Retina International

Recommendation of the Retina International Age-related Macular Degeneration (AMD) Advocacy taskforce

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1. Background

Age-related macular degeneration (AMD) is a significant public health issue that affects over 200 million people worldwide. Of these, 10 million people live with the advanced form of AMD, which includes neovascular AMD (nAMD) or Geographic Atrophy (GA).[1] The global prevalence of AMD is expected to increase because of an ageing population, yet up-to-date data on the socioeconomic impact at a regional level is lacking. Understanding the burden on the economy, individuals affected, and their caregivers is essential to informing diagnostic and therapeutic research, health care provision and access to new therapies.

To address this gap of inadequate evidence depicting the societal burden of AMD in the literature, Retina International conducted a comprehensive study on the Socio-economic impact of late-stage Age-related Macular Degeneration (AMD) in 2021/2022.[2] To capture a variety of healthcare costs and experiences, three countries were chosen: the USA, which has the highest number of individuals affected by late-stage AMD and a distinct healthcare system, Germany and Bulgaria, which represent developed and developing economies within the EU respectively. The study report was released in October 2022.

This study estimated the socioeconomic cost of illness and its impact on patients and caregivers affected by advanced AMD including Geographic Atrophy (GA) and wet Age-related Macular Degeneration (wAMD).

The cost categories included:

- Direct costs
- Indirect costs
- Well-being (Patients)
- Productivity (Patients + Caregivers)

Estimated per-annum total costs (comprising both economic and well-being) attributable to advanced AMD were 449 million euros in Bulgaria, 7.6 billion euros in Germany and 43 billion Euros in the USA. In Germany and Bulgaria, the costs incurred due to GA and wAMD contributed almost equally to the total cost, while in the USA the cost incurred due to wAMD contributed slightly higher (56%) than the cost incurred due to GA. Across all countries, the direct cost, i.e. the cost incurred due to direct medical expenses, was only a fraction (8–11%) of the total cost incurred. In Germany and Bulgaria, the biggest contributor to the total economic burden was reduced well-being (56% and 70% respectively) whereas, in the USA, the loss of productivity (55%) was the biggest contributor.

2. Rationale

The study on the socioeconomic impact of late-stage AMD conducted by RI revealed that the burden and impact of AMD on patients and their caregivers in the USA, Germany and Bulgaria is immense when considering direct costs, indirect costs, reduced well-being and loss of productivity. The economic repercussions of reduced well-being and diminished productivity emerged as primary drivers of the considerable financial burden associated with late-stage AMD. The prevalence of well-being issues such as low vision (46 - 66%), anxiety (19 - 63%), and depression (27 - 52%) within the affected population played a pivotal role in the augmented burden of reduced well-being. Similarly, the substantial burden resulting from loss of productivity stemmed from the disease's profound impact on employment whereby up to 48% of individuals with advanced AMD experienced job loss and up to 89% were compelled to reduce their working hours due to the disease. Furthermore, our membership has expressed concerns regarding the inadequate rehabilitation and support provisions that are currently available for the AMD community.

The insights garnered from the RI Socioeconomic study and the information we have gathered provide a solid evidence base for the formulation of policy actions aimed at mitigating the burden imposed by AMD. In response to these challenges, we took the initiative to convene an Age-related Macular Degeneration (AMD) Advocacy Taskforce. The taskforce consisted of the representatives from /our member organizations in the USA, Germany, and Bulgaria, along with their esteemed medical advisors. The primary objective of this taskforce was to collaboratively develop recommendations aimed at facilitating effective advocacy action.

3. Objectives of the Taskforce

The aim of the taskforce was to discuss the outputs of the study of the socio-economic impact of AMD in these three countries and to work collaboratively to address the following questions and form a consensus approach to action at local, regional and global level:

What is the existing policy environment in each country?

Where are the opportunities for collaborative efforts and outputs?

What aspects are specific to individual countries, what holds regional significance, and what can be implemented on a global scale?

The deliverable of the taskforce is a recommendation on policy action for people living with AMD at local, regional and global level.

4. Methods used

- Literature Review: which confirmed to us the magnitude of the public health issue related to AMD.
- Review of the available policy documents and ongoing initiatives for eye health, healthy aging and AMD to provide an overview of existing resolutions, reports and stakeholders.
- Formation of a panel of experts from Foundation Fighting Blindness USA, Pro Retina Germany and Retina Bulgaria
- Three Meetings with pre-defined agenda containing the questions to be answered by the panel of experts and the expected output from the taskforce took place in the period from December 2022 to March 2023.
- A process of consultation between national experts consulted and their teams, relevant medical advisors on the pre-defined topics in order to prepare and present their representative perspective to the taskforce.

The themes discussed at the meetings were:

Meeting 1: the global policy landscape for AMD; the country specific outputs from the RI report;

Meeting 2: country policy priorities for AMD; The AMD-related policy landscape in the USA, Germany and Bulgaria; the related active country stakeholders and the relevant ongoing initiatives (in the field of AMD; Eye health policies; Healthy aging policies, research, epidemiology/public health.

Meeting 3: the outputs of RI report with regional and global significance and the opportunities to address them regionally and globally; the room for cross-country collaboration on outputs; Recommendations for future advocacy.

5. Results

Global eye health and healthy aging policy landscape

The taskforce agreed that the UN 2030 Agenda and its Sustainable Development Goals (SDGs)[3] provide an important framework for addressing the full spectrum of needs of the aging population living with eye disease.

Addressing the needs of people with aging eye disease is central to achieving the UN 2030 Agenda, the SDGs and its pledge to leave no one behind.

As such, global institutions working for sustainable development and protecting human rights must seek to address the challenges of aging people living with eye disease.

The UN resolution[4] from 2021 "Vision for Everyone: accelerating action to achieve the Sustainable Development Goals" was discussed.

It was noted the resolution is "…Welcoming the adoption of World Health Assembly resolution 73.4 of 3 August 2020, entitled "Integrated people-centered eye care, including preventable vision impairment and blindness", in which Member States are urged, taking into account their national circumstances and priorities, inter alia, to take action to implement the recommendations contained in the World Health Organization World Report on Vision, including to make eye care an integral part of universal health coverage and to implement integrated people-centered eye care in health systems across the spectrum of promotive, preventive, curative and rehabilitative services."[5]

It was highlighted the UN Resolution is "…Recognizing that the risk of vision loss increases with age and that many older persons live with vision impairments or blindness, while noting the United Nations Decade of Healthy Ageing (2021–2030) and the need to ensure that issues of relevance to older persons are taken into account in the implementation of the 2030 Agenda".

It was noted the WHO Global Eye Health Targets for 2030 adopted at the 74th WORLD HEALTH ASSEMBLY, April 2021, address the two leading causes of blindness and vision impairment, cataract and refractive error, which together account for 80% of the unmet need in eye care.[6]

It was recognized that the WHO provides a Practical tool called Eye Care Situation Analysis Tool (ECSAT) that intends to support countries in the planning, monitoring of trends and the evaluation of progress towards implementing integrated people-centered eye care IPEC.[7]

- The tool aligns with the WHO strategic recommendations made in the World report on vision. It was discussed that the Eye Care Situation Analysis Tool ECSAT provides a questionnaire component, allowing country specific eye health priorities to be set based on the analysis of the national eye care situation.
- It was marked the UN Convention on the Rights of People with Disabilities promotes social inclusion for people with disabilities, including those whose disability is a result of living with eye condition.[8]

It was noted the UN Decade of Healthy Ageing 2021 – 2030[9] addresses four areas for action:

- Age-friendly Environments
- Combatting Ageism
- Integrated Care
- Long-term Care

It was highlighted the UN Healthy Aging Resolution calls upon all States to promote and ensure the full realization of all human rights and fundamental freedoms for older persons, including by progressively taking measures to combat age discrimination, social isolation and loneliness, to provide social protection, access to health-care services, employment and to address issues related to social integration through mainstreaming the rights of older persons into sustainable development strategies, bearing in mind the crucial importance of intergenerational solidarity for social development.

It was noted the Lancet Global Health Commission is a clear call to action for better integration of vision and ageing research, policy, and clinical care.[10]

Country policy landscape; Country AMD policy priorities

Bulgaria:

Policy priorities in AMD:

- Recommended by Retina Bulgaria: Screening and prevention with the aim of early detection to allow timely treatment and support, including early rehabilitation.
- Recommended by the Medical Advisors: Policy for data collection for AMD.

Current policy landscape:

- Published policy recommendations documents exist.[11]
- Regulations provided to treat only one eye.
- National health care strategy – elderly population not represented except dementia.
- National health care strategies is required – related to European recovery plan.
- Amendments to the national health strategy needs to be made – due to be adopted – due to European Recovery plan – funding.
- National Eye Care plan needs to be developed.

Stakeholders:

- Bulgarian society of Retinal Specialists; Bulgarian Ophthalmological Society; Retina Bulgaria

Germany:

Policy priorities in AMD:

- Prevention and awareness of AMD.
- Screening program for early detection of AMD, prevention, and awareness

Current policy landscape:

- Existing policy tools can be strengthened.
- Bring the European Health Data Space (EHDS) to the national level – digitally – Big efforts in Germany – data can be used secondarily for research.
- Local level events are organised to inform ophthalmologists.
- Initiatives from ophthalmic society for the members – don't reach all of the members

Stakeholders:

There are many actors in this space – Blind and low vision society, Pro-Retina Germany, AMD Network

USA:

Policy priorities in AMD:

- Most important priority – developing medicine for AMD.
- Treatment available for nAMD for many years but haven't reduced the economic burden.
- Early detection and prevention from early to later stages – productive losses happen – biggest policy priority.

Current policy landscape:

- Complicated policy environment in the USA
- US is fragmented in terms of health care provision, NIH (talking about standard), Medical societies.
- Coverage for annual exam – no annual exam, insurance

Stakeholders:

- FFB; AAO; AOA

Regional policy pillars (Europe)

- **Aging:** GREEN PAPER ON AGEING[12]: Fostering solidarity and responsibility between generations.
- Policy recommendations on Geographic Atrophy launched in the European Parliament, 2022.[13]

- Acceleration of European Health data Space (EHDS): the central platform MyHealth@EU allowing the primary use of health data and the central platform HealthData@EU allowing the secondary use of data.
- Targeted and implementable actions for mental health in Europe.
- Retina International Global Initiative
- Retina action
- Retina Action project aims to develop the tools to allow the Vision and Aging community to take action now to alleviate the burden of vision impairment today and in the future!

6. Conclusions

1. Vision loss has implications for physical, cognitive, and mental health, and can exacerbate inequities in employment, healthcare access, and income. As a result, research cannot be limited to prevention, treatments, and cures, because there is an urgent need to identify strategies that will equitably maximize the health and opportunities of people with vision impairment as they age.
2. The landmark UN Resolution for Eye Health is placing the issue of eye health at the heart of the 2030 Agenda for Sustainable Development.
3. The UN Resolution on Active and Healthy Aging is stressing the need to ensure that older persons are taken into account in the implementation of the 2030 Agenda for Sustainable Development in order to ensure that no one is left behind,
4. Although the UN Resolutions reflect the degree of intergovernmental agreement on Eye Health and Aging, governments are not legally compelled to act on the UNGA decisions. The UN Resolutions recall important conventions and treaties that are binding and so act as reminders to Member States of their obligations.
5. Global Online knowledge exchange Platform has been established to connect and convene the stakeholders who promote the four action areas of the Healthy Aging Decade at country level. Engagement with older people themselves will be critical to each of the action areas, as they are agents of change as well as service beneficiaries. Their voices must be heard.
6. The WHO is setting global targets to improve global vision health by 2030. The targets are in 2 areas: cataract and refractive error.
7. While the WHO can make recommendations and suggest courses of action, particularly in unprecedented times of global health risk, it depends on each government to determine their response and act upon it.
8. chronic eye diseases such as glaucoma, age-related macular degeneration, and diabetic retinopathy now account for a greater proportion of blindness and vision impairment globally.
9. The Lancet Global Health Commission on Global Eye Health highlights how this epidemiological transition necessitates a refocused public health and clinical response.

10. Eye care needs to be included as a crucial component of health care for older adults. Vision and eye health are often not well integrated within primary health and prevention strategies in efforts to improve health-care outcomes, quality, and safety or when developing health interventions and behavioral change programs.
11. Cross-disciplinary collaboration between gerontology and eye health experts is needed to identify and address health inequities that arise as people age with vision impairment.
12. There are no specific AMD related global policy documents and recommendations. Regional policies could provide additional ground for the development of specific regional legislation and national plans of actions. In the case of Europe, there are some aging specific, AMD-related and mental health policies developments (GREEN PAPER ON AGEING: Fostering solidarity and responsibility between generations; Policy recommendations on Geographic Atrophy launched in the European Parliament, 2022; Development of targeted and implementable mental health actions).
13. No comprehensive Eye Care plans in the 3 selected countries: USA, Germany and Bulgaria
14. Screening and early detection seems to be the common policy priority in AMD for the 3 countries.
15. The aging population is usually co-morbid. Neurological problems are addressed through policies and by policy-makers. Vision issues need to be addressed at the same time so that the elderly is compliant.
16. ACTION Retina concludes targeted screening, early diagnosis and optimal care including treatment, rehabilitation and education are the keys to avoiding unnecessary hardship and burden in the future.

7. Recommendations for future advocacy:

The AMD Policy Recommendations present the conclusions of the AMD Policy & Advocacy Taskforce initiated by RI. This 8-month effort with participating patient representatives experts and medical advisors and RI members from countries across all regions over the world has resulted in 10 overarching recommendations to ensure that 20 million aging people with advanced AMD won't be le left behind.

The recommendations are setting the need for a global policy framework for the aging eye to guide the development of regional and national strategies and plans of actions for Eye Health and for Healthy and Active Aging with the same measurable objectives; facilitate the amendments in the national legislation; Encourage investments in Research and Development (R&D), health and social care for the aging community on regional and national levels.

The 10 final recommendations covering prevention, early detection and screening, diagnosis, treatment, care, research and national and regional infrastructures are setting out the road map for Policy & Advocacy for the next decade to ensure the wellbeing of the AMD patients and their caregivers and to guarantee their productivity won't be lost any more.

RI AMD Policy & Advocacy recommendations:

RECOMMENDATION 1:

Establish a comprehensive global ageing eye policy framework guiding the development and implementation of regional and national strategies aligned with the UN 2030 agenda for sustainable development. This framework should be regularly monitored and assessed by an international multistakeholder group.

RECOMMENDATION 2:

Implement standardized screening programs at regional and national levels to enable early detection and more accurate diagnosis of age-related macular degeneration (AMD) among individuals aged 50 and above. These programs should leverage innovative technologies and approaches that cater to the specific needs of the aging population.

RECOMMENDATION 3:

Prioritize research efforts, spanning basic, translational, clinical, and social domains, to develop cost-effective treatment options for AMD. This research should also generate evidence-based recommendations regarding antioxidants, supplements, and nutrition that address the unmet needs of AMD patients, supporting policy and program implementation for the aging community.

RECOMMENDATION 4:

Promote regional collaboration among countries to ensure the availability, accessibility, and affordability of AMD treatments, medical devices, and assistive aids. This collaboration should address inequalities and include national public funding for therapies, devices, and all associated direct and indirect costs.

RECOMMENDATION 5:

Establish accessible, affordable, and standardized rehabilitation services for elderly individuals with low vision, addressing their mobility needs and bridging digital inequalities. This should be achieved through regional collaboration among countries and consistent implementation of national programs.

RECOMMENDATION 6:

Improve the availability and accessibility of social support and benefits for the aging eye community, including personal assistance, peer-to-peer support, and other resources that facilitate daily functioning.

This can be achieved through regional collaboration to develop best practice models, followed by implementation through national legislation and programs.

RECOMMENDATION 7:

Enhance data collection, curation, and utilization to improve the health and well-being of individuals with AMD. This involves implementing regional and international regulations to establish principles and infrastructure for e-medical records, patient registries, data access, and management. Cross-country collaboration and amendments to national legislation are essential for this endeavor.

RECOMMENDATION 8:

Address the mental health needs of aging eye patients and their caregivers by developing actionable regional and national initiatives. These initiatives should prioritize emotional well-being and ensure the availability of psychological support and guidance, with funding secured through regional and national programs.

RECOMMENDATION 9:

Promote the inclusion of the aging eye community in the workforce to enhance productivity, with regional countries collaborating to outline best practices. This should be followed by national implementation through programs and regulations that raise employer awareness, provide adequate support, and facilitate strategic workplace modifications for the health and safety of all employees. Additionally, creating accessible and barrier-free public and digital environments is crucial.

RECOMMENDATION 10:

Ensure meaningful participation, engagement, and leadership of the aging eye community by involving their representatives and organizations in the policy development and decision-making processes at all levels of the public and private sectors.

8. Acknowledgements

FFB USA

PRO-Retina, Germany

Retina Bulgaria

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