



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

# **National Strategic Action Plan for Macular Disease - Evidence Appendix**

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**March 2019**



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# Introduction

In May 2018 the Australian Government announced funding to Macular Disease Foundation Australia (MDFA) to lead the development of a National Strategic Action Plan ('Action Plan') to better support people with macular disease. Macular disease being the leading cause of severe vision loss and blindness in Australia.

The Action Plan is Australia's national response to macular disease with the goal of reducing 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.

The Action Plan contains four key areas of focus and action:

1. Prevention and early detection
2. Treatment
3. Support
4. Data and research

This background paper has been prepared to provide the evidence and rationale that supports the recommended actions in the Action Plan.





## **Pillar 1 – Prevention and early detection**

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

## **Pillar 2 – Treatment**

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

## **Pillar 3 - Support**

*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*

## **Pillar 4 - Data and research**

*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*



# 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>1</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 age-related macular degeneration (AMD) raises risk by as much as 50%<sup>2</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>3</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>4</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>5</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>6</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.

**Rationale:** There are many examples of effective education campaigns that have improved consumer understanding of risk and disease including anti-HIV, Quit Smoking and more. This recommended action directly aligns with recommendations in the 2017 *National Strategic Framework for Chronic Disease* (Strategic Priority Area 1.4). The strategic priority area shows that timely and appropriate detection and intervention reduces the risk of chronic conditions and/or disease severity, through delayed progression of disease, and improved health outcomes and quality of life.<sup>7</sup>

Given the scale of increasing prevalence of macular disease as well as the amount of people who are at risk, strengthening public education campaigns will ensure improved understanding of risk and disease to effect behavioural change in Australians at risk of macular disease.

#### 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.

**Rationale:** National education campaigns have proven to have a significant impact on consumer behaviour. For example, Macular Disease Foundation Australia's (MDFA) previously sponsored national campaigns resulting in a change from 1 in 3 (1.9 million) people in 2007 to 2 in 3 (6.6 million) people in 2016 over 50 years of age having regular eye examinations including a check of the macula.<sup>8</sup> However, with reduced funding to implement campaigns in 2015 and 2016, awareness of AMD and risk factors dropped from 82% in 2014 to 73% in 2016.<sup>9</sup>

#### 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 diabetic retinopathy (DR), including diabetic macular edema (DME).
- Minimise the risk of developing DR through good diabetes management.

**Rationale:** The collective impact model is recognised as an effective model to solve large scale social problems.<sup>10</sup> An example of this is the Australian Government's Partners in Recovery (PIR) program whereby several agencies worked collaboratively to bring about improved service models in mental health resulting in better consumer outcomes.<sup>11</sup> The increasing prevalence of DR in Australia means that collaboration between expert bodies such as Diabetes Australia and MDFA is necessary for measurable change.

**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.

*Rationale:* This action is underpinned by Australia’s Closing the Gap policy whereby cultural competency is a key strategy for reducing inequalities in healthcare access and improving the quality and effectiveness of care for Aboriginal and Torres Strait Islander people. Australia’s multicultural policy commits to an access and equity framework that all government services and programs must be responsive to the needs of our culturally diverse communities.<sup>12</sup>

Given the higher rates of blindness in Aboriginal and Torres Strait Islander Australians<sup>13</sup>, and the number of culturally and linguistically diverse (CALD) communities in Australia, the need for tailored information is essential so that people at risk can self-identify, take action and manage their condition.

**1.5 Establish mechanisms for regular evaluation and improvement of education campaigns to make sure there is a measurable positive impact.**

*Rationale:* The proposed evaluation mechanism is based on the globally recognised Theory of Change model to measure outcomes, understand which strategies and messaging have greatest impact and to inform continual improvement. The Theory of Change framework supports informed decision making across the eco-system for better patient outcomes.

**1.6 Increase the availability of genetic testing and counselling for people with a macular disease with genetic causation.**

*Rationale:* For Australians with inherited retinal disease affecting the macula, genetic testing can in many cases determine which mutation and gene is causing the disease. Genetic testing to confirm diagnosis as well as genetic counselling services to help better understand and cope with a genetic condition are available in most states across Australia, however, not all facilities offer genetic testing for eye conditions, particularly inherited retinal disease.<sup>14</sup> Likewise, there is general lack of knowledge and awareness about the role of genetic testing and available services.

Prevalence data is lacking on the exact number of cases of many rare genetic eye conditions – mainly due to the lack of specialised genetic diagnosis. There is a lack of infrastructure for careful retinal phenotyping, which is key to genetic analysis. Testing is often undertaken ad hoc and many general ophthalmologists may not be in a position to discuss pathogenicity because it is a highly specialised area of ophthalmology. Improved education and awareness of inherited retinal disorders by ophthalmologists and optometrists would also be valuable to reduce the time delay in getting the correct diagnosis through genetic testing.<sup>15</sup>

The Australian Inherited Retinal Disease Register and DNA Bank, supported by Charles Gairdner Hospital in Western Australia is a research resource which collects DNA from consenting participants from all over Australia and genetically analyses this DNA in order to establish the cause of a participants inherited retinal disease.<sup>16</sup> Many institutions around Australia rely on the expertise of this service for genetic analysis of patients with inherited retinal diseases.

## 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.**

*Rationale:* Given the importance of lifestyle and diet in optimising macular health and reducing the risk of certain types of macular disease such as AMD and DR<sup>17</sup>, this action serves to work in collaboration with like-minded agencies, such as Diabetes Australia and Heart Foundation Australia, to leverage health promotion messaging where possible. Communicating key messages through multiple channels will have greater impact in influencing real change across the Australian population.

**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.

*Rationale:* This action aligns with the Australian Government’s Digital Health Strategy.<sup>18</sup> Australian healthcare consumers are increasingly using digital technology to access information and manage their care. MDFA’s Health Survey (Feb 2018) found people with macular disease prefer to access information, education and navigational support through increasing use of technology and online resources. Proposed technology will e-manage their care by leveraging more cost-effective technology options in access to education.

**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.

*Rationale:* GPs play a key role in supporting health literacy amongst Australians with chronic disease and can also play an important role in eye health and vision care. They can treat minor eye conditions and help identify patients who are at risk of eye disease and educate them about the importance of regular eye examinations. However, because the detection of eye disease involves specialized testing and diagnostic equipment not readily available in general medical practices, many GPs rely on eye care professional to take care of the needs of patients with eye conditions. Nevertheless, targeted education, training and support for GPs would ensure they continue to play an important role in eye health and vision care.

RANZCO held campaigns in 2015 to educate GPs about common eye conditions, through workshops held across the country. The workshops were presented by experienced ophthalmologists and continuing professional development (CPD) points were given to GPs who attended.<sup>19</sup>

‘Vision Initiative’, an integrated eye health promotion program funded by the Victorian Government and managed by Vision 2020 Australia collaborated with RANZCO, Optometry Victoria and ThinkGP (a CPD education platform) in 2009 to develop an online education module titled ‘Common eye conditions’ designed to provide general information about eye disease and indications for appropriate referral.<sup>20</sup> This has since been updated and is available via the ThinkGP website.<sup>21</sup>

MDFA provides free resources to health care professionals including GPs and has also contributed to targeted education of GPs about macular disease through articles in GP journals.<sup>22</sup>

Targeted education programs and resources specifically related to macular disease will enable GPs educate patients and help identify those who are at risk of macular disease and look for signs and symptoms in their patients and refer them appropriately to eye care professionals for early detection of disease through comprehensive eye examinations.

**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.



**Rationale:** Eye health professionals such as optometrists are key partners in promoting early and regular screening and detection of macular disease. Optometry Australia run regular education programs with their members and inclusion of education about macular disease (the leading cause of severe vision loss and blindness in Australia), information about research breakthroughs and provision of practical resources will be key enablers for earlier detection and management of macular disease.

**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.**

**Rationale:** Pharmacies are in a unique position to take a role in educating their clients on macular disease, as many Australians at risk and living with macular disease, especially those with age-related disease, would be accessing pharmacy services for other co-morbidities. Through knowledge obtained via online platforms, community pharmacists would be in a better position to promote the prevention, early detection and/or management of macular disease. This would help ensure that people at risk or living with macular disease access services sooner to help preserve sight.

The Pharmacy Guild Australia (PGA) administers and supports a range of professional programs and services. For example, PGA operates Guild Learning and Development, providing excellent online training, support and continuing professional development (CPD) to pharmacists, pharmacy staff and interns to ensure better health care services by community pharmacies.<sup>23</sup>

An existing program in Victoria called Vision Initiative, funded by the Victorian Government and managed by Vision 2020 Australia, aims to prevent avoidable blindness and address impact of vision loss in the Victorian community. Their 'Working eye-to-eye with optometry for better patient care' program is a free online webinar developed in 2018 in partnership with the Pharmaceutical Society of Australia – Victorian Branch, which provides up-to-date information on general eye health and vision care for practicing pharmacists.<sup>24</sup>

**1.12 Promote the development and delivery of specialised eye health training in general health professional training programs by specialist bodies such as the Royal Australian and New Zealand College of Ophthalmologists (RANZCO).**

**Rationale:** RANZCO, being the medical college responsible for the training and professional development of ophthalmologists in Australia and New Zealand, has conducted education workshops for GPs about eye health and common eye conditions.<sup>25</sup> This type of education could be further developed and delivered during the training of GPs and other general health professionals, which would ensure that those professionals once they graduate have adequate knowledge and understanding of eye health to provide optimum care for their patients, including their eye care needs. Other bodies such as Optometry Australia could also be involved in developing and delivering this training in general health professional training programs.

**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.

**Rationale:** MDFA's 'vision and eye healthcare study in residential aged care facilities' showed that there is an urgent need for reform of vision care within the residential aged care system. The study found that over 70% of residents who participated were found to have some form of eye disease, almost 30% had untreated cataracts, and of particular note, more than 60% had some degree of AMD.<sup>26</sup> The Australian Government Department of Health funded this study and the development of online training resources for aged care staff to incorporate vision checks as part of the care planning and review process.<sup>27</sup> Given that during 2017-18 there were 234,798 older Australians living in aged care facilities<sup>28</sup>, the aim is to reduce the number of undiagnosed eye disease and subsequently reduce the number of related falls.

## 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, retinal vein occlusion (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>29</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.**

*Rationale:* Public hospitals/clinics are jointly funded by federal and state/territory governments, but essentially managed by the states/territories by arrangement formalised through the National Healthcare Agreement and the National Health Reform Agreement.<sup>30</sup> The vast majority of treatment is being conducted in ophthalmologists’ private rooms, and not all public hospitals/clinics provide a full range of services, with ophthalmology generally being limited to larger metropolitan hospitals, teaching hospitals and some larger hospitals in regional centres.<sup>31</sup>

Importantly, although registered medicines used to treat macular disease are well funded on the PBS, the provision of free eye injections (intravitreal injections) which are highly effective for treating conditions such as wet AMD, DME, RVO and others, is generally limited to outpatient clinics in a few large hospitals in each state capital.<sup>32</sup> Some of these clinics have long waiting lists; others attempt to move patients into the private sector once they have been stabilised and some are not accepting new patients.<sup>33</sup> Likewise, only a very limited number of public outpatient eye injection clinics are available in rural and regional areas.<sup>34</sup> Exact knowledge of which hospital/clinics offer this treatment option is also limited.

Publicly available services for macular disease ensure that Australians who cannot afford private treatment are able to access treatment. Access and persistence to treatment leads to better health outcomes for Australians with macular disease by maintaining best functional vision for as long as possible, improving independence and quality of life and allowing people to work for as long as possible.

### 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.**

*Rationale:* Guidelines reflect evidence-based practice and ensure effective and efficient patient care and management of disease, which ultimately leads to improved health outcomes for all Australians.

There are currently no nationally endorsed clinical practice guidelines in Australia for the management of AMD. However, RANZCO has developed New Zealand guidelines for the management of wet (neovascular) AMD.<sup>35</sup> Optometry Australia is developing clinical practice guidelines for its members on the management of AMD and has already developed guidelines for diabetes, glaucoma and anterior eye conditions.<sup>36</sup>

NHMRC guidelines for the management of diabetic retinopathy were developed in 2008.<sup>37</sup>

There have been no revisions since then, yet there have been changes over the past decade in the diagnosis and management of diabetic retinopathy (including diabetic macular edema), which would need to be updated and reflected in the guidelines. There are also 2010 NHMRC guidelines for glaucoma<sup>38</sup>, however, none for AMD.

RANZCO, as part of their collaborative care model, has developed referral pathways for both AMD and DR management.<sup>39</sup> Although these are not formal guidelines, they serve to provide health professionals

(namely optometrists and GPs) with information and recommendations based on best practice, to use in identifying and referring potential cases of AMD and DR for specialist care.

A modern approach would be that specialist bodies such as RANZCO could take a lead in developing Australian guidelines for the management of AMD as well as updating the 2008 NHMRC guidelines for diabetic retinopathy, after which NHMRC endorsement of these guidelines could then be sought.

## 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.**

*Rationale:* While registered medicines for macular disease are subsidised through the PBS and MBS rebates eliminate the need for people to pay for their treatment entirely out of their own pockets, people with macular disease such as wet (neovascular) AMD, DME, RVO and others can incur significant out-of-pocket (OOP) costs associated with consultations, diagnostic testing and injection procedures related to their treatment.<sup>40</sup> Due to the chronic nature of some conditions such as wet (neovascular) AMD, treatment with intravitreal injections in many cases is ongoing and indefinite. For some people, OOP costs can be high, especially until the Extended Medicare Safety Net (EMSN) is applied.<sup>41</sup> Ophthalmologist fees can vary significantly, as medical practitioners are permitted to charge in excess of the MBS rebate, and few ophthalmologists bulk-bill for treatment.<sup>42</sup>

MDFA provides basic information about treatment costs and rebates to its clients on its website and through a downloadable factsheet.<sup>43</sup> Improved knowledge and information, especially before treatment will result in patients being better informed about the costs associated with treatment so that measures can be taken to ensure continuity and adherence, in order to maintain best functional vision and remain independent and/or working for as long as possible.

### **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.**

*Rationale:* Australia's small population, advanced economy and nationalised, universal health system delivers some of the best health outcomes globally. Registered medicines which are subsidised by the PBS, as well as subsidies through the MBS for consultation, diagnostic testing and procedures relating to treatment eliminate the need for Australians to pay for their treatment entirely out of their own pockets.<sup>44</sup> Expanded subsidies for existing medicines as well as subsidies for new medicines and treatments which have the potential to preserve and in some cases improve vision will not only ensure cost savings to patients, but will allow better access to treatment which will keep people independent and/or working for as long as possible.

### **2.6 Review the impact of any change in Medicare rebates and the Medicare Safety Net for item numbers related to macular disease.**

*Rationale:* Many Australians, pensioners in particular can incur significant out-of-pocket (OOP) costs associated with consultations, diagnostic testing and procedures associated with treatment of their macular disease. For some people, these costs can be high, particularly until the Extended Medicare Safety Net (EMSN) is applied.<sup>45</sup> The burden of increased yearly OOP costs, especially for pensioners who require repeated and indefinite treatment, would eventually reach an unsustainable point that they will be unable to afford ongoing treatment.

Recent studies have shown that cost of treatment has been a major factor associated with around 20-25% of patients being lost to follow-up for macular conditions such as wet (neovascular) AMD and DME within 12 months of receiving treatment.<sup>46,47</sup>

By stopping such effective treatment, there is a high risk of irreversible vision loss and permanent legal blindness. Losing vision will lower the quality of life for patients, requiring them to access higher levels of support from the health and aged care systems, resulting in higher costs to government.

### **2.7 Pursue optical coherence tomography (OCT) Medicare rebates for the ongoing monitoring of macular disease, through collaboration with eye health professional organisations.**

*Rationale:* An OCT scan shows the cross-sectional layers of the retina. It is initially performed to confirm a diagnosis, and is also undertaken on a regular basis while undergoing injections for macular disease in order to monitor response to treatment.<sup>48</sup>



From November 2016, reimbursement for OCT is for an initial diagnosis only (MBS item 11219), to confirm eligibility for PBS-funded medicine used for treatment, with a maximum of one reimbursement per year.<sup>49</sup> OCT scans for ongoing monitoring of disease are not currently reimbursed by Medicare.<sup>50</sup>

For many patients with macular disease, treatment may be indefinite. The need for ongoing OCT scans to monitor disease and response to treatment can lead to accumulating out-of-pocket costs to patients. Medicare rebates for the ongoing monitoring of macular disease would reduce out-of-pocket costs to patients.

## 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.**

**Rationale:** The development of innovative service models would aim to address a substantial market failure for specialist medical services in rural and remote Australia. There is still a lack of information and access to such services, contributing to poorer health outcomes in these areas. Although there are some innovative service models relating to eye health in rural and remote Australia, these are however locally-specific programs, designed by local ophthalmologists, and are shaped around the needs and conditions in each region.<sup>51</sup>

One example of a local approach is the Lions Outback Vision Program (Lions Eye Institute), which operates in Western Australia and provides coordinated visits by ophthalmologists to regional communities across the state.<sup>52</sup> The Lions Outback Vision Van is a mobile eye health clinic consisting of three consulting rooms with specialist equipment, providing regional ophthalmology care for eye conditions such as cataracts, trachoma, glaucoma and diabetic retinopathy.<sup>53</sup>

### **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.**

**Rationale:** With many public hospital eye clinics at capacity and limited availability of public eye clinics in rural and remote locations, redistribution of aspects of eye health care to different roles is paramount to increasing the capacity of ophthalmologists to treat macular disease. The role of optometrists in delivering primary eye health and vision care services is well recognised. All optometrists in Australia must be registered with the Optometry Board of Australia (OBA), an entity of the Australian Health Practitioners Regulation Agency (AHPRA). Optometrists are well trained to screen and detect eye disease and know when to refer to ophthalmologists for specialist care. In Australia, optometrists are able to use medicated eye drops for diagnostic procedures and are authorised to possess, use and prescribe scheduled medicines such as anti-inflammatory and corticosteroid eye drops to treat eye diseases such as conjunctivitis, keratitis and others.<sup>54</sup> Because of their skills, optometrists work in a variety of settings, including sessional work in eye clinics at public hospitals, as well as providing eye care to regional, rural and remote communities as well as Aboriginal and Torres Strait Islander communities through visiting services, such as the Visiting Optometrists Scheme.<sup>55,56</sup>

Orthoptists are eye health professionals that play a crucial role in the detection, diagnosis and management of eye diseases in both adults and children.<sup>57</sup> Most orthoptists work alongside ophthalmologists in investigating and managing patients with eye disease.<sup>58</sup> The role of the orthoptist is continuously evolving and they are in a unique position to help increase the capacity of ophthalmologists because of the close working relationship between both professions.

In the United Kingdom (UK), this has seen the role and responsibilities of the orthoptist extend into specialised areas such as monitoring of glaucoma and AMD. In many National Health Service (NHS) hospitals, there are dedicated glaucoma and macula clinics run by specialist orthoptists, in collaboration with ophthalmologists, to monitor stable patients to ensure efficacy of treatment, determine when treatment is needed and watch for any progression of disease.<sup>59,60,61</sup> Likewise, in some NHS hospitals, the role of the orthoptist has been extended to include administering anti-VEGF intravitreal injections for the treatment of wet (neovascular) AMD under supervision of ophthalmologists.<sup>62</sup> Before being able to administer injections, orthoptists undertake practical and theoretical training and many NHS hospitals are developing clinical guidelines for orthoptists to administer intravitreal injections.<sup>63</sup> Although the UK health system differs from the Australian health system in many respects, these innovative models are examples of ways in which aspects of eye health have been redistributed to other roles to increase capacity.

In 2016, representatives of State based Ophthalmic Nursing Associations formalised the Australian Ophthalmic Nurses Associations National Council (AONANC), to seek to include ophthalmic nurses in the wider national and global vision dialogue and strategies.<sup>64</sup> In 2018, the AONANC launched the first professional practice standards for ophthalmic nurses in Australia, to provide a foundation for a better understanding of their role in supporting the wider eye care sector to reach the collective national eye care needs.<sup>65</sup>

Through specific training and skill-building, a multidisciplinary approach to public health care through increased and better utilisation of optometrists, orthoptists and ophthalmic nurses in public hospital, and rural and remote settings would increase the capacity of ophthalmologists to treat those patients who are in most need of specialist care.

**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.**

*Rationale:* Culturally appropriate services deliver the best patient outcomes for rural and remote Aboriginal and Torres Strait Islander communities. Mainstream services may have difficulty gaining access and trust with these communities. Empowering local health workers who have local skills and knowledge can lead to effective and sustainable interventions and ultimately better outcomes.<sup>66</sup>

Strong advice from health leaders engaged as part of the development of the Vision 2020 Australia 5-year plan was that local community members, particularly those accessing treatment can find it intimidating on a number of fronts, and can benefit significantly from having local people who they know and trust involved.<sup>67</sup> Other members have reported stronger success in engaging, and keeping people engaged in treatment where there is the involvement of local people who are attuned to local circumstances, culture and other key factors and know how to best navigate and integrate eye care and broader health systems.<sup>68</sup>

To demonstrate the importance of culturally appropriate services, the Australian Health Practitioner Regulation Agency (AHPRA) has committed to work with Aboriginal and Torres Strait Islander health leaders to embed cultural safety in the way they work as regulators, and making it an important part of how registered practitioners practise.<sup>69</sup> A strategy group represented by 37 organisations has been formed to lead this work, part of which is to embed cultural safety into standards, codes and guidelines for practitioners.<sup>70</sup>

**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.**

*Rationale:* RHOF is a successful Australian Government initiative to support the delivery of, and improve access to, medical specialist, GP, nursing and allied health services in rural and remote Australia. Eye health is one of the four priority areas of the RHOF.<sup>71</sup>

## 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.**

*Rationale:* New and improved treatments for macular disease have the potential to preserve vision and maintain quality of life. Research is being undertaken both nationally and internationally to develop treatments for macular conditions for which there is currently no treatment (eg. early AMD and late dry (atrophic) AMD and others), as well as treatment to prevent and slow progression of disease. Rapid adoption of effective and efficient evidence-based treatment innovations will lead to better patient outcomes.

For example, the introduction of highly effective anti-VEGF treatment to Australia revolutionised the management of wet (neovascular) AMD, an advanced stage of AMD.<sup>72</sup> For the first time, it became possible to save sight in a significant proportion of Australians with this form of the disease.<sup>73</sup> Anti-VEGF treatments are considered one of the most significant medical developments in the history of ophthalmology.<sup>74</sup>

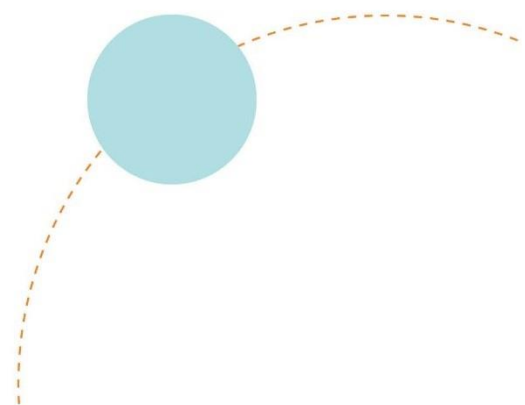
## Explore innovative disruptive technologies and strategies to support people with treatment adherence

**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.**

*Rationale:* Innovative disruptive technologies and strategies can be more cost effective compared with traditional means of delivering health services. For example, Telemedicine / Telehealth initiatives have worked well in other countries to assist local eye care professionals not only in the diagnosis and management of eye diseases, but also in reducing outpatient appointments at health facilities, non-adherence rates and waiting times.<sup>75</sup> Disruptive technologies and strategies could help improve access and quality of care for rural and remote Australians with macular disease, ultimately improving outcomes at a reduced total cost to the health system.

### 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>76</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>77</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>78</sup>

There is rising demand for low vision support services.<sup>79</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>80</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.**

*Rationale:* The National Macular Health Patient Portal will address the key challenges identified by the CSIRO regarding the future of the Australian healthcare system:<sup>81</sup>

- A continued and increasing need to support the ageing population and better manage chronic disease and mental health and wellbeing.
- Substantially improving national health outcomes require the provision of quality health services for all Australians and shifting away from a one-size-fits-all service model.
- Consumers are demanding more from their healthcare experiences and embracing new technology for low-risk decision making relating to their health.
- Increasing consumer’s trust, knowledge and access to a more integrated and data-enabled health system.
- Fragmented and inflexible health systems due to multiple and complex funding arrangements, siloed data streams, ever-evolving regulatory requirements and dated infrastructures.
- Unsustainable financing, with costs and the dependency ratio continuing to rise, placing significant financial pressure on all stakeholders.

The Portal is also aligned to the National Digital Health Strategy as it aims to provide digital solutions to:<sup>82</sup>

- better coordinate care and better inform treatment decisions;
- contributing to a more efficient health system, through less time searching for patient data, reduction of avoidable hospitalisations, and reduced duplicated ophthalmology tests and x-rays which inconveniences patients and increases the cost of healthcare;
- improve patient experience by putting the patient at the centre of their healthcare, and keeping people out of hospital;



- provide greater access to healthcare for people living in rural and remote areas of Australia;
- protect the national digital health infrastructure and secure the personal health information of Australians.

### 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.**

*Rationale:* The benefits of group peer support are wide-ranging and can include the provision of a safe environment to freely express and share emotions and thoughts about one’s current situation and challenges; sharing of information and experiences and learning from others in similar situations that can help provide ideas and solutions to overcome challenges that group members are facing; the opportunity to build new relationships and strengthen social support networks which helps to reduce isolation and feelings of loneliness; sharing of knowledge about available community resources and practical support to help group members access resources and support, for example, helping others complete administrative procedures to access social and disability benefits, employment programs and so on.<sup>83</sup>

The National Self-Management Support Program will be based on the design of the successful Macular Support Groups by The Macular Society in the UK. It has over 400 Macular Support Groups which are run by volunteers and supported by regional managers.<sup>84</sup>

### 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.**

*Rationale:* The National Hearing Program is a proven model that provides access to subsidised hearing aids and services to eligible Australians irrespective of where they live.<sup>85</sup> For Australians with low vision, access to similar subsidised vision aids and equipment is limited and dependent on which jurisdiction you live. Low vision aids are currently not covered under Medicare, therefore people who cannot afford to purchase devices privately rely on either national or state-based subsidies to cover the cost. Subsidised programs supporting access to low vision services and aids vary from state to state. Some states currently have no provisions around access to low vision aids through current disability equipment schemes. The states that do provide aids have limitations such as low subsidies, co-payments and different eligibility criteria. The National Disability Insurance Scheme (NDIS) excludes the majority of people with vision loss who have not progressed to legal blindness, and those who are aged 65 years or over. Aged care consumers receive home care or residential care packages, which are not designed to provide funding for low vision aids and technologies.<sup>86</sup>

### 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.**

*Rationale:* Funding of low vision aids and technologies by private health insurers in ‘Extras’ policies is variable and mostly very limited in scale. This is despite near universal coverage of hearing aids and spectacles in these policies. Not all private health insurers offer rebates for low vision aids, equipment and assistive technologies, and those that do, only provide it at the higher and more expensive levels of cover.<sup>87</sup>

## 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.**

*Rationale:* The Australian Government's Employment Assistance Fund (EAF) provides financial assistance to eligible people with disability and mental health conditions and employers to buy work related modifications, equipment, Auslan services and workplace assistance and support services.<sup>88</sup> Despite this, a survey of blind and partially sighted adults in Australia, New Zealand and Canada found that Australia had the lowest full-time employment rate at 24%. However, the full-time employment rate among the general public in these countries, in some cases, were nearly double that.<sup>89</sup> More needs to be done to improve the employment rate for people with vision loss or blindness and employer groups and peak bodies have a key role to play in effecting change.

### **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.**

*Rationale:* Vision impairment can result in both physical and mental challenges that result in social isolation. The use of navigation aids such as white or electronic canes and other low vision aids and technologies, such as navigation and orientation apps and training, can greatly assist a person to live in their home independently, safely and with confidence. Depressive and anxiety disorders attributed to low vision can also affect a person's ability and capacity to participate as a functioning and independent member of their community. Anxiety disorders such as agoraphobia (fear of open/public spaces) and social phobia, have been identified as being significantly higher among visually impaired older adults, indicating susceptibility to disorders related to places or situations, such as being on a bus or in a crowd, and social situations, such as speaking in public or eating in the company of others. Experiencing anxiety disorders increases the risk of social isolation, which has been linked to mortality among older people.<sup>90</sup>

## 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.**

*Rationale:* The National Disability Strategy outlines a unified, national approach, with commitment from the Commonwealth and state and territory governments, to improving the lives of people with disability, their families and carers, and to providing leadership for a community-wide shift in attitudes.<sup>91</sup> The aim of this action is to develop a national accessibility implementation plan that identifies and coordinates the disability programs in all jurisdictions, in a manner that effectively and efficiently supports people with low vision or blindness.

### **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.**

*Rationale:* Currently there is no government endorsed print accessibility guidelines in Australia. Vision Australia<sup>92</sup> and VisAbility<sup>93</sup> are examples of Australian guidelines, and CNIB from Canada<sup>94</sup> also has published guidelines. Policies relating to print accessibility in Australia have to adhere to the Disability Discrimination Act 1992.<sup>95</sup> Commonwealth and state and territory government endorsement for a set of print accessibility guidelines can establish policies based on world's best practice, that have the authority to positively influence government and non-government stakeholders when developing signage and print materials.

### 3.9 Improve the capture of information about consumers' low vision needs, and referral to low vision services, through the aged care assessment process.

**Rationale:** The aged care assessment process could identify and adequately capture the low vision needs of clients, so that assessors can appropriately refer people to low vision services. Without such information, clients are often provided with services that may not appropriately meet their needs. Although the National Screening and Assessment Form (NSAF) captures limited information about vision and eye conditions, the capturing of such information can be improved.<sup>96</sup> Supplementary, clinically-validated assessment tools are included as part of the NSAF and may be used by an assessor to inform a holistic assessment of a client's needs, but these tools do not include any vision assessment tools.<sup>97,98</sup> Clients, for example, may be provided with personal assistance through support workers, instead of low vision aids and technologies which can be more beneficial in enhancing their independence. NSAF, and the knowledge and skills of the aged care workforce are primarily focussed on supporting people's frail ageing needs without necessarily addressing their disability needs.

#### 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>99</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>100</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>101</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.**

*Rationale:* “Improved data access and use can enable new products and services that transform everyday life, drive efficiency and safety, create productivity gains and allow better decision making”.<sup>102</sup> Better utilisation of existing data and improved capture of data provides an evidence base to allow clinicians to make informed decisions to improve quality of care.<sup>103,104</sup> It also provides for a better understanding of the outcomes and impact of treatment and support interventions. Data can also help evaluate programs, support decision regarding healthcare planning and allocation of resources, and help measure return on investment.

The collection and use of big data provides the opportunity to prioritise preventative eye health interventions, advance medical and pharmaceutical innovation, improve efficiencies in healthcare delivery and ultimately improve the quality of life of Australians with or at risk of macular disease.<sup>105</sup> Investigating the feasibility of linking databases and data sets would need to be made taking into account the legislative and regulatory requirements surrounding privacy and security of 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**

*Rationale:* Globally, there is an increasing trend to use real-world data to inform decision making in health care. Real-world data are often collected and used in a patient registry. Considering the unique value of, and increasing demand for real-world evidence, patient registries are an innovative solution to facilitate the collection of real-world data for health care decision-making and could become the new standard.<sup>106</sup>

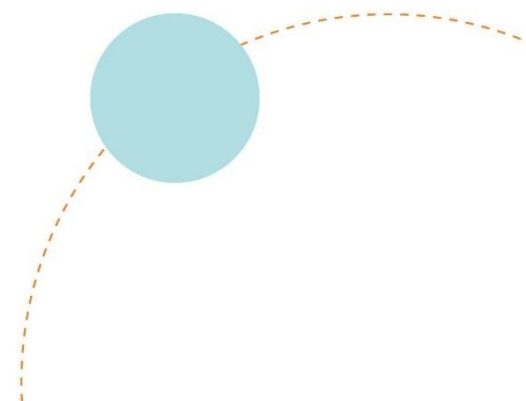
The National Macular Health Patient Data Hub would be an innovative IT health solution that would capture patient reported outcomes and patient reported experiences within the eye health care system. It would be designed to serve as a repository of real-world data that can be used to support better clinical decision making, improve care and service provision, identify health issues within disease communities as well as factors which may contribute to the cause and impact of macular disease. The data would be used not only for research, but also to inform policy development and target taxpayer investment to areas to where it is most needed.



## 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.**

*Rationale:* A national research agenda would focus and promote research aimed at improving health outcomes for Australians with macular disease. It will help define research goals and serve to inform and provide guidance on priority areas for research funding. In the development of the Action Plan, the above listed priority areas were identified from input during workshop consultations with stakeholders. The national research agenda highlights key areas where research should be focussed in order to improve health outcomes, reduce impact and improve quality of life for Australians living with or at risk of macular disease.



## 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.**

*Rationale:* Clinical trials are critically important for eye health, to better understand the causes and impact of disease, as well as the development and testing of new treatments. Although Australia has an efficient regulatory pathway for clinical trials, successful recruitment and retention of participants still remains a major challenge<sup>107</sup>, particularly for trials related to eye research. Challenges include the lack of understanding and awareness about clinical trials, little knowledge about what trials are being conducted, inappropriate communication methods to raise awareness and identification of appropriate participants.<sup>108,109</sup>

The Clinical Trials Action Group (CTAG) was formed in 2009 to identify and progress necessary reforms in the clinical trials sector and has made recommendations to improve recruitment.<sup>110</sup> One initiative was to develop the website <https://www.australianclinicaltrials.gov.au> which is helping to improve awareness and support for patient recruitment to clinical trials.<sup>111</sup>

The Australian Government has also invested in the Australian Clinical Trials Alliance to help build the capacity of new and existing Clinical Trials Networks (CTNs) and to help provide better access to, and increase recruitment of patients into clinical trials across Australia.<sup>112</sup> The development of an Australian Research Collaboration Framework specifically for eye health research would help bring together existing organisations, activities and initiatives to support recruitment and retention of participants for clinical trials specifically related to eye health.

## 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.**

*Rationale:* Eye health research is paramount to understanding the causes and impact of disease, as well as the development and testing of new treatments and ultimately cures. Australia is recognised as a world leader in macular disease research, with major Australian research institutions involved in large clinical trials of potential treatments, as well as focussed development of interventions, which aim to prevent and slow down progression of disease.

Australia has also produced leading research into eye health, in particular, the Blue Mountains Eye Study, one of the first large population-based studies of eye disease and visual impairment in Australia, and globally recognised as one of the landmark studies in ophthalmic epidemiology.<sup>113,114</sup>

Historically, major funding for eye research has been sourced from the highly competitive National Health and Medical Research Council (NHMRC) and Australian Research Council (ARC) funding pools, although these grants are becoming increasingly difficult to obtain.

The Medical Research Future Fund (MRFF) is a priority-based funding pool, and although MRFF has funded research related to eye health, it is currently not one of its specific priorities.<sup>115,116</sup> Other sources of funding include research grant programs from organisations such as MDFA, Retina Australia and Ophthalmic Research Institute of Australia (ORIA).

Given the breadth and depth of research needed, the growing ageing population and prevalence of macular disease, and the potential burden of disease, additional investment is required.

## 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.**

*Rationale:* The development of Artificial Intelligence (AI) systems for detection, diagnosis and management of eye disease is becoming more common, with several studies showing the potential of this technology to improve healthcare quality and medical workflow by being able to screen for conditions affecting the macula, such as AMD and DR.<sup>117</sup>

A recent trial in the UK found that an AI system has the capability of being as effective as clinicians in detecting eye disease in patients. The AI system used in the trial was able to identify more than 50 types of eye disease in

seconds, with 94% accuracy and can help to identify which patients require urgent referral and treatment. Research in this area is ongoing.<sup>118,119</sup> Similarly, Australian researchers are looking to AI as a way to detect referable DR.<sup>120</sup>

Working with professional and peak bodies to develop a professional position on the ethical, access and regulatory challenges and opportunities posed by AI would ensure this technology's potential role in improving patient care and outcomes, through improved efficiency and cost-effectiveness of eye disease detection for all Australians living in both urban, rural and remote parts of the country.

## 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.



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