

Taking Action on Endometriosis in Canada

Canada's endometriosis health gap

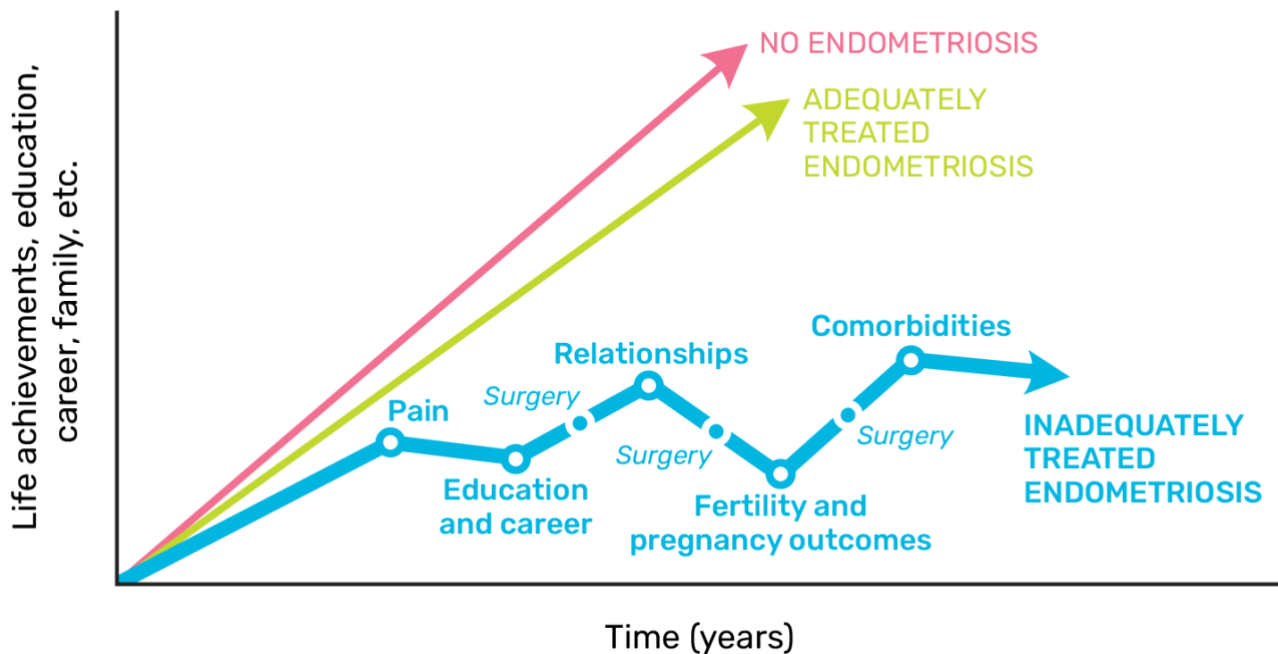
What is endometriosis?

Endometriosis is a chronic condition that affects approximately 1 million people in Canada – 1 in 10 women and unmeasured numbers of transgender and gender nonconforming people. Common symptoms include severe menstrual pain, chronic pelvic pain and infertility. There is neither a definitive cause nor a known cure for endometriosis; the condition is managed using a combination of medical, surgical and supportive care. Despite the burden of endometriosis, awareness of this condition is low because of menstrual stigma and taboo.

What is the impact of endometriosis?

Long waits for diagnosis and difficulties accessing effective treatment lead to years of suffering for many people with endometriosis in Canada, impacting their ability to thrive in life, work and play.

- Average delay to diagnosis in Canada is 5.4 years, but can be as long as 20 years.(1,2)
- Adolescents with symptoms are 10 times as likely to miss school.(3)
- Decreased social and economic participation as well as mental health concerns.(1,4,5)
- Estimated cost of at least \$1.8 billion per year to Canadian society.(6)





How have peer nations mobilized on endometriosis?

Canada has not taken comprehensive action on endometriosis to date, creating knowledge and practice gaps. Peer nations have.

- Australia: In 2018, the Australian government published a National Action Plan for Endometriosis with the objectives of increasing awareness and education about endometriosis, improving clinical management and care, and driving research.(7) The government has committed \$22.5 million to advancing these objectives.(8)
- United Kingdom: In 2020 an All-Party Parliamentary Group recommended a commitment to drive down diagnosis time, access to appropriate care, awareness, and investment in research.(9)
- United States: In 2020, the U.S. House of Representatives passed an amendment doubling annual federal research funding for endometriosis from \$13 million in 2019 to \$26 million.(10)

Potential for impact

By investing in a national endometriosis strategy, Canada will advance patient-centered and evidence-based solutions for the impact of this condition, take a leadership position on gendered health issues, and support the equal and full participation of all people in Canadian life.

References

1. Singh S, Soliman AM, Rahal Y, Robert C, Defoy I, Nisbet P, et al. Prevalence, Symptomatic Burden, and Diagnosis of Endometriosis in Canada: Cross-Sectional Survey of 30 000 Women. *J Obstet Gynaecol Can* [Internet]. 2020 Jan 27 [cited 2020 Feb 6];0(0). Available from: [https://www.jogc.com/article/S1701-2163\(19\)30980-6/abstract](https://www.jogc.com/article/S1701-2163(19)30980-6/abstract)
2. Wahl KJ, Yong PJ, Bridge-Cook P, Allaire C. Endometriosis in Canada: It Is Time for Collaboration to Advance Patient-Oriented, Evidence-Based Policy, Care, and Research. *J Obstet Gynaecol Can* [Internet]. 2020 Jun 2 [cited 2020 Aug 28];0(0). Available from: [https://www.jogc.com/article/S1701-2163\(20\)30472-2/abstract](https://www.jogc.com/article/S1701-2163(20)30472-2/abstract)
3. Suvitie PA, Hallamaa MK, Matomäki JM, Mäkinen JI, Perheentupa AH. Prevalence of Pain Symptoms Suggestive of Endometriosis Among Finnish Adolescent Girls (TEENMAPS Study). *J Pediatr Adolesc Gynecol*. 2016 Apr 1;29(2):97–103.
4. Culley L, Law C, Hudson N, Denny E, Mitchell H, Baumgarten M, et al. The social and psychological impact of endometriosis on women's lives: a critical narrative review. *Hum Reprod Update*. 2013;19(6):625–39.
5. Hansen KE, Kesmodel US, Balduresson EB, Schultz R, Forman A. The influence of endometriosis-related symptoms on work life and work ability: a study of Danish endometriosis patients in employment. *Eur J Obstet Gynecol Reprod Biol*. 2013 Jul 1;169(2):331–9.
6. Levy AR, Osenenko KM, Lozano-Ortega G, Sambrook R, Jeddi M, Bélisle S, et al. Economic burden of surgically confirmed endometriosis in Canada. *J Obstet Gynaecol Can J OGC J Obstet Gynecol Can J OGC*. 2011 Aug;33(8):830–7.
7. Health AGD of. National Action Plan for Endometriosis. Australian Government Department of Health. Available from: <http://www.health.gov.au/internet/main/publishing.nsf/Content/endometriosis>
8. Health AGD of. Endometriosis Progress Report 2021 Update. Available from: <https://www.health.gov.au/sites/default/files/documents/2021/09/endometriosis-progress-report-2021-endometriosis-progress-report-2021-update.pdf>
9. House of Commons - Register Of All-Party Parliamentary Groups as at 11 September 2019: Endometriosis. Available from: <https://publications.parliament.uk/pa/cm/cmllparty/190911/endometriosis.htm>
10. Muller S. House doubles endometriosis research budget with Finkenauer's help. KCCI. 2020. Available from: <https://www.kcci.com/article/house-doubles-endometriosis-research-budget-with-finkenauers-help/33490134>

Updated November 25, 2021 by EndoAct Canada: A pan-Canadian collaboration of people with endometriosis, healthcare providers and researchers working to improve endometriosis awareness, provide information to support evidence-based and patient-centered policy, and link research efforts across Canada.