

How advocacy, awareness and algorithms could shorten the long wait for endometriosis diagnosis and treatment

April 12 2022, by Eileen Mary Holowka, Maria Kathryn Tomlinson, Mie Kusk Søndergaard and Ulrik Bak Kirk



Credit: AI-generated image ([disclaimer](#))

Endometriosis affects an estimated [200 million people worldwide](#). Despite its prevalence, those living with the disease often wait an average of [7.5 years](#) between start of symptoms and diagnosis. This

delay is due to a variety of reasons, including medical dismissal, a low prioritization of the condition and its overall misrepresentation in research funding, policy and media.

Although often represented as a women's reproductive disease, endometriosis also appears in people who have had hysterectomies, transgender men, genderfluid and non-binary people, pre-menstrual and post-menopausal people, and in rare cases, [cisgender men](#).

Its symptoms commonly include [pain](#) with menstruation, as well as [chronic pain](#), infertility, pain with sexual intercourse, fatigue and more. Despite this full-body impact on one's [quality of life](#), endometriosis is commonly associated with just having "bad periods."

We are four authors from three countries looking at different aspects of endometriosis diagnosis, awareness and patient advocacy. This article emerges from a [joint online presentation](#) of our research looking at potential ways to improve awareness and [patient care](#), and promote faster diagnosis.

Our methods include social scientific and qualitative research including interviews, surveys, focus groups, participant observations and collaborations with people living with endometriosis. We identified some clear changes that are needed to promote awareness of the disease, and subsequently reduce diagnostic timelines.

Awareness amongst 16–19-year-olds: An overview

- 28/77 claimed to have heard of endometriosis
- Many struggled to remember the name
- Pain was most identified symptom
- Only two students spoke accurately about the condition (e.g. tissue build up)

"Endometriosis, it is like tumours in your uterus, and the period doesn't come as often, so it is harder to get pregnant"

"What's endometriosis?"

"Endo...endo... How do you say it? I know 1 in 10 women has it"

"It's where... Isn't it where you build...? I actually don't know."



"I've heard of endometriosis, but I don't remember what it is"

Maria Tomlinson's research surveyed young people about their awareness and knowledge of endometriosis. Credit: Maria Kathryn Tomlinson, Author provided

Widespread endometriosis education

Our research suggests that endometriosis education is severely lacking, meaning that many people who have the condition do not even know it exists.

In focus groups with 77 16- to 19-year-olds in the United Kingdom, Maria found that only 28 had heard of endometriosis before. Of these, two were able to accurately define it. Most of those who had heard of the disease had done so through friends and family, with some also hearing about it on social media or the internet. None of them had been told about it in their formal education.

Eileen's survey of 271 people with endometriosis showed that only nine people (3.3 percent) heard about endometriosis from grade school (elementary, junior or [high school](#)) with a few mentioning that they had heard about it briefly in nursing school.

Although Eileen's interviews and surveys showed that social media can be very beneficial to people who live with endometriosis, Maria's focus groups showed that social media is not very effective at reaching people who do not have the condition. People with endometriosis often put enormous amounts of work into sharing endometriosis information online, but it often does not reach the broader population.



Credit: AI-generated image ([disclaimer](#))

Accurately represent menstrual pain and endometriosis pain

As Mie identifies in her fieldwork on menstruation among teenagers and interviews with endometriosis patients from Denmark, the normalization of menstrual pain is one of the main factors delaying diagnosis for people with endometriosis.

Although not everyone who has endometriosis menstruates or has menstrual pain, [it is one of the most common and symptoms, and one of the earliest](#). Many people are encouraged to use painkillers and hormonal contraceptives to manage their pain, instead of having it investigated. Being prescribed [birth control pills](#) without a thorough investigation of symptoms, or consideration for [gender identity](#), were also concerns identified by participants in Maria's focus groups.

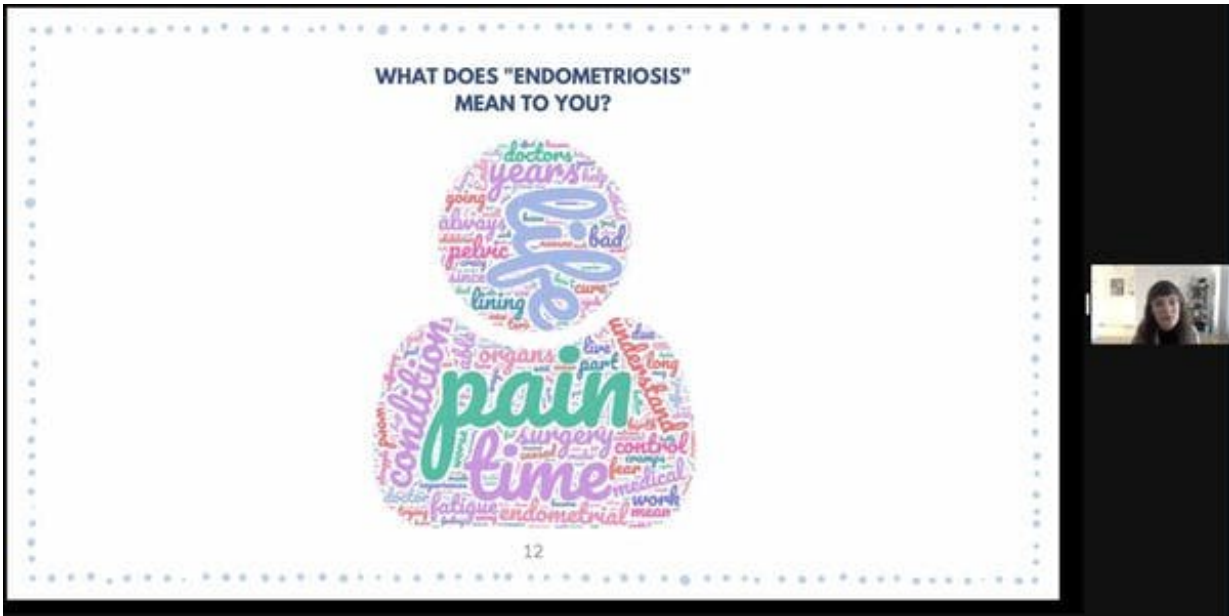
Maria's participants also explained how they believe menstrual product advertisements undermined the severity of menstrual pain. They thought that more realistic representations of painful periods might encourage more young people with periods to seek [medical help](#) when needed.

Mie's work identifies the often cyclical nature of endometriosis symptoms as something that can discourage patients from seeking care, as they feel their symptoms are not as extreme when they are not menstruating. Better awareness that cyclical symptoms can also indicate diseases might help patients seek care earlier.

Eileen's social media analysis shows that people with endometriosis often use social media to represent their lived experiences of [menstrual pain](#) and endometriosis with complexity, in contrast to common media representations.

In a recent example, Amy Corfeli from the podcast and social media platform [@in16yearsofendo](#) used Instagram, Twitter and [Medium](#) to address inaccuracies in the television show *Grey's Anatomy's* representation of endometriosis. Unfortunately, *Grey's Anatomy* has a

larger platform, but [social media](#) pages like Amy's, [@endoQueer](#) and [@endo_black](#) attempt to bring more nuance and diversity into the media depictions of endometriosis.



A word cloud responding to the question, ‘What does endometriosis mean to you?’ Credit: Eileen Mary Holowka

Improving diagnostic time

Endometriosis is an "invisible" condition, meaning it cannot be seen by just looking at someone. Including endometriosis in grade school curricula, covering it more extensively in medical school, and representing it more broadly in media, would help make the disease more apparent so people with symptoms seek care sooner.

However, the burden of care cannot be on patients alone, particularly for

a condition like endometriosis which comes with [a long history of patient-blaming](#). Interventions are needed on the medical side, but limited resources, long wait times, suboptimal diagnostic techniques and knowledge, and the low prioritization of endometriosis all increase diagnostic delays.

It is possible that interventions such as the [FEMaLe](#) (Finding Endometriosis using Machine Learning) project, co-ordinated by Ulrik, could help improve diagnosis in the future. This project, emerging out of Denmark, aims to develop and demonstrate a platform that uses algorithms to detect and help diagnose and treat people with endometriosis, in collaboration with their health-care providers.

In order to develop this kind of work, a multidisciplinary approach to [endometriosis](#) is needed, including not only medical research, but also the kind of qualitative work outlined in this story.

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