Examining Canada’s Policy Desert: Interventions for Chronic Pelvic Pain

by

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Abstract

Chronic pelvic pain (CPP) presents a significant public health challenge in Canada among people with uteruses (PWU) yet remains inadequately addressed within our healthcare system. This capstone explores the dimensions of CPP, proposing a national action plan to enhance quality of life for PWU. Through qualitative interviews with PWU experiencing CPP and a comparative analysis of Australia's National Action Plan for Endometriosis, this research combines these insights to inform the Canadian case. Findings underscore the urgency for interventions in the domains of menstrual pain normalization, health literacy, loss of income, and experiences with healthcare providers. Canada’s proposed plan encompasses a range of policy initiatives aimed at improving awareness and education, diagnosis, treatment, and support services for individuals affected by CPP, including considerations for employment and income support. By implementing targeted policy interventions, Canada can mitigate the consequences of CPP and promote equitable access to services for PWU experiencing CPP.

Keywords: Chronic pelvic pain; healthcare; gender

Dedication

I dedicate this work to every person told their menstrual pain was normal. To the people who missed classes, birthday parties, graduations, and so much more because of pain they were told was part of having a uterus.

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I would like to thank my supervisor, Mohsen, for all his support throughout this process. Mohsen – I came to you with what felt like an unattainable topic to research, thank you for seeing the importance of what I had to say, and encouraging me to pursue it. I put my heart and soul into this research, and I thank you for seeing that and meeting me with guidance and kindness. Thank you for seeing the potential in this work.

To my family, I can't say enough. Thank you for supporting me in undertaking such a niche research topic – it's not an easy one for dinner tables and family reunions! Thank you for guiding me through my own pelvic pain, and encouraging me to take my experiences beyond myself, and make them into something bigger, and more important. Mom – I remember you telling me once "there's two ways to get to the top of an oak tree: you can sit on an acorn and wait for it to grow, or you can climb it." – thank you for helping me climb it. Dad – thank you for always being my biggest fan and learning to be the best pelvic pain ally I could ever hope for.

Lastly, I would like to acknowledge all of participants who made this research possible. Thank you for taking the time to talk to me and be vulnerable about a topic we're told to never speak of from such a young age. Thank you for trusting me with your stories, struggles and hopes for the future. Looking back at the quotes I selected for this research, I hear your voices, courage, and strength in every single one. I learned something from every single one of you.

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List of Acronyms

AI	Artificial Intelligence
AUD	Australian Dollars
CCDSS	Canadian Chronic Disease Surveillance System
CDC	Centre for Disease Control
CHT	Canada Health Transfer
CIHR	Canadian Institutes for Health Research
CPGs	Clinical Practice Guidelines
CPP	Chronic Pelvic Pain
CPP-D	Canada Pension Plan – Disability
CPA	Canadian Pain Association
DTC	Disability Tax Credit
ED	Emergency Department
ESDC	Employment and Social Development Canada
GP	General Practitioner
GPPD	Genito Penetration Disorder
HCP	Healthcare Provider
HR	Human Resources
IUD	Intrauterine Device
IT	Information Technology
IPPS	International Pelvic Pain Society

MHCC	Mental Health Commission of Canada
MOC	Models of Care
MRFF	Medical Research Future Fund
NAPE	National Action Plan for Endometriosis
NAP	National Action Plan
NGSHE	National Guidelines for Sexual Health Education
NSAIDs	Non-Steroidal Anti-Inflammatories
PHAC	Public Health Agency of Canada
PCOS	Polycystic Ovarian Syndrome
PPEP	Period, Pain and Endometriosis Program
PP	Period Pain
PPFA	Pelvic Pain Foundation of Australia
PPP	Persistent Pelvic Pain
PTO	Paid Time Off
PWU	People With Uteruses
RANZCOG	Royal Australian and New Zealand College of Obstetricians & Gynaecologists

SHE	Sexual Health Education
SDoH	Social Determinants of Health
SIECANN	Sex Information & Education Council of Canada
SOGC	Society of Obstetricians and Gynaecologists of Canada
STI	Sexually Transmitted Infection
UBC	University of British Columbia
WFH	Work From Home

Executive Summary

Chronic pelvic pain (CPP) poses a significant public health challenge in Canada, particularly among people with uteruses (PWU). Despite its prevalence and debilitating impact on individuals' quality of life, CPP remains an underrecognized and inadequately addressed health issue within Canada's struggling healthcare system. This capstone aims to explore the multifaceted dimensions of CPP and propose a comprehensive national action plan to improve overall quality of life among PWU in Canada.

CPP represents a critical policy problem within the larger landscape of Canada's healthcare system due to its pervasive impact on quality of life among PWU who already face discrimination within the healthcare system. This research highlights the complex challenges faced by individuals with CPP, including considerable menstrual pain normalization, low health literacy, poor mental health outcomes, inability to perform vocational tasks, challenges in accessing income assistance, and overall negative experiences when interacting with healthcare providers. These findings underscore the urgent need for targeted interventions to address the unique needs of individuals affected by CPP and mitigate its adverse consequences on physical, emotional, and socioeconomic well-being.

In addition to qualitative interviews with PWU who experience CPP, this research project conducts a comparative analysis of Australia's National Action Plan for Endometriosis (NAPE). Australia's piloted NAPE provides valuable insights for the creation of Canada's national action plan for chronic pelvic pain, particularly given their recent (2023) progress report. By examining Australia's approach to addressing endometriosis, including strategies for raising awareness, improving diagnosis and treatment, and enhancing support services, this research seeks to identify key learnings and adapt them to the Canadian context, and applied to CPP more broadly. In other words, by way of comparative analysis, this research aims to leverage international evidence and expertise to develop a comprehensive and effective national action plan for chronic pelvic pain in Canada, ultimately improving outcomes and quality of life for PWU. Moreover, this research examines policies not explored by Australia’s NAPE, including considerations for employment and income support, to create a robust and holistic policy for PWU in Canada. Additionally, interview findings reveal systemic issues such as menstrual pain normalization, low health literacy, and negative experiences with

healthcare providers exacerbate the challenges faced by individuals with CPP, underscoring the need for comprehensive policy reforms.

The proposed national action plan for CPP in Canada encompasses a range of policy initiatives aimed at improving awareness, diagnosis, treatment, and support services, namely, income support, for individuals affected by CPP. Key components of the action plan include: Enhancing public awareness and education campaigns to challenge menstrual pain normalization and promote early recognition of CPP symptoms among targeted groups, implementing standardized diagnostic protocols and referral pathways to ensure timely and accurate diagnosis of CPP, amending disability income support policies to better include CPP and other chronic conditions, and promoting coordinated research efforts on topics of CPP.

By implementing targeted policy interventions and systemic reforms, Canada can mitigate the adverse consequences of CPP and promote equitable access to healthcare services for PWU affected by this condition.

Due to the constraints of this capstone, the number of policies will be lesser than the Australian case, however, a comprehensive analysis of available data provides a key starting point for future policy action in this area. The time and resources afforded to this research are incomparable to those afforded to the Australian plan, thus although detailed and robustly analyzed, the number of proposed policies operates on a smaller scale. Attempts to recruit interviewees with a professional-medical perspective on CPP were made, however no interviewees were available. To fulfill this perspective, clinical practice guidelines (CPGs), among other available diagnostic tools were consulted. Future research on this topic, including the creation of a national action plan for CPP in Canada should integrate this missing perspective to better capture the landscape of CPP in its entirety. Other limitations of this research include under-representation of non-female identifying PWU who experience CPP among interviewees, leaving the non-cisgendered perspective under-discussed. The smaller population size included in this research represents another limitation of this research.

Chapter 1.

Introduction

Chronic pelvic pain (CPP) represents a pervasive and debilitating health concern affecting a significant number of individuals in Canada. Data collected by Katz et al (2021) found that anywhere from 14-24% of women of childbearing age will experience CPP during their childbearing years. This analysis considers the subject group of people with uteruses (PWU) more broadly to include non-binary, transgender, and other gender diverse identities.

The most widely adopted definition of chronic pelvic pain defines the condition as pain occurring in the pelvic region persisting for at least six months (EndoNetwork 2022). The impacts of this complex and often poorly understood condition extend beyond mere physical discomfort, encompassing various aspects of an individual's life, including emotional well-being, interpersonal relationships, and overall quality of life.

The prevalence of chronic pelvic pain in Canada constitutes a matter of considerable concern given its effects on individuals of all ages, genders, and socio-economic backgrounds. Its diverse etiology, which may involve gynecological, gastrointestinal, urological, and musculoskeletal factors, further complicates both diagnosis and treatment subsequently delaying or prohibiting the dissemination of pain management and quality of life amelioration to PWU. The multifaceted nature of CPP demands a comprehensive and interdisciplinary policy approach to address the intricacies of its origins and the unique, multiplicative experiences of those affected.

Beyond physical and mental distress, CPP imposes economic consequences at both the societal and individual levels. CPP poses considerable financial burdens to medical systems globally, largely attributable to complex and delayed diagnostic processes coupled with lasting and persistent pain. Canadian hospital costs associated with CPP alone amount to over $25 million annually, with clinical, ambulatory, outpatient care, and treatment incurring additional costs (Chen et al 2016). Moreover, surgically confirmed endometriosis alone costs an estimated $1.8 billion dollars annually (Levy et al 2011). On the individual level, an Australian study reported that PWU experiencing

CPP missed on average ten paid hours of work per week directly related to their CPP and accompanying symptoms (Armour et al 2019).

Despite the prolific nature of CPP, Canada possesses no formal national action strategy directed toward CPP diseases as of 2023 (Endometriosis Network 2022). Correspondingly, the broad area of CPP comprises a policy desert with thousands of individuals experiencing negative health and social outcomes, while paradoxically receiving insufficient support from the medical system and other services. In 2018, Australia piloted the first national action plan strategy specifically targeting CPP and endometriosis (Australian Government 2018). Subsequently, The United Kingdom, Scotland, New Zealand and France have tabled similar initiatives. However, the Australian case remains the most advanced with numerous initiatives already underway over the last five years and with available progress reports documenting successful strategies. As such, this research calls for a necessary action plan model for the Canadian context to better support PWU experiencing CPP on a holistic level.

With considerable PWU living in Canada destined to experience CPP in their lifetimes, the impetus for supportive policies is clear. CPP occupies an established space in scientific and quantitative literature, however, qualitative inputs from topical experts, including those with lived experiences remain under-examined, particularly in a policy context. This research utilizes an analysis of Australia's Action Plan policies coupled with qualitative interview data from PWU experiencing CPP and professionals working in a CPP adjacent field. Using a combined analysis of available data from Australia and interview data, this research compiles and proposes a national action plan addressing the following three key areas for CPP policies: education and awareness, improving experiences with the medical system, and lastly, economic support for PWU experiencing CPP.

This research positions CPP within a biopsychosocial framework extending beyond an exclusively clinical context. The clinical symptoms associated with CPP etiologies lead to negative lived experiences among those affected, inextricably tethering the condition with lived social realities. CPP debilitates PWU at various frequencies and rates, resulting in precarious employment, loss of income, and fractured interpersonal relationships. Data from Australia found that women experiencing chronic pelvic pain missed an average of 10 paid hours of work per week because of their CPP, or rather, 25% of their weekly income (Armour et al 2019). Moreover, an American study found that 26-52% and 39-75% of CPP patients experienced depression and anxiety respectively (Till et al 2020). Comparably, less than 15% of the general population experience mental illness. The effects of CPP will be discussed in more detail in subsequent sections of this study. In other words, the effects of CPP transcend individual, isolated instances of pain, incurring profound negative impacts on basic quality of life.

This research reviews the literature surrounding CPP to establish understanding of key issues and themes pertaining to CPP and subsequently, outlines Australia's existing action plan for CPP. Used in chorus with considerations from Australia's National Action Plan for Endometriosis (NAPE), qualitative interviews provide necessary qualitative insights into to the needs of PWU experiencing CPP to architect a national action plan for Canada.

Chapter 2. Background

2.1. What is Chronic Pelvic Pain?

CPP is widely defined as “pain occurring in the pelvic region, persisting for at least six months,” with pain ranging from persistent to intermittent (Endometriosis Network 2022). Encompassed within the term CPP are a broad range of diseases ranging in severity, treatability, and duration (Uppal et al 2011). Further, pain symptoms may manifest in relation to menstruation and intercourse, however, many PWU experience these symptoms irrespective of them both (Uppal et al 2011). The operational definition of CPP excludes pains exclusively associated with pregnancy, although existing CPP conditions may manifest during this time (Vincent 2009).

Among the most common CPP diseases is endometriosis, a condition where endometrial tissue deposits, termed legions, grow outside of the uterus resulting in severe pain and heavy bleeding. Although underreported and under-diagnosed, current figures suggest that endometriosis affects 1 in 10 women, and an unknown number of non-binary and transgender peoples. Some researchers speculate higher prevalence of endometriosis nearing 45% given that existing figures rely on surgical diagnoses, which are systematically under-performed for PWU experiencing CPP (Singh et al 2020). Irrespective of which CPP disease may be present, poor outcomes are shared among PWU: worsened quality of life, sleep dysfunction, depression, anxiety, stress, loss of income and issues with sexual and social functioning (Katz et al 2021). In other words, the presence of CPP overlaps with physiological comorbidities and personal consequences amassing toward a diminished quality of life.

2.2. The State of Chronic Pelvic Pain in Canada

Data collected in 2021 found that 14-24% of Canadian women experience CPP during their childbearing years, thus implicating a significant segment of the national population (Katz et al 2021). An unknown number of non-binary, intersex and transgender individuals also experience CPP. Despite the prevalence of CPP among PWU in Canada, CPP diseases remain unaccounted for within the Canadian Chronic Disease Surveillance System (CCDSS), and thus, current, and predicted trends proceed untracked. Tasked with tracing the morbidity and mortality, health events and complications, and use of health services, the CCDSS provides policy levers, medical professionals, and other key actors with critical information for addressing the health needs of Canadian residents. The exclusion of CPP diseases within the CCDSS prohibits such monitoring, thereby hindering policy advancement propelled by and rooted in annual data. Furthermore, none of the thirteen Canadian Institutes for Health Research (CIHR) recognize chronic pelvic pain as a priority area, including the Institute for Gender and Health. The scarce recognition of CPP within Canada's health monitoring and research priorities places PWU who experience CPP within a policy desert, or rather, on the margins of a health care system failing to dedicate resources to their health.

Since 2020, both the EndoAct advocacy group and McGill University Health Centre put forward submissions to the Canadian House of Commons Standing Committees on Health Study on Women's Health and the Standing Committee on Health respectively. Both documents focus on endometriosis specifically, calling for imminent policy action to promote improved health outcomes for those experiencing the disease. However, calls to action may be broadened to include different manifestations of CPP beyond endometriosis and improve the lives of PWU. Several key themes emerge from these documents: the need for increased resource allocation toward clinical outcomes and research undertakings to better understand endometriosis etiology, and the need for a coordinated nationwide response to address the unique needs of those experiencing endometriosis. EndoAct specifically calls for consultation and collaboration with those who have lived experiences with endometriosis in their submissions to the House of Commons, an initiative undertaken by this research. These parliamentary submissions demonstrate a robust non-governmental commitment towards ameliorating the overall quality of life for PWU experiencing endometriosis. This research recognizes these themes and broadens these initiatives to include PWU experiencing CPP including, but not limited to, endometriosis.

2.3. Chronic Pelvic Pain in the Larger Healthcare Context

Although under provincial jurisdiction, challenges with the healthcare system remain consistent across all provinces, indicative of larger systemic issues Since the 2020 COVID-19 pandemic, Canadians report rising concerns over the state of the healthcare system according to a 2023 survey conducted by the Environics Institute and partners (Perrot 2023). Concerns over wait times, physician access, and meeting health care needs prevail, with corresponding shortages of primary healthcare providers (PHPs) contributing to all those issues (Flood et al 2023). Statistics Canada (2023) reports that in 2021, 14.4% of Canadians lacked a regular health care provider, such as a general practitioner (GP), nurse practitioner, family doctor, etc., often forcing these individuals to obtain basic medical care through emergency departments (EDs). Among those with regular health care providers, 58.3% reported waiting less than three days to see their health care providers for minor health problems. Across all age groups, except 50-64 years, women were more likely than men to wait more than three days to obtain care, and racial minorities also experienced longer wait times compared to their non-racialized counterparts (Statistics Canada 2023). Similarly, Statistics Canada (2023) reported women were three percentage points more likely than men to report unmet healthcare needs, indicating that within the last year, they wanted health care but did not receive it. Overall, Canada's healthcare system faces numerous challenges in its capacities to provide reliable, timely, and sustained care for patients.

These findings from Statistics Canada (2023) demonstrate the disproportionate effects of Canada's healthcare system failures on women. Although non-female identifying PWU experience CPP, women comprise most of this population. Statistics Canada makes no specific mention of transgender, intersex, or non-binary experience sin relation to the aforementioned healthcare challenges, however, all other minoritized groups reported disproportionately negative outcomes in relation to these shortcomings. Correspondingly, these healthcare disparities inevitably intersect with CPP to the detriment of PWU. For women with CPP, delays in accessing PHPs lead to missed opportunities for early intervention, diagnosis, symptom management ultimately leading to a diminished quality of life. This report makes periodic references to challenges with Canada's healthcare system in relation to CPP throughout the various components.

2.4. Why Chronic Pelvic Pain?

Several diseases, including CPP, pose challenges for Canadians. However, the specific issue of CPP merits policy action for several key reasons. Firstly, CPP affects women and other gender minorities including transgender and non-binary individuals. Coupled with a healthcare system predisposed to gender discrimination, the domain of

CPP especially exacerbates gender inequality. Although CPP fundamentally stems from sex differences, that is, biological differences between males and females, the corresponding gender inequities render the healthcare experiences of PWU an inequitable reality. Perceptions of female pain rooted in deeply entrenched gender norms lead to tangible instances of gender discrimination in healthcare including infrequent screening for diseases and less aggressive treatment (Heise et al 2019). The role of gender in relation to perceptions of pain, and thus quality of care, will be discussed in future sections of this study. Given the inextricable relationship between CPP and gender disparities in healthcare, a clear pathway for policy intervention emerges to mitigate harms to PWU.

The prevalence of CPP among PWU of childbearing age also signifies economic consequences for individuals and the economy. With up to 24% of women in their childbearing years experiencing CPP, workforce participation among women may correspondingly suffer due to heightened absenteeism and productivity (Katz et al 2021; Armour et al 2020). Statistics Canada (2023) reports a lower employment rate and labour force participation rate among women compared to men, sitting at 58.4% and 61.6% respectively. Already underrepresented in the workforce, the added layer of CPP-related inequalities supplies an additional gendered barrier to the workforce. At the individual level, the prevalence CPP uniquely predisposes women, non-binary, intersex, transgender, and all other PWU to income loss. In this way, CPP again penalizes PWU resulting in personal income loss, thereby interacting with larger issues of pay inequality and poverty (Heise et al 2019). The overall societal and personal economic challenges associated with CPP and their primary effect on women in addition to transgender, nonbinary and intersex PWU unveils impetus for policy work to alleviate the economic hardships associated with CPP. These efforts, moreover, operationalize a further avenue for gender-equity within the overlapping domains of healthcare and economics.

Addressing CPP through coordinated policy responses will strengthen Canada's response to chronic conditions overall. Although a strong case compels a national focus on pelvic pain for the aforementioned reasons, promoting interdisciplinary collaboration across the social, medical, and economic fields to holistically address CPP provides Canada with a replicable framework to address other diseases particularly effecting equity-deserving groups. In other words, the interdisciplinary framework researched and proposed in this report may be extrapolated for analogous medical conditions affecting

Canadians. A reproducible, robust biopsychosocial model for disease management stands to benefit other populations than solely PWU. In subsequent sections, this report references opportunities to utilize existing analogous frameworks to address CPP and identifies opportunities for policies to address more than one health issue.

Chapter 3. Literature Review

The following section surveys literature on various topics surrounding CPP. Themes found in Australia's NAPE largely informed the topics included below: the medical perspective, particularly concerned with diagnostics and treatment, sexual health education, and research. Literature on these topics creates a robust foundation for interpreting qualitative interview data, but moreover, developing a profound understanding of current standards regarding the respective themes. Two additional sections were included, concerning the economic impacts of CPP and biases encountered by PWU. Although monumental int its inception, the Australian NAPE fails to recognize the economic impacts of CPP at the individual and societal levels, and the biases which may underlay experiences with health care systems. The effects of CPP extend beyond clinical contexts, bearing notable consequences for PWU in their day-to-day lives. Including these themes into a Canadian national action plan allows for a more holistic strategy to address CPP.

3.1. The Medical Perspective

3.1.1. The Diagnostic Delay

The term diagnostic delay refers to the time interval between the onset of clinical symptoms and diagnosis (Ballard 2006). Extended diagnostic delays amounting to years are characteristic of CPP across the world, generally lasting anywhere from 3-11 years in duration (Singh et al 2020). In Canada, data indicates that those living with CPP experience a diagnostic delay of 5.4 years on average, however, many PWU face extended delays surpassing ten or more years (Singh et al 2020). Notably, many PWU experience pain prior to declaring their formal symptom onset, often not yet conceptualizing their pain to be abnormal due to profound normalization processes. Resultingly, PWU inadvertently hinder their own diagnoses simply by not recognizing their pain as abnormal and seeking medical help accordingly.

The prompt recognition of symptoms lies at the bedrock of combating diagnostic delays: many PWU struggle to differentiate between normal and abnormal pain, due to the widespread normalization of pain, particularly associated with menstruation and thus delay seeking medical attention (Ballard 2006). A study employing qualitative interviews by Ballard (2006) found that in addition to individual pain normalization, PWU experienced similar outcomes when interacting with the medical system. Participants noted that physicians echoed familial and societal normalization practices, suggesting that pain remained a typical menstrual symptom (Ballard 2006). Normalization practices are a key component to understanding the lived realities of PWU experiencing CPP and will be discussed in greater deal in section 3.3. Furthermore, findings revealed that many participants were prescribed oral contraception to mask, rather than succinctly diagnose, their symptoms, further delaying the diagnostic process (Ballard 2006). A clear link between pain normalization and diagnostic delays for CPP exists: the socio-medical conditions rooted in the belief that menstruation *should* be painful result in delayed help-seeking. Based on these findings, the need for increased health literacy on the individual level, coupled with a denormalization of CPP at the systemic level is clear.

Diagnostic delays invite notable consequences for PWU experiencing CPP, including an overall decreased quality of life (Wahl et al 2021). Wahl et al (2021) found that diagnostic delays result in tremendous loss to PWU experiencing CPP: loss of interpersonal relationships, employment, quality of life, and in some cases, the ability to have children. These "losses" outlined by Whal et al (2020) frequently lead to adverse mental health outcomes, further contributing to diminished quality of life. A qualitative study of ten Canadian women reiterates these trends, finding that participants felt "adrift" in the healthcare system when attempting to access care for their CPP (Bosma et al 2022). Bosma et al (2022) reported these feelings often stemmed from fatigue associated with trying various treatment programs without simultaneous diagnostic investigations taking place.

Other factors contributing to diagnostic delays include a lack of accurate, non-invasive diagnostic tools for CPP (Davenport et al 2023). In other words, the complex etiologies of CPP pose challenges for HCPs in making concrete diagnoses with corresponding treatment regimes. Davenport et al (2023) identify two key issues associated with this unfulfilled diagnostic gap: firstly, the misuse of insufficient investigations used to inappropriately rule out endometriosis. Specifically, Davenport et al (2023) report a misuse of insufficient investigations, such as ultrasound, which cannot reliably rule out certain CPP diagnoses, including endometriosis. Consequently, PWU find themselves undergoing various diagnostic procedures which provide minimal insight into their CPP. The second issue related to a lack of accurate, non-invasive diagnostic tools stems from concerns over performing laparoscopic surgeries, thus presenting patients with unnecessary risks (Davenport et al 2023). Davenport et al (2023) reveal that physician uncertainty over making surgical referrals contributes to these trends. In this capacity, greater research efforts, including transnational collaborations with countries already investigating these technologies, are needed to bridge this specific diagnostic issue.

3.1.2. Treatment Options

In 2010, the Canadian Society of Obstetrics and Gynecologists released a national CPG for endometriosis identifying key diagnostic trajectories: firstly collecting a robust patient history, physical and imaging assessments, followed by administering hormonal treatments as a first line of defense and surgical procedures if all other hormonal treatments have failed (Leyland et al 2010). These findings resonate with those reported by Hunt et al. (2021) who identify the necessary steps prior to prescribing and administering treatment: first, collecting a detailed patient history, mapping, and describing their pain, followed by a physical examination to identify pain zones and visible abnormalities, and lastly, investigation via abdominal and/or transvaginal ultrasound. Treatment options for CPP often adopt an interdisciplinary approach calling upon hormonal, surgical, analgesic, physiotherapeutic, and psychological interventions (Speer et al 2016).

The International Pelvic Pain Society (IPPS) developed a pelvic pain mapping and patient history form including guidelines for physical examination. However, these documents remain solely accessible to physicians. Speer et al. (2016) summarize the key findings from the IPPS physical examination and patient history guide and identify specific diseases with which these symptoms may be related. Of the twenty listed potential findings, and their potential diagnoses, only five findings received the “red flags for serious systemic disease,” none of which are associated with endometriosis, polycystic ovarian syndrome (PCOS), and other common CPP diseases prevalent among PWU in their childbearing years (Speer et al 2016). Speer et al. (2016) identify improving patient quality of life as the foremost goal of treatment. Furthermore, in 2021, the International Journal of Obstetrics and Gynecology (Mardon et al 2021) published a systematic review of international clinical practice guidelines for females with persistent pelvic pain (PPP). In this publication, Mardon et al (2021) analyze a total of 20 guidelines spanning an array of PPP diseases and countries, identifying key areas for clinical practice guidelines (CPGs). These guidelines also center around improving quality of life among PWU. Lastly, Canada boasts its own CPG for endometriosis created by the Society of Obstetricians and Gynecologists of Canada (SOGC) created in 2010 outlining best-practices (Leyland et al 2010). Notably, the Canadian CPGs focus only on endometriosis and are over a decade old and could benefit from updates.

Mardon et al (2021), Leyland et al (2010), and Speer et al (2016) identify common pathways for CPP treatments. Medications and pharmaceutical interventions comprise the first line of defense in the treatment of CPP including the prescription of analgesics, including nonsteroidal anti-inflammatories (NSAIDs), hormonal contraception (including the pill, intrauterine devices [IUDs], and injections), and psychiatric medications to treat neuropathic pain (Speer et al 2016; Mardon et al 2021). Individual patient needs determine corresponding treatment regimes, however, if no confirmed diagnosis exists, the treatment regime best suited to treat the symptoms is pursued (Speer et al 2016). However, MacGregor et al (2023) found that NSAIDs insufficiently managed pain symptoms in ⅕ patients, leading physicians to consult hormonal options in addition to pain relief. Mardon et al (2021) found that over half CPGs recommended the prescription of analgesics, mainly local anesthetics, and in some instances, opioids.

Depending on disease etiology, certain hormonal treatment regimens yield better outcomes, however, prescribing an optimal regime hinges upon the presence of a confirmed diagnosis. In other words, where a CPP diagnosis is known, suitable hormonal regiments are more easily discerned. Hormonal treatment regimens include oral contraceptives, including progesterone-only tablets thought to be more effective at managing conditions such as endometriosis, intrauterine devices (IUDs), Nexplanon inserts (small plastic rods inserted into the arm), and hormonal injections (MacGregor et al 2023, Speer et al 2016). Mardon et al (2021) found that 80% of reviewed CPGs advised the prescription of hormonal therapies to manage a range of PPP issues; hormonal therapies were advised in all CPGs concerning endometriosis, including the Canadian model (Leyland et al 2010), poly cystic ovarian syndrome (PCOS), dysmenorrhea and genito penetration disorder (GPPD). Overwhelmingly, oral contraception, colloquially known as “the pill,” was recommended, followed by progestins, hormone releasing agonists, and hormonal IUDs (Mardon et al 2021). Given the prevalence of the diagnostic delay, scenarios where a diagnosis is known are rare, thus resulting in a series of trial-and-error treatments. A combination of analgesics and hormonal contraception most commonly manage CPP on an interim or long-term basis with mixed results on their ability to improve quality of life on a sustained basis.

Mardon et al (2021) also reported a notable recommendation for psychological interventions in their review. Fifteen CPGs advised psychological interventions for several PPP diseases. Namely, recommendations included psychological counseling, and in some cases, the prescription of medications for anxiety, depression, and other mental health-related comorbidities.

A growing body of literature cites the success of physiotherapeutic interventions. Mardon et al (2021) found that that nearly half (n=9) of examined CPGs recommended physiotherapy interventions for CPP diseases such as vulvodynia, interstitial cystitis, and GPPD. For CPGs concerning endometriosis, PCOS, or dysmenorrhea, physiotherapy was not mentioned.

Surgical interventions for CPP remain a quasi-last resort and are typically diagnosis driven (Speer et al 2016). Mardon et al (2021) found that 80% of CPGs recommended surgical interventions for PPP, namely hysterectomies, laparoscopies, and removal of pathologies, including the excision or ablation of endometrial legions. However, surgical procedures, namely laparoscopies, a procedure involving the insertion of a small probe containing a camera into the abdomen and the excision (removal), or ablation (burning of freezing) of endometrial tissues, remain the diagnostic gold standard for some CPP diseases, including endometriosis (Speer et al 2016). Generally, laparoscopic procedures considerably improve certain CPP diseases among PWU and considerably reduce accompanying mental health comorbidities leading to an overall improved quality of life (Speer et al 2016). Despite the efficacy of surgical intervention in diagnosing and treating CPP, the average wait time for laparoscopic procedures across all provinces resides at 19.6 weeks, or rather, approximately 5 months following specialist referral (Moir and Barua 2022). Noteworthily, not all CPP requires or is adequately addressed through surgical interventions, however, for those requiring surgery, access remains challenging.

Characterized by considerable delays, Canada’s healthcare system poses challenges for all patients living with an array of diseases. Moir and Barua of the Fraser Institute (2022) report overall high wait times across all provinces for many appointment types (i.e., specialist, surgical, imaging, etc.). For PWU experiencing CPP, these delays contribute significantly to an already considerable diagnostic delay. Moreover, due to the nuance and complexities of CPP, patients often require referrals for specialist treatment. A discernible connection exists between surgical, and specialist wait times respectively regarding the diagnostic delay for CPP. Moir and Barua (2022) found that across all ten provinces, the actual wait time between initial specialist appointments and surgical procedures drastically exceeds the predetermined reasonable wait times. Further, Moir and Barua also report that across Canada, patients wait an average of 12.6 weeks after receiving a referral from their general practitioner to see a specialist (2022). In the previous year, the patients could expect a 11.1 week wait time, indicating that patients can expect to wait longer to access specialized care as time goes on (Moir and Barua 2022). Moreover, wait times for diagnostic imaging, including MRI, ultrasound, and CT scans, also exceed reasonable wait times, and face increasing delays (Moir and Barua 2022). Within the domain of CPP, imaging comprises a key step in the diagnostic process, and is often a prerequisite for further surgical or medical interventions, and thus, delaying these procedures contributes directly to overall slow diagnostic processes. These delays affect all patients accessing care for various conditions, however, situated with the context of CPP, the ramifications of systemic delays interplay with existing diagnostic delays and issues of gender, incurring additional challenges for PWU. Although some GP’s will prescribe basic CPP treatments including NSAIDs and lower doses of the contraceptive pill, a gynecological specialist is considered the best point of contact for diagnostic investigations, long-term care, and treatment (Mardon et al 2022). In other words, even accessing gynecological specialists to begin preliminary diagnostics requires PWU to wait, excluding further delays in accessing other diagnostic touchstones such as imaging.

3.2. Research

Of late, CPP research has broadened beyond biomedical approaches, to better understand the challenges faced by PWU more broadly. Across other nations, endometriosis, and to a lesser extent, CPP, have garnered attention to support PWU and understand disease etiology (Australian Government 2018). Of note, Canadian physician, Dr. Paul Yong heads the Endometriosis and Pelvic Pain research laboratory operating out of The University of British Columbia (UBC). Dr Yong also holds Canadian Research Chair status for his team's work at UBC, meaning that his research receives federal funding. The various studies underway at the Endometriosis and Pelvic Pain clinic fall under one of four overarching research categories: clinical research, biomedical research, populations health research and health services research. Active studies include topics pertaining to chronic pelvic pain education for school-aged children regarding diagnostic delays, examining the cost effectiveness of a multi-disciplinary treatment model for CPP, endometriosis and oncogenesis, and the forecasting of surgical candidates among PWU based on clinical and molecular predictors of pain. Although important research undertakings pertinent to CPP are underway, continuing to robustly research CPP etiologies, predeterminants of CPP, advanced treatment methods, and other critical areas is necessary for improving health outcomes among PWU.

3.3. Sexual Health Education

In Canada, education falls under provincial jurisdiction, thus affording individual provinces and territories the authority to create and administer their own curricula (Government of Canada 2022). Correspondingly, the content disseminated to students on topics of sexual health falls under the purview of provincial governments while adhering to federal guidelines funded by Public Health Canada (PHAC) and compiled by the Sex Information and Education Council of Canada (SIECCAN). Currently, none of the ten Canadian provinces mention CPP in their provincial curricula guidelines, nor are topics of CPP included in the most recent version of the Canadian Guidelines for Sexual Health Education (Sex Information & Education Council of Canada 2019). The decentralized nature of SHE under Canadian federalism renders analysis and suggested reforms complex due to the high levels of curriculum subjectivity found within provincial education authorities. Within individual Canadian provinces, municipal or regional school boards shoulder the tasks of hiring and curriculum implementation in accordance with provincial curricula. Across all provinces and territories, the dissemination of sexual health curricula varies further down to the individual school level with some institutions outsourcing sexual health from specialized educators, and others relying on existing teachers or school nurses. In other words, the development and administration of SHE remains highly subjective, reaching all the way down to the individual school level. In 1994, the first Canadian Guidelines for Sexual Health Education were published, receiving funding from the Government of Canada’s Family Violence Initiative, however, in 2008, The Public Health Agency of Canada (PHAC) revised and released The National Guidelines for Sexual Health Education (NGSHE), providing provinces with guidelines for their own SHE curriculum (SIECCAN 2019). This document, however, makes no mention of menstrual health or CPP, leaving ample and necessary room for policy intervention. Since 2008, national guidelines for SHE have been revised, most recently in 2019, however, topics of menstruation and more specifically, CPP, remain unincluded.

Collaborations with SIECCAN to revise and distribute updated SHE guidelines including CPP mark a necessary step in addressing knowledge gaps, which may, in turn, promote health seeking behaviours among PWU at earlier ages. Topics included within the NGSHE aim to promote comprehensive, age appropriate SHE while promoting autonomy, safety, and empowerment among school aged children. Notably, the NGSHE allocates considerable attention to the topic of sexually transmitted infections (STIs) in the most recent document (SIECCAN 2019). This module provides shame-free guidelines for educating youth about STIs, with a focus on preventative practices (SIECCAN 2019). This focus is noteworthy within the context of CPP because a similar framework could be transferable to pallet CPP within an educational framework. In other words, the resources and capacity to create and publish guidelines pertaining to specific SHE topics exist and may be applied to CPP.

3.3.1. CPP and Health Literacy

Health literacy remains closely tethered to both CPP education and awareness both amongst PWU and the larger population. The Institute of Medicine defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Ratzan and Parker 2000). Among Australian women, Armour et al (2020) found health literacy to be low, with many individuals characterizing menstrual pain as normal and moreover, a regular part of menstruation. These findings pose challenges for PWU – with low health literacy linked with poorer health outcomes overall, the need to address this gap remains critical in CPP policy considerations (Ratzan and Parker 2000). Armour et al (2020) report that in addition to low health literacy, less than 20% of study participants felt their schoolteachers constituted trustworthy sources of personal health education, favouring web sources, physicians' advice, and information from relatives. However, most participants chose to manage their pain, usually unsuccessfully, with over-the-counter NSAIDs rather than seeking medical attention due unawareness of CPP (Armour et al 2020). Swedish cohort study found that participants felt the resources available to them through school insufficiently explained and supported their needs, expressing a desire for ameliorated school nurse education (Bodén et al 2013). The same study found that those who did approach school nurses felt their pain was minimized, or that nurses lacked the knowledge to advise or assist with their pain (Bodén et al 2013). Together, these studies demonstrate a succinct need for better education and awareness, not only within the PWU cohort, but moreover, those tasked with disseminating their SHE curriculum, and supporting their care.

3.4. Menstrual Pain Normalization

Topics of menstruation, gynecological health, and CPP remain highly taboo, particularly across younger cohorts. Goss (2023) found that at early ages, young PWU are encouraged to conceal menstruation related to its perceptions of uncleanliness and a profound fear of embarrassment. A different study by Armour et al (2021) reported that among participants, a coalescence of low menstrual health literacy and a profound normalization of menstrual paid led to the underdiagnosis and undertreatment of CPP among Australian women. In chorus, these two studies underscore a clear relationship between health literacy, menstrual pain normalization and diagnostic outcomes; when poorly equipped with knowledge of their own health, coupled with normative social practices to privatize menstruation, PWUs encounter a higher risk of persistent, unmanaged pain.

Goss (2023) identifies key pathways for menstrual pain normalization: through intergenerational menstrual knowledge, pre-secondary education, and HCPs. When knowledge of menstruation is passed down primarily through female family members, modern discourses about the topic are easily overlooked (Goss 2023). Armour et al (2021) support these findings, reporting that across survey respondents, 56.7% of participants cited their families as trustworthy sources of information pertaining to menstrual health. In other words, the simultaneous desire to conceal menstruation from public discourses, and the reliance upon relatives for menstrual information creates a cycle of intergenerational health literacy wherein family members reinscribe normalization narratives among young PWU. In sum, the taboo nature of menstruation described by Goss (2023) and Armour et al (2021) relegates conversations of this topic to private domains, particularly the family, often devoid of modern topics. These closeted conversations foster secretive practices about CPP and discourage health-seeking behaviours.

Another key normalization pathway outlined in literature stems from educators in pre-secondary institutions. In the aforementioned study by Armour et al (2021), found that 20.7% of participants felt their teachers were trusted sources for menstruation education, favouring HCPs (72.1%), family members (56.7%) and the internet (54.6%). School systems are often the first point of contact where young PWU encounter conversations about menstruation. The overlooking of menstrual pain across school curricula contributes to overall diminished health literacy among PWU, and moreover reinscribes menstrual pain normalization. A study of girls aged 15-19 years in the U.K. found a desire to know more about endometriosis specifically, identifying classroom sessions as the preferred opportunity to learn about the condition (Randhawa et al 2021). This same study affirms the findings reported by Armour et al (2021), citing teachers as their least preferred point of contact for conversations about menstruation. In other words, despite their key role in early exposure to topics of CPP, schools fail to garner trust between pupils and teachers. Within this landscape, a clear need for policy action manifests to establish trust, comfort, and reliability across schools to foster denormalization and positive outcomes among PWU and their peers.

The final normalization pathway for CPP concerns interactions with healthcare providers (HCPs). Despite feelings of trustworthiness among young women as reported by Armour et al (2021) and Randhawa et al (2021), a qualitative systematic review conducted by Davenport et al (2023) found that across 37 qualitative studies, patients felt their PCPs, namely GPs, and in some cases, secondary non-specialized gynecologists lacked the sufficient knowledge to recognize their symptoms and pursue the necessary diagnostic pathways. Moreover, among those studies interviewing HCPs specifically, Davenport et al (2023) indicated that practitioners felt they lacked the knowledge to distinguish between normal menstruation and pathologies such as endometriosis. Resultantly, GPs felt ill-equipped with the knowledge needed to form diagnostic questions for patients, perform suitable examinations, and make the appropriate referrals for patients (Davenport et al 2023). Further to these findings, a Spanish study of female nursing students found that many participants normalized their own CPP, despite being future HCPs themselves, reifying that CPP normalization practices transcend individual, interpersonal and educational pathways, residing at a structural level within the medical system (Ramos-Pichardo 2020).To combat these tendencies, PCPs suggested the development of multidisciplinary CPGs to improve knowledge gaps, making a critical step for subsequent policy action within the domain of CPP (Davenport et al 2023).

3.5. Economic Impacts

3.5.1. Personal Income Loss

A clear relationship between CPP and personal income loss exists, with PWU unable to perform their vocational tasks, and in some cases, experiencing unemployment. This trend remains inextricably linked with gendered experiences already shaping workplace experiences for women and other gender minorities. Section 2.3 of this report discussed the impetus for allocating policy efforts to CPP, citing the profound gendered dimensions of this issue. Income and employment marks another such site of gendered inequality, and thus, requires critical consideration in the sphere of CPP. CPP often presents with debilitating pain affecting the ability to carry out daily activities, including vocational tasks. Fachin et al (2018) found that women with endometriosis were more likely to experience unemployment than those without documented experiences with the disease, or those with asymptomatic endometriosis. This is to say, the presence of intense pain contributes to patient employment status, and thus, a similar rationale is applicable to other forms of non-endometriosis CPP; PWU experiencing non-endometriosis CPP likely face similar employment outcomes (Fachin et al 2018). Among participants featured in a study by Fourquet et al (2012), the average loss working hours per week sits at 7.41, or in other words, nearly one full workday in a 40hr/week employment scheme. In a different study, Fourquet et al (2010) reported participants lost an average of 33.6 full workdays per year; this is to say, over a month’s worth of work, and thus income, was lost at the individual level. Another study by Soliman et al (2017) found that among participants with confirmed endometriosis diagnoses, a total of 16.9% of weekly work hours were lost, and 27.9% of household productivity hours were also lost. Adjacent to patient absenteeism, the hours not worked by PWU experiencing CPP, Fourquet et al (2012) found that patients also experienced elevated levels of presenteeism, or rather, impaired work performed to a lower standard, with approximately 65% of their work impaired due to CPP. In this way, the loss of income associated with CPP creates another dimension of inequality unique to women, non-binary, intersex and transgender individuals, correspondingly affecting quality of life. Addressing personal income loss through policy, thus, contributes to nuanced gendered disparities in this field.

The topic of workplace accommodation for PWU experiencing CPP remains closely linked with loss of personal income. If accommodations are available, in some instances the loss of hours may be mitigated for PWU. Gilmour et al (2008) found varying degrees of accommodation among respondents, reporting that many participants felt that disclosing their diagnoses to their employers would result in negative consequences. Culley et al (2011), in chorus with Gilmour et al (2008) report that participants feared trivialization or disbelief of their symptoms. These same studies report that the presence of supportive workplace accommodations not only minimizes individual stress, but moreover, prevented income loss where applicable (Culley et al 2011, Gilmour et al 2008). The role of supportive workplaces marks an additional policy avenue to ameliorate overall quality of life among PWU experiencing CPP by mitigating economic challenges, and potentially unemployment or precarious employment among PWU.

3.5.2. Barriers to Disability Claims in Canada

Currently, the Canadian government recognizes no CPP diseases as disabilities, although PWU experiencing CPP may be eligible for disability support from government programs (Government of Canada 2023). Although individual nations create and administer their own disability support policies, CPP poses challenges for claimants transnationally. Vigilanti (2023) contends that literature examining the legal intersections between endometriosis and national legal frameworks remains sparse, leaving those affected by CPP unsupported by social assistance programs. Canada’s Disability Tax Credit (DTC) identifies eight eligibility categories: walking, mental functions, dressing, eliminating, hearing, speaking, vision, and life-sustaining therapy, none of which obviously pertain to chronic pelvic pain (Canada Revenue Agency n.d.). Further, the Canadian Pension Plan Disability (CPP-D) plan and Disability Insurance policies require proof of disability in the form of supporting documentation from physicians, including a diagnosis (Canada Revenue Agency n.d.). Given the prominence of the diagnostic delay in Canada, obtaining such documents presents a challenge for PWU. The CPP-D presents further barriers for PWU related eligibility criterion stipulating minimum Canadian Pension Program contributions and income requirements, affecting the amount of funding received (Canada Revenue Agency n.d.).

In the Australian framework examined by Vigilanti (2023), similar barriers prevail; the necessity for a confirmed diagnosis and treatment create considerable barriers to accessing disability income support. Australian Disability Support Pension applicants must provide diagnoses for their ailments, while also proving disability permanence and treatment (Vigilanti 2023). For CPP patients, providing such information from physicians is challenging, with many unable or unwilling to provide irrefutable diagnoses (Vigilanti 2023). The unconventional and often changing treatments for CPP, including hormonal regimes, poses further issues in proving sustained treatments for patients' disabilities (Vigilanti 2023). Similarly, the CPP-D application requires extensive documentation attesting to the prolonged nature of a patients' disability (Government of Canada n.d.). Moreover, the CPP-D application fails to encapsulate the chronic and recurring nature of CPP, posing challenges for PWU who experience periodic flare ups. Similarly to the case examined by Vigilanti 2023, the terminology employed by government structures to determine eligibility often excludes CPP due to the unpredictability of CPP diseases and the ease of obtaining diagnoses. Overwhelmingly, the burden of seeking, presenting, and defending documentation to receive disability income assistance falls on PWU, imposing another outlet for considerable stress. Given the profound effects on quality of life and patients' ability to perform daily tasks, including vocational activities, income support should be available to PWU experiencing CPP, making this issue another point for policy intervention. Notably, Canada's disability policies pose challenges for those experiencing chronic conditions, including chronic pain, on the whole, and policies should promote better outcomes across all applicants, not just those experiencing CPP.

3.5.3. Cost of CPP to Society and Government

The costs of endometriosis specifically commands attention across CPP research. An early study titled “EndoCost,” conducted by the World Education Research Foundation examined the cost of illness of endometriosis across nine European countries and the United States found the overall cost of illness at nearly €10,000 in the year 2009.

The cost of illness measure employs a societal perspective on disease providing insight into healthcare resource utilization, termed direct health care resource utilization, and personal productivity losses, termed indirect health care costs (Simoens et al 2011). Accounting for inflation, the estimated cost of illness related to endometriosis in 2009 amounts to almost €14,000 in today’s economy, or rather $20,314 CAD. A more recent study by Armour et al (2019) found that the economic burden of endometriosis and non-endometriosis related CPP nearing a similar rate to other chronic diseases including diabetes and heart disease using an Australian sample. National data collected by Armour et al (2019) revealed the overall cost of illness among PWU with CPP broadly, including endometriosis to sit between Int $16,970 to $20,898 per woman, per year. Most of these costs stemming from productivity losses ranging from 75% to 84% for women with non-endometriosis related CPP and PWU with confirmed endometriosis diagnoses (Armour et al 2019). Findings further revealed that as pain increased, as measured on a scale of 1 to 10, with 10 encompassing severe pain, individual productivity decreased (Armour et al 2019). With the Canadian prevalence of CPP among PWU of childbearing age estimated at 14-24%, forecasted costs of illness are high (Katz et al 2021). The loss of productivity not only results in personal income losses, but moreover, decreases workforce productivity on the aggregate – given these findings, the need for policy intervention is clear.

3.6. Healthcare Biases

The final point of examination within this literature review concerns the unequivocal presence of gender bias at the bedrock of CPP. As aforementioned, although linked with biologically female sex organs, the lived realities of gender norms establish disparities in healthcare (Heise 2019). Experiences of pain remain different social realities based on gender norms and assumptions based on sex. Bartley and

Fillingim (2013) report that women experienced greater pain sensitivity and reduced pain inhibition compared to male study participants, underscoring fundamental sex-differences regarding pain. Socialized conceptualizations of pain dovetail these sex differences, further entrenching gendered ideas of pain within social landscapes, including healthcare. At early ages, young children learn acceptable responses to pain along gendered lines: young boys learn to minimize pain experiences, whereas girls learn to articulate and seek help for their experiences with pain (Samulowitz et al 2018). Resultingly, gender and sex play key roles in not only expressions of pain, but perceptions of pain from others. These social norms shape the lived experiences of people experiencing pain, resulting in gendered healthcare outcomes among PWU. In the healthcare context, social group membership correspondingly creates expectations regarding experiences of pain from care practitioners (Paganini et al 2023). A scoping review by Samulowitz et al (2018) found that in addition to perceptions of feebleness and fragility associated with women's pain, women's pain was often miscategorized as psychological rather than somatic, thus delaying diagnosis and the administration of appropriate treatment. Several studies indicate that in the treatment of pain, female patients were less likely to receive sufficient pain relief; female patients were less likely to receive prescriptions for opioids, and more likely to be prescribed antidepressants, or referred for psychological treatment (Samulowitz et al 2018). A clear relationship between gendered experiences and interpretations of pain and the diagnostic delay exists. If female pain remains minimized within the medical framework, correspondingly, treatments and diagnoses will continue to face delays.

Although most patients experiencing CPP identify as female, those PWU with different gender identities experienced compounding barriers to healthcare access. An American study of transgender and non-binary individuals accessing emergency room services revealed that transgender and non-binary patients experienced discrimination, not only at the systemic level, but with health care actors (Alison et al 2021). Qualitative input from non-binary and transgender participants indicated that their symptoms were ignored, there were delays in examination and treatment, and overall poor care (Alison et al 2021). Participants also reported insufficient practitioner knowledge and sensitivity towards transgender and non-binary patients, leading to further patient discomfort. A transnational study of trans and non-binary individuals with endometriosis revealed a strong tendency to dismiss patient symptoms, invalidate pain experiences, invalidate gender identity, and provide insufficient treatment options for their symptoms (Eder and Roomaney 2023). For some trans and non-binary PWU, the experiences discourage future health-seeking behaviours, contributing to diagnostic delays amongst this population.

PWU experiencing CPP, thus, disadvantages within the healthcare system due to systemic gender biases, exacerbated and compounded by CPP-specific challenges such as diagnostic delays and menstrual pain normalization. Invariably, navigating Canada’s healthcare system remains a gendered experience for all PWU regardless of gender-identity.

Chapter 4. Research Methodologies

This study employs qualitative methods to capture the perspectives of PWU experiencing CPP and existing policy undertakings in Australia. This research centres around two overarching research questions: (1) How can policies meet the needs of PWU experiencing CPP to ensure a better quality of life? (2) What can be learned from National Action Plan policies implemented in comparable jurisdictions? These questions informed the development of interview guides and guided analyses of the Australian case.

Firstly, this study employs semi-structured interviews with PWU who have lived experiences of CPP. This method aims to capture the nuanced perspectives, challenges, and needs of those directly affected by the CPP diseases. Participants were recruited using a combination of purposive and snowball sampling techniques, primarily via social media. All subsequent communication took place via email. The recruitment criteria for PWU experiencing CPP were as follows:

- Aged 18 or over.
- A Canadian resident.
- Are a person with a uterus.
- Have experienced chronic pelvic pain within the last 5 years.

A total of ten interviews took place, conducted and audio-recorded via Zoom and occurring between January 13th and February 22nd. Participants received consent forms via email prior to their interviews and verbal consent was collected at the beginning of the session. Interviews lasted between 50 and 90 minutes, with all findings transcribed thereafter. A semi-structured interview guide facilitated the interview, concerning themes of personal experiences with CPP, the impacts of CPP on day-to-day life/activities, experiences with the medical system, and CPP education schemes. Following a manual analysis and familiarization with all interview data, a thematic approach guided subsequent investigations. Themes were developed using both inductive and deductive reasoning techniques and were analyzed in chorus with literature and Australia’s NAP. These findings will be discussed in subsequent sections of this report.

Additionally, the study employs a case comparison analysis with Australia’s existing National Action Plan for Endometriosis (NAPE). By examining strategies implemented by another nation with analogous political structures to Canada, this comparative approach aims to identify effective policies, strategies, and implementation mechanisms relevant to addressing CPP at the policy level. The analysis will focus on goals, strategies, outcomes, and gaps in existing plans, providing valuable insights for the development of the proposed NAP for Canada. The Australian NAPE is the first of its kind, and subsequently, the most well established. Five years post implementation, Australia’s recent (2023) progress report provides insight into policy actions, and will therefore, be included in this section. The NAPE identifies three similar focus areas, and will be analyzed to identify similarities, strengths, weaknesses, and gaps. Although France also has an operational NAP in the implementation phases, Australia’s case was selected not only due to analogous political structures to Canada, but moreover due to the availability of the progress report.

Chapter 5. Qualitative Interview Findings & Thematic Analysis

The following section outlines the findings from 10 semi-structured qualitative interviews with PWU with lived experiences with CPP. All but one interview participant currently reside in British Columbia. Respondents were asked questions pertaining to their overall experiences with CPP, employment, interactions with healthcare actors, treatment regimens and their education on topics of pelvic pain. Five overarching themes emerged from these interviews: *normalization of menstrual pain, medical gaslighting, self-advocacy and burnout, diagnostic delays, workforce participation and economic challenges, and personal and societal health literacy.* Each of these themes, and their corresponding sub-themes, will be discussed below.

5.1. Normalization of Menstrual Pain

All (n=10) participants touched on the theme of period pain normalization, some feeling that their own pain was normal, and others having their pain externally normalized by family members, friends, health care actors, etc. Both normalization practices led to experiences of anxiety, self-deprecation, and frustration.

Participants identified a lack of health literacy to discern whether their discomfort transgressed the domain of normal and thus came to accept frequent experiences of discomfort as normal. These instances, moreover, delayed participants' access of healthcare services, and prolonged their suffering.

> "[I]t's kind of just been something that I thought was normal. Like, 'oh it's just part of being a girl!' … And so I've been learning over the last couple of years that [...] it's not normal to [...] have to adjust your whole life just because you're a woman." Participant #01.

> "...[I]t never occurred to me that [my periods] might be worse or more serious because there's just no information [about CPP]." Participant #04

5.1.1. Normalization from Relatives

Other participants felt that their pain was normalized by external forces including their own families or medical professionals. In these instances, PWU began to realize their pain was impeding their abilities to fulfill day to day activities, participate in the workforce, or attend school and felt this had to be abnormal. In some cases, respondents' mothers had also experienced debilitating pain, and thus normalized missing school, work, and social engagements, which further delayed respondents' access of healthcare services. Several respondents (n=4) reported that upon voicing their pain to family members, their pain was discredited by their relatives, rather suggesting that they were weak or possessed a diminished capacity to cope with normal pain experienced by all those who menstruate.

> "She [my mother] just assumed that I was experiencing the same pain she was, but I was making a bigger deal about it. I remember she kept saying stuff like 'you'll get used to it'." Participant #04

5.1.2. Normalization from Health Care Providers (HCPs) & Medical Gaslighting

In the case of those who experienced menstrual pain normalization from healthcare professionals, participants typically had expressed concern over their CPP symptoms, some were admitted through emergency departments (EDs). Participants tried to convey the impacts of their pain to professionals, but were met with normalization practices, ultimately resulting in a dismissal of symptoms, and a further delay of treatment access.

The notion of medical gaslighting remains closely tethered to this normalization of menstrual pain vis-a-vis the HCPs. Hoffman et al. (2020) underscore the prevalence of medical gaslighting in relation to CPP wherein HCPs discount and dismiss the symptoms of PWU. As a result, patients begin to question their symptoms, and may minimize their own pain, leading to a delay in pursuing treatment and diagnostic options, and in some cases, exacerbating mental health symptoms including anxiety and depression (Hoffman et al 2021; Walkden 2023). Interview responses mirrored practices of medical gaslighting wherein HCPs often normalized patients' symptoms, sending them home with little to no pain relief.

> “I’m like ‘why is this [ruptured ovarian cysts] happening?... I’ve had this happen almost every month.’ And they [emergency room doctors] say it’s normal?... I always leave with this feeling of not being heard.” Participant #05

> “...[H]e [the doctor] was like ‘you know, this can totally happen. How’syour relationship with your partner? Is he nice?... [T]ry making sure you’re calm [before sex] and relaxed.’ I said well, I’ve been trying that, but I still have pain.” Participant #08

5.1.3. Menstrual Health Literacy

The Center for Disease Control and Prevention (CDC) defines two categories for health literacy. Firstly, personal health literacy, which refers to an individual’s ability to access, understand, evaluate, and apply available health information to make decisions about their health and wellbeing (CDC 2020). Among participants, and closely linked to normalizations of pain, was poor health literacy, particularly at a young age. All respondents grew up either unaware of the potential for menstrual pain, normalizing menstrual pain, or a combination of both.

> “I thought it [really bad cramps] was the normal thing. And this [normalization] would be from… my mother, teachers and doctors, I never thought I would need a doctor.” Participant #03

The second health literacy category refers to the ability of organizations to furnish individuals with the required information to access, evaluate and use health care services to make informed health-related decisions (CDC 2020). All respondents touched on their experiences learning about menstruation and CPP during their school-aged years. Although some (n=3) participants felt they had good experiences with sexual health education (SHE), all but one made no mention of CPP, and largely adhered to normalization practices. Thus, in addition to low personal health literacy, schools failed in their capacity to uphold organizational health literacy.

> “They [teachers] talked about menstruation, but not about any kind of pain associated with it. It was mostly like you’re gonna have some… light cramping and then the bleeding will start…and then basically it ends.” Participant #06

> “[T]here was no conversation about it [getting an IUD inserted], but I didn’t have the information I needed to make that decision. I was still a teenager.” Participant #05

For all but one participant (n=9), their CPP started during high school. Paradoxically, participants received little information about CPP, in some cases leading to uninformed decision-making pertaining to pain management or overusing NSAIDs.

All participants were asked what they wished they could tell younger versions of themselves, or young people in general, about CPP. All participants indicated they would emphasize that debilitating pain is *not* normal and would encourage young people to voice their concerns with HCPs.

> “[I]f you are being debilitated by your…period pain, that’s not normal, and even if you have…a low pain tolerance, it’s still not really normal to not be able to do anything when you’re on your period.” Participant #09

> “Talk about de-normalizing pelvic pain. You don’t have to suffer, it’s not just part of having a uterus. And teach basic health literacy. If kids are learning to [prevent pregnancy] and are considered mature enough to learn about chlamydia, they can also learn about endometriosis or PCOS.” Participant #10

In sum, all participants felt their pain was normalized during their CPP journeys. Normalization pathways included interactions with relatives, HCPs, and educational institutions, and in all cases, respondents were delayed in seeking help for their CPP. Existing literature underscores a clear relationship between diagnostic delays and the deferral of medical care among PWUs experiencing CPP. This pattern aligns with interview findings: the normalization of menstrual pain represents a major hurdle in accessing healthcare and advancing along the diagnostic trajectory.

5.2. CPP and Mental Health

All respondents identified a clear relationship between their mental health and CPP. Most (n=8) specifically identified a relationship between CPP and anxiety; the prospect of a pain flare induced considerable anxiety, with specific concerns about being able to manage pain and fulfill day-to-day activities, including childcare, exams, employment, etc. Two respondents reported having post-traumatic stress disorder

(PTSD) exacerbated by their experiences navigating the healthcare system in relation to their CPP.

> “It was really the anxiety part I needed to figure out… I can’t [spend] all week…thinking about oh do I have the [painkillers] pills on me? Am I going to have an[endometriosis] attack? Am I going to be able to make it to a bathroom for 20 minutes.” Participant #07

Over half of respondents (n=6) reported experiencing feelings of depression associated with their CPP. Participants felt dejected towards their futures, which directly related to their recurring experiences with pain. The uncertainty of receiving a diagnosis, experiencing life without pain, and concerns for future fertility further compounded these feelings. Adjacently, some participants felt alienated, frustrated, or failed by their bodies due to their CPP.

> “On days I [am taken out by pain] and cannot perform normal daily tasks… [I]t causes a bit of… depression…because I am sad that I haven’t been able to get answers for having this pain for so long. And I’m not even sure if I’ll be able to get answers.” Participant #06

> “It [pain] makes me feel… extra depressed. And…it’s dangerous to feel those feelings and not know why and think there’s something wrong. It’s just… this endless cycle.” Participant #1

> “I spent a lot of my life eventually believing the doctors who said it [my pain] was in my head. And even after discovering that that it’s not, I still think that I’m weak, or I’m not doing enough, or I should be able to handle more” Participant #02

Overall, a strong connection between CPP and mental health emerged across all 10 interviews. All participants noted that their CPP negatively affected their mental health, and some (n=3) felt their mental health exacerbated their pain symptoms.

5.3. Self-Advocacy and Burnout

All (n=10) respondents had to strongly push and advocate for their health when engaging with health care actors. When asked who manages their CPP, a question initially designed to understand which health care actors were overseeing participants’ pain, four respondents identified themselves as managing their own cases. These responses highlight the individual labour associated with managing CPP, particularly in self-advocacy capacity. In some cases, participants felt that HCPs were unaware of certain CPP diseases, leading to a dismissal of symptoms and forcing participants to conduct their own research about CPP to better understand their experiences.

> "I fought really, really hard for a diagnosis… They would treat me like I was just anxious… but I had never experienced what not being in pain was like. "Participant #02

> "I honestly [have to] push every time. I'm my own advocate. I ha[ve] to push for [every test]." Participant #05

When asked whether those participants with confirmed diagnoses for their CPP felt their diagnoses aided their navigation of the healthcare system, two respondents described a clear gap between HCP knowledge and their symptoms:

> "If they understand it [PCOS]. If they know what [PCOS] means. Like not just the science of it, but if they know what it means for my life." Participant #4

> "No, [having a diagnosis doesn't help] because most people haven't heard of it [vaginismus]. I still explain to medical professionals. I'm like 'I have vaginismus, have you heard of it?'' Participant #8

Both respondents further indicated they felt that HCPs were more likely to dismiss their symptoms or prescribe what they described as "band-aid" or temporary treatment regimens when they felt practitioners lacked knowledge about CPP.

5.3.1. Burnout

Some respondents encountered burnout because of persistent self-advocacy, yielding insufficient pain management. As a result, some discontinued seeking care and pain management through health care channels for their CPP.

> "I've always felt very brushed off by them [doctors]... I stopped exploring for that exact reason because I got brushed off so many times." Participant #06

> “She [a nurse] told me… to not stop fighting. It [she] was like a miracle, because I was ready to stop fighting. I was done.” Participant #04

Burnout primarily resulted from profound frustrations with the healthcare system pertaining to diagnostic delays and insufficient pain management. Many had been diverting considerable energy, time, and emotions into seeking diagnoses and pain management for years, beginning in adolescence. Continually met with instances of pain normalization, medical gaslighting, and dismissiveness, participants were left feeling burnt out by the medical system.

5.4. Workforce Participation and Economic Challenges

All participants either currently or previously held employment. One participant expressed they could not work directly resulting from their CPP, and another stayed home with her children but felt she could likely not return to work due to a combination of her CPP and mental health comorbidities. Four participants were full-time employees, while four others worked part-time while attending university.

5.4.1. Missed Work and Income

Among those participants actively working (n=8), all but one (n=7) missed work and subsequently lost income.

Two participants identified as self-employed, and thus, lacked formalized support from their workplaces, including sick pay. Based on their individual experiences with pain, each self-employed participant estimated losing between 25-50 workdays per year, ranging in personal financial losses ranging from approximately $5000 to over $150,000 annually. Although the moderate flexibility of their work schedules allowed self-employed participants to configure their workdays around their pain cycles, the loss of income inevitably occurred.

> “I make it [working] doable. But it’s tricky… I can move meetings to days when I know I won’t have it [my period], but I don’t get paid… and it’s hard to get sick pay when you’re self-employed.” Participant #06

5.4.2. Unemployment and Income Support

Of the two participants not currently working, one received financial support primarily from her parents upon realizing they were unable to work, and the other relied primarily on their spouse's income in addition to disability tax credits. Both unemployed participants attempted to apply for social assistance via federal disability programming but found the process complex and resource-intensive. Additionally, one employed participant had investigated applying for income assistance, but found the applications challenging to navigate. Two participants obtained or considered obtaining third parties to facilitate the process of building a case file; in one instance where disability tax credits were granted, the third-party organization took 20% of the participants' reimbursement.

> "I think there needs to be a clearer way… I was looking on the government of Canada website…, and I think it would be helpful if there was… a little quiz… to help you figure out if you were eligible. And even if you're not eligible, just like other options or other resources." Participant #05

Issues with receiving mandatory medical documentation and the intense need to "prove" their pain hindered ease of access for both participants. One participant was unable to receive any type of long-term income support, only receiving short term employment insurance (E.I.) payments.

> "It's [E.I.] given to you with the expectation that you get better. But you don't get better." Participant #02.

One respondent was receiving disability tax credit reimbursements but was struggling to navigate a route to obtain monthly payments and receive disability classification. On the aggregate, the processes of determining eligibility and applying incurred notable time, stress, and resources. The challenges associated with receiving a diagnosis for CPP, alongside recognition of CPP as a debilitating condition complicated these processes further.

Six participants who were actively working expressed they weren't aware that income assistance could be obtained for CPP but felt there were times where they could have used benefits.

5.4.3. Working with CPP

Those who were actively working *and* experiencing challenges associated with their pelvic pain (n=6) encountered varying degrees of support from their workplaces in relation to their CPP. Two participants actively accepted positions with work from home (WFH) options to manage their pelvic pain.

Respondents with public facing jobs such as retail, recreational activity coaching, and restaurant work tended to encounter poor support from their workplaces, and were unable to make accommodations to their workdays, such as working from home or remaining seated. Participants felt they were perceived as unreliable, flakey, or lazy.

> “They [employer] will basically shame you for taking time off…[J]ust because they can't see it [CPP], they basically just think it doesn’t exist.” Participant #05

> “It was in a way threatened that if I was to continue having to miss days of work due to something that happened to every single woman every month, then I was no longer going to be able to move forward in the company.” Participant #06

Only one participant felt that their workplace truly and wholly supported their needs experiencing CPP. In addition to receiving extended medical care benefits, this participant felt they could WFH and face minimal consequences from their workplace. They received support and paid time off (PTO) for surgical recovery.

> “For the most part, they’ve been super understanding… It’s really allowed me to focus on it [endometriosis and surgical recovery], and do the most healing work than I’ve been able to do.” Participant #03

Overwhelmingly, participants faced vocational-related challenges in relation to their CPP. These challenges stemmed from both loss of income due to pain and feeling that their workplaces were unsupportive. The three participants who attempted or received disability income insurance expressed a need to simplify application processes and clarify eligibility criteria. As aforementioned, the Government of Canada does not currently consider pelvic pain a disability, thus necessitating rigorous supplemental medical documentation to corroborate symptoms. These barriers left participants unsupported economically.

5.5. Interactions with the Healthcare System

All (n=10) respondents reported interacting with the healthcare system at some phase of their CPP journey. Over half, (n=8) of participants accessed care through EDs, often experiencing similar patterns of dismissal and menstrual pain normalization. Some participants (n=5) had accessed gynecological specialists, while others relied on care from GPs. Key themes identified within interactions with HCPs are explored in the subsequent subsections.

5.5.1. Experiences with Hormonal Treatments

All (n=10) respondents were prescribed hormonal birth control during initial contact with HCPs, some feeling they didn't have other options. Some respondents found relief from hormonal interventions regarding their CPP, although they experienced side effects which offset the positive impacts of such treatments.

> "I have a lot of distrust in the medical system and doctors who just prescribe it [the pill]. It really take[s] away your agency, your autonomy. I didn't feel like there were other options." Participant #02

> "The pill was pretty much the only option I was given from my doctor." Participant #10

Even among respondents whose symptoms were managed satisfactorily by hormonal treatments, some expressed concerns over their long-term use, also feeling that they were temporary solutions which did not address the root causes of their pain. Some respondents were advised to start hormonal treatment regimens as young as thirteen, retroactively stating they felt too young to understand or make decisions regarding their care.

> "My initial [doctor's appointment] wasn't like a diagnosis of [my endometriosis] right away. It was more like, that's an option, but just try this

> hormone [the pill]. And then I tried it… and it didn't help a lot… I ended up getting an IUD put in when I was in grade 10. They [doctors] didn't advise a laparoscopy because what I've been prescribed is working… but I… haven't been tested further for it[endometriosis]" Participant #07

> "I'm still on birth control [the pill]... [but] not by choice I would say. I've had a lot of side effects being on it, so ideally I want to be off [of it]... but I know… that as soon as I go off of it… I'm going to have those painful periods again. The pill isn't really what's treating the pain, it's not having a period, but we still don't know what makes them [periods] so painful" Participant #10

Generally, participants were apprehensive about long-term reliance on birth control options and felt their concerns when asking for more testing or voicing concerns over side effects were dismissed.

5.5.2. Healthcare System Delays

After dismissal by HCPs, respondents' biggest concerns with the healthcare system involved the ease and timeliness of receiving care. These sentiments reflect the larger picture of the Canadian healthcare system which remains highly backlogged. Many participants experienced challenges with finding a general practitioner (GP), and thus, could not access more specialized care pathways for their pain, including obtaining a referral to a gynecologist, imaging appointments, and surgical appointments. Indeed, a link between dismissing symptoms and the availability of next-step resources exists; when respondents were minimized by HCPs, it took considerable time and effort to receive future treatments.

> "[I]t's unbelievably and excruciatingly painful to try and get anything done. The amount of hoops that you have to jump through, like the waiting period to even someone [a gynecologist] is kind of unbelievable." Participant #06

Respondents with confirmed or suspected diagnoses experienced delays ranging from 1 to 15 years from their initial HCP interactions. Those still awaiting diagnoses have been seeking answers for anywhere from 2-20 years in total. Many respondents struggled with getting referrals to gynecologists, imaging, and surgical interventions, resulting in years of unmanaged, persistent, and debilitating pain. Rather than undergoing diagnostic investigations, many respondents, as previously discussed, were prescribed hormonal treatments intended to reduce pain, but not necessarily provide diagnostic insights.

5.5.3. Finding the Right HCP

Almost all participants reported that they only felt they received a diagnosis or satisfactory symptom management upon finding the right doctor who validated their symptoms. Most (n=6) participants indicated they had deliberately changed GPs or gynecologists to receive better care for their CPP. Those who had positive experiences with HCPs from the beginning considered themselves lucky compared to others, to have compassionate care providers.

> "I'm lucky, I love my specialist [gynecologist] so much. We just do six month check ins, even if I have nothing to say, just so I stay in her schedule and don't have to get a new referral and go on the waiting list." Participant #07

> "I was fortunate in a sense, to *have* a GP because I think GPs are kind of the key that unlocks the door to the healthcare system if you have the right one." Participant #08

Compassionate practitioners were crucial in easing patient distress, facilitating rigorous investigations into root causes of pain, and finding appropriate interventions. One participant had been referred to the Endometriosis and Chronic Pelvic Pain Clinic at B.C. Women's Hospital described immense gratitude and relief from their care describing it as refreshing and life-changing compared to the dismissive narratives espoused by their GP.

> "I've had the most positive experiences with… the while team at B.C. Women's… It really solidified that what I was feeling [CPP] was valid." Participant #03

Overall, participants described both positive and negative experiences with their primary care providers (GPs) and specialists. Only one respondent felt their practitioner took their symptoms seriously from the initial consultation, whereas others spent as much as years pushing for further explorations into their pain. As highlighted by one participant, supportive GPs remain key access points to the rest of the healthcare system. The antithetical scenario, moreover, remains true: dismissive GPs hindered access to pain management and further clinical investigations into root causes of pain.

Chapter 6. Case Comparison: Australia

The Australian case was selected for comparison not only due to similar political structures to Canada vis à vis federalist structures, but moreover, the established nature of their National Action Plan for Endometriosis (NAPE). Like Canada, the Australian provinces hold jurisdiction over education and healthcare while receiving federal funding and adhering to federal guidelines.

Australia NAPE focuses specifically on a coordinated response for endometriosis specifically. This research, however, includes endometriosis within the larger category of CPP. Given the prominence of diagnostic delays, taking a broader CPP approach allows PWU awaiting diagnoses to access certain policies outlined below, including income support, while continuing to pursue diagnostics. Moreover, although endometriosis remains the most commonly observed CPP disease, not all pain denotes this diagnosis; many PWU experience debilitating pain in relation to other CPP diseases requiring quality of life improvements vis-à-vis policy. In other words, the prospective development of such policies for Canada will include policies directed towards CPP overall to improve quality of life.

6.1. Overview - Population Affected, Political Structures, Impetus for Policy Intervention

The impetus for the implementation of the National Action Plan for Endometriosis in Australia stemmed from the recognition of the significant health, social, and economic impact of endometriosis on individuals, families, and society. Endometriosis affects an estimated one in ten women and individuals with uteruses worldwide (Australian Government, 2018), yet remains a poorly understood and often overlooked condition. In its early stages, the impulsion to draft the NAPE originated primarily from advocacy groups but received notable federal government support thereafter (Armour et al 2022). A collective, cross-sectoral desire to address the challenges faced by those living with endometriosis, including diagnostic delays, inadequate access to care, and limited research funding underpin the development of the NAPE. By launching the NAPE, Australia catalyzed the first ever coordinated effort across governmental, healthcare, research, and advocacy sectors to improve outcomes for PWU experiencing endometriosis, and to fill in gaps of understanding the diagnosis, treatment, and support for this disease.

6.2. Education and Awareness

The NAPE recognizes Education and Awareness as an important step in shifting negative health outcomes amongst PWU experiencing endometriosis. The impetus behind the inclusion of this policy area originates from a societal and individual tendency to normalize and stigmatize endometriosis, and by extent, menstruation, and menstrual pain (Armour et al 2020). The core aims of this NAPE component align with interview findings, underscoring the need to raise awareness among the public about CPP to foster understanding and compassion, and work towards ameliorating learning experiences about CPP to promote better health outcomes among PWU. Correspondingly, the NAPE presents four policies designed to elevate awareness and promote the education of Australians:

Table 1: NAPE Policies for Education and Awareness

Policy	Action
Develop widespread, visible, context specific community awareness campaigns delivered through multiple channels (Government of Australia 2018).	Members of the public are the target audience for this policy. Schools, workplaces, higher education institutions, human resource (HR) departments, poster campaigns in public washrooms, and the packaging of menstrual, hormonal, and analgesic products are suggested entry points for awareness campaigns. Campaigns are designed to dispel myths pertaining to endometriosis, define the disease, facilitate the recognition of symptoms, and provide resources for further support. Campaign materials are intended to be tailored to cultural and social contexts, including Aboriginal peoples (Australian Government 2018)
Promote early education on women's health delivered in school settings and provided for all genders (Government of Australia 2018).	This component aims to teach young people, and educators about endometriosis, hopefully resulting in an earlier recognition of symptoms. Educational curricula should be tailored to cultural groups, including specific teachings for Aboriginal peoples, people with disabilities, and those with language barriers.

Improve awareness and understanding of endometriosis among health professionals working at every stage of the clinical pathway (Government of Australia 2018).	This policy area focuses on educating health care workers including but not limited to general practitioners (GPs), nurses, sonographers, emergency department (ED) staff, etc., on endometriosis to better recognize the symptoms of the disease and make the appropriate medical decisions to support patients with psychosocial care. Education pertaining to the appropriate pathways for receiving help for endometriosis is emphasized. This policy area further calls for the upgrades to medical teaching standards to include endometriosis and pelvic pain for all healthcare workers (Australian Government 2018).
Improve access to information, self-education and self-management tools for individuals living with endometriosis at all stages of their journey (Government of Australia 2018).	This policy area hones in on promoting health literacy amongst those living with endometriosis. These provisions include the creation of a resource kit for those newly diagnosed, creating a succinct flow chart diagram mapping the pathways through the healthcare system for accessing care, and promoting advocacy undertakings designed to educate about endometriosis (Australian Government 2018).

6.2.1. Implementation

Since the formal governmental commitment to the NAPE in 2018, the Australian government allocated $8.57 million dollars to the area of Awareness and Education. The unanticipated COVID-19 pandemic resulted in delays in policy implementation, however, noted successes transpired. Over the five-year span of the plan, implementations included: launching a social media campaign architected to reduce stigma and promote awareness, developing 20 educational videos on endometriosis for those affected by the disease and medical professions, creating, and delivering the pilot Period, Pain and Endometriosis Program (PPEP) Talk to 80 Australian high schools, among other funding endeavours (Australian Government 2023).

When thinking forward towards the Canadian case, Australia's PPEP represents an important policy undertaking. The PPEP is delivered to tenth grade students by trained professionals who specialize in endometriosis and CPP (Pelvic Pain Foundation of Australia [PPFA] 2022). PPEP sessions focus on demystifying CPP through a de-normalizing framework which considers menstrual pain a serious issue meriting investigation and conversation, and is delivered across all independent, catholic and government schools (PPFA 2022). Students receive the appropriate knowledge to access services in response to menstrual pain, in addition to take-home resources to facilitate family learning on topics of CPP. Currently, the PPEP receives insufficient funding from the federal government to administer programming at all schools across Australia (PPFA 2022). Due to the infancy of the PPEP program, alongside disruptions from the COVID-19 pandemic, measurable outcomes from this program are not yet available. However, studies have shown that PWU experiencing CPP with greater health literacy led to reduced diagnostic delays and overall improved quality of life among affected individuals (Bennis et al 2023). Given these findings, we can infer that the PPEP will further elevate CPP awareness, and in turn, reduce diagnostic delays, destigmatize CPP, and through encouraging proactive medical care, will lead to overall better quality of life among PWU experiencing CPP.

The tangible results on the effects of these campaigns amongst the general public have yet to be released by the Australian government (Government of Australia 2023).

6.3. Clinical Management and Care

The inclusion of policies for improving the clinical management and care stems from a considerable global trend for increased diagnostic delays in the domain of CPP. Australians with suspected endometriosis, therefore, spend many years with untreated discomfort resulting in a diminished quality of life for patients. Initiatives outlined in this section create clear pathways for patients with suspected CPP or endometriosis, thus omitting the recurring cycle of trial and error. This section of the NAPE emphasizes the importance of providing comprehensive and multidisciplinary care for patients with endometriosis. In other words, this policy stream targets the amelioration of quality of life for endometriosis patients specifically through medical pathways. The NAPE identifies five key areas for policy intervention:

Table 2: NAPE Policies for Clinical Management and Care

Policy	Action

Develop clinical guidelines and clinical care standards to promote integrative care for all stages of the care pathway (Government of Australia 2018)	This policy area calls for standardized national clinical guidelines on endometriosis for health care providers, the development of a best-practice, evidence-based patient pathways system, establish models of care (MOC) for self-management, and the medical treatment of endometriosis, and to improve accreditation guidelines for advanced laparoscopic surgery. Another key initiative within this domain includes the development of a CPG for endometriosis (Government of Australia 2018)
Target diagnostic delay and promote early access to intervention, care, and treatment options (Government of Australia 2018)	These policies entail the development of Centres of Expertise especially for endometriosis and CPP, to devise and disseminate an at home tool for symptom recognition, and to clearly outline criteria which improve triaging processes for patients (Government of Australia 2018).
Improve affordability, accessibility, and national consistency of management and care options throughout Australia (Government of Australia 2018)	Policies in this area include the development of telehealth services for endometriosis for patients with access barriers, to develop and implement clinical guidelines for supporting at risk populations with endometriosis, and to overall reduce the overarching health care burdens of long wait times and cost associated barriers (Government of Australia 2018).
Ensure endometriosis is recognized as a chronic condition by all health practitioners, acknowledging its physical, psychological, and social impacts (Government of Australia 2018)	These policies aim to inform medical practitioners about the social, economic, and fertility impacts of CPP on patients to increase practitioner sympathy (Government of Australia).
Narrow the gap in quality of life between patients and their peers (Government of Australia 2018)	Action items include improving access to specific pain management physicians, promoting a multidisciplinary approach across different sectors to manage endometriosis (Government of Australia 2018).

6.3.1. Implementation

A total of $49.65 million was allocated to the area of Clinical Management and Care over the five-year tenure of the NAPE (Government of Australia 2023). Despite a lack of publicly available data reporting on the tangible successes of thus far undertaken policy initiatives, several important initiatives took place. Notably, the development of a specialized MRI scan to investigate infertility, the establishment of specialized endometriosis and CPP clinics, the development of the Endometriosis Management Plan which supports primary care patients, and the development of an Endometriosis Living Guideline all received considerable funding. Further, financial allocations supported the creation of a clinical practice guideline for endometriosis for physicians, and the introduction of curriculum for midwives and nurses specifically considering the management of people with endometriosis (Australian Government 2023).

The Australian Clinical Practice Guideline for the Diagnosis and Management of Endometriosis marks a key emergence in this policy domain. Created by the Royal Australian and New Zealand College of Obstetricians and Gynecologists (RANZCOG), this extensive document fulfills multiple overarching NAPE goals, first by promoting the denormalization of menstrual pain among physicians, but moreover, enhancing treatment pathways for patients (RANZCOG 2021). This document reflects the NAPE goals by creating a nationally recognized CPG which also defines evidence-based best-practices and establishes clear models of care (MOCs) (RANZCOG 2021).

6.4. Research

Despite the estimations that 1/10 women will experience endometriosis, research of the disease remains scarce globally. The final pillar of the NAPE specifically examines funding further research on endometriosis and CPP to identify and develop enhanced treatment regimes. Health advancements in the domain of CPP remain a vital action item in the improvement of quality of life for patients with CPP. Within this policy arena, Australia's NAPE outlines three overarching priority areas:

Table 3: NAPE Policies for Research

Policy	Action
Build a collaborative environment that enables world-leading research on endometriosis (Australian Government 2018).	This policy area calls for the establishment of a National Clinical Trials Network which supports endometriosis treatments and services, an Australian Research Collaboration Framework which oversees patient recruitment and management, and a targeted call for endometriosis through a Medical Research Future Fund (Australian Government 2018).

Mine existing data and improve data linkage between sources to improve understanding of the current state of endometriosis in Australia (Australian Government 2018).	Policy initiatives include making use of existing databases to enrich data on endometriosis, creating user-friendly tools for both physicians and patients to capture data, and collaborating with international research undertakings (Australian Government 2018).
Conduct further research to understand the causes and impacts of endometriosis and progress towards the development of a cure (Australian Government 2018).	Policy priorities include funding research to develop surgical alternatives to the diagnosis of endometriosis, research investigating the etiology of endometriosis to understand underlying causes of the disease, investigating the costs of illness associated with endometriosis, and lastly to continue researching the epidemiology of endometriosis and CPP using longitudinal research studies to better encapsulate the burden of disease in Australia and to measure the long term success of policy interventions on endometriosis (Australian Government 2018).

6.4.1. Implementation

To date, the policy area of research commands $28.97 in funding with notable allocations to the Medical Research Future Fund (MRFF), a project encapsulating five major research projects examining areas such as diet, alternative therapies, longitudinal studies of teenagers with endometriosis to identify early risk factors, and the role of early life exposures and genetic variants in understanding endometriosis. Several other research grants associated with the MRFF were also funded. Other research undertakings entail creating user-friendly access points to disseminate information about endometriosis to patients so they can make informed health decisions (Australian Government 2023).

6.5. Lessons from the Australian NAPE

Although the NAPE marks a critical step forward in addressing CPP and its effects on quality of life among PWU, certain policy areas remain unaddressed. The narrow focus on endometriosis only limits the scope of the NAPE, leaving many PWU unassisted. The ramifications of this focus were stated at the beginning of this chapter. Correspondingly, this study recognizes that not all CPP corresponds to a diagnosis of endometriosis despite similar symptoms and quality of life outlines, and thus widens the scope of proposed policies.

Moreover, although the NAPE briefly addresses the impacts of endometriosis on the Australian economy, income support policies for PWU experiencing CPP remain excluded, leaving a clear window for policy action. Resultantly, this research considers economic outcomes related to CPP within policy.

Considerations for mental health support for PWU remain under-explored by the NAPE and are an important component to holistic care. With literature corroborating a clear relationship between CPP and mental health, providing support for PWU in this capacity remains a key component to holistic care regimes enforced through policy.

Although equity-related considerations are mentioned in the NAPE, greater efforts to assure equitable outcomes for PWU are needed. Firstly, the NAPE utilizes gendered language, referring to patients almost exclusively as women; this study, however, employs the term people with uteruses (PWU) to include those experiencing CPP who do not identify as women. Efforts to provide equitable outcomes for Indigenous and PWU of colour, those living in rural settings, and other equity deserving groups require further exploration, particularly given Canada’s persistent colonial framework.

Chapter 7. Policy Recommendations

This section makes formal policy recommendations for each targeted policy area. These recommendations should operate in chorus with one another to promote a coordinated policy response for CPP across Canada. As established by previous sections, the four overarching policy domains considered by this research remain deeply intertwined; diagnostic delays can be reduced when PWU receive better health literacy rooted in denormalization programming; a reduction in diagnostic delays will ease the access of disability income support, and all separate components will amount to a better quality of life for PWU. Due to constraints of this capstone and smaller sample size, these recommendations are not comparable to the rigour of the Australian model, however, provide an important launch point for larger policy discussions about a national action plan for CPP in Canada. Improving overall quality of life remains the core overarching goal of this NAP, akin to the Australian model.

7.1. Education and Awareness

The focus of this area is to increase awareness of CPP at the societal level. This analysis identified three key pathways for period pain (PP) normalization, all of which can be altered to encourage early symptom recognition and health seeking behaviours: information relayed by female relatives, SHE curricula in schools, and interactions with HCPs about PP. All approaches to awareness must be rooted in de-normalizing pelvic pain and menstrual pain to shift intergenerational, educational, and medical discussions of CPP. Hand in hand with denormalization resides the promotion of health literacy among PWU, further accomplished through policies rooted in denormalization which raise awareness of CPP. In many ways, tackling PP normalization enables the success of all policy actions outlined in this chapter.

Policies in this section make use of existing resources where possible, however, federal spending is anticipated. In the first five years of implementation, Australia's NAPE spent a total of $7.0 million AUD on education and awareness policies, with the majority of this funding targeting school-aged children through the development of third-party led CPP education sessions (Government of Australia 2023). Cost-related considerations are discussed for each policy goal below.

Policy Goal 1: **Standardizing CPP topics across Canadian SHE curricula.**

a) **Action Item 1: Revising the NGSHE to include CPP:** Implementing comprehensive menstrual health education in school curricula for Canadian youth, specifically addressing the normalization of menstrual pain and promoting early recognition of abnormal symptoms. Currently, Canada possesses no federally standardized education curricula, however, national guidelines on various topics, including SHE do exist with avenues for the inclusion of CPP. The first step in addressing this policy goal is the inclusion of CPP within an updated version of the RGSHE utilizing a similar framework to the existing STI curricula. Attention should be given to topics of menstrual health, de-normalizing menstrual pain, and recognizing early signs of CPP. Given the reliance on existing government funding schemes and structures, this policy marks a key, relatively non-complex point of entry to the promotion of education and awareness. Central actors relevant to this policy undertaking include SIECCAN and their existing working group members, however, the addition of a member with CPP expertise is recommended to assure curriculum accuracy.

b) **Action Item 2: Establishing Joint-Funded Third Party CPP Education Programs:** Following the successes of the Australian model and bearing Canada's federalist structures in mind, funding a third-party organization like the Australian PPEP-Talk would ensure a standardized curriculum across all provinces, territories, and school districts. Providing CPP-specific education is a crucial step in promoting menstrual health literacy among young PWU, thereby encouraging early symptom recognition and earlier diagnoses. Standardizing this curriculum moreover, bridges healthcare disparities, by ensuring that regardless of geographic or social-locations, PWU can access high-quality healthcare information bereft of potential misinformation. Australia's PPEP receives funding from the federal government, in addition individual Australian states. A similar funding model is proposed for Canada. A shared funding model promotes provincial buy in and commitment and ensures equitable implementation across the nation which may otherwise be cost-prohibitive in some provinces.

Considerations for Equity Deserving Groups and Indigenous Peoples:

a. In the cases of Indigenous, Inuit and Métis peoples, cultural considerations accounting for Indigenous epistemologies and the role of settler colonialism are necessary. Collaboration between third-party menstrual health education designers and Indigenous communities is recommended to assure culturally relevant and safe curricula, which considers Indigenous ways of knowing pertaining to menstruation and other relevant topics. Within this capacity, it is recommended that educators tasked with administering this program receive cultural sensitivity training to understand the role of colonialism in shaping the lived experiences of Indigenous PWU. Developing a strong understanding in Indigeneity in concert with other social determinants of heath (SDoH) and structures of oppression, is necessary to culturally relevant curriculum.

Policy Goal 2: Increasing CPP awareness among HCPs

a) **Action Item 1: Review and update CPGs for endometriosis and CPP to reflect current best practices:** In 2010, the Canadian Society of Obstetrics and Gynecologists released Canada's first CPG for endometriosis, however, this document merits revesting to reflect evolving best practices, and to include other CPP diseases. In response to analogous challenges with HCP uncertainty and knowledge gaps pertaining to CPP, Australia designed a rigorous CPG which extensively and holistically examines endometriosis, thereby creating best-practice and evidence-informed documents accessible to all HCPs and supported by the Royal Australian and New Zealand College of Obstetricians and Gynecologists. Similarly, this policy action item calls for the Canadian Society of Obstetrics and Gynecology to perform a substantive overhaul of the existing CPGs to develop a more granular and in-depth reference document for HCPs. The creation of this document standardizes knowledge of CPP across all Canadian HCPs and providing clear diagnostic pathways and next streps for diagnoses. This policy action item also facilitates a reduction of diagnostic delays by creating clear steps for diagnoses and promoting earlier symptom recognition by HCPs. Moreover, this policy proactively prevents the burnout experienced by

PWU in this study by standardizing care pathways, thus reducing the need for self-advocacy simply to access basic care.

b) **Action Item 2: The inclusion of mandatory CPP modules in physician training:** Knowledge of CPP among HCPs remains variant across Canada, leading to diagnostic delays and patient frustration. This policy action mandates the integration of CPP modules into existing medical school curricula to establish baseline knowledge among future physicians. By augmenting physician knowledge of CPP, diagnostic delays may be reduced while improving interactions between HCPs and their patients. The Australian NAPE provides a similar recommendation, topics concerning CPP may be easily integrated into existing courses concerning gynecology and obstetrics, urology, and pain management. Regarding implementation, this policy recommends a collaboration between Canadian medical schools and the Canadian Society of Obstetrics and Gynecologists, who offer existing online modules on various CPP-relevant topics, including the diagnosis and care of endometriosis, to integrate CPP within existing curricula. An ancillary component to this policy is the training of relevant educators on topics of CPP, which requires an up-front financial investment into training programs. Thus, a joint funding structure between federal government and existing medical school operating budgets is proposed. Similarly to the join funding scheme described in the previous recommendation, this model promotes institutional buy-in from universities, while supported by government funding to assure equitable implementation. Overall, integrating CPP-specific training into medical curricula marks a crucial step towards improving diagnoses, management and patient experiences.

Policy Goal 3: Increasing CPP awareness among the members of the public and PWU

a) **Action Item 1: Launching Public Health Campaigns to Raise Awareness**: This policy recommends the creation and dissemination of CPP knowledge to the general public using social media and public poster campaigns. Since the implementation of the Australian NAPE, several organizations received federal funding to promote awareness of endometriosis not only among PWU who may be experiencing the disease, but also to destigmatize the disease amongst the public. In Canada, the Endometriosis Network (EndoNetwork), a registered charity, undertakes the mission of raising awareness about the disease, and constitutes a key actor for policy collaboration. A collaboration between the EndoNetwork and Health Canada and/or PHAC may be utilized to broadcast a national campaign pertaining to CPP employing federal funding and the existing resources and materials collected by the charity. Similar campaigns operate under this model, including a collaboration between the Mental Health Commission of Canada (MHCC) and the federal, provincial, and territorial governments. Merging efforts between established activist groups and federal health authorities marks a vital pathway for raising awareness of CPP at the national level.

b) **Action Item 2: Increasing awareness and autonomy among PWU experiencing CPP.** Even among PWU experiencing CPP, understanding diagnostic and treatment trajectories remains convoluted, often leading to patient burnout. This recommendation calls for the dissemination of key CPP-related information designed for patients using printouts or digital brochures. Information included in these materials should reflect the CPGs, to ensure uniformity across HCPs and patients, while promoting a gold standard for care. Key information reflected in these materials include: general information about CPP, explanations of available treatments (i.e., hormonal, NSAID and surgical options), and the diagnostic trajectory ahead of them. Like the recommended CPGs, collaborations with the Canadian Society of Obstetrics and Gynecologists are advised in consultation with provincial health authorities. Stakeholder engagement with PWU experiencing CPP emboldens this initiative to better capture the needs of this community regarding understanding their condition, but requires additional cost to recruit, consult, and relay information.

7.2. Improving Clinical Pathways

This area aims to minimize diagnostic delays and improve patient experiences within the healthcare system. Diagnostic delays prolong the pain of PWU experiencing CPP, leading to negative physical and mental health, interpersonal, vocational, and in some cases fertility outcomes. Although raising awareness remains vital in preventing diagnostic delays, the multifactorial nature of this issue requires a multifaceted response. Moreover, patients who negatively interact with HCPs delay seeking further care, fearing future negative interactions. By mitigating these two areas through the following policies, clinical pathways will experience notable improvements:

Policy Goal 1: Establish a national standard of care.

a) **Action Item 1: Developing robust CPGs for CPP in collaboration with the Canadian Society of Obstetrics and Gynecologists**: This policy was already discussed in relation to ameliorating knowledge and awareness of CPP among HCPs. To avoid repetition, refer to the previous section (7.1) for the mechanics of this policy. Regarding this specific policy goal, the creation of a nationally endorsed CPG not only augments HCP knowledge of CPP, but moreover, provides a robust anthology of recommended actions and/or treatments informed by experts. By implementing this policy, multiple key goals are met, thereby reaffirming the importance of actualizing CPGs for CPP in Canada.

Policy Goal 2: Ameliorate CPP-specific care across Canada.

a) **Action Item 1: Establish specialized CPP clinics across Canada:** This policy action provides comprehensive and coordinated CPP care, including timely access to diagnostic tests and interdisciplinary treatments. The Australian federal government allocated over $17 million AUD in support of 22 specialized endometriosis and pelvic pain clinics (Australian Government 2023). This policy represents one of the more costly undertakings associated with this action plan, requiring large up-front investment to establish new clinics, and is more administratively complex to administer. Following clinic establishment, costs are estimated to decrease, and reflect operational spending. A joint funding scheme utilizing both federal and provincial resources is recommended to ensure equitable funding and ensure multi-level buy in. Funding for such clinics may be bundled within Canadian Health Transfer (CHT) payments, and ancillary funding from Provincial and Territorial Health Authorities. Implementation mechanics, including choosing locations, or making use of existing infrastructure where possible, and staffing would operate at the provincial level, utilizing Provincial/Territorial health ministries, and regional health authorities to reflect the unique health landscapes and community names of the provinces and territories. Currently, only Ontario, Manitoba, Saskatchewan, Alberta, British Columbia, and Nova Scotia host their own CPP and/or endometriosis clinics in small numbers. Establishing CPP clinics in all provinces and territories, and augmenting numbers in provinces with already operational clinics, broadens the reach of specialized care, and contributes to overarching goals of reducing diagnostic delays. Additionally, by matching CPP patients with specialized cares, general practices and emergency departments may be less burdened by CPP. This policy represents a core long-term intervention within the CPP landscape.

Policy Goal 3: Reduce CPP-related diagnostic delays: Diagnostic delays present a multi-factorial challenge within the domain of CPP. In this way, not all policies designed to improve this challenge pertain directly to medical intervention. Nevertheless, many of the already-mentioned policies, including those within this section, actively address this issue through multiple pathways. Both action items in section 7.2 facilitate a reduction in diagnostic delays by identifying clear instructions for physicians on recognizing key CPP symptoms, prescribing treatments and making referrals for specialized care or imaging, while also providing tailored medical care at specialized institutions, which in turn, reduces stress on other already backlogged healthcare actors and institutions. Moreover, the education-oriented policies mentioned in section 7.1 foster health literacy among PWU and focus on destigmatizing menstruation among target populations in order to promote early symptom recognition and health seeking behaviours.

7.3. Improving Research on CPP

This area focuses on funding and advancing research efforts to enhance understanding of CPP and to develop better diagnostic tools and treatment options for

PWU. While major gaps in CPP disease knowledge persist, insufficient diagnostic and treatment regimens also persist. Enhancing understanding of CPP diseases, especially regarding the efficacy of treatment regimens over time will promote better health outcomes for the future of CPP. Studies centring on early detection, diagnosis, predictors of pain, and non-invasive diagnostic tools should receive priority resource allocation.

Policy Goal 1: Establish space within health research for PWU experiencing CPP

a) **Action Item 1: Prioritize CPP-related research within the CIHR:** Canada places importance on health research, reflected within the thirteen CIRH institutes. CPP, however, is not yet identified as a priority area for research within any of the thirteen institutes. This policy action calls for the prioritization of CPP-related research within the Institute of Gender and Health, which currently undertakes initiatives exploring the influence of gender and sex on health. Given the inextricable relationship between gender and CPP, the Institute of Gender and Health constitutes a logical network to undertake these research topics. Following the Australian example, key areas requiring further research include non-invasive diagnostic methods for CPP and longitudinal studies to better understand CPP manifestations throughout the life course, among others. The formal prioritization of CPP research within the CIHR requires minimal resources, rendering this imitative cost effective. Moreover, despite there being no current formal research priorities for CPP, researchers across the country do investigate topics of CPP. With a clear avenue for funding applications and the support of a network of researchers via the CIHR, existing researchers may be encouraged to undertake further CPP research, particularly longitudinal studies, which provide valuable feedback pertaining to CPP trajectories.

7.4. Workforce Participation and Economic Challenges

This area addresses the impact of CPP on employment, income, and access to income support. The analysis section of this study describes a clear relationship between CPP and income loss, requiring strategies to reduce the financial burdens of CPP. Moreover, among those who seek income assistance related to the debilitations of their CPP, issues pertaining to ease of access persist. Accessing income support presented multiple barriers in relation to obtaining medical documentation using a diagnosis-oriented paradigm. Policy actions include:

Policy Goal 1: Foster supportive workplace environments for PWU

a) **Action Item 1: Create and disseminate educational materials about CPP, specifically tailored to workplace settings** The prominence of absenteeism and presenteeism among PWU experiencing CPP underscores a need to augment support from workplaces to the ultimate benefit of individuals and their employers. Examples of supportive workplace policies include: flexible work arrangements, remote work options, and access to sick leave for pain management. To ensure continuity across key social actors and institutions, this policy recommends the development of educational modules for employers concerning CPP by the SOGC in collaboration with Employment and Social Development Canada (ESDC). These materials should focus on augmenting knowledge of CPP among employers, to better support and accommodate PWU within the workplace. Further collaborations with the Canadian provinces and territories are advised to work within their existing disability workplace training modules.

Policy Goal 2: Improve accessibility of income support for PWU experiencing CPP

b) **Action Item 1: Amend existing eligibility criteria to improve inclusion:** Challenges faced by PWU experiencing CPP reflect a larger issue with Canada's various disability income support schemes. Alongside CPP, many chronic pain and other chronic conditions pose challenges for individuals seeking income support under Canada's current disability framework. Both the CPPD and DTC require supplementary documents filled in by physicians to corroborate an individual's disability, however, these documents themselves remain un-amenable to chronic pain and other chronic conditions. Relevant actors include: ESDC who is responsible for the CPP-D and DTC programs, the Canadian Pain Association (CPA), and other relevant organizations with specializations in various chronic pain domains including the SOGC. These collaborations ensure that best-practices, as outlined by relevant institutions (i.e., SOGC, Canadian Association of Gastroenterology, etc.), are reflected within screening for disability income support. Specifically, this policy concerns redesigning eligibility criteria to offer a clearer pathway for those experiencing chronic conditions, including CPP by means of expanding lists of diseases and conditions to include chronic diseases which significantly impact an individual's ability to work. Within these eligibility amendments includes a fundamental re-configuration of not only eligibility criteria, but the evaluation techniques used to understand disabilities. The costs associated with this policy concern funding an initial task force or working group to research, refine and implement these recommendations, whereas long term costs associated with monitoring and evaluation are necessary. An amalgamation with existing entities monitoring disability policies constitutes a feasible option. Specific amendments within eligibility criteria and evaluation techniques include (this is not an exhaustive list):

- **Amendment 1: Flexible Duration Requirements:** altering eligibility criteria to allow for flexibility in the duration of a disability, to better capture the experiences of those with CPP. Rather than requiring a continuous period of disability, considerations for episodic disabilities which may fluctuate in severity over time, including CPP, should be integrated.
- **Amendment 2: Holistic Assessment of Functional Limitations:** Revise disability assessment procedures to include a "big-picture" evaluation of functional limitations, instead of relying on traditional measures of impairment such as diagnostic tests (i.e., imaging, blood work, etc.). Multidimensional assessments which understand the impairment on the individual level with special considerations for performing daily activities, work-related tasks, social functioning, and mental well-being are advised. This amendment also accounts for diagnostic delays associated with some chronic conditions by removing the diagnostic-oriented framework, focusing rather on functional impairment relevant to the individual.
- **Amendment 3: Alternative Work History Requirements:** Modify work history requirements to accommodate the unique, often patchwork employment experiences of individuals with chronic pain conditions. Rather than mandating specific duration of type of work history, consider alternative criteria including assessing individuals' efforts to maintain employment despite their chronic pain, participation in vocational

rehabilitation programs, and transferable skills relevant to alternative forms of employment.

- **Amendment 4: Recognition of Subjective Symptoms**: Recognize the subjective nature of chronic pain conditions and their manifestations in individuals. The necessary application paperwork should include considerations for subjective symptoms including: pain intensity, frequency, duration, day-to-day impairment and functional limitations.

When these amendments operate in conjunction with robust CPGs, physicians possess a better toolkit in assessing individual cases for disability income support.

c) **Action Item 2: Amend and simplify application processes for disability income support:** Simplify and streamline the application process for disability benefits to reduce bureaucratic barriers and make it easier for those experiencing disabilities more broadly to access financial assistance. These amendments specifically facilitate these processes for PWU experiencing CPP in addition to other prospective applicants. Similarly, these amendments require engagement with ESDC, including Service Canada. Additional collaborations with advocacy groups representing various disabilities across Canada may be consulted to further understand the burdens and challenges associated with current formats. Costs remain amendment-specific, with some requiring technological improvements necessitating information technology (IT) assistance, and others requiring additional employees to facilitate live chats and other assistance roles. At first glance, recommended actions include: developing online user-friendly application portals, providing free assistance with completing forms, and launching an eligibility questionnaire which redirects ineligible applicants to other useful resources. These individual recommendations will be discussed in more detail below:

- **Amendment 1: Develop and Launch a Centralized Online Platform:** Establish a centralized online platform where individuals can access information about disability income support programs, complete

    application forms, and track the status of their claims. Contrary to current models, this amendment proposes updating federal websites to be more user friendly, and accessible to individuals with disabilities.
  - **Amendment 2: Pre-Screening and Eligibility Assessments:** Many people experiencing disabilities and/or functional impairments remain unaware of their eligibility for income support. This amendment proposes the implementation of pre-screening mechanisms, such as an online questionnaire, to determine eligibility for programs before embarking on the application process. Utilizing Artificial Intelligence (AI), or similar programs, preliminary inputted information pertaining to medical conditions, symptoms, work history and financial circumstances may receive feedback on eligibility, next steps, and other resources where relevant. This amendment prevents allocating unneeded time and energy into unsuitable programs, and may lower the volume of applications, thus optimizing efficiency.
  - **Amendment 3: Self-Service Options**: Offer self-service options for completing and submission disability claims, allowing individuals to apply online or by phone without the need for in-person appointments or paper-based submissions which may be unfeasible for certain applications.
  - **Amendment 4: Assistance and Support Services:** Provide assistance tools, such as chatbots or virtual assistants to help applicants navigate the application process and answer frequently asked questions. Access to trained staff or volunteers who can assist in completing application forms, gathering supporting documentation, and addressing other inquiries or concerns. This specific amendment requires monetary and human resources to implement effectively.

Overall, this national action plan aims to address the multifaceted challenges faced by individuals with CPP in Canada, promoting early recognition, timely diagnosis, comprehensive care, and supportive policies to improve their health outcomes and quality of life.

Chapter 8. Conclusion

This study sought to develop a NAP strategy for CPP in Canada using the lived experiences of PWU experiencing CPP captured through qualitative interviews, a literature review, and a comprehensive case comparison with Australia's NAPE. Ten qualitative interviews with PWU experiencing CPP capture a valuable, and often overlooked perspective in CPP research; understanding the gaps in quality of life from individuals with lived experiences lay an important bedrock for policy action within the domain of CPP. Data triangulation revealed several key recommendations across four overarching policy domains: Education and Awareness, Improving Experiences with Clinical Pathways, Improving Research on CPP, and Workforce Participation and Economic Challenges. Within each pathway, multiple opportunities for policy action exist to ameliorate quality of life among PWU, with special attention to de-normalizing CPP among target groups, standardizing clinical pathways, augmenting research efforts, and improving access to income support.

The findings underscore the urgent need for a coordinated policy response to CPP across Canada. While acknowledging the constraints of this capstone and its smaller sample size compared to the Australian model, the recommendations presented serve as a vital starting point for larger policy discussions aimed at developing a national action plan for CPP in Canada.

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Appendix.

Interview Guide

Interview Guide – People with Uteruses Experiencing CPP

The following questions will shape interviews with people who have lived experience with CPP. Interviews will adopt a semi-structured framework, and therefore, may include questions, or follow-up questions not expressed below.

Theme	**Questions**
Confirmation of Consent	Have you read and understood the terms outlined in the consent form re-distributed to you before this interview? Do you have any final questions about any of the information presented in the consent forms? Are you willing to proceed with an interview today under the terms outlined in the consent form? RECORDING: Do you consent to be audio recorded during our interview? FUTURE CONTACT Do you consent to be contacted with follow up questions? Do you consent to be contacted for future research concerning similar topics to this study? FUTURE DATA USE: Do you consent for the data collected in this study to be made publicly available (without any participant identifiers) for future use in other research
Rapport building	What do you do for work? What are some of your leisure activities/hobbies? Have long have you lived in province of residence? Can you tell me broadly about your journey with CPP?
Understanding pain	How old were you when you first started to notice your pelvic pain? Can you tell me a bit about your experience with pain growing up?

	Do you have any formal diagnoses for your pain? IF YES: if you feel comfortable, would you mind telling me what your diagnosis is? How often are you in pain and for how long? (approximations are O.K.) How was menstrual/period pain described to you growing up? What are your main symptoms associated with CPP? (if participant is comfortable sharing) How does your pain affect your day-to-day life? Describe your ability to fulfill your day-to-day activities (childcare, go to work, attend class, etc.) when you are in pain? How does pain impact your interpersonal relationships?
Diagnostics *Indicate questions for people with CPP diagnostics	*How long after the onset of your symptoms did you receive a confirmed CPP diagnosis? What was the symptom/incident/experience/last straw that pushed you to seek medical attention for your symptoms? What does your treatment regime look like? Does it adequately address your pain? Can you tell me about your diagnostic experiences? What tests/imaging/etc. were conducted? What treatment regimens were you prescribed? *Do you feel that having a concrete diagnosis for your CPP has improved your accessibility to medical/social services? If yes, how? If not, why do you think that is? If you are still awaiting a CPP diagnosis, what in your opinion has delayed this process? Who oversees your regular care for CPP? (GP, Gynecologist, special pain clinic, etc.) For those who access chronic pelvic pain clinics, can you tell me what your experience was like getting into these clinics? How long did you wait? How do their care regimes compare to your past experience with a GP or Gynecologist?
Well Being/General Life/Employment/Education	Can you describe a time where you had to miss work/school/daily activities because of pelvic pain? Can you tell me about a specific event/time/ that was negatively impacted by your CPP? How does CPP impact your mental health? How does your CPP affect your employment? I would like to roughly understand approximately how much work is lost to your CPP. Can you tell me approximately in terms of hours/lost workdays/income you miss because of CPP?

	Have you ever tried to apply for any type of social benefits because of CPP? If yes, can you tell me about your experience with this? Were the benefits you were given sufficient for your pain? Do you feel that your workplace is supportive of your CPP? Can you tell me a little about why/why not? Can you tell me about ways you have changed your day-to-day behaviour to accommodate your CPP? How could social programming better suit your needs as a PWU experiencing CPP?
Treatment Experiences	Have you ever been prescribed hormonal birth control (the pill, IUD, injections, arm rod, etc.)? If yes, what was your experience with this treatment? Did it improve your symptoms? How do available over the counter pain killers (Advil, Tylenol, Aleeve, etc.) manage your pain? Have you ever been prescribed something for pain aside from Acetametaphine (Tylenol), or Ibuprohen (Advil)? (i.e. hydromorphone, naproxen, other opioids, diclophenac, etc.) If yes, how did this specific medication and dosage manage your pain effectively? Have you ever undergone surgery to explore, diagnose or treat your CPP? If yes, how did this procedure influence your symptoms? Can you tell me about your experiences interacting with doctors and other medical professionals in relation to your CPP? Where are you at now in your diagnostic/treatment journey? (are you in a place where your symptoms are well managed? Does CPP still impact your day-to-day life in a negative way?)
Experiences with the Medical Systems	Do you feel that your complaints/symptoms are heard when voiced to medical professionals? Have you ever been admitted to the emergency room for CPP-related symptoms? If yes, can you tell me, to your comfort level, about how you were treated throughout that process? How would you describe the ease of accessing health care services for your CPP?
Education	Can you tell me about your education about CPP? This can be in school programming, general accessible health knowledge, etc. At what point did you recognize that your CPP was classified as abnormal? If you could go back and time and speak to young people with uteruses about pelvic pain, what would you tell them?

	What do you wish other people knew about CPP? What resources (online forums/websites, books, blogs, podcasts, etc.), if any, have helped shape your understanding of CPP?