

## Submission to the Senate Standing Committee on Social Affairs, Science and Technology Bill C-64: An Act respecting pharmacare

October 1, 2024

### Introduction

Canada has one of the highest rates of multiple sclerosis (MS) in the world. An estimated 90,000 Canadians live with the disease, and, on average, 12 Canadians are diagnosed with MS every day. About three-quarters of Canadians who live with MS are women and most people are diagnosed between the ages of 20 and 49.

MS is a neurological disease of the central nervous system (CNS) which includes the brain, spinal cord, and optic nerves. In MS, the body's immune system mistakenly attacks myelin, the protective covering of nerve fibres. Myelin is needed to effectively send messages to and from the brain. Damage to the myelin can result in loss of nerve fibres over time, and these changes contribute to disease progression. Symptoms of MS are unpredictable and vary in severity from person to person and may include fatigue, pain, walking difficulties, weakness, vision problems, bladder and bowel dysfunction, and cognitive and mood changes. The episodic yet progressive nature of MS makes it particularly challenging to maintain an adequate quality of life.

A [recent study](#) by Deloitte Access Economics highlighted the significant socioeconomic cost of MS to Canada, estimating the total annual cost of illness to be more than \$3.4 billion in 2019. Furthermore, the study investigated the impact and economic cost of COVID-19 on MS care in Canada. The study reported a significant reduction in health service access among people with MS during the pandemic, which resulted in a health services backlog and an accumulation of unmet health needs.

This reality will have a long-lasting negative impact on the health outcomes of people with MS. This is due in large part to delayed diagnosis and delayed, altered, or halted treatment and care. As well, it was noted that a reduction in rehabilitation, coupled with a lack of social and cognitive stimulation during the pandemic, is expected to result in increased disability progression. This has a costly effect on Canada, as health system costs related to MS are estimated to rise to \$1.5 billion in 2024, an increase of \$73 million compared to an unaffected year. The rising economic burden is expected to continue in future years.

The MS community knows that time is crucial. The faster an individual can receive a diagnosis, and the faster they are able to get effective treatment, the longer they can preserve function and avoid disability. To borrow a phrase common in the field of stroke, time is brain. Disease-modifying therapies (DMTs) can dramatically alter the course of the disease by reducing annual relapse rates, slowing disability progression, and reducing the number of lesions on the brain and spinal cord. Exposure to any DMT was found to be associated with up to a 33 per cent lower risk in mortality when compared with no DMT exposure.

As the Senate Standing Committee on Social Affairs, Science and Technology studies the legislation to implement a national pharmacare program, MS Canada has identified actions the Government of Canada can take to directly improve the lives of Canadians affected by MS.

## Recommendations

**Recommendation 1:** Prioritize adding all Health Canada-approved MS disease-modifying therapies on the list of essential prescription drugs and related products to a national formulary.

**Recommendation 2:** Ensure all Canadians continue to have access to medications covered on existing insurance plans.

**Recommendation 3:** Ensure the design, implementation, and delivery of the national pharmacare program includes Canadians with lived experience.

## Include all Health Canada-approved MS DMTs on a National Formulary

**Recommendation 1:** Prioritize adding all Health Canada-approved MS disease-modifying therapies on the list of essential prescription drugs and related products to a national formulary.

Bill C-64 stipulates that a list of essential prescription drugs and related products to inform the development of a national formulary be prepared within one year of the bill receiving royal assent. It is imperative that all Health Canada-approved DMTs for MS be included on this list.

Canadians living with MS have a right to access all Health Canada approved disease-modifying therapies. Their voice is central to the goal to eliminate or reduce symptoms, slow, prevent and ultimately cure the disease. This requires timely, equitable, affordable, and consistent access to the full array of approved treatments, ranging from longstanding compounds to more recently approved innovative agents, because no two people have the same disease course or respond in the same way to the same medication.

A central premise of a national pharmacare program must include the concept of "the right medication at the right time." This enables Canadians living with MS to benefit from those medications most appropriate for them regardless of where they live or their income status, and their voice is integral in this decision. As well, early intervention is vital to avoid many of the long-term health, economic, and personal costs that result from unnecessary irreversible disability.

A national pharmacare program must offer the full range of Health Canada authorized medicines for MS. This includes different classes of medications and administrations, as the clinical response to each of these drugs will vary greatly from person to person based on their unique patient journey, including disease type and course, stage of life (pediatric, pregnancy, elderly), and personal preferences driven by lifestyle, health, and economic factors.

Currently, there are significant inequities in access to MS medications across the country. In its report *Accessing Disease-Modifying Therapies for Multiple Sclerosis: A Pan-Canadian Analysis*, the Conference Board of Canada highlighted several factors that have contributed to the current situation. The most prominent is the Canadian drug reimbursement system, which is a “patchwork of over 100 government-run public drug insurance programs and thousands of private drug benefit plans.” Canada’s “fragmented and difficult to navigate” drug approval process has created a significant barrier for individuals seeking coverage for treatment.

Differences across provinces in reimbursement plans and private insurance coverage have resulted in large inequities in financial costs on individuals and provinces, and as a result, has led some provinces to omit certain DMTs from their public formularies due to high cost, while other provinces have the resources to list them.

Additionally, MS Canada believes a national pharmacare program should be designed for the future and accommodate the inclusion of new and emerging therapies that can improve health outcomes – or even cure diseases. A population health perspective may not reflect the needs of individual patients, especially as it relates to a unique disease like MS. All Canadians should be assured that their specific circumstances will be accommodated by a national pharmacare program. In addition to a comprehensive formulary, a national pharmacare program should ensure that Canadians can access publicly funded medications that are not on the formulary through separately adjudicated access programs.

While the creation of a coordinating body as a result of pharmacare may facilitate collaboration among all parties involved in the drug approval process, akin to the pan-Canadian Pharmaceutical Alliance’s (pCPA) work, it would be important to ensure that such a body would not be yet another hurdle in the patchwork of Canada’s approval process, thereby delaying access for Canadians even further. We’ve seen that despite the ‘stronger together’ rationale behind the pCPA (which suggests that by negotiating drug prices together, provinces could improve access and reduce costs), in recent years, some provinces have chosen to opt out of pCPA negotiations, leaving people with MS in those provinces without access to much-needed DMTs.

## Ensure Continued Access for all Canadians

**Recommendation 2:** Ensure all Canadians continue to have access to medications covered on existing insurance plans.

Canadians need access to the complete range of treatments for their conditions. While there have been astounding advancements in the treatment of MS over the past two and a half decades, much remains unknown. No two people living with MS have the same course of the disease, and there remains no guarantee they will respond the same way to the same treatments.

A national pharmacare program should ensure access to all medically necessary drugs. For Canadians, a drug is medically necessary when it is prescribed to them by their healthcare provider. Treatment decisions need to be made on the best evidence available and based on an informed discussion between an individual and their healthcare provider.

Essential to the development of a national pharmacare program is that Canadians should be able continue to have access to medications covered on existing insurance plans upon implementation of a national pharmacare program, including the majority of Canadians who rely on private insurance programs for coverage. Changes to medicine coverage under Bill C-64 must not reduce any Canadian's access to medications compared to levels before pharmacare's implementation.

## Ensure a robust engagement process

**Recommendation 3:** Ensure the design, implementation, and delivery of the national pharmacare program includes Canadians with lived experience.

With one of the stated goals of pharmacare being to protect and promote the health and well-being of Canadians, it is critical the Government of Canada develop a robust consultation process to directly engage with Canadians. People with lived experience are best suited to advise about their experiences with the healthcare system and gaps they've experienced in coverage, which would positively impact the implementation of national pharmacare.

We believe that lived experience perspectives would be best understood and incorporated by involving these individuals in the design and implementation of a national pharmacare program as well as throughout its evolution, so that continuous improvement becomes an important feature of the program.

There are several other reviews and entities involved in decisions that shape access to medicines and – consequently – the design and implementation of a national pharmacare program. A made-in-Canada national pharmacare program should provide formal roles for individuals with lived experience at every level, including research, regulatory reviews, price regulations, health technology assessment, funding decisions, and patient navigation, as well as ongoing patient navigation support for the program.

## Conclusion

The development of a national pharmacare program holds great promise to improve the lives of all Canadians, including the 90,000 Canadians who live with MS. Research shows that DMTs for MS can dramatically alter the course of the disease by reducing annual relapse rates, slowing disability progression, and reducing the number of lesions on the brain and spinal cord. For many with MS, navigating the healthcare system to access MS DMTs can be a challenge.

As the Senate Standing Committee on Social Affairs, Science and Technology considers Bill C-64, MS Canada strongly advocates that national pharmacare: prioritizes adding all Health Canada-approved MS disease-modifying therapies to a national formulary; ensures all Canadians continue to have access to medications covered on existing insurance plans; and, ensures a robust engagement process inclusive of Canadians with lived experience.

# MS Canada

## About MS Canada

MS Canada provides programs and services for people with MS and their families, advocates for those affected by MS, and funds research to help improve the quality of life for people living with MS and ultimately find a cure. The mission of MS Canada is to connect and empower the MS community to create positive change. Since 1948 MS Canada has contributed over \$218 million towards MS research. This investment has enabled the advancement of critical knowledge of MS and the development of a pipeline of exceptional researchers. As part of the MS community, we are committed to ensuring Canadians living with MS, and their families, can participate fully in all aspects of life. We continue to ask governments to remove barriers and improve policies that impact people affected by MS.

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