. 2011 [13]	Ten-country study, first laparoscopy	Average delay 3 to 10 years across countries; mean 6.7
Dutch multicentre [15]	11 hospitals, 2289 charts, 837 questionnaires	Median total 7 years; gynaecologist delay under 1 year
Tewhaiti-Smith et al. 2022 [16]	National survey, New Zealand	Mean 8.7 years; presentation-to-diagnosis fell 8.4 to 2 years
Australian delay survey [18]	Survey advertised as focused on delay	Mean 12.3 years, roughly double a comparable survey
Armour et al. 2020 [17]	Australian survey	Time to diagnosis decreasing over time

Table 1: Principal studies reviewed, with recruitment method and the finding as reported

Why the estimates disagree: The difference is not random. An Australian study reporting a mean delay of 12.3 years was advertised as focusing on diagnostic delay, while a comparable survey reporting 6.4 years was advertised as focusing on endometriosis experiences; the samples were demographically similar, of similar size, and used the same method of calculating delay [18]. Recruiting under a banner of diagnostic delay attracts women whose delay was long. That single observation explains much of the spread in this literature and is rarely mentioned when the largest figures are quoted.

What drives the delay: Symptom overlap with bladder and bowel conditions complicates recognition [7,19]. Normalisation of menstrual pain, by patients and by clinicians, delays presentation [20,21]. Adolescents face the longest delays of any group [12,22]. Diagnosis has historically required laparoscopy, which places a surgical threshold in front of the diagnostic label, though imaging-based and clinical diagnosis are now accepted in guidelines and this is one plausible explanation for the shortening observed [15,23,24]. Symptom-based predictive models have been developed as screening tools [34]. Reported associations with insurance and funding model are inconsistent between countries [13,18,26]. National surveys in Canada and Italy report comparable intervals [25,27], and European studies find the same pattern [32,33].

Segment or factor	What the evidence shows	Implication
Onset to primary care	About 2.0 years on average	Normalisation of menstrual pain [12,20]
Primary care to diagnosis	About 2.5 years on average	Symptom overlap with bowel and bladder [7,12]
After gynaecology referral	About 2.8 years, the longest segment	Delay persists inside specialist care [12]
Dutch chart-based estimate	Gynaecologist delay under 1 year	Chart cohorts give shorter estimates than surveys [15]
Recruitment framing	12.3 vs 6.4 years in similar samples	Advertising the study topic shapes the answer [18]
Era of presentation	8.4 years before 2005; 2 years after 2012	The interval appears to be shortening [16,17]

Table 2: Segments of the diagnostic pathway and methodological factors affecting the estimates

Discussion

Two findings in this literature deserve more prominence than the headline number.

The first is where the delay sits. The longest single segment, on pooled data, is the interval between gynaecology referral and diagnosis at 2.8 years, exceeding both the time women take to present and the time primary care takes to refer [12]. That is uncomfortable, because the usual framing places responsibility on women normalising their pain or on general practitioners failing to recognise it. Both of those contribute. Neither is the largest component. A woman referred to gynaecology has already been believed by someone, and still waits longest.

The second is that the delay appears to be falling. The interval from first presentation to diagnosis dropped from 8.4 years for women presenting before 2005 to 2 years for those presenting after 2012 in one national survey, and a second survey independently reported a decreasing trend [16,17]. The plausible mechanism is the move away from requiring laparoscopy for diagnosis [15,23]. Quoting a ten-year delay to a woman presenting today may therefore describe a cohort diagnosed under different rules.

This is where the methodological point becomes clinically relevant rather than pedantic. A survey advertised as being about diagnostic delay produced a mean of 12.3 years; a demographically similar survey of similar size, advertised as being about endometriosis experiences, produced 6.4 [18]. Chart-based cohorts produce shorter figures still, with gynaecologist delay under a year [15]. All of these are honestly reported. Selecting the largest and presenting it as the typical experience is a distortion, and it happens routinely.

None of that diminishes the underlying problem. A median of 7 years in a chart-based cohort is unacceptable for a condition with recognisable symptoms in a young woman [15]. The argument for asking about cyclical pain, and for referring on symptoms rather than waiting for imaging to confirm what the history already suggests, does not need the twelve-year figure to stand up. It stands on the seven-year one, which is better

evidenced.

Study limitations

The limitations belong to the underlying literature. Almost all delay estimates depend on retrospective recall of symptom onset, over intervals of years to decades [12,16]. Recruitment method demonstrably shapes the estimate, and studies advertised as concerning delay attract longer-delayed respondents [18]. Definitions of the start point differ, with some studies dating from first symptom and others from first presentation [11,15]. Diagnostic criteria changed during the period these cohorts span, from laparoscopic confirmation to imaging or clinical diagnosis, so early and late cohorts are not measuring the same event [15,23]. Women never diagnosed are absent from every study, and a substantial proportion of cases are thought to remain undiagnosed [4,12,30,31]. Only a minority of studies in the scoping review included any comparator group [12]. Response rates in questionnaire studies are modest, at 36.6 per cent in the Dutch cohort [15]. And the literature is overwhelmingly from high-income countries [11,13].

Conclusion

Endometriosis is diagnosed years after it starts causing symptoms, and on the best chart-based evidence the median interval is around seven years. The most useful findings are not that headline but two others: that the largest single segment of the delay occurs after referral to gynaecology, which locates a substantial part of the problem inside specialist care, and that the interval has been shortening as diagnosis has moved away from requiring laparoscopy. The very long averages in circulation come disproportionately from surveys that recruited women by advertising an interest in delay. The case for taking cyclical pain seriously in a young woman is strong enough without them.

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Conflict of Interest

The authors declare no competing interests.

Ethics Statement

This article reviews previously published studies only. No new patient data were collected and no participants were recruited, so ethical approval was not required.

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