

# **Discussion: The need for action on endometriosis in Canada**



# Introduction

- Background material prepared by EndoAct Canada
- For information about the need for a national action plan on endometriosis, please contact EndoAct Canada, [info@endoact.ca](mailto:info@endoact.ca)

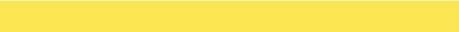
# What is endometriosis?

- Endometriosis is a complex and debilitating chronic disease that occurs when tissue similar to the lining of the uterus implants outside of the uterus to form lesions, cysts, and deep nodules.
- Symptoms often begin in adolescence and may include severe menstrual cramps, chronic pelvic pain, pain during sex, fatigue, and infertility.
- No definitive cause or known cure exists for endometriosis.
- Endometriosis is managed using a combination of surgical, medical, and supportive care.



## Current endometriosis care in Canada

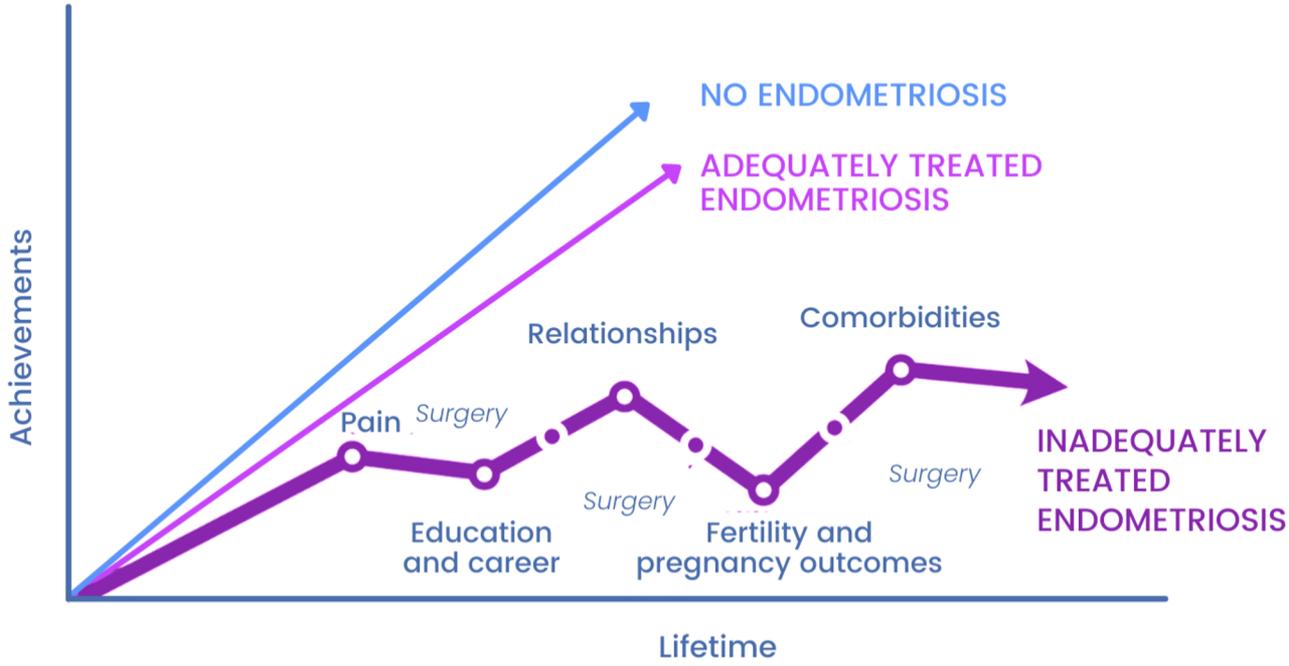
- The average delay to diagnosis in Canada is 5.4 years, and can be as long as 20 years.
- Low awareness of the disease among health care professionals and the public contributes to delayed diagnosis.
- Wait times for specialised surgical and chronic pain care are 6-24 months or longer depending on the province.
- People with endometriosis in Canada are seeking care internationally.



## Consequences of inadequate care

- Adolescents with symptoms are 10 times as likely to miss school.
- Adults with endometriosis lose almost 11 hours of work per week.
- People with endometriosis experience high rates of anxiety, depression, post-traumatic stress, and suicidality.
- Surgically confirmed endometriosis costs \$1.8 billion per year to Canadian society.

# Consequences of inadequate care



## Recommendations

- Support the creation of a ***Canadian National Action Plan for Endometriosis*** to address the substantial burden and cost of endometriosis through funding support and health promotion.
- Consult with the Canadian endometriosis community to develop a national action plan that reflects patient-important priorities and outcomes.
- Consider policies of peer nations to address endometriosis, including the Australian National Action Plan for Endometriosis, as well as strategies proposed in France, England, and Scotland.

# Thank you

## Endometriosis & Its Impact

- Singh et al. "[Prevalence, symptomatic burden, and diagnosis of endometriosis in Canada: cross-sectional survey of 30 000 women.](#)" Journal of Obstetrics and Gynaecology Canada 42.7 (2020): 829-838.
- Wahl et al. "[Endometriosis in Canada: it is time for collaboration to advance patient-oriented, evidence-based policy, care, and research.](#)" Journal of Obstetrics and Gynaecology Canada 43.1 (2021): 88-90.
- Neustaeter. "['Giving these women their lives back': Canadian starts fund to help those struggling with endometriosis get care abroad.](#)" CTV News. (2021).
- Suvitie et al. "[Prevalence of pain symptoms suggestive of endometriosis among Finnish adolescent girls \(TEENMAPS study\).](#)" Journal of pediatric and adolescent gynecology 29.2 (2016): 97-103.
- Nnoaham et al. "[Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries.](#)" Fertility and sterility 96.2 (2011): 366-373.
- Estes et al. "[Depression, anxiety, and self-directed violence in women with endometriosis: a retrospective matched-cohort study.](#)" American journal of epidemiology 190.5 (2021): 843-852.
- Levy et al. "[Economic burden of surgically confirmed endometriosis in Canada.](#)" Journal of Obstetrics and Gynaecology Canada 33.8 (2011): 830-837.

## Endometriosis Policy in Peer Nations

- Commonwealth of Australia (Department of Health). "[National action plan for endometriosis.](#)" (2018).
- Commonwealth of Australia (Department of Health). "[Endometriosis progress report.](#)" (2021).
- République Française (ministre des Solidarités et de la Santé). "[Lancement d'une stratégie nationale contre l'endométriose.](#)" (2022).
- All-Parliamentary Group on Endometriosis. "[Endometriosis in the UK: time for change.](#)" (2020).
- UK Government (Department of Health and Social Care). "[Our vision for the women's health strategy for England.](#)" (2021).
- Scottish Government (Ministry for Minister for Public, Health, Women's Health and Sport). "[Women's Health Plan: A plan for 2021-2024.](#)" (2021).