



The Federal Role in Eye Health and Vision Care

Prepared by

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CNIB

The Foundation Fighting Blindness



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Executive Summary

There is an emerging crisis in eye health and vision care and rehabilitation in Canada. Given our aging population, age-related eye disease is set to skyrocket. Moreover, vision loss is the most feared disability among Canadians,ⁱ and it is expected to cost us more than \$30 billion annually by 2032.ⁱⁱ The good news is that 75 per cent of vision loss can be treated or prevented.ⁱⁱⁱ Vision health care encompasses a wide scope that includes post-vision loss rehabilitation therapy. Early detection and treatment is key to addressing eye health and vision issues. Sight saving research continues into the causes and treatments for irreversible vision loss.

As eye health and vision care providers, rehabilitation professionals, and vision research funders, our organizations have taken an important first step to ensure the rights of Canadians are respected by endorsing the *Canadian Patient Charter for Vision Care*,^{iv} ensuring the highest standard of vision care is met across the country. We believe the patient must be at the centre of health care and research, and that models of collaborative care must be designed with patients to enhance the quality, safety, and accessibility of patient care.

Canada is a signatory to the World Health Organization's resolution on Universal Eye Health, however we have not taken any significant action. Now is the time for the federal government to provide leadership and assistance to address vision health, particularly for children, seniors, and Indigenous Canadians. A greater federal presence will elevate eye health and vision care and research to a population health focus.

We jointly recommend five areas for action. Our proposals fall within the jurisdiction of the federal government. They are realistic and timely:

- Create a pan-Canadian Framework for Action, coordinated and executed by an Office for Vision Health at the Public Health Agency of Canada;
- Enhance funding for vision health research;
- Pursue the recommendations in the report of the Advisory Panel on Healthcare Innovation^v with respect to Health Canada's Non-Insured Health Benefits Program, and also incorporate an enhanced eye care and vision health component;
- Fund collaborative vision care pilot projects; and
- Undertake a public information campaign based on population health strategies to encourage Canadians to think about their eyes and vision health.

As eye health and vision care providers, rehabilitation professionals, and vision research funders, we are willing partners in this undertaking and look forward to working with governments and stakeholders to achieve optimal vision health for all Canadians.

As Minister of Health, your overarching goal will be to strengthen our publicly-funded universal health care system and ensure that it adapts to new challenges. Healthcare across Canada is changing at a rapid pace to keep up with the changing needs of an aging population and advances in health technology. The federal government must be an essential partner in improving outcomes and quality of care for Canadians.

Minister of Health Mandate Letter

Overview

Eye health and vision care require our collective, immediate attention. Vision issues touch all Canadians, with 6 in 10 reporting having had a vision problem. Of these, almost one million Canadians have missed work or school or had their performance affected because of vision problems. Just under half of Canadians report that someone in their immediate family has had a serious vision problem, and 13 per cent said they had personally suffered a serious vision problem. The real impact of vision issues touches Canadians in every walk of life.^{vi} The good news is that 75 per cent of visual loss can be treated or prevented.^{vii} Moreover, sight saving research continues into the causes and treatments for irreversible vision loss.

While many Canadians have access to vision care provided by eye health professionals, this is not the case for all of us. The main factors influencing access to eye health care include workforce supply, public awareness, availability and regularity of services (particularly in rural and remote areas), affordability of services, and physical accessibility, among others.^{viii} Access for the young, seniors, and Indigenous peoples is particularly concerning. Health care policies and the Canadian health system must address these challenges, with vision becoming part of population health agendas and community programs.

Canada is a signatory to the World Health Organization's *Universal Eye Health: A Global Action Plan 2014-2019*, urging member states to take action to prevent avoidable visual impairment and to better integrate eye health into national health plans and health service delivery. The goal of the plan is a world in which nobody is needlessly visually impaired, where those with unavoidable vision loss can achieve their full potential, and where comprehensive eye care services become an integral part of primary health care and health systems development.^{ix} Other countries have embarked on eye health strategies as follow-up to their respective government's commitment to the WHO's *Global Action Plan*. In comparison, Canada's response has been insignificant.

Cost of Vision Loss

There are an estimated 5.5 million Canadians living with a vision-threatening condition.^x According to 2012 analysis from Deloitte Access Economics conducted for CNIB, the total cost of vision loss to Canada's economy is an estimated \$19.1 billion per year. Within this, indirect costs are estimated at \$8.1 billion, while direct health system costs are \$11 billion representing one percent of GDP, equal to about \$550 per capita.^{xi} By 2032, it is estimated the total annual cost of vision loss in Canada could rise to as much as \$30 billion.^{xii}

The cost of vision loss extends right across the economy. Higher absenteeism, lower employment rates, decreased salary, premature retirement, depression, and premature death are more common among those with vision loss.^{xiii} When compared to other diseases, vision loss is a large financial burden, mostly due to the high cost of lost productivity to the Canadian economy.

Vision loss has the highest direct health care costs of any disease category in Canada – more than diabetes, cancer, mental disorders, respiratory diseases, arthritis, or cardiovascular disease.^{xiv} We also know that more Canadians have age-related macular degeneration (AMD) – the leading cause of vision loss among Canadians – than have breast cancer, prostate cancer, Alzheimer's disease, and Parkinson's disease combined.^{xv}

Children

Eye health and vision care greatly affect Canada's children because classroom learning is 80 per cent visual. Students not seeing well are not performing to their full potential. One in four students has undetected vision problems.^{xvi} and Canadian Association of Optometrists' research suggests that 61 per cent of parents mistakenly believe they would know if their child is having vision problems.

There is a need for a more comprehensive childhood functional vision assessment protocol. When vision is adequately managed from an early age, academic and health outcomes are improved, leading to reduced long-term costs in each area.^{xvii} Moreover, early intervention has proven to be effective by reducing the need for costly special education and reducing other health care costs.^{xviii} Conditions such as amblyopia (lazy eye)^{xix} and strabismus (crossed eyes)^{xx} are also more effectively treated with early intervention.

A majority of parents are unaware of the impacts vision problems can have on the long-term health of their children, including speech difficulties and developmental delays. Only 25 per cent of Canadian parents rank vision as one of the top three health concerns for their children, well behind proper nutrition, mental health, exercise, and drug abuse.^{xxi}

Seniors

Canada's rapidly aging population is contributing to the emerging vision crisis. According to the most recent population projections, the share of persons aged 65 years and older will account for 20 per cent of the Canadian population by 2024.^{xxii} Age-related macular degeneration (AMD), glaucoma, diabetic retinopathy, and cataracts are the four major causes of vision loss in Canada today, and the occurrence of these diseases increases with age.

The U.S. National Academies of Sciences, Engineering, and Medicine's recent study on eye health commented, "As a chronic condition, vision impairment remains notably absent from many public health agendas and community programs. Rather, vision is often regarded as a given—until it is not."^{xxiii} Vision impairment among seniors must be effectively addressed. Enabling patients to see the right provider at the right time is a critical success factor.

In terms of activities of daily living, vision loss impedes healthy and independent aging. It doubles the difficulties of daily living, advances nursing home admissions by three years, doubles social dependence and the risks of falls, triples the risk of depression, quadruples the risk of hip fractures, and doubles the mortality rate.^{xxiv}

Primary eye care services can make a difference. A fall prevention program in Manitoba saw decreases in minor and major injuries and an overall decrease in falls after clients were provided with vision screening and on-site optometry services.^{xxv}

Governments are rightly engaged in improving home care for seniors, yet access to vision care and rehabilitative services needs to be part of the solution. Regrettably, investments in post-vision loss rehabilitation therapy represent only a small fraction of the total expenditures related to vision loss – at less than one per cent.^{xxvi}

Indigenous Peoples

Indigenous Canadians represent the fastest growing segment of the Canadian population, increasing at a rate six times faster than non-Indigenous people.^{xxvii} Research commissioned by the CNIB found almost one-third of Indigenous people have not had an eye exam within the last two years. This is less than all respondents, as well as respondents not born in Canada.^{xxviii}

Across Canada, the rate of type 2 diabetes is three to five times higher among Indigenous people than in the general population,^{xxix} and Indigenous Canadians are experiencing vision loss associated with the elevated rates of diabetes. Diabetic retinopathy is the most common cause of vision loss among people with diabetes. However, early detection and treatment can reduce the risk of blindness by 95 per cent.^{xxx} Community-based and culturally appropriate prevention strategies and surveillance of diabetes indicators among this high risk population are essential to reducing health disparities.^{xxxi} The problem is pressing. Eye health professionals play a significant role in detection through screening, as well as the early treatment and management of diabetic retinopathy.

Much information already exists on how to screen and treat diabetic retinopathy, however only a few local programs exist. No infrastructure exists to implement a nationwide screening program tailored to meet the needs of Canada's Indigenous and disadvantaged communities. Such a national program could decrease the prevalence of blindness in a relatively short timeframe.

Finally, Indigenous Peoples who experience permanent and severe vision loss do not receive vision loss rehabilitation services in their communities. In most provinces and territories, Indigenous Canadians must go to a service provider, such as CNIB, for rehabilitation therapy services. These services would be best provided in the communities where patients reside.

Research

There is no dedicated funding for eye health within the Canadian Institutes for Health Research (CIHR). CIHR and the partner organizations have nurtured research, however there is no overarching body like the National Eye Institute in the U.S. to set priorities or coordinate vision research and translate scientific strength into health services that can benefit Canadians. Consequently, vision researchers compete not only among each other for funding, but also against researchers from a wide spectrum of disciplines. As outlined in a report prepared for the National Coalition for Vision Health in 2007, the yearly investment in vision health research at that time was approximately \$10 million.^{xxxii} There is no question that vision research is still significantly underfunded. Given that CIHR now invests approximately \$1 billion each year to support health research, vision health must be included, and could be a signature initiative of one of the granting agencies (CIHR, NCE).^{xxxiii}

The Canadian Association of Optometrists and the Canadian Ophthalmological Society have undertaken a significant, long term collaborative project to establish a common set of evidence-based clinical practice guidelines for periodic eye examinations. Phase 1 of the project targets children aged 0-5 years. Evidence-based guidelines are an important foundational element to anchor a population health approach that advances eye and vision health.^{xxxiv} This important initiative will provide guidance to health professionals, and the public, on the recommended frequency and necessary elements of periodic eye examinations.

Canadian Council of the Blind (CCB) carries out action research designed to improve the quality of life of persons living with vision loss, and to create awareness of vision issues. CNIB has a longstanding record of conducting vital, world-class research studying everything from practical vision loss needs to rehabilitation outcomes to social policy. The Foundation Fighting Blindness funds cutting-edge medical research in Canada's foremost universities and hospitals, with a goal to finding the causes, treatments, and eventual cures for eye diseases. Any appropriated funds for vision health research in CIHR's initiatives must include research funding into future treatments and eventual cures, vision rehabilitation, and research geared toward improving the quality of life for people with vision loss.

The Way Forward – Recommendations

The federal government has reaffirmed its role as a key player in health care in Canada. We welcome this commitment, as we have been working as a collective to promote eye health and prevent vision loss for all Canadians. We propose five recommendations to enhance eye health and vision care. Our proposals fall within the jurisdiction of the federal government; they are realistic and they are timely. The proposals prioritize the needs of children, seniors, the aging population, and Indigenous Canadians.

Proposal 1: Create a pan-Canadian Framework for Action

Building on the 2007 work of the National Coalition for Vision Health, and in partnership with all key stakeholders, we recommend the creation of a pan-Canadian Framework for Action with a focus on children, seniors, and Indigenous peoples. The framework should be based on population health strategies defined by the Public Health Agency of Canada (2007) as “an approach that focuses on the interrelated conditions and factors that influence the health of populations over the life course, identifies systemic variations in their patterns of occurrence, and applies the resulting knowledge to develop and implement policies and actions to improve the health and well-being of those populations.” In order to improve the overall quality of life and productivity of Canadians, we must work together to create the conditions to promote effective population eye health and vision care.

In order to coordinate and execute the Framework for Action, an Office for Vision Health (OVH) would be established at the Public Health Agency of Canada. This office could be modeled on the Office of the Chief Dental Officer. The OVH would contribute to health policy formulation and program development. It would work with provinces and territories on pan-Canadian strategies for eye health, vision care, and the full integration of post-vision loss rehabilitation therapy into the health care continuum.

Proposal 2: Fund Research

As previously indicated, there is insufficient funding for vision health research throughout the health care system. An important step in rebalancing funding would be to ensure eye health and rehabilitation services representation on dedicated CIHR review and evaluation committees. We have an informed and unique perspective that can help shape the vision research agenda moving forward. We represent a diversity of Canadian communities and are natural partners in improving patient engagement and shaping research policy. These research priorities can inform the broader health research agenda. The federal government could act as a catalyst to leverage funding to maximize multi-sectoral approaches to research through the granting agencies.

We have approached the House of Commons Standing Committee on Health to conduct a study to understand the current state of eye health and vision loss in Canada, and to identify and address policy and research gaps. This study would represent an important initial step.

Proposal 3: Focus on Indigenous Peoples

There are numerous vision health issues facing Indigenous peoples. Among them is the potential epidemic of preventable vision loss associated with diabetic retinopathy (DR) due to high rates of diabetes and a lack of vision care services.^{xxxv} Accordingly, the recommendations in the report of the Advisory Panel on Healthcare Innovation^{xxxvi} specifically with respect to Health Canada’s Non-Insured Health Benefits (NIHB) Program should be pursued. The recommendation to improve the management and responsiveness of the NIHB Program to enhance access to care through digital technologies and ensure that it provides coverage comparable to other public and private plans should be implemented.

The Program should also incorporate an enriched eye care and vision health component. Indigenous Peoples who experience permanent and severe vision loss do not receive rehabilitation services in their communities. Rather, in most provinces and territories, Indigenous Peoples must go to a service provider, like CNIB, for rehabilitation therapy services. It is recommended that an MOU be drafted between Health Canada and an accredited organization with certified vision loss rehabilitation specialists, so that rehabilitation therapy services can occur in the communities where people reside.

Proposal 4: Fund Collaborative Vision Care Pilot Projects

Should the federal government follow the recommendation of the Advisory Panel on Healthcare Innovation to create a Healthcare Innovation Fund, we believe the fund could be instrumental in advancing collaborative eye health and vision care. Specific funding should be dedicated to collaborative care models that encompass the entire journey of vision loss from prevention to rehabilitation, and encourage direct citizen engagement.

The Eye Health Council of Ontario is an example of interprofessional collaboration working towards improving health outcomes for the province's citizens. Its mandate is to support the provision of accessible, quality eye care to Ontarians by ensuring the most effective use of the continuum of eye care professionals in the interests of patient safety, quality of care, and cost effective delivery. Its members and stakeholders are drawn from the professions of optometry, ophthalmology, opticianry, their regulatory bodies, professional associations, academic and vision research communities, representatives from family medicine and government, as well as certified vision loss rehabilitation professionals. The Canadian Association of Optometrists and the Canadian Ophthalmological Society have developed a template and suggested guidelines for provincial consideration.

A similar initiative is underway in Nova Scotia where optometrists and ophthalmologists have developed collaborative protocols for the care of patients under the auspices of the Eyecare Working Group.

Proposal 5: Educate the Public

The time has come to help Canadians seize control of their eye and vision health by undertaking a wide-scale public information campaign based on population health strategies that influence individual behaviors. Our organizations have advanced public education initiatives to encourage Canadians to address their vision health, however more can be done.

Many Canadians are still not as aware of the signs and risk factors for vision loss. Eye health, vision care, and post-vision loss rehabilitation therapy should be a core component of overall health care, and the public should be encouraged to think about their eyes. As a case in point, while heredity is a risk factor for most eye diseases, such as glaucoma, more than half of Canadians (53%) do not know their family eye health history.^{xxxvii}

In addition, public awareness of the abilities of people with vision loss is essential to enhancing opportunities for Canadians with sight loss. The federal government's current collaboration with CNIB on the [EmployAbility Campaign](#) is a strong example of partnership for successful public education.

Drawing on our expertise, we are uniquely qualified to provide knowledge translation to those affected and their caregivers, as well as to decision-makers and other vision care stakeholders.

Conclusion

With 5.5 million Canadians currently living with vision-threatening eye conditions,^{xxxviii} now is the time to make vision health a public health priority. In partnership, we have a collective responsibility to create a culture of eye health as part of overall health.

Our proposals are affordable, reasonable, and doable. They clearly fit within the scope of the federal role in health care.

As eye health and vision care providers, rehabilitation professionals, and vision research funders, we are willing partners in this undertaking and look forward to working with governments and stakeholders to achieve optimal vision health for all Canadians.

Appendix A – About the Participating Organizations

The **Canadian Association of Optometrists** is dedicated to collaboratively advancing the highest standard of primary eye care through the promotion of optimal vision and eye health in partnership with all Canadians.

For further information, please contact Laurèl Craib, Manager of Government and Stakeholder Relations at (613) 235-7924, x214 or at lcraib@opto.ca

CNIB is a registered charity, passionately providing community-based support, knowledge, and a national voice to ensure Canadians who are blind or partially sighted have the confidence, skills, and opportunities to fully participate in life.

For further information, please contact Diane Bergeron, Executive Director, Strategic Relations and Engagement at (613) 563-4021, x5050 or at diane.bergeron@cnib.ca.

The **Canadian Council of the Blind** works to improve the quality of life for persons with vision loss through awareness, peer mentoring, socializing, sports, advocacy, health promotion and illness prevention.

For further information, please contact Jim Prowse, Executive Director at (613) 567-0311 or at jprowse@ccbnational.net.

The Foundation Fighting Blindness leads the fight against blindness by advancing retinal disease research, education and public awareness.

For further information, please contact Sharon Colle, President & CEO, at (416) 360-4200 x228 or at scolle@ffb.ca.

Appendix B – The Canadian Patient Charter for Vision Care



Preamble

With an estimated 5.5 million Canadians living with a vision-threatening eye condition, of whom nearly 500,000 already are blind or partially sighted, vision care is an essential component of Canada's health care system. Patients have a right to be active and informed partners in their own vision care. The Canadian Charter of Vision Care Rights and Responsibilities outlines the rights and responsibilities of patients and professionals in ensuring the highest standard of vision care is met across the country.

Prevention of vision loss

Patients have a right to:

- Receive timely access to the right eye health or vision care professional (ophthalmologist, optometrist or optician) at the right time;
- Be provided with credible information about how to maintain good vision health and recognize the signs of eye disease or vision loss and the importance of eye safety.



Patients have a responsibility to:

- Take steps to prevent vision loss wherever possible by making healthy lifestyle choices and receiving regular eye examinations per evidence-based guidelines;
- Monitor their vision and report any changes to their ophthalmologist, optometrist or optician as soon as they are noticed.

Inclusive, accessible and coordinated care

Patients have a right to:

- Be treated with dignity and respect in every interaction relating to their eye health;

- Be an active partner in decision-making at every stage of their vision care experience;
- Expect a collaborative approach to care that brings together ophthalmologists, optometrists and opticians and all other relevant disciplines to create a tailored, holistic plan;
- An open and inclusive care environment that takes into account the accessibility needs of people with vision loss including the formats in which information is made available;

- Have complete access to their medical records on request, with assurance their personal information will be protected from unauthorized disclosure.

Patients have a responsibility to:

- Communicate openly and honestly with their ophthalmologist, optometrist, optician, or family physician if they do not understand their vision care plan;
- Apprise their ophthalmologist, optometrist, optician or family physician of accessibility needs.

Diagnosis and treatment

Patients have a right to:

- Receive an optimum standard of care and a timely and accurate diagnosis of their eye condition by the most appropriate professional; as well as all relevant information about the eye condition, its potential impact on their vision and resources that can assist with the adjustment to vision loss, including rehabilitation therapy and mental health support;
- Make an informed consent to treatment, which includes being provided with the necessary information about potential benefits, side-effects and approved alternatives;

- Receive appropriate follow-up care and support.

Patients have a responsibility to:

- Communicate honestly with their ophthalmologist, optometrist, optician or family physician about their vision health, including visual challenges, so that the best and most appropriate care can be provided;
- To follow the prescribed treatment and self-care instructions or express concerns if they are unable to comply.

Comprehensive vision rehabilitation

Patients have a right to:

- Receive a timely referral and access to the full spectrum of care in their journey through vision loss, from an ophthalmologist's or optometrist's initial assessment to the rehabilitation professional's delivery of intensive therapy, including any required specialized training to allow them to live safely, independently and with dignity;

- Collaborate with rehabilitation professionals in the development of personalized post-vision loss rehabilitation therapy.

Patients have a responsibility to:

- Participate fully in therapeutic sessions and reinforce learned skills through ongoing practice;
- Provide a safe working environment for vision rehabilitation therapists providing training in the home.

Professional rights and responsibilities

Professionals involved in the clinical and/or rehabilitative care of a patient have the right to:

- Safe working conditions whether providing care in clinical or community-based settings;
- Resist any influence / interference that could undermine their professional integrity;
- Contribute to the advancement of the eye care and/or vision rehabilitation professions.

Professionals have the responsibility to:

- Treat patients with dignity, respect and a supportive approach;
- Provide information and care in a manner that is accessible to people with vision loss, making adaptations where needed;
- Improve models of integrated vision care to create a more seamless patient experience;
- Actively engage patients and one another to provide high-quality, personalized and coordinated approaches to care;
- Learn and apply evidence-based best practices in the provision of optimal care and/or therapy;
- Provide timely referrals for treatments and therapies, including comprehensive vision rehabilitation therapy where the patient has vision loss that places at risk their safety, mobility and/or independence.



Appendix C – International Models

Countries around the world have adopted strategies and policies to address eye care and vision health.

Australia

Australia's 2005 National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss^{xxxix} is an example of a government-led initiative to promote of eye health and prevent avoidable blindness and vision loss. The Framework originated with the World Health Organization's *Universal Eye Health: A Global Action Plan 2014-2019*. The Framework provides a blueprint for nationally coordinated action by governments, health professionals, non-government organizations, industry, and individuals to work in partnership. The goals are to reduce the risk of eye disease and injury, increase early detection, improve access to eye health care services, improve the systems and quality of care, and enhance the underlying evidence base.

Australia has published its first National Eye Health Survey; the only nationwide population health survey on the prevalence and causes of major eye conditions ever conducted in the country. It resulted from a partnership between government, eye health providers, and the private sector.

While Canada lags behind in its understanding of the magnitude of the eye health issues of its population, the Canadian Health Measures Survey includes a vision component in 2016-2017. This is a positive step.

Australia's Vision Initiative pilot projects

In 2012–2015, the Vision Initiative successfully tested a novel three-tiered approach to reduce avoidable blindness and vision loss in four local government areas where populations were considered at increased risk of eye disease.

Each pilot project area implemented different interventions to determine the effectiveness of various engagement strategies with health professionals and community. Activities delivered included training and development of primary health professionals, delivering activity to people at-risk of eye disease, and local media campaigns to raise awareness of eye health and vision care.

Evaluation results have been positive across all four pilot project areas. The Vision Initiative is an integrated health promotion program funded by the Victorian Government and managed by Vision 2020 Australia. It aims to prevent avoidable blindness and vision loss, and address the impact of vision loss in the Victorian community.^{xi} It is one of many programs within the National Framework for Action.

United Kingdom

The UK Vision Strategy, whose aims are supported by UK governments, is implemented through a strong alliance of statutory, health and social care bodies, voluntary organizations, eye health professionals, and

individuals.^{xi} Launched in April 2008, the strategy aims to radically improve the eye health of the nation; eliminate avoidable sight loss; improve services to people with sight loss, including children; and increase inclusion in society for blind and partially sighted people.

Significant progress has been made towards addressing eye health awareness among the public and health and social care practitioners. For example, the Department of Health's Public Health Outcomes Framework for England, launched by the Government in 2012, includes a Public Health Indicator for eye health that tracks the rates of three major causes of avoidable sight loss: glaucoma, age-related macular degeneration, and diabetic retinopathy.

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