



**National Pharmacare Consultation**  
**Submission by the Multiple Sclerosis Society of Canada**  
**September 2018**

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## Introduction

The Multiple Sclerosis (MS) Society of Canada is pleased to provide this submission to the Advisory Council for the Implementation of National Pharmacare consultation. We are pleased to be engaged in the consultation process which we feel is an important signal from the Council that patients and patient voices will be valued and will help inform the recommendations.

Multiple sclerosis (MS) impacts all Canadians - not only the affected individuals, but also their families and friends. The unpredictable, episodic, yet progressive nature of MS makes it particularly challenging in maintaining an adequate quality of life. MS is a disability which has both visible and invisible symptoms, and barriers in support programs across levels of governments add immense financial and practical challenges for Canadian families who struggle to manage the realities of living with MS. It is particularly salient in Canada as we have one of the highest rates of MS in the world, and it is one of the most common neurological diseases affecting young adults in Canada, with most people diagnosed between the ages of 15-40 -- their prime family and career building years.

People living with MS are mothers, fathers, sisters, brothers, children, and friends. They are people impacted every day, every hour, and every minute. The needs of people with MS and their families should be at the centre of health and drug policy decisions. Their perspectives and experiences should be a top priority in this consultation.

A key priority for Canadians affected by MS is timely and affordable access to treatments that take into consideration their unique disease where no two people living with MS have the same course of the disease and/or respond in the same way to the same medication.

The MS Society believes that the Government of Canada has a lead role to play in developing a national pharmacare program to address diverse and important gaps in the healthcare system by providing Canadians with access to a broad range of evidence-based therapies through both public and private payers.

This submission reflects a dual perspective, the first being from Canadians affected by MS whose priority is access to timely and affordable treatments. The second perspective is from the MS Society's role as a

***Canada has one of the highest rates of MS in the world!***

MS is a chronic, often disabling, disease of the central nervous system. Since that includes the brain, spinal cord and optic nerve, MS can affect vision, memory, balance, and mobility.

Over 77,000 Canadians live with MS. Approximately 1 in every 385 Canadians live with MS. Women are three times more likely to be diagnosed with MS than men.

MS is the most common neurological disease affecting young adults in Canada. 60% of adults diagnosed with MS are between the ages of 20 and 49 years old. On average, 11 Canadians are diagnosed with MS every day.

funder of research to improve therapeutic options. Additionally, the recommendations are aligned with our partners in the Health Charities Coalition of Canada.

## Summary of Recommendations

**Recommendation 1:** A national pharmacare program should have a clear and patient-focused objective: to improve health outcomes for Canadians.

**Recommendation 2:** Ensure that patient-centred principles be adopted and used to inform the design, implementation and delivery of a national pharmacare program.

**Recommendation 3:** A national pharmacare program needs to ensure that all Canadians have access to prescription medication coverage – including all ages and those with acute, chronic and episodic illnesses.

**Recommendation 4:** A national pharmacare program needs to ensure access to all drugs approved by Health Canada – if not on the national formulary, then via separately adjudicated access programs. Reducing access that citizens currently have to prescription medicines is counterproductive and creates uncertainty for Canadians.

**Recommendation 5:** Funding pharmacare should be shared across different payers to balance sustainability and affordability with improved access to treatments and patient choice.

**Recommendation 6:** Shared leadership among federal, provincial and territorial governments is essential to creating a national pharmacare program that is integrated with existing provincial and territorial health systems. Patient partnerships enable their unique perspectives to be incorporated throughout the design and implementation of the program.

## Objective of a National Pharmacare Program

**Recommendation 1:** A national pharmacare program should have a clear and patient-focused objective: to improve health outcomes for Canadians.

The MS Society recommends that the development of any new national program needs to start with an objective. Canadians should be able to understand the challenge the federal government wants to address by implementing national pharmacare. ***We believe that the aim should be to improve health outcomes for patients.*** This can be accomplished by increasing access to treatments and by not reducing access for the many Canadians who already have timely and comprehensive drug plans.

The MS Society hosted a quality of life initiative/survey in 2013 and heard from 6000 Canadians affected by MS. This initiative was multi-pronged and included surveys, an environmental scan of Canadian legislation and regulations, both federal and provincial, along with the quality of life metrics of people affected by multiple sclerosis. We heard that, in Canada, people affected by MS had difficulties accessing affordable and timely treatments. We heard that they want access to comprehensive health solutions to improve their experience with the system and their health outcomes.

We need to ensure that Canadians living with MS have access to all currently approved disease-modifying therapies (DMTs) approved for multiple sclerosis (MS) by Health Canada as they appear to work by blunting the destructive autoimmune response that targets tissues in the central nervous system (CNS). For many individuals living with MS, DMTs offer measurable therapeutic benefits by suppressing MS relapses and, in some cases, delaying the accumulation of disability. Access to these medications is key to maintaining quality of life including employment and income.

### Principles for a National Pharmacare Program

**Recommendation 2:** Ensure that patient-centred principles be adopted and used to inform the design, implementation and delivery of a national pharmacare program.

The MS Society recommends the advisory council adopt the principles for a patient-centred approach to national pharmacare as developed by the Health Charities Coalition of Canada in collaboration with Best Medicines Coalition and the Canadian Pharmacists Association through the Pharmacare Working Group. These principles initially appeared in the group’s report, [Better Pharmacare for Patients](#).

Additionally, we advocate that an additional principle of patient partnerships be adopted to guide and inform the Council’s recommendations in addition to those below.

1. **Equity.** *Every Canadian should have equitable and consistent access to necessary prescription medicines.*
2. **Timeliness of access.** *Canadians should be able to access the medicines they need in a timely manner.*
3. **Appropriateness of therapy.** *All Canadians should have access to high quality medicines that are appropriate to their individual needs.*
4. **Affordability.** *All Canadians should be able to afford their medicines at the point of care.*
5. **Sustainability.** *All Canadians should benefit from a pharmacare system that ensures ongoing health system sustainability.*
6. **Patient partnerships.** *National pharmacare program design and implementation are developed and monitored in partnership with patients to ensure the right medicine gets to the right patient at the right time in a cost-effective manner.*

### Who Should be Covered Under a National Pharmacare Program

**Recommendation 3:** A national pharmacare program needs to ensure that all Canadians have access to prescription medication coverage – including all ages and those with acute, chronic and episodic illnesses.

The MS Society recommends comprehensive national pharmacare program be developed that ensures that all Canadians have access to prescription drug coverage. We hear from people who are frustrated with the inequality of publicly funded treatments across the provinces/territories. There is unequal access when one province covers the cost for a certain drug that other provinces do not, and that individuals in those provinces may have worse health outcomes because of this. As a result, we’ve heard of people having to move provinces simply to access a drug; this is disruptive to their lives, their families and their employment, and could have serious health implications (changing doctors, stress, loss of support systems, etc.)

Comprehensiveness needs to be included because patients and citizens are different, with varying levels of health and diseases that impact their lives in different ways. They also have different access to drug benefits, most often through private or public programs, which depend on their employment or education status. This is an opportunity to extend eligibility for coverage to Canadians who do not currently benefit from either private or public pharmacare programs. Ultimately, in order to be truly comprehensive, a national pharmacare program would reflect a diversity of patients, from youth to seniors and including those with acute, chronic and episodic illnesses.

### **What Drugs Should be Covered Under a National Pharmacare Program**

**Recommendation 4:** A national pharmacare program needs to ensure access to all drugs approved by Health Canada – if not on the national formulary, then via separately adjudicated access programs. Reducing access that citizens currently have to prescription medicines is counterproductive and creates uncertainty for Canadians.

The MS Society posits that patients need access to a range of treatments for their conditions. We believe that a national pharmacare program should ensure access to all medically necessary drugs. To patients, 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.

We believe that 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. The MS Society believes strongly that a population health perspective may not reflect the needs of individual patients especially as it relates to a unique disease like MS where no two people living with MS have the same course of the disease and/or respond in the same way to the same medication. We would want to ensure that patients are assured that their specific circumstances would be accommodated by a national pharmacare program. In addition to a comprehensive formulary, a national pharmacare program should ensure that citizens can access publicly-funded medicines that are not on the formulary through separately adjudicated access programs.

Of great importance in the development of a national pharmacare program is the principle that no one in Canada should lose access to medicines upon implementation of a national pharmacare program, including the majority of Canadians who rely on private insurance programs for coverage. Reducing access to medicines is counterproductive and is not supported by patients in Canada. ( See Reference: CHPI study, [Coverage of new medicines in public versus private drug plans in Canada 2008-2017](#), August 20, 2018) Furthermore, we do not support an essential medicines list – especially one modelled on the World Health Organization’s Essential Medicines List, which is designed for developing economies.

### **Who Should Pay for a National Pharmacare Program**

**Recommendation 5:** Funding pharmacare should be shared across different payers to balance sustainability and affordability with improved access to treatments and patient choice.

The MS Society believes that the funding of pharmacare should be shared across different payers. Patients are open to a comprehensive national pharmacare program that is financed through multiple sources of funding. We believe that the involvement and incentivizing of the private sector (e.g., private plans,

employers, unions, etc.) can enable the federal government to balance sustainability and affordability of a national pharmacare program with improved access to treatments and patient choice.

For many individuals living with MS, disease-modifying therapies (DMTs) offer measurable therapeutic benefits by suppressing MS relapses and, in some cases, delaying the accumulation of disability. The Conference Board of Canada report *“The Value of Specialty Medications: An Employer Perspective”* noted *“There is strong evidence to suggest that early treatment with specialty medications results in significant health benefits, including reduced disability rates and delays in the rate of disease progression.”* They found that there are societal benefits of those treated with specialty medications including reduced caregiver needs of treated dependents, and reduced use of in-patient and out-patient healthcare resources.

DMTs for MS can cost a minimum of \$16,000 annually, which can go up to approximately \$50,000 (or more). Second line therapies, which are taken after a patient has failed on an initial or first line therapy, are more therapeutically aggressive but are highest in cost. Of the 14 approved DMTs, four are second line options. There is no ‘standard’ MS medication. Comments below from people living with MS highlight the concerns about the cost of medications.

In addition to the high cost of medications, the episodic nature of MS creates unique employment issues. Many people are unable to maintain stable jobs or remain in the workplace due to relapses, symptoms, medication side-effects, disability progression, and psychosocial and cognitive issues. This often results in loss of employment benefits, including private group insurance plans that cover partial or full cost of MS medications, forcing people to apply for public reimbursement. In some provinces, the cost of these medications is not covered one hundred per cent. Many Canadians are therefore left out of pocket or unable afford the medications at all.

### **Designing and Implementing a National Pharmacare Program**

**Recommendation 6:** Shared leadership among federal, provincial and territorial governments is essential to creating a national pharmacare program that is integrated with existing provincial and territorial health systems. Patient partnerships enable their unique perspectives to be incorporated throughout the design and implementation of the program.

The MS Society believes that the development and implementation of a national pharmacare program will

*‘My medication is extremely expensive and I simply wouldn't be taking it if I ever lost my job and wasn't covered under their drug plan.’*

*‘The cost of the medicine is more than I make a month, without my company drug plan this would be financially impossible.’*

*‘If I was not working for a company with benefits, I would not be able to take the drug. It's way too expensive... it's pretty easy to see that.’*

have a profound impact on health systems in Canada. To ensure that the development and implementation of a national pharmacare program positively impacts the healthcare systems in their jurisdictions, shared leadership between the federal and provincial and territorial governments is crucial. A national

pharmacare program should be integrated into existing provincial and territorial health systems to improve patient experiences and their health outcomes, recognizing that pharmaceuticals are too often considered separately from other aspects of patient care.

The MS Society believes that patient perspectives would be best understood and incorporated by involving patients 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. Patients should be supported to navigate a national pharmacare program. Navigators should have a formal role to assist patients in understanding how to use the program. Time and time again the MS Society hears of navigation issues in the healthcare system. This is very important to a national pharmacare program.

There are several other reviews and entities involved in decisions that shape patient 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 patients 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.

Patients are uniquely placed to identify waste in the system through their lived experiences. Everybody wants an efficient healthcare and pharmacare system. A national pharmacare program should draw on best practices in incorporating patient-identified opportunities for reform that contribute to cost savings and more streamlined programs

A patient-centred approach is a holistic approach. Implementation of national pharmacare must consider the ongoing reforms to pharmaceutical policy, including the federal drug pricing review reforms and the evolving role of CADTH as proposed by the Expert Review of the pan-Canadian Health Organizations, each of which will impact patients' access to medically necessary prescription medicines. Neither of these other consultations has adequately incorporated patient perspectives. Each of these individual initiatives will impact patients' access to medically necessary prescription medicines and the government has not provided any sense of how these reforms would work together.

## **Conclusion**

The MS Society appreciates the opportunity to provide input to the Advisory Council for the Implementation of National Pharmacare's consultation. We believe that the development of a national pharmacare program holds great promise to improve the lives of Canadians. This promise will come to fruition by incorporating the 6 key recommendations outlined in this submission. These recommendations will ensure that patient perspectives are incorporated in the design, implementation and delivery of a comprehensive and equitable national pharmacare program across the country.

## **About the Multiple Sclerosis Society of Canada**

The mission of the MS Society of Canada is “to be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.” The MS Society provides programs and services including information, support, education, wellness and other resources for people with MS and their families.

We believe a future free of MS is achievable. We have contributed over \$160 million towards MS research since 1948. Our research investment has enabled Canada to create a pipeline of exceptional MS researchers and become a leading contributor to discovery in the field of MS.

Along with our members, volunteers and staff, we work to ensure Canadians living with MS and their families have the opportunity to participate fully in all aspects of life by advocating for improvements in government legislation and policies, private industry practices and/or public attitudes.

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