Retina Action: Call to Action - Inclusion and Wellbeing

Summary

Retina Action is a global coalition of civil society organisations - including non-governmental organisations and professional associations, concerned with vision health, ageing, caregiving, medical research and the delivery of appropriate and timely treatment options to patients affected by conditions of the ageing retina.

In 2019, 9% of the global population was estimated to be aged 65 years and older, and this figure is projected to rise to 16% by 2050. Current estimates of the global cost of visual impairment due to Age-related Macular Degeneration (AMD) stand at $343 billion US Dollars, with $255 billion of this figure accounting for direct healthcare costs. Additionally, more than 463 million people worldwide are living with diabetes. Over one third of this cohort experience Diabetes-related Retinopathy (DR); a condition of the retina that is the leading cause of blindness in the working-age population today. In countries where systematic screening programs have been implemented, and timely therapeutic intervention has ensued, DR is no longer the leading cause of blindness in their working population.

Visual impairment in older adults leads to functional limitation, poor psychological health, challenges in the management of medication, worse overall health outcomes, and increased health care spending. Promoting the visual health of older people is not only a public health priority, but also an economic concern.

The COVID-19 pandemic has further demonstrated that vision loss - and retinal diseases in particular, are not prioritised in times of crisis. During the first wave of this pandemic, Optometrists - who are often the first line of access for those with early signs of visual disturbance, reported a 40% reduction in services. In clinical settings, high risk patients experienced treatment delays of up to 8 weeks, while in most regions elective treatments and procedures were delayed by 3 months. In addition, clinicians reported some non-attendance due to patients’ fear of contracting COVID-19.

Retina Action is concerned that the restrictions to care and services during the COVID-19 pandemic will further promote decreased physical and social engagement, thus leading to higher rates of morbidity and mortality. As we move towards a world of digitized healthcare - which has been fast tracked as a result of the COVID-19 pandemic, urgent consideration must be given to the digital divide, which impacts the process of validating and standardizing home health monitoring and care for the ageing and vision impaired community.

To safely bring retina patients back to the clinic in order to receive their scheduled sight-saving care, prevent avoidable blindness, and to reduce the associated negative impact on both those affected and their caregivers, Retina Action calls upon governments to:

1. Develop, and where developed, implement screening programs for Age-related Macular Degeneration and Diabetes-related Retinopathy.
2. Sustain and prioritise screening programs for Age-related Macular Degeneration and Diabetes-related Retinopathy during times of crisis;
3. Improve awareness on the issues of digital poverty in the development of remote screening and eye healthcare programs;
4. Prioritise the vaccination of the already vulnerable vision loss community against COVID-19; and
5. Promote the inclusion and wellbeing of the ageing vision loss community.
Introduction

Retina Action is a global coalition of civil society organisations - including non-governmental organisations and professional associations, that are concerned with vision health, ageing, caregiving, medical research, and the delivery of appropriate and timely treatment options to patients affected by conditions of the ageing retina. This coalition is concerned that the COVID-19 pandemic has exacerbated significant gaps in access to support, care, and treatment for those living with conditions of the ageing eye, therein contributing to negative wellbeing and a lack of inclusion.

Today, Retina Action calls upon governments around the world to collaborate with patient and advocacy organisations to develop new, and implement existing public policy actions that address the inclusion and access of older visually impaired citizens as equal members of society.

Vision loss can exist as one of a number of chronic comorbid conditions in older people. Notwithstanding this, eye care is often weighted as less important by patients, their caregivers, families, and health care providers alike. Better education about the value of eye-care services for older people, as well as the benefits of ophthalmologic screening and treatment, is critical to improving the wellbeing and societal inclusion of affected persons (1).

As life expectancy and overall health improves, the ageing population will continue to increase (2). Globally, the population aged 65 years and older has increased from 6% in 1990 to 9% in 2019. That proportion is projected to rise further to 16% by 2050, which means that one in six people in the world will be aged 65 years or older (3). It is estimated that 196 million people globally live with Age-related Macular Degeneration (AMD), a condition that affects the ageing retina causing varying degrees of vision loss. It is projected that this number will rise to 288 million in 2040 (4). Estimates of the global cost of visual impairment due to AMD is $343 billion US dollars, including $255 billion in direct health care costs (5,6).

Coinciding with rapid population ageing, is the increased prevalence of diabetes. More than 463 million people worldwide are living with diabetes. Over one third of this cohort experience Diabetes-related Retinopathy (DR); a condition of the retina that is the leading cause of blindness in the working-age population today (7). One in ten of those living with diabetes will develop a vision-threatening form of DR in their lifetime (7). In several countries, early screening and timely therapeutic interventions have meant that DR is no longer the leading cause of blindness in their working population (8).

In 2017, a declaration by the International Council of Ophthalmology, World Council of Optometry, International Agency for the Prevention of Blindness and International Diabetes Federation, called for governments, medical associations, service providers and patient organisations to strengthen health systems to manage diabetes-related eye disease and integrate care for diabetes and eye health (9).

The ageing population faces many challenges and are greatly impacted by the disparities in access to eye care. Many older adults do not receive regular eye examinations, screening services, or treatment for preventable causes of blindness such as wet Age-related Macular Degeneration (wAMD); a more severe and rapidly developing form of the condition that affects 15% of all AMD cases and can lead to severe vision loss, or DR. Furthermore, the composite
effect of visual impairment in older adults is one of functional limitation, poor psychological health, challenges in the management of medication, worse health outcomes overall, and increased health care spending. Promoting the visual health of older people is not only a public health priority, but also an economic concern (1).

Recent studies show that in times of crisis eye care is not prioritized. At the height of the first phase of the COVID-19 pandemic, a study by Retina International highlighted that even in countries where optometry is considered an essential service, optometrists were providing care at less than 40% of pre-COVID-19 capacity. In many countries only urgent services could be provided and limited personal protective equipment has impacted the services during the initial phase of the pandemic.

While ophthalmologists across the globe strived to tend to emergency surgeries and provide time sensitive treatment, in some regions high risk patients experienced treatment delays of up to 8 weeks, while in most regions elective treatments and procedures were delayed by 3 months. Clinics reported at the height of the pandemic working at 50% capacity or less, though some clinics remained closed for up to 4 months. All clinician ophthalmologists reported some non-attendance due to patients’ fear of contracting COVID-19. This is in spite of numerous reported measures taken by clinics and clinicians to ensure safety. This highlights the need to support the overall wellbeing of those living with AMD and supporting the prioritization and management of their eye health appointments.

Retina International has found that retinal health was not considered a priority during the COVID-19 pandemic. Many regions report a further delay in ophthalmology appointments for screening and follow up for AMD and DR of 8-12 weeks or more, compared with delays experienced prior to COVID-19. This is coupled with negative impact statements including "I have anxiety about the delay between injections", and has led to unanswered questions; “Will the delay between injections cause my vision to deteriorate further?” Indeed, anecdotal reports from clinicians indicate patients have lost vision due to not having kept their appointments, where available, during this time.

The concerns of wAMD and DR patients extend beyond the treatment itself. The restrictions associated with COVID-19 have meant patients in some regions must attend the clinic on their own, with many reporting new fears such as: being “afraid of using public transport” to attend treatment, “my husband cannot come into the clinic with me”, “I’m afraid I will have to sit for hours in a waiting room with other people”, and “I avoid my eye exams now because I am an ‘at risk’ (of severe health implications if I get COVID-19) patient”.

The negative impact on wellbeing associated with vision loss is well documented. Retina Action is concerned that the restrictions to care and services during the COVID-19 pandemic will further promote decreased physical and social engagement leading to higher rates of morbidity and mortality. The prevalence of depression for those newly diagnosed with AMD has been reported at 15.7 – 44% (10-13). While there is an association of increased depression as vision deteriorates (14), it also remains associated with patients undergoing regular injections for treatment of AMD (15). Despite the high prevalence of depression in people with AMD, it is often neglected by the healthcare system. However, a number of cognitive behavioural methods, (some of which were coupled with low vision rehabilitation), are proving effective in decreasing depression (16).
Similarly, reviews of studies on the association between DR and depression reported a bidirectional relationship between depression and DR i.e. people with higher levels of depression showed greater depression and more severe DR, while having DR was associated with higher levels of depression (17,18). Since a strong association has been established between diabetes and depression(19), it is essential that people with diabetes be monitored for depression to protect both their wellbeing and their vision.

In light of the availability of such interventions, the United Nations Sustainable Development Goals, and the United Nations Decade of Healthy Ageing 2021-2030, it is essential that more attention be given to the treatment of wellbeing associated with AMD and DR, and it is imperative to promote public policy actions that eliminate age-related discrimination, and secure preventive care to maintain maximum functional capacity of individuals, which will in turn result in improved health and wellbeing (3).

Moving towards a world of digitized living and healthcare, that has been fast tracked by the COVID-19 pandemic, we acknowledge the improvements assistive technologies provide to quality of life (20). However, to promote inclusion of older people in the vision community, it is essential to consider and incorporate international standards for accessibility (21) in the development of digital resources and solutions. One must also understand the challenges facing those with limited or no access to online resources and digital solutions, in addition to the challenges of validating and standardizing home health monitoring and care for the aging and vision impaired community (22).

**Call to Action**

Ensuring the mental, physical and emotional wellbeing of older people living with actionable and treatable sight loss such as wAMD and diabetic eye diseases is central to their care. The COVID-19 pandemic has brutally exposed those living with vision impairment to even greater stress than the sighted community due to social distancing requirements impacting their ability to negotiate the outdoors and public spaces. Many of those who need assistance are no longer able to go out, leading to greater solitude and depression (23).

To safely bring retina patients back to the clinic to receive their scheduled sight-saving care, prevent avoidable blindness, and reduce the associated negative impact on those affected and their caregivers, Retina Action calls upon governments to:

1. Develop, and where developed, implement, screening programs for age-related macular degeneration and diabetes-related retinopathy.
2. Sustain and prioritise screening programs for age-related macular degenerations, and diabetes-related retinopathy during times of crisis;
3. Improve awareness on the issues of digital poverty in the development of remote screening and eye healthcare programs;
4. Prioritize the vaccination of the already vulnerable vision loss community against COVID-19; and
5. Promote the inclusion and wellbeing the aging vision loss community.

Emerging from the COVID-19 pandemic, there is opportunity to build back better, and to provide equitable access to healthy ageing services to a community that has been underserved to date.
References:

(1) Umfress 2016 Eye Care Disparities and Health Related Consequences in Elderly Patients with Age-Related Eye Disease
https://www.who.int/data/gho/data/themes/mortality-and-global-health-estimates


(20) Nguyen 2018 Improvement in Patient-Reported Quality of Life Outcomes in Severely Visually Impaired Individuals Using the Aira Assistive Technology System
(21) https://www.w3.org/WAI/standards-guidelines/
(22) Ward 2020 Monitoring for neovascular age-related macular degeneration (AMD) reactivation at home: the MONARCH study
About Retina Action:
Retina Action is a coalition of vision and aging groups representing the voice of people affected by vision loss and the aging population. The partnership has worked together informally for many years and in 2017 decided to formalise and develop a work stream to assist in its objectives of improving awareness of conditions such as Age-related Eye Disease, AMD, Geographic Atrophy, GA and Diabetes-related Eye Disease, DED. In late 2017 they launched retina-amd.org, a toolkit designed to provide the most up to date scientific information and therapeutic developments in the area of AMD. This information was developed for the members of the patient bodies that make up the coalition to use not only in their local communications and advocacy work but also to ensure those affected or at risk of developing these conditions were up to date on the latest scientific advances, therapy development and rehabilitation services. In January 2019 Retina Action launched retina-ded.org, a toolkit that provides high quality information to those at risk and affected by Diabetes-related Retinopathy, Diabetes-related Macular Edema and other diabetes-related eye diseases, a group of very complex conditions, to equip advocates with the information they need to educate policy makers on the importance of screening for this degenerative retinal disease. 
www.retinaaction.org

Partners:
Retina International
For 43 years, Retina International (RI) has been the voice of patient-led voluntary groups, charities and foundations worldwide who fund and support retinal research that is seeking a cure for inherited and age related forms of retinal diseases. Millions of people all over the world are living with severe vision loss, a significant proportion of which is due to retinal degenerations. For individuals and families who have been diagnosed with a retinal dystrophy, be it rare, genetic and inherited, or age-related, access to relevant, detailed and clearly understandable information is essential. Retina International strives to improve the lives of these people living with retinal conditions by making this information timely, accurate and accessible. Additionally, we lead and support national and global evidence-based advocacy campaigns to improve healthcare and treatment access for people living with retinal conditions. www.retina-international.org

Prevent Blindness
Founded in 1908, Prevent Blindness has become the US leading volunteer eye health and safety organisation dedicated to fighting blindness and preserving sight. Focused on promoting a continuum of vision care, Prevent Blindness touches the lives of millions of people each year. www.preventblindness.org
**International Federation of Ageing**
The International Federation on Ageing fondly known as “IFA” is an international non-governmental organization (NGO) whose members are government, NGOs, academia, industry, and individuals in nearly 80 countries. IFA believes that all these members working together are essential to help shape and influence policy and good practices. IFA stands to drive the agenda for the world’s population ageing. We are proud to have general consultative status at the United Nations. The International Federation on Ageing is a non-State actor in official relations with the World Health Organization (WHO).

[www.ifa.ngo](http://www.ifa.ngo)

**Canadian Council for the Blind**
The Canadian Council of the Blind (CCB) is a membership-based not-for-profit organization that brings together Canadians who are blind, deaf-blind or living with vision loss through chapters within their own local communities to share common interests and social activities. CCB works to improve the quality of life for persons with vision loss through awareness, peer mentoring, socializing, sports, advocacy, health promotion and illness prevention.

[www.ccbnational.net](http://www.ccbnational.net)

**Blind Low Vision NZ**
Blind Low Vision NZ believes everyone who is blind, deafblind, or has low vision should have the opportunity to be self-reliant and do the things they need and want to in life. As well as supporting individuals, Blind Low Vision NZ seeks to make big-picture change by advocating for inclusive communities and for optimal eye care services for all New Zealanders.

[www.blindlowvision.org.nz](http://www.blindlowvision.org.nz)

**European Council of Optometry and Optics**
The European Council of Optometry and Optics (ECOO) is the European organisation which represents the interests of optometrists and opticians from 24 countries. It aims to promote eye health to the public across borders and to harmonise clinical and educational standards of optometric and optical practice throughout Europe.

[www.ecoo.info](http://www.ecoo.info)

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