



Reducing the Diagnostic Delay of Endometriosis



How do clinical, institutional, and knowledge-related barriers within the Dutch healthcare system contribute to the delayed diagnosis of endometriosis, and what structural improvements could enhance diagnostic efficiency and affordability?

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190M People affected worldwide	400K Estimated affected in NL	7-8 yrs Avg. Diagnostic Delay (NL)	€9,579 Annual Cost per Patient (EU)	1 in 10 AFAB of reproductive age
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Medical Background

Endometriosis is a **chronic inflammatory disease** in which tissue similar to the uterine lining grows outside the uterus, causing inflammation, severe pain, adhesions, and reduced quality of life.

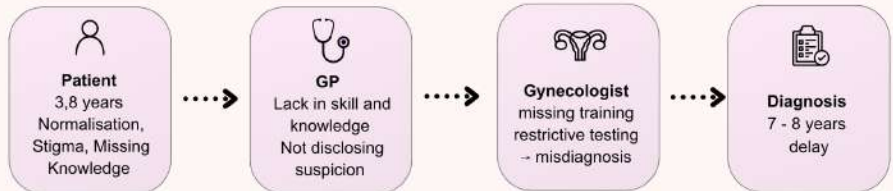
Symptoms are heterogeneous and may include severe dysmenorrhea, chronic pelvic pain, dyspareunia, fatigue, infertility, and gastrointestinal or urinary complaints.

The disease is commonly classified into **three main types**: superficial peritoneal endometriosis, ovarian endometrioma, and deep endometriosis. Although it mainly affects pelvic organs, rare extrapelvic cases involving the lungs, diaphragm, or even the central nervous system have been reported.

Adenomyosis, where endometrium-like tissue is located within the uterine muscle, can co-occur and contribute to heavy bleeding and menstrual pain.

Despite **affecting millions worldwide**, endometriosis often remains undiagnosed for years. Delays may occur because symptoms are normalised, dismissed, or treated separately as gynaecological, gastrointestinal, urinary, or psychosomatic complaints rather than recognised as one underlying disease.

Accumulation of Diagnostic Delay



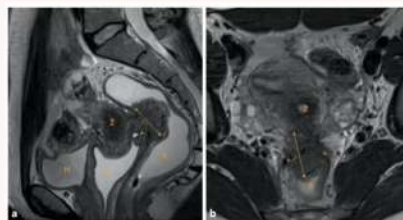
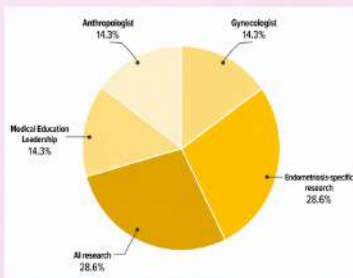
Impact of Diagnostic Delay

Physical Delayed diagnosis prolong pain, uncertainty, psychological distress, repeated healthcare visits, and delayed access to appropriate care	Psychological Anxiety, depression, feeling dismissed. Chronic pain and emotional invalidation reduce quality of life significantly.	Economic €9,579/year per patient (EU). €30B/year productivity loss for EU employers. Absenteeism and presenteeism prevalent.	Social Reduced participation in education, employment, and relationships. Cyclical symptoms make interpretation and support harder.
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Methods

- Literature review
- Data collection: 7 semi-structured expert interviews (NK/DE/DK)
- Data Analysis: thematic analysis

Expert knowledge contribution:



Willer D et al, 2023, Springer Nature

"Nearly all experts are knowledgeable — the real issue is GPs who suspect endometriosis but don't disclose it, because it wouldn't change treatment but could cause anxiety."
— Epidemiologist interview

"From an AI perspective, the problem is not a technical problem. The problem is a political problem...When people decide to solve this problem and give the money necessary to do so, we will solve it."
— Expert Interview

"They are thrown around in the system... symptoms overlap with so many other conditions."
— Expert Interview

Multi-level Approach to Reduce Diagnostic Delay

Patient Empower Recognition	GP Improve Suspicion	Specialist Standardise Accuracy	Policy & Governance Structural Reform
Menstrual health education in schools Use of symptom tracking tools National / EU awareness campaigns	Mandatory CPD + practical training Endometriosis in NHG guidelines Diagnostic Flowcharts for GPs	Pilot in NL referral centres first AI - supported ultrasound analysis Combining imaging with symptom data	Expertise centres ↔ GP link Standalone NL action plan Target: 8 years → 12 months

