

Submission to the House of Commons
Standing Committee on Health Study on
Women's Health

Endometriosis in Canada

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Purpose

This submission describes the challenges facing women, transgender, non-binary, and two-spirit people living with endometriosis in Canada. It also highlights opportunities for the federal government to support the more than 1 million Canadians who have this disease by leading coordinated action to ensure timely diagnosis and management.

Endometriosis affects 1 in 10 Canadian women

Endometriosis impacts at least one in ten women and unmeasured numbers of transgender, non-binary, and two-spirit individuals. It is a complex and debilitating chronic disease that occurs when tissue that is like the lining of the uterus implants outside of the uterus to form lesions, cysts, and deep nodules. These growths are inflammatory and can be invasive, resulting in severe distortion of pelvic anatomy and infiltration of the abdominal cavity. Although endometriosis is commonly thought of as a gynecological disease, growths are often found on non-gynecological structures such as bowel, ureters, bladder, diaphragm, and even lymph nodes and the lungs.¹ Left unmanaged, invasive endometriosis can result in life-threatening complications including bowel obstruction and organ death.

There is no definitive cause or a known cure for endometriosis. Symptoms of endometriosis often begin in adolescence and include, but are not limited to, severe menstrual pain, chronic pelvic pain, and infertility as well as whole-body symptoms like fatigue. People with endometriosis also experience high rates of anxiety, depression, and suicidality.² Endometriosis is managed with medication, specialized surgery, and multidisciplinary services depending on the individual's goals and severity of disease.

It takes an average of at least 5 years for an individual to receive a formal diagnosis of endometriosis in Canada.³ In that time, persistent and chronic symptoms associated with endometriosis limit participation in daily life – adolescents with symptoms are 10 times as likely to miss school than their healthy peers, and adults lose 11 hours of work per week.⁴ People with endometriosis also face disruptions to developmental milestones like getting professional training or starting a family, and undergo potentially unnecessary investigations and treatment for other conditions.⁵ This diagnostic delay is in part attributed to low awareness of the disease – many health care providers and members of the public think that the severe pain experienced by women and people with endometriosis is normal.⁶

¹ Leonardi et al. "[Ignored because it is benign – it is time to treat endometriosis as if it were cancer.](#)" JOGC. 42.4 (2020): 507-509.

² Estes et al. "[Depression, anxiety, and self-directed violence in women with endometriosis: a retrospective matched-cohort study.](#)" Am. J. Epidemiol. 190.5 (2021): 843-852.

³ Singh et al. "[Prevalence, symptomatic burden, and diagnosis of endometriosis in Canada: cross-sectional survey of 30 000 women.](#)" JOGC. 42.7 (2020): 829-838.

⁴ Suvitie et al. "[Prevalence of pain symptoms suggestive of endometriosis among Finnish adolescent girls \(TEENMAPS study\).](#)" J Pediatr Adolesc Gynecol. 29.2 (2016): 97-103.; Nnoaham et al. "[Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries.](#)" Fertil Steril. 96.2 (2011): 366-373.

⁵ Hudson et al. "[‘We needed to change the mission statement of the marriage’: biographical disruptions, appraisals and revisions among couples living with endometriosis.](#)" Sociol Health Illn. 1.38 (2016) 721–35; Ballard et al. "[What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis.](#)" Fertil Steril. 86.5 (2006): 1296-301.

⁶ Greene et al. "[Diagnostic experience among 4,334 women reporting surgically diagnosed endometriosis.](#)" Fertil Steril. 1;91 (2009): 32–9.

Once diagnosed, Canadians wait 9 months to 2 years for specialized surgical and chronic pain care.⁷ This timeframe has been extended during the COVID-19 pandemic, causing the endometriosis community to be significantly impacted.⁸ The situation has become so dire that members of the endometriosis community are actively crowdfunding to support individuals seeking international surgical care.⁹ In an article entitled *It Is Time to Treat Endometriosis as if It Were Cancer*, experts agreed, “We, as a medical system, are failing people with endometriosis.”¹⁰

Hundreds of people from across Canada have shared their experiences living with endometriosis on the EndoAct Canada storytelling platform (www.endoact.ca/stories/). We strongly encourage members of the House of Commons Standing Committee on Health to read these stories to directly understand the devastating impact of this disease, and the challenges Canadians with endometriosis face when they try to access the care that they need.

Endometriosis is a societal issue

Endometriosis is not only a health issue affecting individuals, but also a societal issue that requires leadership for a coordinated response. Research shows that the annual cost of surgically-confirmed endometriosis in Canada is \$1.8 billion.¹¹ A significant proportion of this is due to lost productivity, highlighting that people with the disease do not have the support that they need to fully contribute to Canada’s economy.

In all areas of health, there is a recognition that chronic diseases like endometriosis are becoming the leading causes of disability. Compared to asthma, osteoporosis, rheumatoid arthritis, and other chronic diseases that are more common in women than men, endometriosis has received less attention and investment. Federally, endometriosis is not included in the Canadian Chronic Disease Surveillance System, and the Canadian Institutes of Health Research (CIHR) have not invested in endometriosis as a priority area. At the provincial level, endometriosis is not consistently included as a chronic disease eligible for premiums in medical services schedules of benefits and fees, and multidisciplinary services for chronic pelvic pain are scarce. Within hospitals, surgeons with the expertise to operate on endometriosis (i.e. completion of a minimally invasive gynecologic surgery fellowship) have limited access to operating rooms and other necessary resources. The consequence for Canadians with endometriosis is that from bench to bedside, insufficient resources are available for their health across the lifespan.

Peer nations have recognized the challenges faced by people living with endometriosis and are taking action. In 2018, the Australian government launched a National Action Plan for Endometriosis and has committed \$22.50 million to awareness and education, clinical management and care, and research.¹² In 2022, France announced a National Strategy Against

⁷ Wahl et al. "[Endometriosis in Canada: It is time for collaboration to advance patient-oriented, evidence-based policy, care, and research.](#)" *JOGC*. 43.1 (2021): 88-90.

⁸ Ashkenazi et al. "[COVID-19 pandemic and the consequential effect on patients with endometriosis.](#)" *Hum Reprod Open*. 2 (2022): hoac013.

⁹ Neustaeter. "[‘Giving these women their lives back’: Canadian starts fund to help those struggling with endometriosis get care abroad.](#)" *CTV News*. (2021).

¹⁰ Leonardi et al. *JOGC*. 42.4 (2020): 507-509.

¹¹ Levy et al. "[Economic burden of surgically confirmed endometriosis in Canada.](#)" *JOGC*. 33.8 (2011): 830-837.

¹² Commonwealth of Australia. "[National action plan for endometriosis.](#)" (2018); Commonwealth of Australia. "[Endometriosis progress report.](#)" (2021).

Endometriosis, with the objectives to lead endometriosis research and innovation, guarantee timely diagnosis and access to quality care, and raise awareness of the disease.¹³

Endometriosis is also a priority identified in the Scottish Women’s Health Plan 2021 – 2024 and the 10-year Women’s Health Strategy for England published in 2022.¹⁴ A similar Pan-Canadian model must be supported to address the neglect of people with endometriosis in this country. It is our turn to step forward as a leader on this issue.

Taking coordinated action on endometriosis aligns with current government commitments and policies. EndoAct is supportive of the mandate priority to ensure that *all* Canadians have access to sexual and reproductive health services they need, no matter where they live, through actions such as developing a sexual and reproductive health rights information portal, supporting mechanisms for families to cover the costs of in vitro fertilization, and supporting youth-led grassroots organizations that respond to the unique sexual and reproductive needs of young people in Canada.¹⁵ EndoAct is also encouraged that as part of Budget 2021, funding of up to \$45M over three years will be distributed by Health Canada through the Sexual and Reproductive Health Fund to support access to sexual and reproductive health care information and services.¹⁶ EndoAct is hopeful that recent one-year women’s health funding opportunities from the CIHR are indicative of an intention to make long-term investments in this portfolio.¹⁷

Recommendations

Although the federal government is not responsible for health care delivery, it has the opportunity to address the substantial burden of endometriosis through health promotion, research, disease monitoring, and funding support. Importantly, the government can also convene partners to ensure coordinated action is taken on this disease.

The following key policy priorities should be considered by the House of Commons Standing Committee on Health during this reporting stage to better support the health of those living with endometriosis:

- Consultation with the Canadian endometriosis community to understand gaps and barriers to endometriosis diagnosis and treatment.
- Development of a comprehensive plan to address endometriosis, in line with commitments made by peer nations and responsive to the priorities of Canadians living with this disease.
- Initiatives to offer more professional training on endometriosis for health care providers and to promote public endometriosis awareness.
- Meaningful, sustained, and strategic funding for endometriosis research that focuses on patient-identified priorities and measures patient-important outcomes across all areas of health research.

¹³ République Française. “[Stratégie nationale de lutte contre l'endométriose.](#)” (2022).

¹⁴ All-Parliamentary Group on Endometriosis. “[Endometriosis in the UK: time for change.](#)” (2020); UK Government. “[Women’s health strategy for England.](#)” (2022); Scottish Government. “[Women’s health plan: A plan for 2021-2024.](#)” (2021).

¹⁵ Prime Minister of Canada. “[Minister of health mandate letter.](#)” (2021); Prime Minister of Canada. “[Minister of women and gender equality and youth mandate letter.](#)” (2021).

¹⁶ Department of Finance Canada. “[Budget 2021: A recovery plan for jobs, growth, and resilience.](#)” (2021).

¹⁷ CIHR. “[Women’s health clinical mentorship grant.](#)” (2020); CIHR. “[Women’s health research – early career researcher grant.](#)” (2022).

- Prioritization of endometriosis in the development and implementation of a national survey on sexual and reproductive health by Statistics Canada, included in Budget 2021, and in chronic disease monitoring initiatives.
- Provisions for endometriosis in transfer funding agreements, particularly to enable meaningful improvements in access to expert surgical and multidisciplinary care.

Conclusion

The submission was prepared by EndoAct Canada, in partnership with our co-founding organizations The Endometriosis Network Canada (TENC) and The Canadian Society for the Advancement of Gynecologic Excellence (CanSAGE). EndoAct Canada is an unincorporated not-for-profit organization with the goal of driving action on endometriosis in Canada. TENC is the first patient-led, registered charity in Canada dedicated to raising awareness of endometriosis and providing support and educational resources to those it affects. CanSAGE is a professional society with a mission to promote and maintain high standards of excellence in the diagnosis and management of complex gynecologic conditions including endometriosis. By bringing those living with endometriosis together with health care providers and researchers, we represent a collective Pan-Canadian expertise on this disease. Together, we are raising awareness about issues facing the endometriosis community in Canada, as well as solutions to ensure that those in Canada who have endometriosis get the right care, in the right place, at the right time.

EndoAct Canada would like to thank the House of Commons Standing Committee on Health for the invitation to participate in the study on women's health. We would also like to thank Emily Rowan and all the EndoAct volunteers for contributing their diverse expertise as people living with endometriosis, health care providers, and researchers to this brief. Together with TENC and CanSAGE, EndoAct is well-positioned to offer our subject matter expertise on measurable, achievable short-term actions to support long-term transformational change in women's health. We would be happy to appear before the House of Commons Standing Committee on Health, and to participate in the 2023 federal budget consultation.

EndoAct Canada, TENC, and CanSAGE look forward to the federal government taking action to support the more than one million people in Canada who suffer with endometriosis. Taking action on endometriosis will help ensure that women, transgender, non-binary, and two-spirit individuals suffering with the disease can access the care they need and thrive at work, at home, and in our communities.