



SUMMARY REPORT RECOMMENDATIONS



The Cost of Vision Loss and Blindness in Canada

The Canadian Council of the Blind

Keith D. Gordon, Ph.D. M.Sc. (Epid.)

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Summary Report
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BACKGROUND

In December 2020, the Canadian Council of the Blind (CCB) commissioned Deloitte Access Economics, a world-renowned consultancy with expertise in disease prevalence and health economics, to conduct an updated assessment on the prevalence and cost of VL in Canada using 2019 data. The CCB then invited Fighting Blindness Canada to partner on the project together. The results of this study are impactful revealing that VL cost Canadian individuals and governments a staggering \$32.9 billion in 2019. This consists of a cost to the health care system of \$9.5 billion, productivity losses of \$4.2 billion due primarily to reduced workforce participation, other costs of 1.8 billion and a cost of lost well-being of \$17.4 billion. This study also determined that there are 1.2 million Canadians living with VL, representing 3.2 percent of the total population. The number of people with VL is projected to increase to 2 million by 2050.

In short, the 2021 report reveals that Canada is experiencing an emerging crisis in preventable or treatable vision loss that has the potential to get even worse unless action is taken immediately. In response to this need for action, CCB and FBC have drafted the following recommendations from the report for governments, individuals, and society in general, that should help alleviate the critical situation we are currently experiencing.

The full report by Deloitte Access Economic is available in its entirety along with the Summary Report by Dr. Keith Gordon, Principal Investigator on the project at www.StopVisionLoss.ca



THE COST OF VISION LOSS AND BLINDNESS IN CANADA

Recommendations

A Vision Health Plan for Canada

Recommendation 1: It's recommended that the Government of Canada keep its long-overdue promise and develop a Vision Health Plan for Canada. In 2003, the Canadian government made a commitment to the World Health Organization (WHO) that it would develop a Vision Health Plan for Canada by 2007 and implement this plan by 2009. To date, no plan has been developed.

At the 66th World Health Assembly (WHA) in 2013, Canada voted in support of a resolution entitled "Towards Universal Eye Health: A Global Action Plan (GAP) 2014–2019." This resolution opened up a new opportunity for member states to progress with their efforts to prevent visual impairment and strengthen rehabilitation of the blind in their communities. In particular, objective 2 of the GAP encourages the development and implementation of integrated national eye health policies, plans, and programs to enhance universal eye health with activities in line with the WHO's framework for action for strengthening health systems to improve health outcomes.

In August 2020, Canada was again a signatory to a WHA resolution, which adopted the WHO World Report on Vision that included a recommendation that all member countries incorporate "integrated people-centred eye care, including preventable blindness and impaired vision." This resolution sets the global agenda for eye health for the decade up until 2030, committing to a plan to make eye care an integral part of universal health coverage.

In spite of these ongoing commitments to the incorporation of vision care into health care planning, to date there is no vision care plan for Canada.



We therefore call on the Government of Canada, in consultation with the vision loss community and its stakeholders, to develop and implement a national Vision Health Plan, as recommended by the Canadian Association of Optometrists, the Canadian Council of the Blind (CCB), the Canadian National Institute for the Blind, and Fighting Blindness Canada in their 2017 document, *The Federal Role in Eye Health and Vision Care*, with the goal of providing the best possible outcomes and quality of care and rehabilitation for Canadians who are blind or partially-sighted.

Recommendation 2: Establish a “Vision Desk” within the Public Health Agency of Canada. Vision issues are currently handled by departments within the Public Health Agency that deal with other diseases and conditions. For effective planning of eye health in Canada, it’s essential that vision issues be handled within a vision-specific department.

Regular Comprehensive Eye Examinations

Recommendation 3: Provide funding for regular comprehensive eye examinations for all age groups. The most important measure that an individual can undertake to prevent vision loss is to have one’s eyes examined on a regular basis. Early diagnosis and treatment of eye diseases can minimize vision loss, and in some cases can restore lost vision.

As discussed in the current report, there’s a high percentage of seniors who have undiagnosed eye problems. This is true for children as well, where undiagnosed or uncorrected vision problems are among the most common causes of learning difficulties in school-age children.

Covering the costs of comprehensive eye examinations has been shown to increase the number of people getting them, which in turn leads to the early detection, diagnosis, and treatment of eye diseases. Currently, comprehensive eye examinations aren’t fully covered in all provinces, leading to different levels of access depending on where you live. This needs to change.



Recommendation 4: All provincial and territorial governments need to investigate the highly effective eye examination model currently being utilized in Ontario by the CCB in collaboration with Lions Clubs. Mobile clinics are designed to conduct comprehensive eye examinations for seniors in long-term care facilities, as well as for children in schools. Mobile eye clinics bring portable eye examination equipment, a registered optometrist, and an experienced support team, including volunteer members of Lions Clubs, to each venue. Through its partners, the mobile eye clinic program provides free eyewear to all children and seniors who cannot afford them. Research has shown that accessible mobile health clinics are a cost-effective and efficient way to provide vision health awareness, early detection, and remedial treatment to underserved rural and urban communities that would otherwise go unvisited, and therefore undiagnosed and untreated.

Recommendation 5: Ensure that regular eye examinations are incorporated into all falls-prevention programs in long-term care facilities as well as within the community. This study has documented the large financial and social costs associated with falls as a result of vision loss. As discussed above, mobile eye clinics should be investigated as a means of providing regular eye examinations to seniors.

A World Accessible to All

Recommendation 6: All governments, public and private sector organizations, professionals, and individuals need to work to ensure that all workplaces, systems, communications, and the built environment are designed to be accessible from the start. We need to work toward the goal of having a world that is accessible to people with all disabilities, not only those with vision loss, and to make accessibility built in to all we do, not added on as an exception. We need to design our society — work, education, the built environment, recreation, cities, and so on — so that people who have vision loss can participate fully. The return on investment is huge. It will benefit not just people who have vision loss but everyone.



To make the world fully accessible to all people of all abilities requires political will driven by a mandate from the majority. But the majority of people don't live with a disability, so aren't aware enough or inclined to advocate for a universally-accessible world. We must be aware of an injustice in order for it to be the catalyst for political action. It's essential that we all work toward increasing awareness of the need for accessibility in the first place.

Recommendation 7: All governments, public and private sector organizations, professionals, and individuals need to work toward removing barriers that may preclude full participation in society by people living with vision loss as well as other disabilities. Such barriers may be as simple as human resources policies within organizations, or as complex as transportation systems. We all need to be sensitive to the fact that almost everything we do may possibly create a barrier for people living with vision loss.

Making Eye Health a Priority

Recommendation 8: Ensure that the Canadian health care system, i.e. all provincial and territorial governments, can meet the growing need for eye care services. Vision loss should be an issue for everyone, as almost everyone will experience some level of vision loss over their lifetime. The current report tells us that about one in six Canadians is living with an eye disease that could potentially result in vision loss. Most people will have a close family member or close friend living with vision loss. Most people, therefore, will either be accessing eye care services themselves or on behalf of a family member or friend.



Recommendation 9: Eye health needs to be reframed as an enabler —to live a healthy, productive, and prosperous life — rather than being simply disability-focused.

Eye health is essential for the full participation of people in society.

There's extensive evidence showing that improving eye health contributes directly and indirectly to achieving the reduction of poverty and improving productivity in the workplace, as well as contributing to general and mental health, education, and equity. Improving eye health is a practical and cost-effective way of unlocking human potential.

The Aging Tsunami

Recommendation 10: Incorporate vision health into aging strategies and programs. All of the major eye diseases that are associated with vision loss are also associated with aging. Many older people with vision loss also have other age-related disabilities. It's essential that all aging strategies specifically incorporate a vision health component.

Recommendation 11: It's recommended that all information being communicated to the vision loss community be communicated in as many formats as possible in order to maximize the possibility of people accessing the information — for example, including traditional forms of media such as radio, TV, and print in addition to social media platforms. This is particularly important since a recent CCB survey showed that 32% of respondents over the age of 65 had other disabilities in addition to vision loss, most commonly hearing loss.



Universality of Eye Care

Recommendation 12: Eye care should be an integral part of universal health coverage. The 2019, the WHO's World Report on Vision's number one recommendation was that eye care be an integral part of universal health coverage. This is currently not the case in Canada, where coverage for the most important preventive measure, a regular eye examination, isn't part of universal health coverage for all age groups across the country.

Furthermore, not all devices or medications are universally reimbursed by provincial and territorial governments. We recommend that the federal and provincial governments develop a taskforce to investigate all areas where universal health coverage as it relates to vision care may be lacking.

Recommendation 13: Integrate vision rehabilitation into the continuum of eye care. Vision health should be regarded as a continuum, from the prevention of vision loss through to the diagnosis and treatment of vision-impairing eye conditions and vision rehabilitation. Integration of this continuum of care will optimize the outcomes for the patient and help prevent vision loss while enabling people experiencing vision loss to integrate into the community.

Access to Eye Care Treatments, Technologies, and Services

Recommendation 14: Improve access to sight-saving surgeries in all provinces and territories. Wait times for eye surgeries, most notably cataract surgery, have been increasing and the number of surgeries in most jurisdictions hasn't increased in spite of the increase in demand. People shouldn't have to live with vision loss when sight-saving surgeries could be made available through greater financial support.



Recommendation 15: Improve regional availability of eye care. Inequities exist in terms of regional availability of many eye care services. It's essential that all governments examine methods for delivering essential eye care services to rural and remote regions of the country through innovative methods, including, but not limited to, the use of telemedicine and digital technology.

Recommendation 16: Improve access to new, innovative sight-saving medications and devices for blinding eye diseases. Coordinated action is required from all stakeholders — government, industry, academia, patient groups, and more — and at all levels of vision policy and care to encourage access to innovative medicines and treatments, the availability of assistive technologies and devices, and the funding of essential research that will accelerate discoveries that lead to new treatments for vision loss. It's essential that all treatments and devices be affordable and accessible to people with vision loss who may otherwise not be able to afford them.

Recommendation 17: Enhance access to eye care for Indigenous peoples and priority populations. Certain populations exhibit a higher risk of developing specific eye diseases. Most notably, Indigenous populations exhibit a higher risk for the development of diabetic retinopathy. Eye care planning needs to ensure that high-risk populations be given priority access to care.

Recommendation 18: Provide financial support so that people with vision loss who have limited means can acquire the necessary assistive devices. We call on all provincial and territorial governments to develop and implement assistive devices programs to supplement the expenses incurred by people who are blind or have vision loss in acquiring life-altering devices to ensure they can gain employment and fully participate in society.



Improving Employment Participation

Recommendation 19: All levels of governments need to assist people who are blind or have vision loss with the acquisition of employment, thereby minimizing the social and economic costs associated with vision loss. An integral part of this initiative should be to undertake a survey on employment of people with seeing disabilities. This survey should include, for example, questions on: job search, barriers, accessibility, inclusion, the use of assistive technology, devices, entering the digital economy, employment standards, education and training, equal opportunity, workplace bias, and more.

Recommendation 20: Ensure that the technologies deployed within the work environment are accessible to everyone, without the need for segregated assistive technologies. Currently, people with vision loss need to acquire additional technology in order to fully engage in the workplace. A fully-inclusive workplace would mean that all technology would be accessible to all employees, without the need for additional adaptive software or devices.

Recommendation 21: Employers and technology companies need to pursue technological solutions for a more accessible workplace.

Recommendation 22: Create a standard for accessible workstations designed for all employees, not just for those with a seeing disability.

Recommendation 23: Federal and provincial stakeholders need to develop initiatives that reward employers for meeting high standards in accessibility, for hiring employees with blindness or low vision, for implementing diversity agendas, and for achieving other progressive goals. To accomplish this, it's recommended that the government and stakeholders create an affirmative action program to investigate the potential of this suggestion and to audit the effectiveness of present employment programs.



Recommendation 24: The federal government, in collaboration with the provinces and territories, the post-secondary sector, and employers, should work toward increasing funding and providing incentives for employers to develop and implement work-integrated learning opportunities for all students, including students who are blind or partially-sighted.

Recommendation 25: Websites at all levels of government need to meet the four pillars of accessibility: that they're perceivable, operable, understandable, and robust. It's further recommended that these same governments ensure that their websites meet the highest recognized international (European) standard of accessibility. Now may be the best time to create new accessibility standards. As we move forward from today's pandemic circumstance to a time of new normalcy, it's recommended that the vision loss community's employment challenges be recognized and accommodated with the design of a set of ethical standards for workplace accessibility. Most importantly, the details of these standards should be driven by the vision loss community.

Research and Evidence

Recommendation 26: Governments and other stakeholders need to increase investment in eye health research, with particular emphasis on treatments with the potential to prevent vision loss or restore vision. Increased funding should include financial support for new genetic and stem cell treatments, new pharmaceutical therapies, new surgical and non-surgical devices, devices that assist vision rehabilitation, as well as diagnostic and screening initiatives. Clinical trials for medications and devices should be encouraged and supported in order to facilitate their availability to patients as early as possible.



Recommendation 27: The Government of Canada, in collaboration with all departments dealing with disabilities, needs to increase the evidence base related to people living with blindness or vision loss by requesting Statistics Canada to broaden the census to provide more direct and expanded information about people with disabilities. Specifically, it's recommended that the census assume a broader approach to demographics (including ages 1-14), employment, technology, and training, amongst others.

Recommendation 28: To further increase the evidence base, it's recommended that the Government of Canada fund a pan-Canadian population health study on the prevalence and causation of vision loss in Canada in order to have solid data on which to base health care planning.

Public Awareness of Vision Health

Recommendation 29: Governments and public health authorities need to undertake robust health promotion campaigns designed to improve public knowledge of vision health and to minimize preventable vision loss. It's estimated that 75% of vision loss is either treatable or preventable. However, many people aren't taking the best care of their eyes through regular eye examinations or by managing the many modifiable risk factors, mainly due to a lack of awareness of the importance of these factors. It's essential that people be made aware of the importance of early identification of eye conditions and the fact that most conditions that cause vision loss don't display symptoms, such that people may contract eye diseases and even lose significant amounts of vision without being aware of it.



Research Leads

Keith Gordon, Principal Investigator

Dr. Keith Gordon is the Senior Research Officer of the Canadian Council of the Blind (CCB) and the author of the CCB report “The Impact of the COVID-19 Pandemic on Canadians Who Are Blind, Deaf-Blind, and Partially-Sighted,” published in April 2020.

Dr. Gordon is past Vice President Research of the CNIB and past Research Director of Blind and Low Vision New Zealand. He is also a board member of BALANCE for Blind Adults, and Chair of the Board of the international organization Retina Action.

He is an adjunct professor in the Department of Ophthalmology and Vision Sciences at the University of Toronto and an Honorary Teaching Fellow in the School of Optometry and Vision Science at the University of Auckland in Auckland, New Zealand.

Larissa Moniz, Investigator

Dr. Larissa Moniz joined Fighting Blindness Canada (FBC) in December 2019. She has a Ph.D. in molecular and cancer biology from the University of Toronto and has continued her research in the UK at University College London. Dr. Moniz has worked in research and knowledge translation at a number of health charities, both in the UK and Canada, most recently at Prostate Cancer Canada.

At FBC, Dr. Moniz’s team works to deliver on the mission of the organization, which is to fund research toward treatments to preserve and restore vision, to ensure that all Canadians have access to appropriate vision care, and to provide support and information to individuals living with VL.

Chad Andrews, Investigator

Dr. Chad Andrews is a researcher and writer with a Ph.D. in Cultural Studies. As a consultant and advisor, he works with stakeholders in health science and policy to analyze and comprehend the physical, psychological, and socioeconomic impacts of disease and disability.

Collaborating with patients and patient groups, he has been involved in a number of burden of illness projects that study the personal and social dimensions of vision loss, including an article on patient communication and diabetic macular edema (DME) that was recently published in the *Canadian Journal of Diabetes*.



Dr. Andrews is also active in the humanities, occasionally teaching and publishing in the areas of literature, primarily speculative fiction; policy, especially frameworks that govern the products of technoscience; and political and technological theories.

Michael Baillargeon, Project Co-Lead

Michael Baillargeon is Senior Advisor, Government Relations and Special Projects for the Canadian Council of the Blind (CCB). Over the last 16 years, he has been an advisor to and advocate for the VL community. He has played a key role on a wide range of issues before the Council, including being publisher of *White Cane Week Magazine* and managing White Cane Week events.

Most recently, Baillargeon project-managed CCB studies on accessible technology and assistive devices, as well as the Survey Report on the Impact of COVID-19 on People with Vision Loss in 2020. Through advocacy and research, Baillargeon is dedicated to building public awareness and improving the well-being and quality of life of those living with VL. Baillargeon is proud of his efforts with the CCB to dismantle barriers to accessibility and to change what it means to be blind.

Doug Earle, Project Co-Lead

Doug Earle joined Fighting Blindness Canada (FBC) in December 2018 as President and CEO. Since then, he has been leading FBC through a transformation to accelerate research into all blinding eye diseases in order to discover treatments and cures for blindness, and to improve access to innovative gene and cell therapies and medications. Earle co-chaired the Canadian Vision 2020-21 Summits with Michael Baillargeon, consulting the community to identify its advocacy agenda in these symbolic years.

Over Earle's 30-year career, he has served in progressively more senior roles at five health charities, two hospitals, two universities, and TVOntario public television. He played instrumental roles in the advocacy that led to the Krever Commission of Inquiry on the Blood System in Canada and compensation for people living with HIV and hepatitis C through tainted blood, and has worked with philanthropists to fund millions in medical research and other projects.





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