



European Alliance for Vision Research and Ophthalmology

Feedback on

World report on vision of the World Health Organisation

April 2018

The European Alliance for Vision Research and Ophthalmology (EU EYE) has welcomed the updated World Report on Vision of the World Health Organisation as an opportunity to improve the long-term population visual outcomes globally.

The EU EYE has submitted its feedback on key issues using the template provided by the WHO consultation. This document informs more extensively on the EU EYE's views and the evidence in support to the EU EYE's feedback to the WHO report.

Views on *World report on vision* of the World Health Organisation

Executive Summary

The EU EYE has welcomed the updated World Report on Vision of the World Health Organisation but believes that the picture emerging from the current health data collection, may not be representative of the real needs and challenges in eye diseases. Current disease inequities persist and drive social care costs higher than necessary and with potential adverse impact on population health outcomes. We suggest the inclusion of the following points to gather further political support for eye health globally:

- it should be highlighted that corneal diseases are still a major cause of blindness or visual disability despite the fact that some such as trachoma or fungal keratitis are preventable in developing countries and the existence of minimally invasive surgical corneal procedures;
- solutions to address the shortage in corneal tissue for transplantation should be tailored to their cause if they are to address effectively such shortage.
- the inclusion of additional data of quality of life measures will strengthen the evidence base regarding the burden from poor vision being larger than that caused by other chronic diseases in the general population;
- a fairer assessment of cost-effectiveness in the management of non-fatal chronic conditions with the broadening of the definition of value in the context of decision making and the constrained budgets and a balance in metrics regarding the disease impact on the quality of life;
- a review of what health data must be collected to obtain a true picture in eye diseases especially regarding the distribution of chronic disease and risk factors within countries.

Eye diseases - Specific Points

The European Alliance for Vision Research and Ophthalmology (EU EYE) agrees that measures are needed to monitor population health outcomes while assessing access to services and cost-effectiveness of interventions under limited resources and the rising demands of the ageing populations across the world.

The EU EYE is however concerned with the appropriateness of such measures and the impact they have at political level: eye diseases causing permanent disability and for which metrics are lacking are not included among political priorities¹ despite the severity of disease impact on the wellness of the citizens and the cost of vision loss². The report could therefore benefit from including key evidence regarding the magnitude of the burden of poor vision compared to that caused by other chronic diseases in the general population. Burden of poor vision is experienced more than diabetes type II, coronary syndrome, and hearing impairments, but less than stroke, multiple sclerosis, chronic fatigue syndrome, major depressive disorder, and severe mental illness^{3, 4}.

The EU EYE draws specific attention to the fact that corneal diseases remain a major cause of blindness or visual disability⁵ despite that some diseases are preventable in developing countries such as trachoma or fungal keratitis⁶. There should be encouragement in adopting minimally invasive surgical corneal procedures⁷ which ensure a good outcome without demanding extensive follow-up regime.

Shortages in supply and demand of eye tissues differs from country to country and it is essential to understand the reasons behind such shortages in order to address them effectively. It is important to develop alternative and/or complementary solutions, such as biomaterials for corneal bioengineering for countries where ingrained beliefs and cultural

¹ Maher, A., & Sridhar, D. 2012. Political priority in the global fight against non-communicable diseases. *Journal of Global Health*, 2(2), 020403. <http://doi.org/10.7189/jogh.02.020403>

²Centre for Eye Research Australia (CERA). 2004. Clear Insight - The Economic Impact and Cost of Vision Loss in Australia”

³ Langelaan M. et al. 2007. Impact of Visual Impairment on Quality of Life: A Comparison With Quality of Life in the General Population and With Other Chronic Conditions *Ophthalmic Epidemiology* 14(3):119-26

⁴ Centre for Eye Research Australia.2004. *Clear Insight - The Economic Impact and Cost of Vision Loss in Australia*.

⁵ Oliva, M. S., Schottman, T., & Gulati, M. 2012. Turning the tide of corneal blindness. *Indian Journal of Ophthalmology*, 60(5), 423–427. <http://doi.org/10.4103/0301-4738.100540>

⁶ Acharya, Y., Acharya, B., & Karki, P. 2017. Fungal keratitis: study of increasing trend and common determinants . *Nepal Journal of Epidemiology*, 7(2), 685–693. <http://doi.org/10.3126/nje.v7i2.17975>

⁷ Panda A, et al. 1995. Therapeutic penetrating keratoplasty in nonhealing corneal ulcer. *Ophthalmic Surgery*;26(4):325-9. PMID: 8532284

attitudes impede organ donation such as China^{8, 9}. Elsewhere low availability of corneal donor tissue is linked to policies and only a strong evidence base regarding patient safety can precipitate. For example demand for cornea tissue in many countries (particularly in some Member States in Eastern Europe¹⁰) cannot be met by supply due to strict clinical donor selection criteria in the European Union as a number of diseases are contra-indications to transplantation. Such exclusion is however not supported by evidence as in the case of corneal transplants of Hepatitis B donors when transmission has only been reported when the donor did not undergo serology tests¹¹, or in the case of chronic fatigue syndrome, Alzheimer or Parkinson disease.

Eye diseases - Outcome measures in general

The EU EYE believes that reviewing is needed on what health data must be collected and what metrics are used for assessing demand and supply in eye health. This is particularly important as the European health systems move towards self management of chronic diseases.

Current health information focuses on mortality rather than impact on life quality. Non fatal conditions such as eye diseases do not attract political attention as a result despite the severity of impact on the wellbeing of patients and their families. Population health summary measures (Health-Adjusted Life Years (HALYs), Disability-Adjusted Life Years (DALYs) and Quality-Adjusted Life Years (QALYs) discriminate against people who are already at a disadvantage socially or in terms of their health state. For example older people, or people with pre-existing disabilities, contribute to lower HALY values because they are considered a “bad investment” with limited potential for health improvement. Policy makers often ignore that DALY and QALY estimates are not strictly objective, and can only provide some of the information regarding distribution of morbidity and mortality and which is needed in resource allocation¹².

European guidelines define a ‘cost per QALY’ (Quality Adjusted Life Year) when assessing cost-effectiveness of interventions. Although the QALYs tool is advantageous for health technology appraisal, it is an aggregate measure of health expectancy on a spectrum of ‘being alive to death’ and it relies on measures of age, context, and responsibilities in

⁸ Wang, X. et al. 2016. Attitudes and Knowledge Concerning Corneal Donation in a Population-Based Sample of Urban Chinese Adults. *Cornea*. 35. 1. 10.1097/ICO.0000000000000943.

⁹ Wong, K. H., et. al 2017. Corneal blindness and current major treatment concern-graft scarcity. *International Journal of Ophthalmology*, 10(7), 1154–1162. <http://doi.org/10.18240/ijo.2017.07.21>

¹⁰ Gain P et al. 2016. Global Survey of Corneal Transplantation and Eye Banking. *JAMA Ophthalmology* 134(2):167-73.

¹¹ Joint United Kingdom Blood Transfusion Services and Health Protection Agency Professional Advisory Committee. 2011. Risk assessment for immunosuppression and corneal donation. JPAC 11-56.

¹² NCCID. 2015. Understanding Summary Measures Used to Estimate the Burden of Disease All about HALYs, DALYs and QALYs; https://nccid.ca/wp-content/uploads/sites/2/2015/03/GBD_Factsheet_FINAL_E.pdf

different life stages¹³. It may not be suitable in quantifying preventive measures or as a measure of outcome for non-fatal chronic conditions when the quality of life is a bigger issue than survival; the impact on health outcomes may not occur for many years; or when comparing the efficacy of two competing but similar drugs. More importantly however the QALY tool does not consider the disease impact on the emotional and mental health, and on the quality of life of carers and other family members. As a result of lacking such dimensions and sensitivity, QALY metrics do not accurately reflect the experience even of cancer patients as the technological advances secure longer survival than previously possible¹⁴. Such compromises in measuring value unintentionally may ignore in part social values precipitating high resource allocation to low-priority areas leaving high-priority areas under-resourced. A broadening of the definition of value may be needed in the context of informed decision making, and the constrained budgets. A variety of aspects of health and wellness should therefore be measured in addition to population health outcomes, access to services and cost-effectiveness of interventions in eye services.

Current measures monitoring access to eye services for policy purposes do not create an accurate picture regarding eye diseases and unintentionally may contribute to disease inequities; such inequities cause adverse population health outcomes and drive social care costs higher than necessary. For example using *cataract surgical rate* (CSR) as a proxy indicator for general eye care service delivery (Eye Care assessment tool, WHO 2015) confuses the real picture of diseases for which metrics are lacking such as diabetic retinopathy, glaucoma, age-related macular degeneration (AMD).

Political decisions do not respond to shifts observed in the relative importance of the various diseases causing blindness and visual impairment: for example regional and temporal variations are observed in the percentage of blindness caused by glaucoma with low figures in regions with relatively young populations such as South Asia and Sub-Saharan Africa, and high figures in regions with relatively old populations such as the high-income regions; also the proportions of vision impairment and blindness due to cataract and trachoma have decreased in contrast to the increase observed due to glaucoma, macular degeneration, diabetic retinopathy, and uncorrected refractive error during 1990-2010¹⁵. Political pressure on the eye services has often led to resource distribution that does not address population needs and disease severity as in the case of cataract: although the condition is a direct cause of blindness in some areas, it is reversible; pressure to meet cataract surgery targets has deviated resources from irreversible yet preventable blindness caused by diabetes, macular degeneration and glaucoma. Most existing commissioning practices fail to look ophthalmology as a whole: ophthalmic elective procedures are considered in isolation applying arbitrary rationing that funds more

¹³ Philips, C and Thompson G, 2001. What is a QALY? Volume 1, Number 6, ONC 195058 Hayward Group plc. http://www.vhpharmsci.com/decisionmaking/Therapeutic_Decision_Making/Advanced_files/What%20is%20a%20QALY.pdf

¹⁴ Devlin, N J. and Lorgelly P.K. 2017. *QALYs as a measure of value in cancer* Journal of Cancer Policy, Vol 11, pp19-25

¹⁵ Bourne, R. R. A., et al. Vision Loss Expert Group of the Global Burden of Disease Study. 2016. Number of People Blind or Visually Impaired by Glaucoma Worldwide and in World Regions 1990 – 2010: A Meta-Analysis. *PLoS ONE*, 11(10), e0162229. <http://doi.org/10.1371/journal.pone.0162229>

of one disease by funding fewer of another. Decisions are often left at individual level as doctors attempt to reduce what they perceive as low-value activity and increase capacity for higher risk patients with potentially sight-threatening conditions such as glaucoma, diabetic retinopathy or AMD¹⁶. A more holistic approach is needed that considers the long-term population health outcomes and cost-effectiveness of elective procedures and interventions in general.

The EU EYE calls therefore for a balance in measures used to address the current disease inequities and improve population health outcomes; inclusion of metrics that monitor impact on quality of life such as Health Related Quality of Life measures from the citizens' perspective in addition to QALYs will create an robust evidence base regarding the impact on non fatal conditions on people's life.

About EU EYE

The European Alliance for Vision Research and Ophthalmology (EU EYE) was formed in 2015.

As a partner to the European Innovation Partnership on Active Healthy Ageing since December 2017, we advocate for people-centred eye health care with an on-going commitment to the integration of research priorities, policies and strategies in eye health at European level.

We maintain a varied portfolio of activities with the aim to open up the space for the patient empowerment process and the creation of new translational and fundamental research networks in our discipline.

We strongly believe that registry- and biobanking based research can build medical knowledge and guide the process of improvement of health systems across Europe. We want to ensure continued support for the pilot efforts of our members in setting up European clinical quality registries to study, benchmark and improve patient care and health outcomes. Our long-term ambition is to develop multicentre international clinical trial studies following the Good Clinical Practice regulations.

The essence of our alliance is to advance interdependence and inspire collaborative work while recognizing members' independence.

Our members hold international congresses, courses, wetlabs and exams in each subspecialty and support the next generation by harmonising education and providing fellowships and world renowned training programmes.

Member organisations maintain their own links to their national equivalent societies with some having committees specifically assigned to identify areas where national societies can provide experience that would be of value in Europe at large.

¹⁶ Royal College of Ophthalmologists. 2016. *The Way Forward: Options to help meet demand for the current and future care of patients with eye disease. Cataract*