

EQUITY AND ACCESS TO VISION CARE

This paper was developed by Fighting Blindness Canada, the Canadian Council of the Blind, and the CNIB Foundation with feedback from members of the Canadian vision loss community. It outlines themes in the area of equity and access to vision care, as well as recommended actions for government, industry, and other stakeholders. The recommendations—bolded throughout the paper—provide a general framework for policy and advocacy activities in 2020 and beyond. What final form a recommendation takes, who it is directed towards, and in what context it is articulated will be determined by each stakeholder.

Introduction

Pioneered in the 1960s by Tommy Douglas in Saskatchewan, Canada's public health care system has long been a source of national pride.¹ That said, many policy analysts and commentators are quick to point out that our system has aged poorly, particularly when treating chronic illnesses, maintaining electronic records, providing access to pharmaceutical care, adopting personalized medicines, and in other areas.

At the same time, due to health care being delivered in Canada by each of its provinces and territories—which amounts, essentially, to thirteen separate micro-systems—issues and inconsistencies have led to inequitable care in certain contexts. Our regulatory systems are unique as well, with four separate national agencies reviewing new treatments before recommendations are passed to provinces and territories for public funding. This framework is designed to ensure the safety and cost-effectiveness of drugs and technologies, but the fact remains that Canada adopts new treatments later than many other countries.

These systems affect Canadians with vision loss in various ways—sometimes beneficially, if a treatment is widely available and integrated into public plans. But several aspects of our vision research and health care system are in need of development and support, including clinical trials, new medicines for rare diseases, and overall research and development. Incorporating survey responses from the vision loss community—from patients, caregivers, health professionals, researchers, and others—this paper uses the symbolic year 2020 as an opportunity to reflect on issues of access and equity in Canadian vision care. It also seeks to identify opportunities for improvement as we move into an exciting new decade for vision science and policymaking.

Access to Existing Vision Treatments and Services

Canada is the only industrialized nation with a universal health care system that does not include universal pharmacare. Specialized public plans exist to cover those in particular

¹ Redden, C. J. Rationing Care in the Community: Engaging Citizens in Health Care Decision Making. *J Health Polit Policy Law* 24(6) 1363-1389 (1999) doi:10.1215/03616878-24-6-1363

categories and situations, and these combined with the many private plans cover approximately 80% of Canadians. But this patchwork arrangement leaves one-fifth of the Canadian population with no or inadequate insurance to cover the cost of their drugs.² This of course includes those with vision issues that rely on medications to manage their diseases, including patients with glaucoma, diabetic retinopathy, age-related macular degeneration, and more. **Whether it takes the form of pharmacare or additional public programs, many community members have stressed the importance of expanding coverage to those currently struggling to access existing vision treatments, regardless of socioeconomic factors.**

In addition, other barriers exist that can impede equity and access to care for certain patients. Transportation was flagged by several community members as a pronounced barrier, especially for those living in rural and remote parts of Canada. Patients living with wet age-related macular degeneration (wet AMD) or diabetic macular edema (DME), for instance, and who rely on regular injections of anti-VEGF to control their vision loss, typically receive injections every one-to-three months. Travel can be an enormous strain on these and other patients, as well as the caregivers who often take time off work to accompany them. **For these and other reasons, equitable access to existing services and medicines is a key concern for those living in Canada's remote areas.**

Visual rehabilitation is a central component of vision care, and access to these services is not equitable across the country—in Quebec, for instance, low vision services are publicly funded, while in other provinces they are only accessible through specialized programs and organizations. When treatments are either unavailable or undesired, resources that help patients live with their vision loss are essential, including white cane, guide dog, and accessible/assistive technology services. In many cases, community members seek out these services from charities and non-profit organizations such as Vision Loss Rehabilitation Canada (VLRC) and BALANCE for Blind Adults. But in cases where those with vision loss struggle to access rehabilitation—due to funding models, transportation, mental illness, isolation, and other barriers—they are in danger of the many issues we know are associated with vision loss: social isolation, depression, catastrophic falls, and others.³ **In 2020 and beyond, access to existing treatments should expand, but so too should access to low-vision rehabilitation services.**

It has been shown that routine eye exams play a crucial role in the prevention of vision loss.⁴ If certain eye diseases are diagnosed early enough, they can be managed before expensive and sometimes invasive measures are required. In diseases that show no or little symptoms during their early stages—so-called “silent robbers of sight” such as glaucoma—early detection is the key to saving vision. Unfortunately, routine eye exams are not covered equitably across the

² Advisory Council on the Implementation of National Pharmacare. *A Prescription for Canada: Achieving Pharmacare for All*. Ottawa, ON: Health Canada; 2019

³ Freeman, E.E., Gresset, J., Djafari, F. *et al.* Cataract-related vision loss and depression in a cohort of patients awaiting cataract surgery. *Can J Ophthalmol* 44(2), 171-176 (2009) doi:10.3129/i09-001

⁴ Jin, Y., Buys, Y., Xiong, J. *et al.* Government-insured routine eye examinations and prevalence of nonrefractive vision problems among elderly. *Can J Ophthalmol* 48(3), 167-172 (2013) doi:10.1016/j.jcjo.2013.01.002

country, with each province and territory maintaining its own policies and typically covering only age groups that are most at risk. **There is strong research to show that a lack of coverage for routine eye exams, even for those groups less at risk, can have dangerous and unforeseen consequences for the vision loss community.⁵ This research should guide the development of far-reaching plans to provide comprehensive eye exams to as many Canadians as possible.**

Optometrists play a vital role in the delivery of eye exams, and as such they are often considered front-line workers in our vision care system. Whether it be myopia or a genetic condition, a patient's first point of contact is often with an optometrist or family physician. While ophthalmologists are not always the front line of vision care—though they can be—they perform a vital role in treating eye disease. Ophthalmologists are Doctors of Medicine who specialize in the diagnosis and treatment of disorders of the eye. Ideally, these fields and professions work in tandem to deliver coordinated and effective eye care. **The year 2020 presents an opportunity to envision how these fields can be more fully integrated into a broader vision care continuum, one that also includes education, diagnostics, low vision services, and other key components of care.** In many cases, such as genetic testing, our country has a wealth of expertise in place, and progress is a matter of leveraging existing resources through coordination and integration.

Regulatory Frameworks and the Accessibility of New Vision Treatments

New treatments poised to enter the Canadian market are first reviewed by Health Canada, which considers clinical data and other evidence to determine whether a drug or technology meets standards in safety and efficacy. Shortly after, the treatment is considered by the Patented Medicines Prices Review Board (PMPRB), where its price is considered in relation to other treatments and contexts. PMPRB is in place to protect against excessive pricing, and ultimately sets a ceiling price for new, patented treatments entering the Canadian market. After receiving Health Canada approval and a ceiling price from PMPRB, the treatment is able to be sold and used in Canada, but is not at this point listed on any of the country's provincial and territorial plans. To facilitate this, the treatment is reviewed by the Canadian Agency for Drugs and Technologies in Health (CADTH) and by the Institut national d'excellence en santé et en services sociaux (INESSS) in Quebec, where it undergoes a health technology assessment to determine its therapeutic value and cost effectiveness. These bodies then make recommendations to provinces and territories regarding whether the treatment should be integrated into public insurance plans.

If our provinces and territories decide to incorporate the treatment—they almost always do if CADTH or INESSS recommends as much—price negotiations occur between the relevant company and the pan-Canadian Pharmaceutical Alliance (pCPA), who determine a confidential, contracted price as well as criteria for proper use. This can be a long and difficult process that does not always lead to agreeable terms. To complicate matters, even if a pCPA

⁵ Kiran, T., Koop, A., Moineddin, R. *et al.* Unintended consequences of deslisting routine eye exams on retinopathy screening for people with diabetes in Ontario, Canada. *Can J Ophthalmol* 185(3) 167-173 (2013) doi.org/10.1503/cmaj.120862

contract is agreed upon, it is still up to each province and territory to decide when and if the drug will be placed on their formularies. This can take as little as one month or as much as an additional year, adding to the already-lengthy regulatory process.

From Health Canada to PMPRB to CADTH, INESSS, pCPA, and the public plans, the regulatory pathway for new treatments in Canada is designed to protect consumers and secure the widest access possible. Our system is a complicated one, though arguably less complicated than others, including the U.S.⁶ In some respects the complexity of this pathway is in place to ensure rigorous analysis and to prevent dangerous medicines from entering the country. It has evolved since the introduction of the Food and Drugs Act in 1920 with just this in mind—the protection and safety of Canadian citizens.

At the same time, there is little doubt that some companies are weary of pushing their products through such a lengthy, rigorous, and multi-stage process, and that, as a result, we receive many patented medicines later than our OECD counterparts—and in some cases not at all. **It is essential that we continue to review our regulatory framework to identify key areas for efficiency, harmonization, and waste reduction.** This is particularly essential in vision, where the pipeline for gene therapies in particular appears robust. It is crucial that we locate new efficiencies to ensure that Canadians, especially those with inherited diseases, do not lose the opportunity to benefit from the life-changing medicines that either exist or are in development.

For example, the emerging market of biosimilars is one area that would benefit from coordinated efforts and streamlining. Biologics are medicines produced from the material and cells of living organisms—in vision, the anti-VEGF injections used to treat wet-AMD and DME are good examples. These drugs are a large and growing portion of the overall pharmaceutical market in Canada. Biosimilars can be considered the generic versions of biologics, though they are not identical to the original drugs in the same way that conventional generics are. But just as the generic versions of synthetic drugs transformed the market in the 1980s, lowering prices in Canada and globally, biosimilars show a similar promise. CADTH is currently reviewing its practices in relation to biosimilars to locate ways to accelerate their uptake in Canada. As in other areas, savings from biosimilars could be directed back into the public system to improve equity and access for all Canadians.

Similar reviews are necessary in relation to gene therapies, ground-breaking cures, and other key areas that we currently fall behind on. Our regulatory goal this decade should be the establishment of harmonious, streamlined pathways that keeps costs low while also facilitating the uptake of innovative and life-changing treatments. Many community members have articulated that this should not be an either-or scenario: either low costs or innovation, for instance. Instead, we should work to achieve cost-efficiency and universal access while also fostering an environment of transformative innovation, research, and clinical trials—in the vision loss sphere and across other disease categories as well.

⁶ Berwick D.M., Hackbarth A.D. Eliminating waste in US health care. *JAMA* 307(14), 1513–1516 (2012) doi:10.1001/jama.2012.362

The incorporation of patients and their perspectives into regulatory decision-making was a key development last decade. As part of the broader movements of patient-centered care and patient-oriented research, bodies such as CADTH and PMPRB are now consulting patients before recommending specific products or advancing reforms. This is far from being a completed project, however. **Additional action is needed to integrate patients more thoroughly into key decision-making, and to avoid the kind of tokenism on display in the worst forms of patient engagement.**

Patients need to be consulted as early as possible and their views need to be comprehensively incorporated into reports. Evidence from these interactions should be considered on par with—though of course distinct from—clinical evidence. With CADTH, patient groups are currently given the chance to provide feedback on drug and technology reviews. However, they need to be given more time to do this, and ideally resources to facilitate the complex and demanding work of representing and synthesizing patient perspectives. **Patient-oriented research needs to be more than just a catchphrase; it must be cultivated, practiced, and ultimately spearheaded by Canada’s leading institutions.** The shared objective of bringing safe and effective vision treatments to Canada will benefit enormously from full collaboration with the patients who have lived experience of the diseases in question.

Pharmacare and Other Policy Innovations

Providing the vision loss community with access to the treatments and resources they require is a vast undertaking. Doing this within a complex health system that often struggles to provide out-of-hospital care for certain populations is even more challenging. To achieve progress in 2020 and over the course of the decade, stakeholders across government, industry, academia, and patient communities will need to work together closely. This sentiment is echoed in feedback from the vision loss community: many have pointed towards a need for better and increased collaboration between government and industry in particular. Others have expressed feelings of helplessness and alienation in the face of vast systems and decision-making bodies that seem to operate at a distinct remove from the realities of lived experience. Developing new, progressive policies that better represent our country’s many voices demands that we recognize the value of each other’s perspectives.

One issue that plagues the vision loss community and many others across the country relates to drug shortages and discontinuations. This problem has become so prevalent that there are currently close to 2,000 drugs listed as being in shortage on Health Canada’s website. These shortages and discontinuations mean that clinicians often struggle to find suitable substitutions, and that, more often than not, surgeries and treatments are delayed, sometimes leading to a worsening of the issue. All of this causes enormous stress for patients and providers. The problem was addressed directly by the Prime Minister in his mandate letter to the newly appointed Minister of Health, specifying that we must “Ensure that Canadians have access to the medicines they need by taking action with manufacturers, provinces and territories and other stakeholders to address drug shortages.”⁷

⁷ <https://pm.gc.ca/en/mandate-letters/minister-health-mandate-letter>

The subject of a national pharmacare program has been top-of-mind for policymakers and health professionals as well. In conversations regarding the future of Canadian vision care—or any form of care, for that matter—pharmacare is unequivocally the elephant in the room. To complicate matters, how pharmacare affects issues of access and equity almost entirely hinges on the form that our national program ultimately takes. Since those details are still in development, the role that pharmacare will play in equity and access to vision care remains uncertain.

Despite this, certain hopes and concerns have been expressed by the vision loss community in relation to a national pharmacare initiative. Many community members share an optimistic perspective, believing that a successful program could fill the gap in pharmaceutical care that we know currently exists. Pharmacare could align Canada with other industrialized nations, shrinking or filling gaps to ensure that those who rely on medicines to manage eye diseases and other conditions do not fall through the cracks. Others are anxious about what national pharmacare means for so-called expensive drugs for rare diseases (EDRDs). A national program may broaden access to common drugs, but there is some concern that it will shrink access to rarer medicines, especially those for small patient populations.

Currently, Canadian provinces and territories must negotiate with the pharmaceutical industry individually, though their efforts are coordinated through the pCPA. A national pharmacare program could lead to increased buying power, since it would be the entire country negotiating for access as opposed to individual provinces and territories. Some community members are excited about the possibility of this increased negotiating power, which holds the potential to lower the ceiling on drug prices in Canada—currently some of the highest in the world for both new and generic drugs.⁸ Others are worried that lower prices could function as a deterrent for companies with first-in-class drugs. These medicines involve costly research and development, and companies set prices to reflect these factors. The question remains: will securing lower prices block innovative drugs and technologies from entering the Canadian market?

At the same time, some community members are concerned that national pharmacare could lead to a smaller or more restrictive formulary. Currently, each province and territory maintains its own list of drugs and technologies that are approved for reimbursement through public plans. Among the many questions raised by a looming pharmacare program is whether a single, unified formulary could be as robust and comprehensive as a single provincial or territorial one.

Whether it is pharmacare or other changes to Canada’s health policy frameworks, many members of the vision loss community insist on a balanced approach to equity and access, one that does not enhance access at the cost of innovation, or vice versa. In other words, there is some agreement that, on the one hand, existing drugs and technologies need to be broadly and equitably accessible, more than is currently the case. On the other hand, we need to develop a scientific and regulatory environment that welcomes innovative

⁸ Vogel, L. Drug pricing reforms promising but problematic. *CMAJ* 189(26), 899-900 (2017) doi: 10.1503/cmaj.1095436

treatments that have the potential to improve the lives of patients, regardless of the size of the treatment's market. Community members are seeking to access new treatments, but they are wary of doing so at the cost of existing ones. In 2020 and beyond, our policies and frameworks should aim to broaden access in both areas. This is not a choice between gene therapy or asthma inhalers, to use a reductive example. Instead, there is strong support for new policies that widen access to both existing and emerging health technologies.