



**Neighbourhood
Pharmacy**
Association of Canada

Association canadienne
**des pharmacies
de quartier**

Building a National Strategy for High-Cost Drugs for Rare Diseases

**Submission by the Neighbourhood Pharmacy
Association of Canada**

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Introduction

The Neighbourhood Pharmacy Association of Canada (Neighbourhood Pharmacies) appreciates the opportunity to provide this submission to inform Health Canada's consultation on Building a National Strategy for High-Cost Drugs for Rare Diseases.

Neighbourhood Pharmacies represents Canada's leading pharmacy organizations who deliver high value, quality care to Canadians in all models including chain, banner, long-term care, specialty and independent pharmacies as well as grocery chains and mass merchandisers with pharmacies. Our members are home to the most trusted providers of drug therapies, pharmacy-based patient services and innovative healthcare solutions. We advocate for community-based care through our members' high accessibility and proven track record of providing optimal patient care closer to where patients live, work and play. By leveraging over 11,000 points of care with pharmacies conveniently located in every community across Canada, Neighbourhood Pharmacies aims to advance sustainable healthcare for all stakeholders.

We need to ensure that drugs for rare diseases are made available, in a timely manner, to all Canadians, regardless of where they live. By extension, we also need to ensure that Canadians have access to the person-centric services to receive maximum benefit from the medicines they've been prescribed. We must consider the individual, their needs, and the benefits to their quality of life and their capacity to contribute to society through a healthy and productive life, rather than simply focusing on the cost of the drug itself.

Pharmacists are the first and most frequent touchpoint most Canadians have with the health system and are a key community health resource. Their role in education, adherence, financial support, handling and monitoring, as well as medication waste reduction, is vital when evaluating reimbursement and coverage for high-cost drugs for rare diseases and the services and infrastructure that support them. Including our sector's expertise and acknowledging the critical role pharmacist play in the design of a funding model will achieve the benefits that a coordinated approach to specialty medications can deliver. Furthermore, leveraging community pharmacy's data infrastructure on rare disease medications will facilitate ongoing evaluation of the clinical and cost effectiveness of these medications.

All Canadians Deserve Access to the Medications They Need

Neighbourhood Pharmacies' top priority has, and always will be, improving access to prescription medications for all Canadians. We want to be a part of the solution that ensures no Canadian will go without the prescription medication they need.

For this reason, Neighbourhood Pharmacies has engaged extensively to support the work the government is doing to create a healthier and safer Canada including the development of a national pharmacare program and introduction of changes to the Patented Medicine Prices Review Board (PMPRB) Regulations and Guidelines.

Pharmacies serve millions of patients from across the country every year and we have a deep understanding of the gaps that currently exist in Canada's pharmacare policies. As pharmacists, we know the importance of ensuring that our patients have access to the medication they need without financial barriers.

It is our view that a rare disease strategy should, not only preserve the level of care and service that currently exists, but also extend it to those who lack sufficient coverage, or do not have coverage at all through their current drug plan. To best support Canadians and to ensure access to the medications they need, we need to maintain and build on the current drug coverage millions of Canadians currently receive through private and public drug plans. With more comprehensive formularies, private drug plans are seen to provide more options for their participants, as well as more timely access to medicines. It is important that policy decisions and new programs do not put this comprehensive coverage at risk.

While our advocacy around a national pharmacare plan seeks to ensure that we are building on the extensive coverage Canadians currently have, we strongly believe that a strategy for rare diseases is an entirely separate issue that deserves a more drastic intervention.

How Pharmacies are Already Supporting Canadians Taking Specialty Medications, including those Treating Rare Diseases

Specialty medications have revolutionized the treatment of complex illnesses. Not long ago, patients with complex and debilitating diseases had very few treatment options. Innovations in the field of specialty medicines are changing the progression of many diseases by improving outcomes for patients, and for the healthcare system. And this is particularly true when it comes to drugs used to treat rare diseases.

These medications differ from traditional medications because they require individualized services to manage complex rare diseases. They typically require frequent dosage and regimen adjustments from the patient's healthcare provider – often through recommendations from the community pharmacist, who is routinely monitoring therapy, outcomes and adverse reactions.

Pharmacy has always engaged patients in the treatment of their disease by promoting understanding, participation, and adherence to their drug therapy. However, for rare disease medications, pharmacies are increasingly stewarding many other aspects of these unique drug therapies, including shipping and handling, cold chain management, reimbursement navigation, monitoring, and administration – both in clinics and in patients' homes. These additional services require expensive infrastructure investment by the pharmacies providing them to an increasing number of patients.

Once treatment is prescribed, a patient typically enrolls in a manufacturer funded patient support program (PSP) which is administered by pharmacies and pharmacists who work hand in hand with other healthcare providers in the circle of care to provide the support and assistance required through treatment. PSPs are well positioned to work with multiple payors to help individuals access available financial supports and ensure adherence to these medications. They are designed to provide personalized patient care and support, anticipating the needs of patients with complex medication therapy, to ensure patients receive the greatest value out of the medicines they are prescribed. These services are critical to an individual's success on these complex medicines, and a sustainable model for their delivery need to be considered when developing a broader strategy for drugs for rare diseases.

Specialty pharmacies have invested heavily in infusion clinics and other highly customized services and infrastructure to provide a high and customized level of sustained patient centred care. These investments in patients and patient services deliver tremendous economic value to the healthcare system. Specifically, patient services delivered by pharmacies help optimize clinical outcomes to achieve the best value-for-money for the medicines covered by public drug programs.

Through pharmacy's accessibility, high level of expertise and ongoing support, patients taking drugs for rare diseases can benefit from increasingly positive health outcomes, and health systems and payors can maximize the value of these high-cost, life-saving treatments.

Issue 1: How to improve patient access to high-cost drugs for rare diseases and ensure that access is consistent across the country

Neighbourhood Pharmacies supports a strategy for drugs for rare diseases that ensures every patient confronting a rare disease has equitable access to potentially life-saving treatment through a drug program regardless how they are paid for or where they live across our country.

The rare disease landscape varies from province to province each with a different mix and prevalence rate. To address gaps in coverage, Neighbourhood Pharmacies would favour Federal government support for a rare disease drug program that builds consistency in coverage, and a funding framework across provinces. This approach should address the affordability of drugs for rare diseases while remedying provincial inconsistencies by enabling provincial governments the ability to close coverage gaps.

It is important to underscore that access to drugs for rare disease not be dependent on cost alone. Canada should consider a holistic approach to patient access to treatment that includes drug availability, patient support services, distribution, and coverage.

Issue 2: How to ensure decisions on covering high-cost drugs for rare diseases are informed by the best evidence available

Specialty medications for rare diseases have revolutionized the treatment of complex illnesses. Their capabilities, many of which are still under research, are incredibly impressive. Government has an opportunity to leverage data and evidence collected by pharmacies and patient support programs to facilitate the evaluation of the clinical and cost effectiveness of rare disease medications.

To ensure that government has access to the best data and evidence available to inform coverage decisions, Canada needs a national platform to enable ongoing patient data capture that can be integrated and analyzed along with global data collection. Due to the low prevalence of rare diseases, national patient pool data is more meaningful than data collected by province or jurisdiction. Pharmacies are well positioned to collect patient data and have existing digital infrastructure and access to their patients' medication records in every province.

It is important that implemented data collection systems and services are designed and sufficiently funded so that data can be aggregated across various sources including pharmacies, patient support programs, hospitals, physicians and laboratories.

Issue 3: How to ensure spending on high-cost drugs for rare diseases does not put pressure on the sustainability of the Canadian healthcare system

All participants in the healthcare system share the responsibility for optimizing the value of the high cost of rare disease medications. Early detection and effective management of individuals using drugs for rare diseases are both critical to minimizing the associated costs and ensuring value for money. With these more complex therapies comes more complex care. As we move toward increasingly individualized medicine, patient-centred care will become equally complex.

For patients and the healthcare system to realize the full benefit of these medications, the services supporting the patient journey must themselves be supported and understood. A collaborative approach between the government and the pharmacy sector is needed to ensure pharmacy's role in rare disease medication evolves effectively beyond a focus of the cost of the medications themselves towards promoting delivery of innovative patient-centric care.

Where these medications are concerned, pharmacists' role in monitoring and educating patients is vital to the broader ecosystem in achieving successful treatment outcomes. Supporting patient-centred care involves pharmacists assessing patient readiness for therapy, monitoring effectiveness, and advising patients through monitoring and managing of adverse effects.

Even if better coverage for these life-saving and life-altering therapies is offered, we will not realize their full value and benefit without ensuring that patients can access and adhere to these medications. Pharmacists play a pivotal role in ensuring adherence through patient education, and by helping patients navigate the financial burden associated with specialty medications. While there is sensitivity around the higher cost of these drugs, the overall cost of any medication must consider the potential downstream costs of compromised adherence, and morbidity or mortality resulting from non-optimized care.

For many patients, even those with public or private drug coverage, out-of-pocket costs for rare disease medications are considerably higher than traditional medications. This cost issue is one of the main reasons reimbursement navigation and patient assistance is such an important part of specialty pharmacy: to ensure patients access their medication on time and to ensure they adhere to their therapy without interruption due to financial barriers. There are often multiple payor levels to navigate to secure funding such as private drug plans, spousal plans, manufacturer support and alternative levels of public funding which can be highly complex where pharmacies and patient support programs are able to navigate.

In the case of specialty medications where the diseases have greater morbidity, increased risk of non-adherence heightens cost and increases risk, potentially leading to disease progression impacting need for hospitalization which is burdensome to the patient and the health system. Non-adherence may also result in wastage of the medication itself, which, in the case of a specialty medication, represents a very significant cost. For these reasons, pharmacists take extra care to counsel these patients on the importance of remaining adherent to therapy and will work with patients to develop strategies that help them stay adherent. The comprehensive management of drug usage through the close monitoring of patients, helps ensure that no expensive, prescribed medicine, is being wasted.

Pharmacy patient support services are executed with compassionate care, and support and ease the burden of care for patients and healthcare professionals. Interdisciplinary care teams, comprised of nurses, pharmacists and other healthcare providers with expertise in managing multiple conditions and associated therapies, oversee all elements of care including patient enrollment, reimbursement assistance, drug distribution and delivery through either a retail pharmacy or specialty pharmacy network, patient and healthcare professional education and training, and adherence support with robust data reporting. Leveraging pharmacy's existing data infrastructure can not only help to support ongoing evaluation of these therapies but can also be used to help support outcome-based reimbursement of these drug therapies.

To ensure the principles of value and responsibility remain closely associated with these high-cost therapies, funding pharmacy services for these complex drug therapies will help support the efficient use of resources for patients taking specialty medications.