

## Exploration of the Epidemiology of Endometriosis

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### Abstract

*Endometriosis is a disease whereby endometrial tissue grows outside of the uterus, often resulting in debilitating pain and serious loss to a woman's quality of life. Despite the severity of the disease, little is understood about the basic epidemiology of endometriosis, such as prevalence. The number of patients and the amount of data available through OHDSI present an unprecedented opportunity to better understand the epidemiology of endometriosis. We seek to describe epidemiologic characteristics of endometriosis such as patient demographics and social history, comorbidities, medications, treatments, diagnostic procedures, laboratory tests, genetic markers, tissue markers, and healthcare utilization using Columbia University Medical Center's implementation of the Observational Medical Outcomes Partnership (OMOP) common data model. Using Columbia's implementation of OMOP as a testing ground, we will develop an accurate and reliable query algorithm that can be implemented by the Observational Health Data Sciences and Informatics (OHDSI) consortium to characterize endometriosis at scale.*

### Introduction

Endometriosis is a significant cause of morbidity for women of reproductive age, causing pain and masses in the pelvic area as well as infertility. Ectopic endometrial implants cyclically bleed, leading to inflammation and adhesions that produce symptoms such as chronic pelvic pain, fatigue, dysmenorrhea, dyspareunia, dysuria or dyschezia<sup>1</sup>. The etiology of the disease remains largely unknown and diagnosis is most often delayed, even though the symptoms are debilitating<sup>2</sup>. Unfortunately, few good treatment options exist, resulting in greatly reduced quality of life for women with endometriosis. For example, endometriosis-associated symptoms generate 0.809 quality-adjusted life years per woman, and the disease is associated with substantial health care and productivity loss costs<sup>2</sup>.

The need for surgery to diagnosis endometriosis makes it difficult to determine the disease's prevalence. Most prevalence estimates are based upon cohorts of women undergoing surgery, and are therefore highly selective<sup>3</sup>. Early estimates of the prevalence of endometriosis used billing records of women undergoing gynecologic surgery. For example, in 1989 Wheeler reviewed the surgical and billing records for 21 gynecologic practices in Houston to estimate that approximately 10% of the general population is affected, basing this number off of 71 cases of histologically confirmed endometriosis among 858 women undergoing vaginal hysterectomy for preoperative diagnoses excluding endometriosis, pelvic pain, and adhesions<sup>4</sup>. This estimate is based on procedures that did not examine the entire peritoneal cavity and on an older group of patients than the general population<sup>3</sup>. In 1997 Eskenzai and Warner reviewed the literature at the time to come up with a 10% prevalence estimate for all women and a disease prevalence of 30%–50% of symptomatic premenopausal women<sup>3</sup>.

Newer estimates have reported lower prevalence numbers, although these studies were based upon symptomatic women and self-reported data. For example, in a study of self-reported cases of endometriosis 48 out of 1193 survey respondents had a surgically confirmed diagnosis, giving a point prevalence of 4.0%<sup>5</sup>. In a similar study, among a sample of 1291 women with self-reported endometriosis symptoms and no diagnosis of endometriosis, endometriosis was confirmed among 3.6% (46/1291) women<sup>6</sup>. A study based on inpatient and outpatient data from a statutory health insurance fund in Germany produced similar estimates, with standardized prevalence and incidence rates at 8.1 and 3.5 per 1000 women, respectively<sup>7</sup>.

Due to the burden of the disease, we seek to better understand the basic epidemiological characteristics of endometriosis such as prevalence using the Observational Health Data Sciences and Informatics OHDSI consortium. In addition, we aim to leverage OHDSI to develop hypotheses about the risk factors associated with and potential causes of endometriosis. For instance the disease has been associated with several types of cancer such as ovarian and breast cancer, autoimmune diseases, asthma and atopic diseases<sup>1</sup>.

In short, we aim to characterize the natural history of women with endometriosis. The clinical and public health implications of this work are significant given the exact cause(s) of the disease are unclear and modifiable risk factors to prevent or control the disease have not yet been fully identified<sup>1</sup>.

## **Methods**

Before developing and distributing a query algorithm for the OHDSI community to implement we will first refine our methods on Columbia University Medical Center's implementation of the Observational Medical Outcomes Partnership (OMOP) common data model. First, we seek to systematically summarize comorbidities, treatments, procedures, and selected lab values of women with at least one year of observation before the index diagnosis date and at least 60 days of observation after the index diagnosis date and one official diagnosis of endometriosis.

We define a cohort of women with endometriosis as females with at least one year of observation before the index diagnosis date and at least 60 days of observation after the index diagnosis date as well as an official diagnosis of endometriosis (and no restriction on pre-onset observation). Onset is defined as time of first official diagnosis of endometriosis. Among these women, we aim produce estimates of the following:

- Demographics: date of birth, race, ethnicity
- Social history: for each observation in time, whenever available height, weight, exercise level, smoking status, caffeine use, and alcohol use
- Comorbidities
- Medications
- Treatment procedures: surgery (removal of endometriotic implants or adhesions with restoration of normal anatomy; laparotomy or laparoscopy for any reason; hysterectomy; presacral neurectomy)
- Diagnostic procedures: MRI, Ultrasound , and Pelvic exam
- Laboratory tests
- Genetic markers
- Tissue markers
- Healthcare utilization: clinical visit time and visit type

The process for obtaining reasonable estimates for the data elements listed above will provide insight into how best to formulate an accurate and reliable OHDSI query algorithm. Once our procedure has been refined, we can begin to report similar estimates on a much wider population drawn from the OHDSI network.

## **Conclusion**

In conclusion, we will develop an algorithm that can be used by the OHDSI network to describe epidemiological characteristics of endometriosis. Such characteristics include patient demographics and social history, comorbidities, medications, treatments, diagnostic procedures, laboratory tests, genetic markers, tissue markers, and healthcare utilization. Description of these disease characteristics on a very large and heterogeneous population is vital to better understanding the epidemiology of endometriosis.

## **Conflict on Interest**

The authors report no conflicts of interest.

## **Acknowledgements**

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