Australian Government

Department of Health

Summary of consultations for the development of a National Strategic Action Plan for Macular Disease

A supporting document to the National Strategic Action Plan for Macular Disease

March 2019

Contents

Introduction

A series of workshops were held in August 2018 with key stakeholders to guide the development of the National Strategic Action Plan for Macular Disease (the Action Plan).

The purpose of the workshops were to:

- Discuss and refine the proposed goals and focus areas for each of the pillars underpinning the Action Plan.
- Identify and prioritise actions that are required to achieve the goals.

Workshop participants were encouraged to be "bold and transformational" in identifying goals and actions and to consider a visionary and collaborative approach to eliminating vision loss and blindness due to macular disease.

Four half-day workshops were facilitated by KPMG:

- Two workshops focussed on prevention and early detection, data and research (one each in Melbourne and Sydney).

- Two workshops focussed on treatment, support, data and research (one each in Melbourne and Sydney).

A total of 43 stakeholders attended the workshops.

An additional session was held with 9 consumers to discuss their views on key priorities to be reflected in the Action Plan.

Additional consultations with several leading ophthalmologists, eye health researchers and other key government and non-government stakeholders were undertaken to further investigate some concepts raised at the workshops.
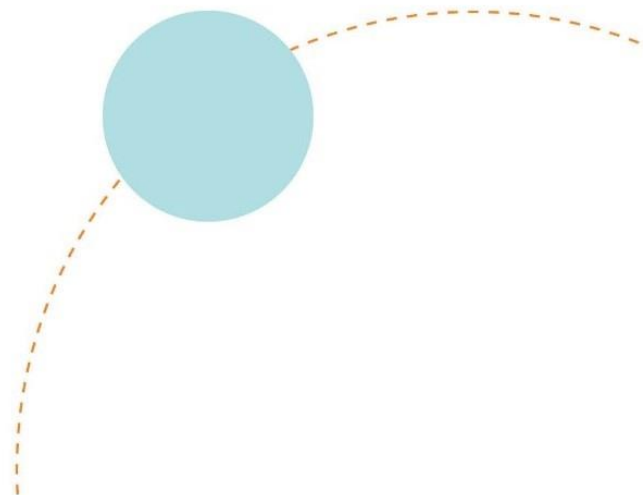
Structure of workshops

The workshops were structured as follows:

- *An introductory session*, where KPMG outlined the purpose of the workshop in informing the development of the National Strategic Action Plan for Macular Disease, provided an overview of macular disease in Australia, and presented the pillars underpinning the Action Plan.

- *A discussion session focussing on "Prevention and early detection" (workshops 1 and 3) or "Treatment" and "Support" (workshops 2 and 4).* KPMG presented the proposed goals and focus areas for the relevant pillar, and facilitated a mix of small and larger group discussions to confirm and revise these goals and identify a range of potential actions for consideration in the Action Plan (using the How-Now-Wow matrix[1] as a method for classifying actions).

- *A second discussion session focussing on "Data" and "Research"*, utilizing the same format described above.

Key themes from the consultations

There were a number of key themes which emerged from the workshops:

- The need for community awareness of eye health and risk factors and broadening education of non-eye health healthcare professionals, to better meet the needs of the population.

- The increasing need to recognise the economic burden of treating macular disease and reduction in treatment adherence.

- The importance of improving communication between eye health professionals, to improve the patient journey from early detection to treatment and support services.

- Ensuring early access to support services.

- Limited funds and uncoordinated activities relating to data and research.

- A consumer-centric approach is necessary for the success of the Plan.

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[1] The How-Now-Wow matrix categorises ideas based on their originality and the ease of implementation

The following pages provide a summary of the consultations.

Proposed pillars and guiding principles

Participants agreed with the selection and definition of the proposed Pillars as relevant and suitable to underpin the Action Plan.

There was some conversation around the definition of "treatment" and potential use of the term "management", but it was agreed that it would remain as originally presented. There was also some discussion around the differentiation between "data" and "research", but overall there was agreement that these should be two separate areas of focus.

In addition, the group agreed that there was a need for actions to be truly nationally focussed and ensure coverage across Australia – especially around prevention and early detection.

Implications for the Action Plan

- The Action Plan should be presented in terms of the proposed Pillars:
    1. Prevention and Early Detection
    2. Treatment
    3. Support
    4. Data and Research

- The Action Plan should clearly draw on the intersections between early detection, treatment and support for macular disease with other chronic conditions such as diabetes, and ensure the Action Plan highlights these intersections promoting coordination and cooperation across conditions/sectors.
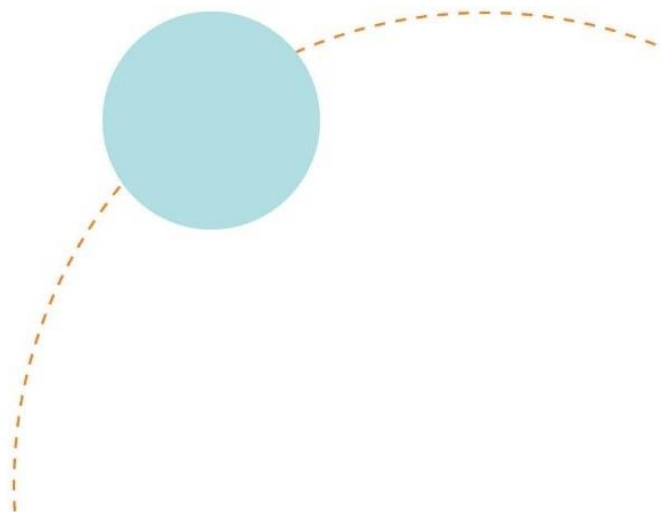
Pillar 1: Prevention and early detection

General points

- *Preventing* macular disease will have the greatest impact and should be a key focus for the Action Plan.

- Prevention and early detection should be considered in the context of eye health in general rather than focusing solely on macular disease.

- Prevention and early detection strategies need to consider the diversity of the Australian population and geography - there is no "one-size-fits-all" approach.

- Accessible, every-day language should underpin all awareness-related activity.

- Variable awareness and understanding of macular disease among health professionals was seen as a major issue.

  o General Practitioners (GP) are not educated/trained to include eye health as part of a patient assessment, which contributes to late diagnosis.

  o Pharmacists may not be fully equipped to be able to raise awareness of eye diseases and encourage people to access screening on a regular basis, however they are in an ideal position to provide eye health awareness.

Goal

A number of participants suggested that the goal should be re-phrased to either refer specifically to "legal blindness" or to remove the term "blindness". Three alternatives were identified:

  o "Prevent vision loss and **legal** blindness due to macular disease".

  o "Prevent vision loss due to macular disease".

  o "Prevent vision loss **leading to** blindness due to macular disease".

Other participants recommended leaving the term blindness in as it is more likely to engage peoples' attention.

Suggested actions and considerations

Building awareness

- Awareness includes educating people on eye health in general, eliminating the fear factor that puts people off from getting screened or receiving treatment, *or* instilling a different kind of 'fear' for people (that of losing their vision) to motivate people to get regular eye checks.

- There needs to be more done to translate awareness into action and get people to see optometrists for eye examinations.

- Raise awareness through advertisements (although participants recognised that this may require a significant monetary investment).

Reducing risk

- Importance of smoking cessation, modifying lifestyle and nutrition/diet needs to be emphasised. 'Quit Now' and other smoking cessation programs could actively refer people to eye health professionals, due to the risk of smokers developing macular disease.

- There needs to more emphasis on people being aware of their family history of macular disease and the potential genetic component.

- Clinicians should be confident in having conversations around risks and there should be consistent messages across the professions.

Early detection

- Any early detection effort should be consistent, not ad-hoc, and should be part of a continuum of care.

- Screening should occur for eye diseases in general rather than focusing only on macular disease.

- There needs to be improved access to screening in rural/regional locations.

- Currently, services are organised in an ad hoc way and access is restricted in rural/remote locations. Local coordinators/ Aboriginal health workers and mobile clinics improve access by redirecting people to the most appropriate services.

- Pharmacists, GPs and support services (such as aged care facilities) play an important role in prompting or encouraging people to access screening or testing for macular disease, and GPs are key in referring people to optometrists/ophthalmologists. Clinicians need to have the knowledge and understanding of who is at risk, who/when to prompt for screening/testing, and to whom/when to refer.

- A Commonwealth-funded outreach for eye screening should be implemented (recognising the significant cost associated with a program such as this).

- GPs should include eye health in chronic disease checklists (especially for those over 50 years) to embed it as an essential component of health assessments.

- Practical suggestion to utilise imaging kiosks was discussed as an accessible point of screening (as are used overseas).

High-risk populations

- People at greater risk for macular disease should ideally have the knowledge and awareness of macular disease to self-refer to screening. Many people are not aware of their risk factors.

- People over 40 could be screened for macular disease, following the example of the Diabetes screening program in the UK. Alternatively, screening could be offered every 2 years for those over 50 years old and every 3 years for those under that age.

- There are already screening programs for people over 50 years such as bowel and breast screening. Could there be a collaboration with these programs so people receive a notification for eye checks?

- There are emerging technologies for the detection of macular disease that need to be considered in the near future, particularly the development of artificial intelligence (AI).

Pillar 2: Treatment

General points

- It was agreed that an "eye health care plan" is needed to take a person through their journey from diagnosis to treatment and to community support.

- Lack of capacity in the public system and high cost of treatment in the private system were identified as major issues and barriers to accessing treatment.

- Treatment adherence (and longer-term consequences of not accessing treatment) was identified as a significant issue, and participants noted that there is about a 20 per cent drop-off in access to treatment in the first year of treatment.

Goal

- "Treatment", "Management", or "Outcomes" were all names put forward for Pillar 2.

- Two alternative goals put forward:

- o "All people with macular disease are **guaranteed** access to transformative, evidence-based and affordable treatments to reduce the progression and long-term impact of macular disease"

- o *Note – it was discussed about the feasibility of guaranteeing access and what the implications might be, with a recognition that this might be too aspirational at this time.*

- o "Ensure that all people with macular disease **achieve the best possible outcomes through** access to transformative, evidence-based and affordable treatments and services".

Suggested actions and considerations

Improving access and building health system capacity

A number of suggested actions were identified by participants to improve access and build health system capacity:

- Increase funding to public hospitals for eye health services to better match demand, improve access to outpatient services (treatment and review) through eye health clinics, improve resources and facilities.

- Improve access to services for people in rural areas – for example through better distribution of ophthalmologists and creation of a network of outreach clinics. There are some financial incentives to support this, but more could be done.

- Increase the Medicare rebate, and/or utilise a means-tested subsidy where a higher Medicare rebate is paid for low income population.

- Improve triaging of patients with macular disease accessing public eye health services to ensure that each individual receives the best possible care by the most appropriate health professional. Many individuals do not need immediate assistance and may not need to see a specialist ophthalmologist.

- Greater flexibility in the provision of public eye health services would improve access. For example, through evening/ weekend outpatient clinics.

- Better utilise existing orthoptists, optometrists and ophthalmologists in public eye health clinics.

Improving adherence

- Address cost and access barriers, e.g. increasing the Medicare rebate, increasing access to publicly-funded services, and address transport issues associated with accessing services.

- Better utilise technology to improve adherence and create automatic alerts for treatment.

- Consider the development of roles that would support people undergoing treatment. For example, the role undertaken by diabetic educators/care coordinators.

Consistency and effectiveness

- Develop collaborative care plans for patients ("eye health care plans") which can be available to people caring for patients.

- Develop and/or update clinical guidelines –e.g. develop age-related macular degeneration (AMD) management guidelines, update the National Health and Medical Research Council (NHMRC) diabetic retinopathy management guidelines.

New developments

- There needs to be increased funding to better understand the genetic characterisation of inherited retinal disease and develop prevention and treatment options.

- Ensure imaging technology is part of medical, specialist, and optometry training.

- New treatments are being researched and trialled which will become available in the near future. They must be affordable and accessible.

Pillar 3: Support

General points

- The medical model is too limited and prescriptive to be helpful in supporting people with low vision. Ophthalmologists often do not have the capacity to discuss all the support needs an individual may require.

- Re-enablement is an important underpinning principle for the provision of supports – that is, focussing on assisting people to develop the skills and capacity to undertake daily living activities and other practical activities themselves, maintain their independence and autonomy, and continue to participate socially and economically (i.e. in work).

- There is currently a gap in the transition from treatment to support, and a lack of continuity in care.

- There is also a lack of coordination of supports for people with macular disease, and a lack of information on the supports available. People affected by macular disease frequently are not provided with details of support services.

- It needs to be recognised that a diagnosis, and vision loss from macular disease (or other eye disease) is a major life event. People often require support to accept a diagnosis, and actual or possible vision loss, and encourage them to access support (and treatment). Some people may require support to assist them to address associated mental health concerns from their diagnosis, reduced independence and social isolation (for example, depression and anxiety).

- People in residential aged care facilities are frequently not able to access supports. Staff are often unaware of the equipment and aids available to them and/or do not know how to access them.

Goal

Participants suggested that the proposed goal was too prescriptive, and that reference to "remain independent in the home" be removed.

There were two suggested alternative goals:

- "Ensure people with macular disease are able to access support that enables them to **fully** participate in their communities"

- "People with macular disease **have information** and support to **live with an optimal quality of life**".

Suggested actions and considerations

Access to support and information autonomy

- Participants stressed the importance of supports being available for people with macular disease *and their families, carers and communities.*

- Necessary next steps include increasing support for families and carers, as well as offering support to those who wish to stay in employment, through the provision of better information to employers.

- Participants also stressed the importance of access to information about support services and aids that can improve day to day life.

- The importance of emotional support services was discussed, to assist patients with coping with vision loss and grief.

- Improved coordination of treatment and support and the person's journey from diagnosis, is important – for example through an individualised "support map" and/or a "blue book" for monitoring milestones through a person's journey.

- Provide better education to residential aged care facilities to be aware of how to access low vision aids and technologies.

- Participants discussed the importance of access to aids and equipment, and equity of access to aids and equipment under different State/Territory and Commonwealth Government programs for different cohort groups - for example, access to aids and equipment for people over 65 funded by States/Territories should be aligned with access for younger people through the National Disability Insurance Scheme (NDIS).

- Participants suggested training be made available (e.g. through library networks or neighbourhood houses) that assists people to identify new support tools, such as traditional low vision aids or technology solutions (e.g. applications that magnify smartphone screens) and teaches them how to use them.

- A parallel was drawn between vision aids and hearing aids and it was pointed out that the latter are much more accessible.

Empowering individuals, their communities and networks

- Individuals should be willing to be educated about the support available, in order to make informed choices about their care.

- Quality indicators and standards should be tied directly to supports.

- Education about dealing with vision loss in daily life should be simple and delivered in "bite size" chunks, allowing time to process the information received. Participants described information on support services and aids being provided from a range of people – from the doctors' receptionist to their ophthalmologists but most did not receive any information. They had to seek out information about support themselves via the internet and through organisations such as Macular Disease Foundation Australia (MDFA).

Pillar 4: Data and Research

General points - Data

- There is a range of data currently collected relating to macular disease (and eye health), though in many cases data is collected and stored 'in silos', is not linked and is difficult to access.

- It is important to identify macular disease data needs from a range of perspectives (e.g. research, treatment/service provision, population/prevalence) and define the data items that need to be collected.

- There is a need for national coordination of data and research plans.

- There are real concerns relating to access to and privacy of individuals' data.

- There needs to be more effective methods of capturing data related to patient experience.

General points - Research

- 'Research' needs to have a broad focus beyond treatment – should also encompass prophylaxis, supports, person-centred practice and social impacts of macular disease.

- It is important to involve consumers, primary care providers and community in research.

- Macular disease and eye health research can be better coordinated, and cross-sector and cross-discipline research should be encouraged.

- Increased access to research funding from government and philanthropic sources is critical.

Goal - Data

There was broad agreement on the proposed goal statement, with the following addition:

"Improved *capture and* use of data to enable better planning, decision making and monitoring and contribute to better outcomes for people with macular disease".

Goal - Research

- Participants agreed with the suggested goal for the Research Pillar – that is, "Strengthen prevention, treatment and support for people with macular disease through transformative research".

- There was one suggestion to replace "macular disease" with "eye health" in the goal statement.

Suggested actions and considerations - Data

Improving data quality and access

- All existing data collections and data sources relating to macular disease (and potentially eye health) – across public and private health systems, support service sectors, industry, research, existing databases and registries – should be identified and described, including specific data items.

- Establishment of a macular disease (or eye health) registry should be the main priority.

- There should be a focus on improving data relating to diagnosis and treatment, improving consistency of data entry, standardising terminology, and expanding the granularity of ICD-10 codes (e.g. Incorporating Beckman classification for AMD).

- Oculo, a cloud-based network designed especially for eye health professionals to share clinical information, referrals and other clinical correspondence between eye health professionals, is in its infancy, but could be a great source of information *Note – there is a cost associated with clinicians purchasing the program.*

- Action: lobby the pharmaceutical industry and equipment providers for better access to macular disease data e.g. the number of people on treatment.

Improving data linkage

- There is a need for a data custodian to provide quality assurance for eye health data, and linked data.

- Any data linkage needs to consider combining datasets from a number of different sources and organisations and relate to eye health more broadly (including macular disease, glaucoma, retinal dystrophy etc). Data linkage should also consider linkage to support data (aged care and aged care assessment data, disability support data), as well as consider demographic and population-level characteristics.

- It is important to understand the potential and value of "myHealthRecord" capability in improving access to more comprehensive (linked) data.

Suggested actions and considerations - Research

National research agenda

- Develop a coordinated national research agenda to better coordinate macular disease and eye health research (currently there is fragmentation of research and a lack of visibility of what research is being undertaken. There is also competition for limited research funds).

- Explore how the Medical Research Future Fund (MRFF) can fund and facilitate research in eye health.

- Include inter-disciplinary NHMRC clinical guidelines in current national research agenda for eye health, and explore mechanisms for embedding these guidelines in eye health research.

- Develop and fund specific research relating to measures across whole of life, functional vision activities of daily living for people with vision loss.

- MDFA could drive consumer-focused research.

- There is a need for a "clearing house" of research for eye health.

- There is a potential research gap, in studying the level of improvement in quality of life through the use of low vision equipment, in comparison to the absence of them.

Coordination and linkages

- Explore models of research collaborations in other sectors (such as cancer) to increase cross-sector and cross-discipline collaboration in eye health research.

Research and practice

- Some participants expressed their interest in seeing a second repeat or expanded National Eye Health Survey (though this view was not shared by all participants).

- Fund further research into assistive technology – for example, smartphone apps.

- A journal could be created on the topic of eye health or macular disease in particular. *Note – there are already a number of journals relating to eye health.*

Consumer feedback

Two main issues were identified in the discussion with consumers:

1. Access to and cost of treatment

- Costs associated with regular treatment (intravitreal injections with anti-VEGF agents) was the most significant concern for consumers and most had incurred significant out-of-pocket costs (for private treatment, including both consultation and administration of the injection) that would likely continue for the rest of their lives.

- Significant out-of-pocket payments exist due to the high (and variable) fees specialists charge and the gap between fees and Medicare rebates, and lack of regulation of fees.

- It was suggested that private services or clinicians with good reputation charge more than average. The range of fees reported vary from as little as $545 to $1,057 and patients also reported that they are eligible for a safety net after the first few payments. Depending on whether the patient chooses to have one or both eyes injected during the same visit, these costs may vary further, but it is rare that practices are open to price negotiations.

- Other considerations relating to the cost of treating AMD include the lack of transparency, at the first visit, regarding the ongoing cost of treatment and the timing and size of the rebate.

- Discontinuing treatment is often a result of cost factors.

- Consumers identified transport to and from treatment services as a critical enabler to accessing treatment, and is a key issue for many consumers (particularly those who need to travel long distances, have no access to private transport, or have limited family/carer support).

- Some clinicians will inject both eyes on the same day whilst others will treat one eye per day, in which case those people needing bilateral treatment have to pay for two visits.

- Accessing AMD treatment in the public setting would assist patients who find it difficult meeting the cost otherwise, but patients reported long waiting times. They suggested reforms should be made so that a means tested approach would take those who can afford private health cover out of the public hospital system, allowing for resources to be redirected to those in need.

- Patients appeared concerned about the fact that only a small number of injections are covered publicly, after which they would still be required to cover their treatment out-of-pocket.

- Consumers suggested that inherited forms of macular disease (e.g. juvenile macular degeneration) are generally treated through the public health system so there are no out-of-pocket costs, with infrequent specialist visits required.

2. Access to support

- Consumers reinforced the importance and value of organisations like MDFA and Vision Australia in supporting the macular disease community.

- Accessing support can be challenging for people with macular disease who are always not aware of support services available. Many people rely on their own research to identify appropriate support services, assistive technologies, aids and equipment and support groups. MDFA plays a practical role in this space, redirecting patients to the most appropriate services or organisations such as Vision Australia and Guide Dogs Australia.

- The role of the GP is very limited in supporting patients through their journey, offering very little information on eye disease. It was suggested that GPs, or other, specific eye health professionals provide more information on treatments, costs and available aids as a "one stop shop".

- Consumers felt they would benefit from additional support around the lifestyle changes following a diagnosis of macular disease and/or treatment.

Other issues

Other issues and suggested actions raised by consumers included:

- There is a lack of information and explanation on what macular disease is, the potential impact of the disease and progression over time, and treatments and supports available. Eye health professionals tend not to explain in detail what macular disease is and often refer patients to MDFA for further information.

- Consumers put forward two suggestions to improve early detection which include:

  o Government-subsidised scans that could help with the early detection of the disease.

  o Eye tests that include the Amsler grid be conducted when renewing a driving license.

- There was a significant level of distrust and disappointment with the NDIS. General comments were about how difficult the process was and the length of time it took to access services.

- An eye health registry – a national record of all people who have macular disease (and other eye diseases) was suggested by some consumers. However, some consumers had concerns around privacy and the way the data would be used.
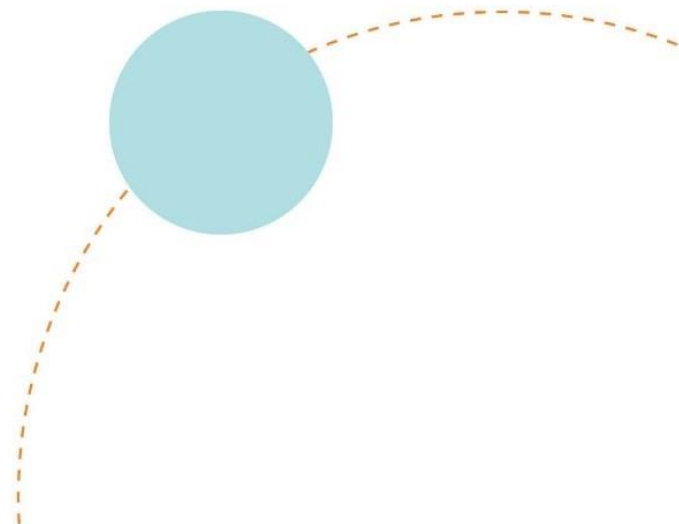
Consultations

Macular Disease Expert Advisory Group

Judith Abbott, CEO Vision 2020 Australia

Dr David Andrews, CEO Royal Australian and New Zealand College of Ophthalmologists (RANZCO)

Lyn Brodie, CEO Optometry Australia

Ron Hooton, CEO Vision Australia

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Associate Professor Nitin Verma AM, ophthalmologist, MDFA Board Member, Chair MDFA Research Committee, Member MDFA Medical Committee

Associate Professor Peter van Wijngaarden, ophthalmologist, Deputy Director and Principal Investigator, Centre for Eye Research Australia, Member MDFA Medical and Research Committees

Stakeholder Consultations

Name	Title	Organisation
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Peter Wilkinson	Consumer representative	
Daniel Chan	Consumer representative	
Jenny Solomon	Consumer representative	
Carole Karpin	Consumer representative	
Kham Chee Chan	Consumer representative	
Val Nicholson	Consumer representative	
Ashley Chapman	Consumer representative	