



**Australian Government**  
**Department of Health**

# A better view

**National Strategic Action  
Plan for Macular Disease**

**March 2019**



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We acknowledge Traditional Owners of Country throughout Australia and recognise the continuing connection to lands, waters and communities. We pay our respect to Aboriginal and Torres Strait Islander cultures, and to Elders both past and present.

Development of the National Strategic Action Plan for Macular Disease was led by Macular Disease Foundation Australia with funding from the Australian Government Department of Health.

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National Strategic Action Plan for Macular Disease

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# Acknowledgements

The National Strategic Action Plan for Macular Disease (the Action Plan) has been developed by Macular Disease Foundation Australia (MDFA), with valued input from a Macular Disease Expert Advisory Group comprised of representatives from:

- MDFA;
- Royal Australian and New Zealand College of Ophthalmologists (RANZCO);
- Vision 2020 Australia;
- Vision Australia;
- Optometry Australia; and
- leading clinicians and researchers in macular disease.

The many individuals and organisations who have given their time and expertise in the development of this Action Plan should also be acknowledged.



# Executive Summary

**The Australian National Strategic Action Plan for Macular Disease (the Action Plan) aims to outline Australia's national response to macular disease and inform how limited health care resources can be better coordinated and targeted across all levels of government.**

This Action Plan responds to the unique challenges of macular disease in Australia. As the leading cause of severe vision loss and blindness in Australia, macular disease affects people of all ages. 'Macular disease' covers a range of conditions that affect the central retina (the macula) at the back of the eye. It is estimated there are approximately 8.5 million people over the age of 50 years at risk of macular disease and over 1.7 million Australians have some evidence of macular disease.

Australia is a world leader in fighting macular disease. Over the past decade key stakeholders from across the health sector united in a unique collaboration to help change the lives of thousands of Australians living with macular disease. This collaboration between government, health care professionals, research agencies, the pharmaceuticals industry and Macular Disease Foundation Australia (MDFA), has delivered a continuum of care for Australians from awareness and prevention to management and support of those living with or at risk of macular disease.

This Action Plan identifies the most effective and appropriate interventions to reduce the incidence and impact of macular disease. It recognises the social and economic burden of the disease and provides action areas that:

- Prevent, detect and manage macular disease
- Improve macular disease-related services and care
- Promote collaboration across the macular disease community
- Facilitate coordinated and integrated care for clients
- Increase recognition of the needs of people affected by macular disease

A multi-sectoral response, led by governments, and implemented at the local level is required to achieve these actions. This Action Plan provides the necessary framework for collaborative efforts by governments and other parts of the community, including people living with macular disease, health care professionals, non-government organisations, researchers, families, carers, communities and industry, to reduce the incidence and impact of macular disease.



*As the leading cause of severe vision loss and blindness in Australia, macular disease affects people of all ages. It is estimated there are approximately 8.5 million people over the age of 50 years at risk of macular disease and over 1.7 million Australians have some evidence of macular disease.*

The vision of this Action Plan is to strengthen all sectors in developing, implementing and evaluating an integrated and coordinated approach for reducing the social, human and economic impact of macular disease in Australia. To achieve this, the Action Plan has four key pillars with potential areas for action and measures of progress:

### **1. Prevention and early detection**

Prevention and early detection of macular disease and prevention of vision loss and blindness.

### **2. Treatment**

People with macular disease should achieve the best possible outcomes through access to transformative, evidence-based affordable treatments and services.

### **3. Support**

People with macular disease should be able to access support that enables them to fully participate in their communities.

### **4. Data and research**

Improving the capture and use of data, and strengthen treatment and support for people with eye health diseases through transformative research.

MDFA led the development of this Action Plan with funding from the Australian Government Department of Health. It has been informed by the Macular Disease Expert Advisory group and consultations with Australians living with, and at risk of macular disease, their families and carers and key stakeholders in the eye health sector. It builds on the extensive work that has been undertaken by the many agencies involved with people who have, or are at risk of developing, macular disease. It will also leverage cross-sectoral activities already underway through peak bodies such as MDFA and Vision 2020.

The implementation of this Action Plan will involve collaboration across government, the eye health community and relevant organisations. Stakeholders are encouraged to proactively seek out opportunities to develop new and strengthen existing partnerships to develop and support the achievement of this Action Plan.

# Abbreviations

ACCHO	Aboriginal Community Controlled Health Organisation
AI	Artificial intelligence
AMD	Age-related macular degeneration
Anti-VEGF	Anti-vascular endothelial growth factor
AREDS2	Age-Related Eye Disease Study 2
DME	Diabetic macular edema
DR	Diabetic retinopathy
MacTel	Macular telangiectasia
MBS	Medicare Benefits Schedule
MDFA	Macular Disease Foundation Australia
MMD	Myopic macular degeneration
MRFF	Medical Research Future Fund
NDIS	National Disability Insurance Scheme
NDSS	National Diabetes Services Scheme
NHMRC	National Health and Medical Research Council
OCT	Optical coherence tomography
PBS	Pharmaceutical Benefits Scheme
RHOF	Rural Health Outreach Fund
RVO	Retinal vein occlusion
RANZCO	Royal Australian and New Zealand College of Ophthalmologists
WHO	World Health Organization
VOS	Visiting Optometrists Scheme

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# Introduction

**The National Strategic Action Plan for Macular Disease (the 'Action Plan') is an opportunity to articulate a shared goal for reducing the incidence and impact of macular disease on the community and identify effective, evidence-based priority areas for action. It also aims to better coordinate resources across all levels of government and to focus these resources where they are needed most.**

Over the last decade, key stakeholders from across the health sector and industry, have united in a collaboration that has made Australia a world leader in the prevention, detection and management of macular disease, as well as in the field of research. This continued partnership will help reduce, and ideally prevent, the economic, social and emotional costs of vision loss and blindness as a result of macular disease.

This is the first national plan specifically for macular disease. Previously there was the 2005 National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss (the Framework).<sup>1</sup> The Framework did not focus on any one specific eye condition, but sought to cover the underlying issues common to the prevention and treatment of eye disease and vision loss in general. It outlined key action areas that had the potential to lead to the prevention of avoidable low vision and blindness.

The 2017 National Strategic Framework for Chronic Conditions (the Strategic Framework)<sup>2</sup> provides guidance for the development and implementation of policies, strategies, actions and services to reduce the impact of chronic conditions, such as macular disease, in Australia. This Action Plan has been designed to align with, and support, the policy directions outlined in the Strategic Framework.

It also builds on the World Health Organization (WHO) international action plan: *Universal Eye Health - a Global Action Plan 2014-2019*<sup>3</sup> which sets out a global target of a 25% reduction in the prevalence of avoidable visual impairment by 2019.

## Purpose

This Action Plan identifies the most effective and appropriate interventions to reduce the incidence and impact of macular disease. It recognises the social and economic burden of the disease and provides action areas that:

- Prevent, detect and manage macular disease
- Improve macular disease-related services and care
- Promote collaboration across the macular disease community
- Facilitate coordinated and integrated care for clients
- Increase recognition of the needs of people affected by macular disease

The development of this Action Plan has recognised the current fiscally constrained environment and so should guide the Australian Government and state and territory governments in planning and directing funding in a cost-effective and sustainable way to improve the health of all Australians – specifically, to reduce the incidence and impact of macular disease. Governments will use the activities in this Action Plan to inform their prioritisation of effort. Action will vary in each jurisdiction depending on available resources, current programs and local needs.

## Audience

This Action Plan has been developed for government, non-government organisations, local health service providers, stakeholder organisations, researchers, health professionals and individuals who provide education, management, support and advocate for people with macular disease, their families and carers.

# The approach

The Action Plan articulates a vision for macular disease in Australia that is supported by four high-level pillars. Within each pillar are actions that have been informed by the Macular Disease Expert Advisory Group and consultations with key stakeholders.

The pillars are underpinned by key principles to guide actions with enablers representing cross-cutting themes that are required to successfully achieve the desired outcomes.

## Goal

**To reduce the social, human and economic impact of macular disease in Australia by strengthening all sectors in developing, implementing and evaluating an integrated and coordinated approach.**

## Pillars

The Action Plan is structured on the basis of four 'pillars' of action:

1. **Prevention and early detection:** prevention and early detection of macular disease and prevention of vision loss and blindness.
2. **Treatment:** people with macular disease should achieve the best possible outcomes through access to transformative, evidence-based affordable treatments and services.
3. **Support:** people with macular disease should be able to access support that enables them to fully participate in their communities.
4. **Data and research:** improving the capture and use of data and strengthen treatment and support for people with eye health diseases through transformative research.

## Principles

The Action Plan is underpinned by the following principles:

- **Equity of access:** everyone across Australia should have access to services and care relating to macular disease.
- **Partnerships and collaboration:** collaboration and partnership of individuals and organisations is necessary to achieve a greater impact than working independently.
- **Person centred care and empowering the individual:** the unique and individual needs of each person, their families and carers must be recognised. Individuals should be empowered to be partners in their care and be fully involved in making decisions about their care.
- **Evidence based:** rigorous, relevant and current practice informs best practice and strengthens the knowledge base to effectively prevent, detect and manage macular disease.
- **Sustainability:** actions must be able to be sustained and deliver long term outcomes.
- **Measurement of outcomes:** progress must be analysed and reported through robust data collection.

## Enablers

The following enablers are embedded in the Action Plan and contribute to achieving positive change:

- **Leadership and governance:** effective and appropriate oversight and accountability is needed.
- **Workforce:** actions will be supported by appropriately trained staff.
- **Information and research capacity:** improvements in care will be supported by translating research into practice and policy, including new innovations and medical technologies.
- **Financing and infrastructure:** funding arrangements and financial incentives are needed to better support access to, and provision of services.
- **Resources:** resources must be appropriately distributed and used efficiently.
- **Technology:** offers opportunities for new and improved technologically driven initiatives as well as more effective and accessible prevention and management strategies.

## Partners

The effective prevention and management of chronic conditions is strongly influenced by the contributions made by a wide range of Partners. These Partners include:

- individuals, carers and families;
- communities;
- all levels of government;
- non-government organisations;
- the public and private health sectors, including all health care providers and private health insurers;
- industry; and
- researchers and academics.

All Partners have shared responsibility for health outcomes according to their role and capacity within the health care system. Greater cooperation between Partners will lead to more successful individual and system outcomes. Actions included in this Plan are intended to guide Partner investment in the prevention and management of macular disease and should be implemented collaboratively to achieve the best health outcomes.



# The challenge of macular disease

'Macular disease' covers a range of conditions that affect the central retina (the macula) at the back of the eye. There are a number of conditions that affect the eye other than macular disease, including cataracts, glaucoma and stroke.

Macular disease can affect detailed central vision, required to read, drive, recognise faces, and carry out many other critical activities of daily life. The macula is the small area at the centre of the retina responsible for what we see straight in front of us, at the centre of our field of vision. The macula is important as it gives us the vision needed for detailed activities such as reading and writing, and the ability to see colours clearly.

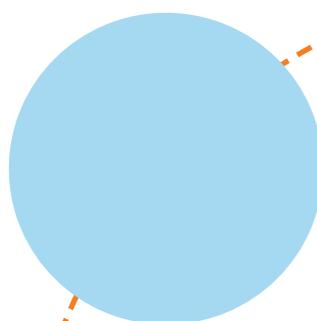
Macular disease affects people of all ages. It is the leading cause of blindness and severe vision loss in Australia. It is estimated there are approximately 8.5 million people over the age of 50 years at risk of macular disease and over 1.7 million Australians with some evidence of macular disease (Table 1).

The two most common conditions in Australia affecting the macula are age-related macular degeneration (AMD) and diabetic retinopathy (DR) (including diabetic macular edema (DME)). A more detailed description of the different types of macular disease is provided at Appendix A.

AMD is the most common macular disease and affects approximately 1.29 million older Australians.<sup>4</sup> Approximately 300,000-400,000 people have some degree of DR, with DME occurring at any stage of DR.<sup>5,6,7</sup>

As the population ages these numbers will continue to increase, as will the social and economic impact of macular disease and low vision more broadly. In the absence of prevention and treatment measures, it is estimated 1.7 million Australians will have evidence of AMD by 2030.<sup>8</sup>

In 2009, the total financial cost of vision loss in Australia (excluding loss of wellbeing) was estimated to be \$7.2 billion.<sup>9</sup> Eliminating avoidable vision loss as a result of macular disease would substantially reduce the associated costs.



## Prevalence of macular disease

There is no single source of data related to the prevalence of the different types of macular disease. The table below provides estimates of the prevalence of each disease type which has been gathered from different sources.

**Table 1 - estimated prevalence of the most common macular diseases in Australia (2018)**

Disease	Estimate
Age-related macular degeneration (AMD)	1,290,000 <sup>10</sup> (1 in 7 over the age of 50)
- <i>Early and intermediate AMD</i>	1,075,000 <sup>10</sup>
- <i>Late 'dry' AMD</i>	80,000 <sup>10</sup>
- <i>Late 'wet' AMD</i>	135,000 <sup>10</sup>
Diabetic retinopathy (DR)	300,000 – 400,000 <sup>11,12,13</sup>
- <i>Diabetic macular edema (DME)</i> (DME is a complication of diabetic retinopathy)	72,000 <sup>51</sup>
Retinal vein occlusion (RVO)	135,000 <sup>14</sup>
Myopic macular degeneration (MMD)	125,000 <sup>15</sup>
Macular telangiectasia (MacTel)	10,000 – 15,000 <sup>16</sup>
Inherited conditions (e.g., Stargardt, Best, Usher, Leber, Bardet-Biedl, and others)	15,000 <sup>17,18,19,20,21,22</sup>

\*Other structural conditions affecting the macula include macular holes, epiretinal membrane, vitreomacular traction syndrome, central serous chorioretinopathy and others (see Appendix A).

## The eye health workforce

There were around 1,020 registered ophthalmologists in Australia in August 2018.<sup>23</sup> Approximately 84% of ophthalmologists are based in major cities.<sup>24</sup> In June 2018, there were around 5,361 active optometrists registered in Australia.<sup>25</sup> Numbers and rates are highest in major cities and very low in remote and very remote areas.<sup>26</sup>

In 2010 there were 641 ophthalmic nurses, 643 orthoptists and 73 occupational therapists specialising in eye health.<sup>27</sup> The number of occasions of service provided to Indigenous patients under the Visiting Optometrist Scheme (VOS) more than tripled between 2009–10 and 2016–17 rising from 6,975 to 24,511.<sup>28</sup>

## The impact of macular disease

Macular disease and resulting vision loss can have a significant impact on the individual, their families and carers as well as the community. The impact can be emotional, financial, social and/or vocational and can result in a significant reduction in independence and contribute to increasing social isolation and mental health issues.<sup>29</sup> Macular disease can cause difficulties with daily activities, such as routine activities, self-management of chronic disease or medication adherence. It can increase the likelihood of injury and reduce workforce participation. There are also direct costs to health system expenditure, and indirect costs such as those to wellbeing and productivity, for both those living with macular disease as well as their carers. Further detail on the impact of macular disease is provided at Appendix A.





Macular disease is the **leading cause** of blindness and severe vision loss in Australia.

Macular disease and resulting vision loss can have a **significant impact** on individuals, their families and carers as well as the community.

**Macular disease covers a range of conditions that affect the central retina (the macula).** Approximately 8.5 million people over the age of 50 years are at risk and over **1.7 million Australians** have some evidence of macular disease.

Age-related macular degeneration is the **most common** macular disease in Australia and affects approximately **1.29 million** older Australians.



Approximately **1 in 7 Australians** over the age of **50 years** have some evidence of age-related macular degeneration. This is predicted to **increase to 1.7 million by 2030**, in the absence of adequate treatment and prevention measures.

**Everyone with diabetes is at risk of developing diabetic eye disease.** In 2018 the estimated prevalence of diabetes in Australia was approximately 1.7 million people (1.2 million diagnosed and 500,000 undiagnosed Type 2). Of the 1.2 million Australians diagnosed with diabetes, approximately **300,000-400,000** have some degree of diabetic retinopathy.

In **2009** the total financial cost of vision loss in Australia (excluding loss of wellbeing) was estimated to be **\$7.2 billion**.



# Pillar 1 - Prevention and early detection

**People are experiencing preventable vision loss and blindness as a result of macular disease. There is a lack of awareness of risk factors and those at risk are not routinely having eye examinations.**

The goal is to prevent vision loss and blindness due to macular disease.

Health promotion and prevention activities can have a significant and positive impact on improving outcomes for chronic disease, including macular disease.<sup>30</sup> There are characteristics that increase the likelihood of developing macular disease that people need to be aware of. These can be potentially modifiable such as diet, exercise and well-controlled diabetes, or non-modifiable such as age or genetics.

## **There is variable understanding of macular disease, and the importance of regular screening among at-risk groups**

People may not be aware they are at risk of developing macular disease as they age, e.g. a first degree family member with AMD raises risk by as much as 50%<sup>31</sup> or if they have diabetes.

In addition, people who know they are at risk may not understand the impact of macular disease and the importance of regular eye examinations. For example in 2015-2016 over one third of Aboriginal people with diabetes did not have an eye examination in the preceding 12 months, with the rate being over 60% in Queensland.<sup>32</sup> In a 2018 Galaxy poll, only 33% of people associated eyes as a body part that can be affected by diabetes and only 36% of those diagnosed with diabetes mentioned eyes as being affected by diabetes.<sup>33</sup> Initiatives such as the 'KeepSight' program, have been developed to better support people with diabetes by sending eye examination reminders.

In a recent 2019 YouGov Galaxy poll, only 35% of people 50 years and over knew that family history is a risk for AMD.<sup>34</sup>

People who can self-identify as being at risk can be more empowered and be actively involved in making decisions about their health.

## **Early detection of macular disease is vital**

For macular diseases where treatment is available, it should start as early as possible to have an impact on the course of the disease, and to limit or slow the rate of vision loss. Therefore, early detection and prompt intervention is essential for better outcomes.

## **Accessing eye examinations may be difficult for some groups**

Accessing eye examinations can be difficult, particularly for those in rural and remote regions. In some areas there are visiting and outreach services, however 94% of optometrists and 97% of ophthalmologists are based in major cities or inner regional areas.<sup>35</sup> People may need to travel extensive distances to receive services. For some people the variable costs associated with eye examinations may also act as a barrier.

## Areas for action

### Strengthen education about macular disease in the general community

- 1.1 Strengthen current education campaigns for the general public to promote:
  - Understanding of the risk factors for macular disease.
  - Understanding of the symptoms (or lack of) for macular disease.
  - Understanding the potential implications of macular disease such as vision loss and blindness.
  - Self-identification as being in an at-risk group.
  - Strengthening of behavioural change in high-risk groups.
- 1.2 Develop education campaigns to people over 50 years of age to:
  - Increase knowledge of the risk factors for developing macular disease and identifying if they are in a high-risk group.
  - Increase the uptake of annual comprehensive eye examinations.
- 1.3 Partner with diabetes and other key organisations, to combine expertise in diabetes and macular disease, to develop targeted education programs for people with diabetes, who are at greater risk of developing macular disease to:
  - Improve the understanding that anyone with diabetes is at risk of developing diabetic eye disease.
  - Improve understanding of the need for regular eye examinations and the potential implications of untreated DR, including DME.
  - Minimise the risk of developing DR through good diabetes management.
- 1.4 Support the development of accessible macular disease and eye health information materials tailored for specific groups (with a focus on preventing vision loss and blindness):
  - People in rural and remote areas.
  - Aboriginal and Torres Strait Islander communities.
  - People from culturally and linguistically diverse groups.
- 1.5 Establish mechanisms for regular evaluation and improvement of education campaigns to make sure there is a measurable positive impact.
- 1.6 Increase the availability of genetic testing and counselling for people with a macular disease with genetic causation.

### Develop innovative strategies to reduce modifiable risk factors for macular disease

- 1.7 Partner with organisations delivering public health campaigns to reduce tobacco use and improve healthy eating, which will positively impact macular disease.
- 1.8 Develop disruptive technologies and strategies to reduce modifiable risk factors in the general population by:
  - Facilitating consumer engagement and education.
  - Developing interactive tools to increase health literacy that results in behavioural change.
  - Promoting proactive self-management behaviours.

## Improve understanding of macular disease among health professionals through targeted education, training and support

- 1.9 Develop and deliver targeted education for general practitioners (GP) to include eye health as an essential component of:
  - Chronic disease reviews in people over 50.
  - Reviews of people with a family history of macular disease.
  - Annual Aboriginal Health Checks.
  - The management of people with diabetes.
- 1.10 Partner with Optometry Australia to develop better educational information for optometrists to:
  - Improve communication with clients about macular disease and its impact.
  - Manage and reduce modifiable risks.
  - The need for people identified as high-risk having regular eye examinations.
  - Provide assistance to people diagnosed with macular disease by linking them into appropriate supports and services relevant to their needs.
- 1.11 Work with the Pharmacy Guild of Australia to develop on-line training packages for pharmacists so they can take a proactive role in educating clients on macular disease.
- 1.12 Promote the development and delivery of specialised eye health training in general health professional training programs by specialist bodies such as RANZCO.
- 1.13 Develop a model of care for the management of vision and eye health to be adopted by residential aged care facilities to ensure:
  - Awareness of vision as a risk factor for falls, mobility issues and increasing dependency in activities of daily living.
  - Better understanding of eye health and vision loss screening and care, and better linkages with eye health and low vision services.
  - The importance of regular eye examinations for early detection of macular disease.

### Measures of progress

- Increased number of people undertaking comprehensive eye examinations.
- Increased number of people diagnosed in early stages of macular disease.
- Decreased incidence of macular disease among people with diabetes.
- Increased awareness and understanding of macular disease among optometrists, GPs, pharmacists and other health professionals.
- Increased awareness and understanding of macular disease and low vision among residential aged care facility staff.
- Increased genetic testing and counselling for people with inherited forms of macular disease.

## Pillar 2 - Treatment

**There are treatments for a range of macular conditions, but there are many that remain untreatable and only a few can be cured.**

**Where treatments are available, there may be a number of barriers relating to access and adherence.**

The goal is for people with macular disease to achieve the best possible outcomes through access to transformative, evidence-based, affordable treatments and services.

**There are now treatments for a range of macular conditions, but many remain untreatable and few can be cured**

There are a number of highly effective treatments that have been introduced revolutionising the management of people with 'wet' (neovascular) AMD, DR, DME, RVO and other neovascular conditions.

Sight can be preserved in a significant proportion of people with neovascular conditions using intravitreal injections of medicines that inhibit the effect of vascular endothelial growth factor (VEGF). The Pharmaceutical Benefits Scheme (PBS) listed medicines are Lucentis® (ranibizumab) and Eylea® (aflibercept). Avastin® (bevacizumab) is sometimes used in people who do not qualify for the PBS-listed medicines, and is deemed 'off label'. These injections must be administered by a registered ophthalmologist.

Ozurdex® (dexamethasone) intravitreal implant is another PBS-listed treatment option for patients with DME and RVO. The implant contains the anti-inflammatory corticosteroid, dexamethasone, which is implanted into the back of the eye by a registered ophthalmologist.

For people with wet AMD, DME and RVO, treatments (intravitreal injections) should be commenced as soon as possible after the development of leaking vessels, and need to be accessed frequently and in most cases, continued indefinitely. Any delay in accessing treatment can result in a greater level and speed of vision loss.

At this time there are no registered treatments for earlier stages of AMD nor late-stage dry (atrophic) AMD.

**Clinical practice guidelines are due for updating**

There are National Health and Medical Research Council (NHMRC) guidelines from 2008 for the management of DR. Over the previous decade there have been changes to treatment which need to be reflected in the guidelines. There are no NHMRC guidelines for the management of AMD.

**People may experience barriers to accessing and adhering to treatment**

Some public hospitals provide up to three initial treatments and patients are then referred to private clinicians. For many Australians with macular disease, their treatment options are completely limited to the private sector. There is an urgent need for better access to intravitreal injection treatment for macular disease in the public hospital system. Not all public hospitals provide treatment and waiting times for the public hospital treatment are very long in all states. Ready access to public hospital treatment is needed because late diagnosis and treatment can result in permanent vision loss.

In many cases there is simply no regular access to an ophthalmologist to provide treatment, particularly in remote areas. Outreach services exist, and these fill significant gaps in local services, however outreach services are inherently limited. Given the complex needs of eye health examination, treatment and support, these services often lack access to optical coherence tomography (OCT), laser or visiting clinicians at sufficiently regular intervals.

Although injections are highly effective in the majority of people if commenced early enough, their use involves substantial treatment burden for patients and their family or carer.

This is related to the ongoing frequency of treatment, the need to prioritise injections ahead of other matters, travel time to appointments, the high volume of other medical appointments related to co-morbidities, financial stress due to out-of-pocket costs for services, and for some, the emotional stress of having regular injections in the eye.

A lack of access to culturally appropriate care can also act a barrier, especially for people from Aboriginal and Torres Strait Island communities, and culturally and linguistically diverse (CALD) communities.

People from various ethnic and cultural populations may face additional obstacles that can interfere with or prevent access to treatment, impede compliance with treatment recommendations, and produce poorer treatment outcomes. Obstacles may include language barriers and cultural differences.

For some people, the burden of treatment can lead to inadequate frequency of treatment by missing or delaying appointments. They may also choose to prematurely stop treatment, both of which can lead to a loss of vision. The rate of 'loss to follow-up' to treatment is approximately 20%.<sup>36</sup>

## Areas for action

### Improve access to public hospital services for people with macular disease

- 2.1 Work with State and Territory governments to review and increase the current publicly available services for macular disease.

### National endorsement of approaches to the management of macular disease

- 2.2 Develop nationally endorsed evidence-based clinical guidelines for the management of AMD.
- 2.3 Review and update the 2008 NHMRC Guidelines for the management of DR.

### Minimise costs

- 2.4 Work with peak eye health bodies to consistently provide information to patients on the costs associated with treatment, prior to commencement.
- 2.5 Pursue Pharmaceutical Benefits Scheme (PBS) and Medicare Benefits Schedule (MBS) funding for newer treatment options for macular disease, through collaboration with eye health professional organisations.
- 2.6 Review the impact of any change in Medicare rebates and the Medicare Safety Net for item numbers related to macular disease.
- 2.7 Pursue OCT\* Medicare rebates for the ongoing monitoring of macular disease, through collaboration with eye health professional organisations.

\* OCT is currently reimbursed by Medicare (MBS 11219) for initial diagnosis only, to confirm eligibility for PBS-subsidised medicines used for treatment of macular disease. OCT scans enable an ophthalmologist to confirm an initial diagnosis of macular disease and monitor a person's individual response to treatment. OCT scans for ongoing monitoring of macular disease are not currently reimbursed by Medicare.

## Develop innovative service models, particularly in rural and remote Australia

- 2.8 Develop innovative and flexible service provision options as a means of delivering information and services. For example, increasing the use of digital solutions and an increased availability of OCT, particularly for those in rural and remote areas where access to specialist eye health services is limited.
- 2.9 To increase the capacity of ophthalmologists, work with professional bodies to consider opportunities to redistribute aspects of eye health care to different roles.
- 2.10 Work with Aboriginal Community Controlled Health Organisations (ACCHO) to develop strategies to enhance local provision and address local gaps in service provision. This includes strategies to strengthen the skills and confidence of staff working in local services about eye health, vision care and available services, and working with local communities to design and deliver culturally appropriate services based on the needs of the local population.
- 2.11 Continue to build on the successes of the Australian Government Department of Health's Rural Health Outreach Fund (RHOF) in improving access to eye health specialists in rural, regional and remote areas of Australia.

## Promote new evidence-based treatments

- 2.12 Rapidly adopt effective and efficient evidence-based treatment innovations developed internationally and nationally through collaboration with industry, health care professionals and consumer eye health groups.

## Explore innovative disruptive technologies and strategies to support people with treatment adherence

- 2.13 Enhance remote support interventions through telephone, email, websites and other channels to encourage people undergoing treatment, and to provide better follow-up when treatments are delayed, missed or stopped. This includes leveraging existing systems and embedding eye health in ACCHOs so that local health workers are better able to support people needing treatment for macular disease.

## Measures of progress

- Clinical practice guidelines developed for AMD and updated for DR.
- Increased number of people accessing publicly funded eye clinics.
- Increased number of people accessing eye health services in non-metro areas.
- Increased access to new, evidence-based treatments for AMD.
- Increased rates of adherence to intravitreal injection treatment.

## Pillar 3 - Support

**With the right support, people with low vision and blindness as a result of macular disease are able to engage with the community and maintain their independence and quality of life. Barriers to accessing support include a lack of awareness, gaps in current support services and cost.**

The goal is for people with macular disease to be able to access supports that enable them to optimally participate in their communities and maintain their independence.

There is strong evidence reinforcing the benefits of supports for those with vision loss to connect and engage with the world and maintain their independence.

Supports may include provision of information about macular disease and impacts of macular disease, vision and adaptive aids and other assistive technologies, home modifications or adaptations, assistance with household tasks, transport, and accessing the community, and emotional and wellbeing support.

**Timely access to information, supports and technologies can assist people to maintain their independence and to make informed decisions and choices about their lives**

People with macular disease do not go completely blind. They still have peripheral vision and with the help of vision aids and innovative technology - glass or electronic magnifiers, electronic readers, screen reading software, and wearable technology for example, they can often continue with many of their normal activities and can lead rewarding and reasonably independent lives. Timely access to vision aids, equipment and assistive technologies can reduce the need for higher-cost supports.<sup>37</sup> There is a low referral rate for specialist low vision support services because of a lack of awareness by consumers and health care professionals.

People affected by macular disease are likely to need a range of supports – for example from specific disease information, to assistance with accessing low vision aids, dietary information, emotional support to deal with a diagnosis and (potential) loss of vision. Many people need opportunities for in-depth conversations about their disease and its potential impact on quality of life.

**There are a range of supports for people with low vision and blindness available through health, aged care and disability support programs and schemes**

There are barriers to accessing low vision aids, particularly for older Australians with vision loss and blindness.<sup>38</sup> These include a lack of an awareness of available services, the costs, eligibility criteria and access. For example, the Home Care Packages Program can fund a range of goods, equipment or assistive technologies to enable frail, older people aged 65 years and over (or 50 years and over for Aboriginal and Torres Strait Islander people) to perform tasks they would otherwise be unable to do or promote the older person's safety and independence.

Only about 10 to 15% of visually impaired people who could benefit from support access and use the services available to them. The best results are achieved when support is implemented early, while some vision remains, although commonly, people are not referred for support until they have serious vision loss.<sup>39</sup>

There is rising demand for low vision support services.<sup>40</sup> Accessing information on where to locate resources and support can be difficult. Often people are not referred or connected with support services, particularly those identified as being in the greatest need such as those aged over 65 years and young people. Other specific groups that most often need additional support in accessing and receiving services are remote populations, Aboriginal and Torres Strait Islander people, and culturally and linguistically diverse groups.

The major barrier is cost associated with the purchase of aids, equipment and assistive technology, for training or for access to services.<sup>41</sup> The accessibility and affordability of low vision aids and technologies varies greatly between jurisdictions, with different subsidies/rules in each state (some have no subsidies). There is limited availability through private health insurance funds.

People who acquire a disability, such as low vision, at the age of 65 or older are excluded from the National Disability Insurance Scheme (NDIS). They are required to obtain their support through the aged care system, yet the aged care system is neither funded nor designed to primarily provide the supports that people with disability require. Additionally, many younger people with vision less than that of legal blindness are excluded from the NDIS. These people can have significant impairment to their functional vision and could also benefit from additional services and supports relating to their low vision.

Barriers to the access of low vision services lie not only at a service model level. Personal attitudes towards low vision, poor knowledge of available services, problems with physical access to often urban-based low vision facilities, and issues around cultural appropriateness may present further obstacles to a person with low vision accessing services appropriate to their functional needs.

## Areas for action

### Develop a National Macular Health Patient Portal

3.1 Aligned to the principles of the Australian Government's National Digital Health Strategy, develop a Macular Health Patient Portal to improve health literacy and deliver improved services to Australians living with macular disease.

The portal will empower people to self-manage with a range of innovative and practical support but not limited to:

- Self-registration to access a tailored care plan specific to their diagnosis incorporating recommended diet and lifestyle adjustments with free, macula friendly meal recommendations.
- Interactive e-education forums to support self-management throughout disease journey including live webinars and Q&A.
- Navigational support to government subsidies, Medicare safety net and rebate information, self-referral and links to low vision service support and occupational therapy home modification supports. This will be tailored to individual diagnosis and needs.
- Online peer support forums.

### Enhanced National Self-Management Support Program

3.2 Develop a national program of support for people with complex needs including people with AMD and DR including but not limited to:

- Development of peer to peer support networks and support groups and leveraging Australians with lived experience of macular disease.
- Early intervention support for managing mental health to better manage transition to a life with vision impairment and referrals for complex needs.
- Education and resources to empower better self-management including home safety with low vision and building resilience and coping skills to adjust to a life with vision impairment.

## Establish a national low vision aids and technologies program

- 3.3 Establish a nationally funded, accessible, affordable and consistent low vision aids and equipment “National Vision Program” to complement and connect with existing programs, such as the NDIS and other disability, aged care, and health programs. This would be similar to the established National Hearing Program.

## Work with private health insurance to ensure benefits for low vision aids and technology

- 3.4 Establish financial support across more private health insurance policies for aids and technologies, demonstrated to be beneficial and effective for people with functional vision loss.

## Expand technologies to support people who are blind or have low vision

- 3.5 Engage with the employer groups and peak bodies to expand the disability and employment policies to include use of and access to low vision aids and technologies in the workplace, leveraging work currently in progress.
- 3.6 Support the development of assistive technologies that focus on communication and orientation to enable people with low vision to interact with those around them, fostering human interactions and relationships.

## Improve accessibility in communities for people who are blind or have low vision

- 3.7 Develop a national accessibility implementation plan for people with low vision or blindness that incorporates recommendations from the National Disability Strategy and other Commonwealth and State Government initiatives.
- 3.8 Develop national guidelines on the ideal characteristics of print accessibility for publications and signage, to provide the opportunity for people who are blind or who have low vision to optimally participate in the mainstream of Australian life.
- 3.9 Improve the capture of information about consumers’ low vision needs, and referral to low vision services, through the aged care assessment process.



## Measures of progress

- Development of a National Macular Health Patient Portal.
- Development of a continuity of care framework that can be implemented to inform care needs of patients within aged care, disability and health systems across all jurisdictions.
- Increased availability and consistency of government subsidies and programs for low vision aids and technologies across the country, accessible to all Australians with vision loss or blindness.
- Increased number of private health insurance reimbursement policies and rebated amounts for low vision aids and technologies.
- Increased utilisation of low vision aids and technologies.
- Development of a national accessibility implementation plan for people with low vision or blindness.
- Development of national print accessibility guidelines.
- The Aged Care National Screening and Assessment Form is reviewed and amended to improve capture of eye health and low vision needs.



# Pillar 4 - Data and research

**Macular disease has a significant impact on the health and productivity of Australia. To strengthen the evidence base and improve health outcomes, more research is required.**

The goal is to strengthen prevention, treatment and support for people with macular disease through transformative research and better capture and utilisation of data related to macular disease.

Australia is recognised as a world leader in macular disease research. There are major Australian research organisations focussed on studying the impact of eye diseases and working towards preventing blindness through early diagnosis and developing better treatments for maintaining or restoring sight.

## **Research is vital to better understand macular disease, its cause, treatments and impact**

There are still many unknowns. For example:

- There are macular diseases for which there are no treatments.
- Damage to the eye as a result of macular disease remains largely irreversible.
- There are genetic factors to be better understood to develop preventative measures or even a cure.
- For those conditions for which there is a treatment, there is still more research to be undertaken into their impact, effectiveness and long-term outcomes.

There are also technological advancements in development which have the potential to significantly improve the lives of people with macular disease and have real impact on their quality of life including the use of smart apps, retinal cameras and monitoring devices providing real-time clinical data.

As well as developing treatments, research can provide important information about disease trends and risk factors, outcomes of treatment, the impact of support, prevalence, functional abilities, patterns of care, and health care costs and use.

## **Real-world data is needed to inform decision-making**

Decision-making approach in health care can be a complex task and should be based on the best available level of evidence. The existence of eye health data is pivotal in informing research, but also in providing prevalence and incidence statistics of eye diseases and treatment patterns at the population level.

Meaningful data also allows clinicians to make informed decisions to improve quality of care and supports evidence-based care. At a population level, data is needed for service planning. However, there are significant inhibitors to the collection, linkage and sharing of big health data.<sup>42</sup>

Globally, there is an increasing trend to use real-world data to inform decision-making in health care. Real-world data are often collected used a patient registry. Considering the unique value of and increasing demand for real-world evidence, patient registries may become the new standard.<sup>43</sup>

## Rapidly developing new advances

Researchers in Australia and around the world are continuing to develop new approaches to macular disease at a rapid pace. As well as developments in gene therapy and stem cell treatments, there have been recent advancements in vision restoration with visual prostheses/implants as well as the use of artificial intelligence (AI).

A trial at Moorfields Eye Hospital in the United Kingdom has found that an AI system was as effective as world leading experts at detecting eye disease in patients. The system was able to identify more than 50 types of eye disease in seconds, with 94% accuracy. Clinical trials are due to begin in 2019.<sup>44</sup>

Australia needs to understand the ethical, practical, access and regulatory challenges and opportunities these new innovations present, in particular the impact of AI.

## Areas for action

**Better utilise existing data and improve data collection, linkage and sharing of big health data to improve understanding of the macular disease cohort, treatment for macular disease and treatment outcomes**

- 4.1 Review and simplify the access to health data collections for research purposes and service planning whilst also maintaining privacy and security of individual records.
- 4.2 Undertake a stocktake of all existing databases, data sets, registries and other data sources relating to eye health, eye diseases (including macular disease), eye health treatment, treatment outcomes, and eye health supports.
- 4.3 Investigate the feasibility of linking databases and data sets to better understand the population with eye diseases (including macular disease), treatment for eye diseases, treatment outcomes, and ongoing supports accessed by people with eye diseases, low vision and blindness.
- 4.4 Engage with researchers and eye health professional organisations to pursue longitudinal research on outcomes and impacts of eye health (including macular disease) treatments and supports, utilising existing (linked) data sets as well as new data.

**Develop a National Macular Health Patient Data Hub and impact evaluation framework for macular disease**

- 4.5 Develop a National Macular Health Patient Data Hub to access real-world data to support better decision-making in service planning and delivery, establishment and evaluation of health care policy as well as future investment.

This includes development of a patient reported measures evaluation framework that would provide valuable information such as:

- Disease progression and treatment adherence.
- Patient reported experience with eye health and related sectors.
- Quality of life impact.
- Effectiveness of interventions, supports and programs.

## Develop a national research agenda

- 4.6 Develop a national research agenda integrating research supported by both public and private funding, designed to coordinate eye health research across multiple funding streams. Priority areas for the national agenda include (but are not limited to):
- Strategies/treatments to prevent or slow progression of earlier stages of AMD to late stage (vision-impairing) disease.
  - Treatment for late dry AMD (geographic atrophy).
  - Quantification of the impact of low vision aids, technologies and services can have on quality of life and independence for people with low vision and blindness, particularly new technologies.
  - The long-term effectiveness of different models of care that aim to reduce time from initial presentation to referral, diagnosis and treatment.
  - Frequency of disease monitoring.
  - Adherence and compliance strategies for treatment.
  - The long-term cost effectiveness of different review frequencies/strategies for people at risk of progression to late AMD.
  - Effectiveness of self-monitoring strategies.
  - Longitudinal research to monitor disease burden.
  - The direct and indirect costs of vision loss to the individual and the community.
  - Prevalence of macular disease regionally mapped.
  - Translational research that looks at how best to translate research into practice and/or policy and potential clinical application.

## Coordinate recruitment of research participants

- 4.7 Develop an Australian Research Collaboration Framework for eye health research to support a coordinated approach to recruitment for clinical trials and research.

## Increase funding for eye health research

- 4.8 Secure support for additional research funding into eye health and eye disease including the prevention, management and support of macular disease.

## Prepare for new developments

- 4.9 Work with professional and peak bodies to develop a professional position on the ethical, practical, access and regulatory challenges and opportunities posed by AI in the clinical diagnosis and management of macular disease.

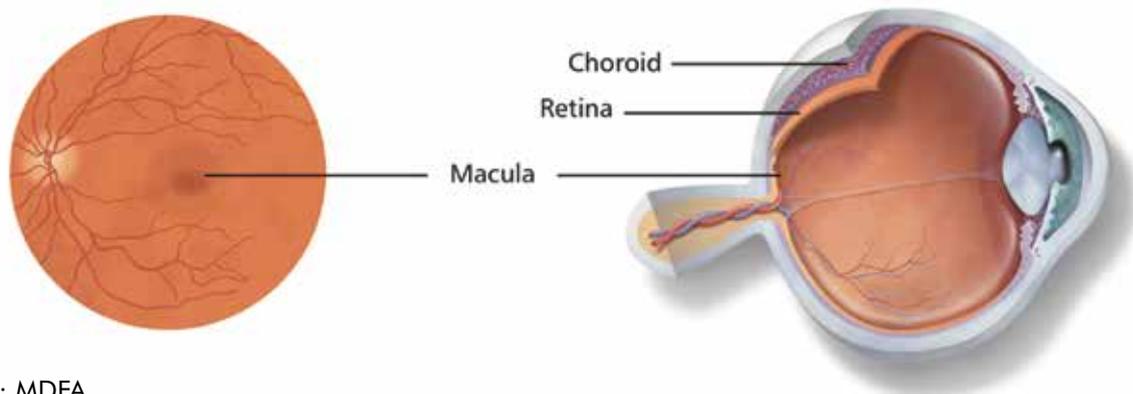
## Measures of progress

- Completion of a stocktake of all existing databases, data sets, registries and other data sources relating to eye health and eye diseases.
- Development of a National Macular Health Patient Data Hub and impact evaluation framework for macular disease.
- Data linkage projects for specially identified purposes have been completed or underway.
- Development of an Australian Research Collaboration Framework for eye health.
- Development of national research agenda for eye health.
- Development of a position statement on AI in detecting and managing macular disease.

# Appendix A: conditions affecting the macula

'Macular disease' covers a range of conditions that affect the central retina (the macula) at the back of the eye.

**Figure 1 - Structure of the eye**



Source: MDFA

## The key macular diseases include:

### **Age-related macular degeneration (AMD)**

A chronic and progressive disease of the macula. It is the leading cause of blindness and severe vision loss in Australia, affecting people over the age of 50 years. AMD is influenced by genetic and environmental risk factors. Highly effective treatment (anti-VEGF injections) is available for the wet (neovascular) form of AMD. There is currently no treatment for early stages of AMD or late 'dry' (atrophic) AMD.

AMD is classified as:

#### **– Early and intermediate AMD**

Caused by the progressive build-up of waste material (drusen) under the retina. These stages typically have little or no impact on vision, however some people with the intermediate stage may notice changes to their central vision. Currently there is no treatment available for the early and intermediate stages. Research is being conducted to develop treatments.

Progression to late stage may occur, however progression in each eye can differ. Diet and lifestyle are important for maintaining healthy eyes. A select combination of vitamins and minerals may reduce the risk of progression in some individuals.

#### **– Late AMD**

This is the vision impairing stage, which can be further divided into dry (atrophic) AMD or wet (neovascular) AMD.

##### **– Dry (atrophic)**

Caused by the gradual atrophy (loss) of retinal cells. It may lead to a gradual loss of central vision. Currently there is no treatment available for the dry form. The development of treatments for dry AMD is a research priority.

– *Wet (neovascular)*

Caused by the formation of fragile blood vessels which leak fluid and blood within and under the retina. It often leads to a rapid loss of central vision. Highly effective treatment (anti-VEGF injections) is now available. Early treatment produces the best outcomes. Treatment is usually undertaken on an ongoing basis. Research is ongoing to develop other forms of treatments, including gene therapies and stem cell therapies.

AMD has a prevalence of 50 times that of multiple sclerosis and four times that of dementia.<sup>45</sup> AMD is predicted to be the main cause of blindness in Australians aged over 40 by 2020.<sup>46</sup>

Exactly what causes AMD is not known, but it is thought that an interaction between genetic factors and the environment is responsible. The following risk factors make it more likely that a person has AMD<sup>47</sup>:

- Older age
- Presence of AMD in the other eye
- Family history of AMD
- Smoking
- Hypertension
- Body mass index (BMI) of 30 kg/m<sup>2</sup> or higher
- Diet low in omega 3 and 6, vitamins, carotenoid and minerals
- Diet high in fat
- Lack of exercise

An important consideration in AMD is that as it primarily affects those over 50, with risk increasing with age, many people will be affected by other co-morbidities associated with ageing. For example, cataracts and AMD are common causes of decreased vision that often occur simultaneously in people over age 50.<sup>48</sup> In 2010, the total cost of vision loss associated with AMD, including direct and indirect costs, was estimated to be \$5.15 billion.<sup>49</sup>

**Table 2 - estimated prevalence of AMD by State/Territory**

<b>State/Territory</b>	<b>2014</b>	<b>2030 - projected</b>	<b>Growth</b>
ACT	14,000	24,000	68%
NSW	361,000	549,000	52%
NT	5,000	10,000	99%
QLD	205,000	352,000	72%
SA	91,000	132,000	45%
Tasmania	28,000	42,000	50%
Victoria	271,000	426,000	57%
WA	106,000	178,000	67%

Source: Deloitte Access Economics

## **Diabetic retinopathy (DR), including diabetic macular edema (DME)**

DR, which includes DME are complications of diabetes and the leading cause of blindness in working age Australians. Everyone with diabetes is at risk of developing diabetic eye disease. In 2018 the estimated prevalence of diabetes in Australia was approximately 1.7 million people (1.2 million diagnosed and 500,000 undiagnosed Type 2).<sup>50</sup> It is projected that this will increase by 42% to 2.45 million people in 2030.<sup>51</sup> Of the 1.2 million who have been diagnosed with diabetes, approximately 300,000-400,000 (25-35%) have some degree of DR.<sup>52</sup>

Many cases of vision loss from DR can be prevented with regular eye examinations, careful management of diabetes, medication and in some cases, treatment with injections (anti-VEGF agents or steroids) and/or laser.

People with diabetes who are most at risk include those whose diabetes is poorly controlled, those with related problems including high blood pressure, and those who have had diabetes for many years. With optimal management of diabetes, and with regular eye examinations and timely treatment when indicated, almost all vision loss due to diabetes may be prevented.<sup>53</sup>

One in three people over the age of 40 with diabetes has DR.<sup>54</sup> The longer a person has diabetes, the greater the likelihood of DR. Almost everyone with type 1 diabetes and more than 60% of those with type 2 diabetes will develop some form of DR within 20 years of diagnosis.<sup>55</sup> DME, which directly affects the macula, can occur at any stage of DR. DME is the most common cause of vision loss in people with DR.

Around 1 in 8 (13%) Aboriginal and/or Torres Strait Islander adults (46,200 people) have diabetes. It is more common in Indigenous females than males (25,900 and 20,300, respectively; or 56% and 44%). Aboriginal and/or Torres Strait Islander adults were almost four times as likely to have diabetes as their non-Indigenous counterparts (18% compared with 5%).<sup>56</sup>

The 'KeepSight' program has been established to implement an alert system to encourage eye examinations for people registered on the National Diabetes Services Scheme (NDSS). Over the next five years the program will alert people with diabetes who are currently missing out on recommended eye examinations and will enable early detection and treatment of vision loss and blindness as a result of DR. This is a collaborative initiative between the Australian Government and leading organisations in the eye health and diabetes sectors.

## **Retinal vein occlusion (RVO)**

Blockage to one of the veins at the back of the eye. When a blockage occurs, the pressure increases inside the small retinal blood vessels causing them to bleed and leak fluid into the retina, resulting in swelling. The main risk factors include high blood pressure, high blood lipid levels, diabetes and smoking.

Treatment is with anti-VEGF or steroid injections. Targeted laser may be used in select cases.

## **Myopic macular degeneration**

A form of macular degeneration which occurs in people with severe short-sightedness (myopia). Stretching of the retina from severe myopia can lead to loss (atrophy) of cells in the macula. In some people, fragile blood vessels grow under the retina and leak blood under the macula; similar to the wet (neovascular) form of AMD.

There are no treatments available to stop the progression of severe myopia. Treatment is available (anti- VEGF injections) to manage the growth and leakage of fragile blood vessels.

## **Inherited forms of macular disease**

A number of rare inherited diseases that can affect younger people, but some not being diagnosed until later in life. They are caused by specific defects (mutations) in one or two genes. Examples include Stargardt disease, Best disease, Sorsby fundus dystrophy and others.

Although gene therapy has been developed for only one very rare condition caused by a defect in the RPE65 gene, this form of treatment is not yet available to treat other inherited retinal diseases.

## **Macular telangiectasia (MacTel)**

A rare, slowly progressive disorder of the macula resulting in cyst-like structures and loss of tissue in the fovea (central macula).

Effective treatment is currently not available. Research is being conducted to develop treatments.

## **Other conditions affecting the macula**

These include macular holes, epiretinal membrane, vitreomacular traction syndrome, central serous chorioretinopathy and others.

Some of these conditions can be managed with surgery, some with injections and others may only require monitoring.

## **Risk factors**

Macular diseases are impacted by genetic and environmental risk factors. Reducing risk factors where possible is crucial as vision loss and blindness can occur for which there is no cure. In some conditions, there are no available treatments.

General recommendations to reduce modifiable risk of developing macular disease include:

- Stop smoking. In particular for people with wet AMD where treatment is less effective for smokers.
- Eye health foods in the context of a healthy diet with regular consumption of fish and dark green leafy vegetables, low GI carbohydrates and limiting fat and oil intake.
- Maintaining a healthy weight and getting regular exercise.
- For people with established AMD, the appropriate use of an AREDS2-based supplement to reduce the risk of progression to late stage disease.
- For people with diabetes, the risk of developing DR can be reduced by keeping blood sugar levels, blood pressure and cholesterol levels under control.
- Adequate protection for the eyes from sunlight exposure, particularly for young children and those people with exposure throughout their working life.

Many macular diseases have a direct genetic causation and may not be preventable. For those affected individuals who are young, diagnosis is usually during childhood or adolescence and they have many decades of life ahead of them at the time of diagnosis. Early access to support for these children and their families is vital. In some cases, the impact of these conditions can be reduced with support provided.

Early detection of macular disease is vital so that risk reduction measures can be adopted early to maximize macular health. Early detection and prompt intervention for wet (neovascular) AMD, DME, RVO and other neovascular conditions, can help stabilise and maintain best functional vision for as long as possible.

People 50 years and over with a family history of AMD have an increased risk of developing the disease and should have a regular, comprehensive eye examination performed by an optometrist or ophthalmologist, and self-monitor regularly using an Amsler Grid (Appendix B).

## The impact of macular disease

### Difficulties with daily activities<sup>57</sup>

The challenge of not being able to see well can affect routine activities such as crossing a street, walking up and down stairs, completing household tasks, shopping and reading. These daily activities can be challenging, require additional effort and can take longer to complete.

It can also affect various tasks that rely on the use of vision, in relation to good chronic disease management. This can include self-care such as foot care in people with diabetes; and transportation such as travelling to appointments. Vision loss may also create difficulties in adherence to medication regimes. For example, vision loss can make it difficult to administer medication such as insulin.<sup>58</sup>

People may become increasingly reliant on others to assist them. For older people with increasing frailty and vision loss, earlier entry into residential care may be necessary.<sup>59</sup>

### Reduced safety

Mobility is greatly affected by vision loss and people with vision loss are at higher risk for several types of injury including slips, trips and falls. Vision impairment has been shown to be associated with an increased risk of fractures in multiple studies.<sup>60</sup>

### Impact on social and community participation

Participating in community and social activities may be more difficult. People may also not recognise friends and family leading to misunderstandings and embarrassment.

People may also experience changes in their family and social role because of the visual loss, and they can no longer do things for their friends and families as before.

### Lower workforce participation<sup>61</sup>

People with vision impairment experience lower employment rates as it often poses barriers to employment opportunities. The rate of unemployment of people with vision impairment is more than four times that of the Australian population, which is at 5.4%.

Although there is a relatively small proportion of children with vision loss as a result of macular disease, there are large potential productivity impacts expected to occur over the working lives of these children.<sup>62</sup>

### Impact on psychological health

People frequently experience psychological stress during the early stage of illness and at the initial signs of vision loss. Depression is common, and people experience feelings of grief for the loss of their sight and independence.

There is also an impact on families and carers. They may also go through a transition process themselves, adjusting to a change in roles, and potentially taking on a role as carer.

## Financial impacts

The aggregated data on health system expenditure for various eye conditions are available from the Australian Institute of Health and Welfare (AIHW) by special request. This dataset includes the costs of hospital admitted services, out-of-hospital medical services, pharmaceuticals requiring a prescription and research for eye diseases.<sup>63</sup> However, such data are not specific to macular disease therefore direct health care expenditure related specifically to macular disease cannot be accurately estimated.

However, indirect financial and wellbeing costs associated with DME were estimated in 2015 to amount to approximately \$2.07 billion. Productivity losses from lower workforce participation and absenteeism as a result of DME totaled approximately \$570 million.<sup>64</sup>

There are a range of indirect costs, such as productivity losses for people of working age who have macular disease, and the cost of providing care for people living with macular disease. Informal carers provide care to others in need of assistance or support on an unpaid basis. Most informal carers are family or friends of the person receiving care. Carers may take time off work to accompany people with vision loss to appointments, stay with them in hospital, or care for them at home. This includes those responsible for a child impacted by macular disease.<sup>65</sup>

### The estimated cost of vision loss

In 2009, the total financial cost of vision loss in Australia (excluding loss of wellbeing) was estimated to be \$7.2 billion. This includes the following:<sup>66</sup>

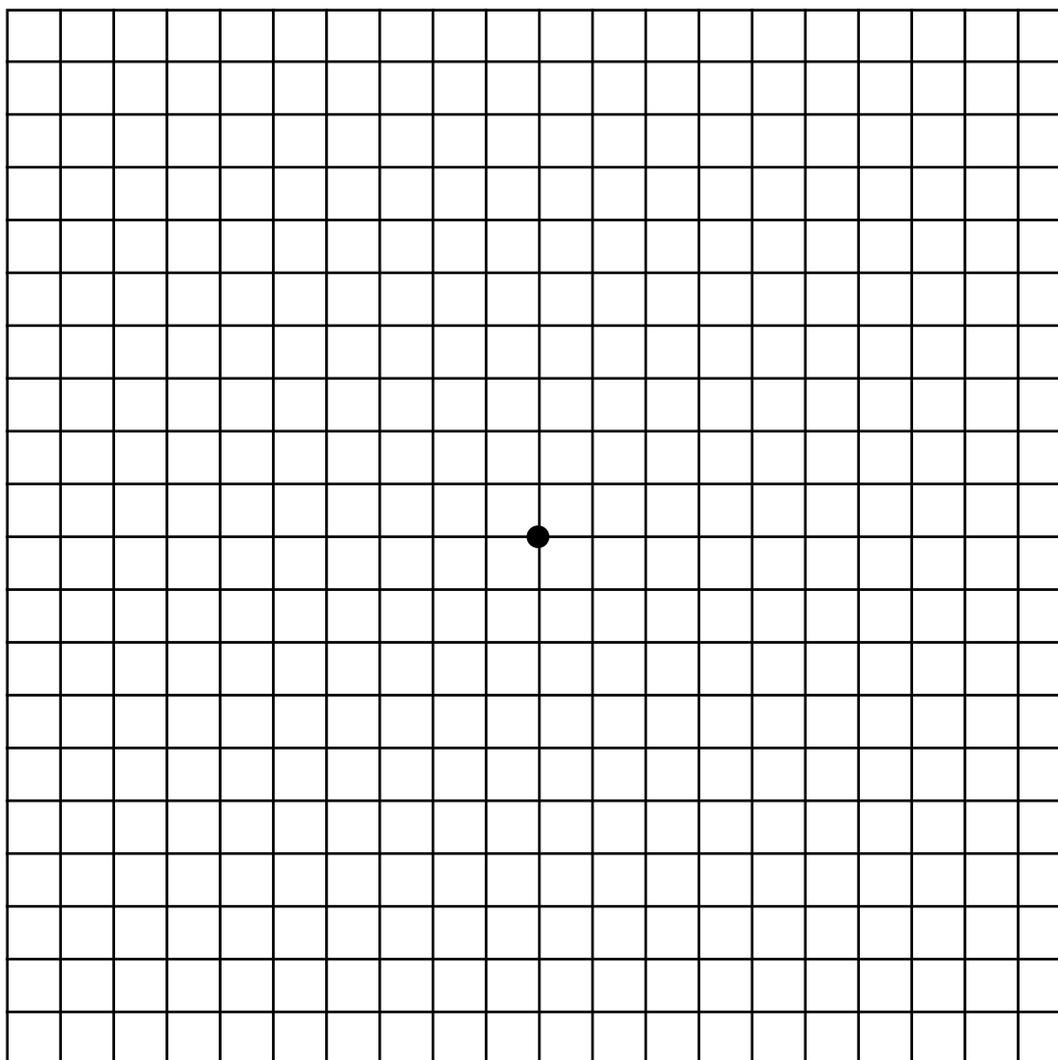
- Productivity losses of those with low vision and blindness were approximately \$2.3 billion in 2009. This included losses due to lower than average employment rates (adjusted for age) of those with low vision, losses resulting from premature mortality, and the 'bring forward' of employer search and hiring costs due to premature mortality.
- Productivity losses of family and friends who care for people with low vision and blindness on an unpaid basis were around \$251 million. This reflects the opportunity cost of informal carers' time.
- The monetary value of the loss of well-being in 2009 was \$9.4 billion. If this is added to the financial costs, the overall cost of vision loss in 2009 was \$16.6 billion.

# Appendix B: Amsler Grid

**The Amsler grid is an essential, 'easy to use' self-monitoring tool that can detect changes in vision.**

It is a grid of horizontal and vertical lines used to monitor a person's central visual field. People over the age of 50 should test for symptoms of AMD at home once a week using an Amsler grid.

Those already diagnosed with AMD (or early signs of the disease) should use the Amsler grid every day.



## **How to use the Amsler grid:**

- Wear the glasses or contact lenses you normally use for reading
- Hold the Amsler grid at normal reading distance in a well-lit room
- Fully cover one eye then use the uncovered eye to focus on the centre dot
- Repeat the process with the other eye.

When used in this way, one eye at a time, potential issues can be identified in individual eyes. These changes may include distortion of lines – for example, straight lines may appear wavy or bent. Additionally, dark patches in central vision may appear.

The Amsler grid should not be relied upon for medical diagnosis or replace a professional eye exam or macular check. Any sudden changes in vision noticed while using an Amsler grid should be reported immediately to the eye health professional.

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