

# HIGH INCIDENCE OF DIAGNOSTIC ERROR OF ENDOMETRIOSIS IN AUSTRALIA, CANADA, IRELAND, AND THE UK

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## ABSTRACT

**Background:** Endometriosis is a reproductive disease resulting in pain, infertility, and considerable physical and psychosocial dysfunction. Endometriosis affects at least 10% of women, yet its aetiology is unknown and there is no known cure. The profound diagnostic delay of endometriosis ( $M = 10$  years) warrants study into its diagnostic error (DE) rates; thus, the aim of this research was to establish DE rates for five countries and by whom DE was made. **Methods:** Participants were 200 women with endometriosis from Australia, Canada, Ireland, Romania, and the UK, who participated in a cross-sectional online research study. DE incidence and by whom DEs were made were obtained from single-item questions. Frequency analysis was performed. **Findings:** 93.9%, 84.2%, 80.0%, 66.7%, and 92.2% of women reported being misdiagnosed in Australia, Canada, Ireland, Romania, and the UK, respectively. The majority of DEs were made by general practitioners (61.8%, 50.8%, 53.3%, 12%, and 51.9%, respectively) and gynaecologists (35.5%, 45.8%, 30%, 64%, and 50%, respectively), whereas a minority were made by endometriosis specialists (8.8%, 8.5%, 0%, 0%, and 0%, respectively) and other healthcare providers (23.5%, 10.2%, 13.3%, 4%, and 7.7%, respectively). **Discussion:** The incidence of DE in this online endometriosis sample is much higher than the estimated incidence of DE in medicine in general (10-15%). The long diagnostic delay cited in prior research supports this increased incidence. Unveiling the high incidence of DE in endometriosis is critical to provide the necessary motivation to provide more extensive training to healthcare providers—especially gynaecologists—in the recognition of endometriosis.

## BACKGROUND

### Endometriosis

- Endometriosis is a female reproductive disease resulting in pain, infertility, and considerable physical and psychosocial dysfunction<sup>1,2</sup>
- Endometriosis occurs when tissue similar to that which lines the uterus (i.e., the endometrium) forms *outside* the uterus (e.g., pelvic cavity, ovaries, fallopian tubes, bladder)<sup>1</sup>
- Endometriosis affects roughly 10% of females of reproductive age, yet its aetiology is unknown and there is no known cure<sup>3,4</sup>

### Endometriosis care

- The profound diagnostic delay of endometriosis ( $M = 10$  years)<sup>4</sup> warrants study into the diagnostic error (DE) rates of this disease

### Objectives

- Determine the incidence of DE in women with endometriosis
- Determine by whom DEs are being made



Endometriosis of the pelvic cavity  
Source(s): Giudice (2010)<sup>5</sup>, who retrieved above image from Dr. Christopher Herndon, UCSF.

## METHODS

### Participants

- A combined 200 women from Australia ( $n=34$ ), Canada ( $n=59$ ), Ireland ( $n=30$ ), Romania ( $n=24$ ), and the UK ( $n=51$ )
- Self-reported a surgically-confirmed diagnosis of endometriosis

### Procedure

- Consented to and completed a one-time cross-sectional online research study April–August 2017

### Measurement

- Data were obtained from single-item survey questions

Has a physician ever misdiagnosed your endometriosis as [another physical/a mental] health problem (before you were diagnosed with endometriosis)?

Yes No

By whom was this diagnosis made?

## RESULTS

	Australia	Canada	Ireland	Romania	UK
<b>DE, total (% of N)</b>	93.9	84.2	80.0	66.7	92.2
<b>DE, physical (% of N)</b>	82.4	81.4	80.0	66.7	86.3
General practitioner	50.0	45.8	46.7	12.0	38.5
Gynaecologist	35.3	37.3	30.0	64.0	46.2
Endometriosis specialist	5.9	5.1	0.0	00.0	0.0
Other <sup>a</sup>	17.6	8.5	13.3	04.0	7.7
<b>DE, mental (% of N)</b>	57.6	36.8	50.0	20.8	35.3
General practitioner	38.2	20.3	33.3	0.0	23.1
Gynaecologist	8.8	15.3	20.0	12.0	13.5
Endometriosis specialist	2.9	5.1	0.0	4.0	0.0
Other <sup>b</sup>	8.8	1.7	3.3	4.0	0.0

### <sup>a</sup> Other HCP types: (physical misdiagnosis)

- Gastroenterologist
- Consultant for irritable bowel syndrome (IBS)
- Nephrologist
- Hospital/ER physician
- Naturopath

### <sup>b</sup> Other HCP types (mental health misdiagnosis):

- Endocrinologist
- Pediatrician
- Consultant for irritable bowel syndrome (IBS)

## CONCLUSIONS

### Discussion

- DE incidence in this online endometriosis sample is considerably higher than the estimated incidence of DE in medicine in general (10-15%)<sup>6</sup>
- In previous work, Graber (2013)<sup>7</sup> noted that retrospective case reviews yielded DE incidences for a range of diseases that are “unacceptably high”; however, none of which had approached the unacceptable rates of misdiagnosis, missed diagnosis, and delayed diagnosis readily documented in the endometriosis literature
- The long diagnostic delay of endometriosis cited in prior research supports this increased incidence

### Implications and applications

- Results provide the necessary motivation to provide more extensive training to health care providers—especially gynaecologists—in the recognition of endometriosis
  - Behavioral medicine researchers could play a pivotal role, with their focus on health services and implementation research
- Results highlight the need for interdisciplinary medicine
  - Clinical psychologists may play a pivotal role in ruling out the high number of incorrect mental health diagnosis prescribed to these women during their search for a diagnosis

In a current medical climate that has placed patient safety at its forefront<sup>8</sup>, one must ask: *what efforts are currently in place for addressing this diagnostic crisis?*

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