Submission to the
Senate Select Committee on Health

Inquiry into health policy, administration and expenditure

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Executive summary

In this submission, Macular Disease Foundation Australia highlights and discusses the issues faced by people with macular degeneration, the leading cause of blindness and major vision loss in Australia. In some cases, other disease states are discussed where relevant.

Access and availability of public hospital outpatient eye treatment
The management of ‘wet’ macular degeneration typically involves regular, ongoing, intravitreal injections (into the eye) of anti-vascular endothelial growth factor (anti-VEGF), performed by an ophthalmologist.

The vast majority of people receiving injections for the treatment of ‘wet’ macular degeneration will do so in private ophthalmologists’ rooms. Patients are typically elderly and many on limited fixed incomes. For people who find accessibility and affordability of private treatment for macular disease challenging, there are currently few viable alternatives. Some people need to access the public hospital system, however there is presently limited availability of free outpatient eye treatment in public hospitals across Australia.

Despite the introduction of anti-VEGF treatment in 2007, which revolutionised treatment for ‘wet’ macular degeneration, Australian health and hospital systems have been slow to adapt to the required treatment schedules.

Without access to free and timely public outpatient eye treatment, people who cannot afford private treatment can be at risk of permanent vision loss or blindness.

Out-of-pocket costs for treatment
People with ‘wet’ age-related macular degeneration can, in addition to the standard co-payments for Pharmaceutical Benefits Scheme (PBS) registered drugs, experience significant out-of-pocket healthcare costs in a number of areas.

Calls to the Foundation’s national Macular Disease Helpline from patients, family members and carers included concerns about the out-of-pocket costs for regular anti-VEGF injections, starting necessary treatment schedules and continuation of treatment. Some patients have stated that they had ceased treatment due to the cost. Vision loss or blindness will most likely result if treatment is not undertaken or if ceased prematurely.

The prospect of older Australians losing their vision because they are unable to afford treatment is simply unacceptable.
Complexities with the health billing system and subsidy programs

Complexities with the health billing system and subsidy programs make it difficult for older Australians and those with vision loss to receive the benefits to which they are entitled. The Foundation, through the Macular Disease Helpline, has received calls regarding awareness issues related to the requirement for couples to register for the Extended Medicare Safety Net, and concerns about the online shift of customer support by various Commonwealth services.

Funding OCT scans for ‘wet’ macular degeneration treatment

Australian patients with ‘wet’ macular degeneration are not reimbursed through Medicare for clinically essential optical coherence tomography (OCT) scans that are necessary for the ongoing management of their disease.

Reduced rebate for same day bilateral treatment

With bilateral treatment, where the ophthalmologist charges a treatment fee for the second eye that is similar to the first eye, patients are penalised when the two anti-VEGF intravitreal injections are given on the same day. This is because the Medicare Benefits Scheme (MBS) rebate is reduced to 50% for the second eye injection when performed on the same day. This is despite the fact that the two injections must be performed as completely separate procedures, with very limited ‘economies of scale’ by performing them on the same day.

Impact of proposed GP co-payments

The Foundation is concerned that the proposed $7 co-contribution for GP visits could have a number of adverse effects on people with macular degeneration, diabetic eye disease and other eye conditions, and requires further review by Government.

In the case of ‘wet’ macular degeneration, a sudden retinal bleed can occur and cause rapid deterioration in vision. There is a limited window of opportunity to commence treatment. The GP co-payment may be a disincentive that discourages people from visiting their GP when symptoms initially appear or extend the amount of time between visits to the GP, in order to get a referral to an ophthalmologist for rapid treatment. This may increase the risk of patients delaying diagnosis and treatment until vision loss becomes more severe. By that stage, permanent damage to the macula may have already occurred, resulting in permanent vision loss.

Reforms to Medicare safety nets

The availability of safety nets is an extremely important mechanism to minimise the impact of out-of-pocket costs. The Foundation supports the Commonwealth Government’s recent amendments, announced in the 2014 Federal Budget, regarding the simplification of the original and extended Medicare safety nets, and the lowering of the thresholds. However, the Foundation has some reservations regarding the new, lower capping of the total Medicare benefit at 150% of the MBS fee for specialists.
Health promotion, prevention and early intervention for macular disease
The Foundation is the national organisation that conducts health promotion, prevention and early intervention programs for macular degeneration in Australia.

Despite the high prevalence of macular degeneration, being four times that of dementia and more than half that of diabetes, and its impact as a chronic disease, Commonwealth Government funding is limited to $147,000 (annual average) for a macular degeneration education program.

The Foundation’s National Macular Disease Helpline and essential awareness, support services, and representation programs are, despite numerous requests, not presently funded.

Eye checks in residential aged care facilities
There is a need to reduce the incidence and impact of macular degeneration in residential aged care facilities.

Residential aged care facilities often do not provide a mechanism for the provision of routine eye examinations. An Australian study found 58% of residents had uncorrected near vision impairment and 29% had not had an eye test within the recommended two years.

To begin to address this problem, the Foundation recently submitted a funding application for a pilot project to the Department of Social Services under the Aged Care Service Improvement and Healthy Ageing Grants program. As yet, funding has not been provided.

Greater government investment in rural, regional and remote public treatment
Very few of the public hospitals outside the major capital cities have the necessary equipment and facilities to provide outpatient eye services for macular degeneration, so people with macular degeneration in rural, regional and remote areas are typically dependent on private specialists for diagnosis and treatment, unless they travel large distances to their capital city.

Rural, regional and remote patients travelling long distances for treatment
People living in rural, regional and remote areas are required to travel to large regional centres or capital cities to receive treatment. Depending on the distance travelled, this may require overnight accommodation, flights, meals, and other transport costs.

State and territory governments provide some assistance to rural, regional and remote patients travelling long distances for treatment through patient assisted travel schemes, however the subsidies provided are often inadequate and most patients
have to first pay upfront before claiming back the rebate later. The programs are also inconsistent between states and territories, with different benefits and requirements.

Where you live in Australia should not determine how well you can see. The Commonwealth Government needs to provide appropriate review, oversight and intervention when required to ensure equity of access to treatment for patients with macular degeneration in all the states and territories.

**Medicare funded comprehensive eye examinations**

Australians without any symptoms of eye disease currently receive full MBS coverage for a comprehensive eye examination every two years, which provides a reasonable frequency to enable the detection of early, asymptomatic disease for early intervention in order to reduce the risk of progression to sight-threatening disease.

While the Foundation supports the Commonwealth Government’s proposed changes to improve access to eye examinations for people aged 65 and over, the proposed reduction in access to Medicare funded eye examinations for people under the age of 65 is not considered optimal.

**Ophthalmologists**

Demand for ophthalmology services is increasing with Australia’s ageing population, as the prevalence of eye diseases correlates strongly with age. Furthermore, the introduction of anti-VEGF treatment for macular degeneration, with the need for regular and ongoing monitoring and treatment, has significantly increased the workload on the profession, especially for those with a retinal sub-specialty.

The shortage of ophthalmologists is particularly acute in the public hospital sector for those in need. There is a clear need to expand public treatment and the need to provide more ophthalmologists with specialty training to treat patients with macular degeneration.

**Access to low vision aids and technologies**

The Foundation has been actively advocating the Commonwealth Government to improve access to low vision aids and technologies since it first approached then Prime Minister John Howard in March 2007.

During the development of the National Disability Insurance Scheme (NDIS), there were consultations between the Commonwealth Government and stakeholders, and it was indicated that the NDIS could be touted as the solution to the lack of access to low vision aids and technologies.

Since the NDIS excludes people who acquire a disability at the age of 65 or over, low vision aids and technologies need to be accommodated in the aged care system.
so that there is some support available for those who acquire vision loss or blindness at the age of 65 or over.

The considered view of the Foundation is that the likely costs of including people over 65 who are vision impaired or blind within the NDIS would have been minimal in comparison to accommodation within the aged care sector.

Unlike the NDIS, the aged care system is presently not powered to care for those with a disability of blindness or severe vision loss, even under the present aged care reform, as it has neither the funding, capacity nor expertise to fully provide necessary services such as low vision aids and mobility training to maintain independence and quality of life.
Summary of recommendations

1. The Commonwealth Government develop adequate, sustainable funding models to enable state and territory governments to provide appropriate and accessible outpatient eye treatment services for ‘wet’ macular degeneration and other related eye conditions at public hospitals. These services must also include adequate treatment equipment and appropriate training for medical and allied health staff. This must also include a mechanism so that in NSW and ACT (which have not signed up to the federal PBS agreement) public hospitals are able to access federally funded PBS treatments.

2. The Commonwealth Government give consideration to:
   a. Decrease the impact of out-of-pocket costs on patients by addressing the key levers and drivers of cost which include supply factors, such as the number and location of qualified and appropriately trained specialists, and the supply of treatment options in the public system; and
   b. Supporting ophthalmologists to provide bulk billing options when needed, for genuine cases of need.

3. The Commonwealth Government provides ongoing awareness programs for older Australians on the requirements and benefits of the Extended Medicare Safety Net.

4. The Commonwealth Government is mindful of the accessibility needs of older Australians and those with vision loss when planning customer support for Commonwealth services.

5. The Commonwealth Government support the Medicare funding of OCT scans, when performed by an ophthalmologist, as an essential part of the ongoing management of people with neovascular conditions such as ‘wet’ macular degeneration, diabetic macular edema and retinal vein occlusions.

6. The Medicare rebate for a second intravitreal injection performed on the same day should be increased, ideally to 100%, instead of the current 50% rebate.

7. The Commonwealth Government take into consideration the potential impact of a GP co-payment on prevention, early detection, early referral for diagnosis and possible treatment, and rehabilitation outcomes, especially for patients who are financially vulnerable.

8. The Commonwealth Government consider its efforts to ensure the sustainability of Medicare, so that there is no cost shifting to patients as this may result in cessation of treatment and subsequent vision loss, becoming an even greater cost to government.


10. The Commonwealth Government fund Macular Disease Foundation Australia’s pilot program to reduce the incidence and impact of macular degeneration in residential aged care facilities.
11. The Commonwealth, state and territory governments provide adequate support to improve the provision of free public outpatient eye treatment services in rural, regional and remote areas, including mechanisms to encourage more retinal specialists to undertake rural, regional and remote outreach programs.

12. The Commonwealth Government work with state and territory governments to improve access to and equity of rural, regional and remote patient assisted travel schemes.

13. The Commonwealth Government maintain the status quo of Medicare funded eye examinations on a two yearly basis for people aged between 45 and 65 who show no symptoms of eye disease.

14. The Commonwealth Government allow people with diabetes of any age to have Medicare funded comprehensive eye examinations on a two yearly basis, or at least annually if there is any evidence of retinopathy.

15. The Commonwealth Government address the shortage of ophthalmologists in the workforce, especially in rural, regional and remote areas in several ways, including:
   a. Continuation and increase of funding for the Medical Specialist Outreach Program.
   b. Provision of incentives to encourage specialists to set up in larger regional centres.
   c. Work with the Royal Australian and New Zealand College of Ophthalmologists (RANZCO) to ensure adequate training places are maintained.
   d. Work with RANZCO and the states to address the acute shortage of public outpatient treatment services available, in both metropolitan areas and regional centres.
   e. Speedy approval and reimbursement of new technologies and treatments which may reduce treatment burden for patients (and providers).

16. The Commonwealth Government provide equitable access to and affordability of low vision aids and technologies for people with vision loss and blindness, regardless of their age.
About Macular Disease Foundation Australia

Macular Disease Foundation Australia is a charity established in 2001 and is the only national charity committed to working on behalf of the entire macular disease community.

The Foundation’s mission is to reduce the incidence and impact of macular disease in Australia through five major objectives:

1) Education: Provide accurate, specific, current and ongoing information
2) Awareness: Increase awareness of macular disease
3) Support services: Provision of support to clients and facilitation of access to relevant support
4) Research: Support and pursue research
5) Representation: Advocate for the best interests of the macular disease community

The Foundation’s activities and programs are guided by four overarching strategic pillars:

1) Building healthy communities
2) Building strong positioning in the development of public policy
3) Building a sound knowledge base
4) Building strong relationships and partnerships

The Foundation is the voice of patients, families and carers, and all people at risk of developing macular disease. The Foundation also supports healthcare professionals through professional development, information and resources.

The Foundation’s activities encompass all macular diseases, including macular degeneration, diabetic retinopathy, retinal vein occlusions, and macular dystrophies. Macular degeneration is the Foundation’s primary focus, and the Foundation has provided outstanding measured health outcomes for the Australian public in addressing macular degeneration. The Foundation is involved in all aspects of the continuum of care for people with macular disease including prevention, early detection, timely access to affordable, effective treatment and rehabilitation.

For over 13 years, the Foundation has a proven track record of outcomes for public health in Australia and has been recognised internationally, with published work in the prestigious *American Journal of Public Health (AJPH)*¹ and *Aging and Mental Health*², collaborations with internationally renowned organisations such as The Angiogenesis Foundation, and sharing the Foundation’s work at international forums in Europe, South America and shortly Asia Pacific. Given the recognition in its best
practice approach to public health in relation to macular degeneration, the Foundation organised and co-hosted the first-ever Global Ageing and Vision Advocacy Summit held on 17–18 April 2013 in Barcelona, Spain in collaboration with the International Federation on Ageing.

**About macular degeneration**

This submission will focus primarily on macular degeneration, however many of the issues raised also apply to other macular diseases, including diabetic retinopathy, retinal vein occlusions, and macular dystrophies.

Macular degeneration is the leading cause of serious vision loss and blindness in Australia; 50% of all blindness is due to this disease\(^iii\).

The prevalence of macular degeneration is four times that of dementia and more than half that of diabetes.\(^iv\)

The total cost of blindness and vision loss from macular degeneration has been estimated to exceed $5 billion per year.\(^v\)

Most blindness from macular degeneration results from the neovascular (‘wet’) form of the disease. Over 90% of people who lose vision from macular degeneration do so after the age of 65.\(^vi\)

Highly effective treatments for ‘wet’ macular degeneration have been available since 2007 which require regular injections of an anti-vascular endothelial growth factor (anti-VEGF) drug into the eye, which must be performed by an ophthalmologist.

Typical treatment involves one injection per month for three months (per affected eye) with subsequent treatment frequency determined by patient response.

According to a Pharmaceutical Benefits Advisory Committee (PBAC) Drug Utilisation Sub Committee (DUSC) report in 2012\(^vii\), the average patient with ‘wet’ age-related macular degeneration receives about 7.4 injections in the first year. This declines somewhat in subsequent years, assuming the patient doesn’t stop treatment. It is of note that about 30% of people continue to need monthly injections in order to maintain vision. Furthermore, 22% of people receive injections in both eyes\(^viii\).

Treatment of diabetic macular edema is similar although most people will require injections in both eyes.
Addressing the Terms of Reference

“That a select committee, to be known as the Select Committee on Health, be established to inquire into and report on health policy, administration and expenditure, with particular reference to:”

a. the impact of reduced Commonwealth funding for hospital and other health services provided by state and territory governments, in particular, the impact on elective surgery and emergency department waiting times, hospital bed numbers, other hospital related care and cost shifting;

a.i) Access and availability of public hospital outpatient eye treatment

The management of ‘wet’ macular degeneration typically involves regular, ongoing, intravitreal injections (into the eye) of anti-vascular endothelial growth factor (anti-VEGF).

The vast majority of people receiving injections for the treatment of ‘wet’ macular degeneration will do so in private ophthalmologists’ rooms. Patients are typically elderly and many on limited fixed incomes. For people who find accessibility and affordability of private treatment for macular disease challenging, there are currently few viable alternatives. Some people need to access the public hospital system, however there is presently limited availability of free outpatient eye treatment in public hospitals across Australia.

In all states, only a small number of public hospitals are delivering anti-VEGF treatment services and these are invariably working at or above capacity with long waiting lists. With the exception of the Gold Coast, Fremantle, Broken Hill and Alice Springs, the Foundation is not aware of any public services available outside the state or territory capitals. There is no known list of the public availability of treatment that would help consumers in making decisions about their treatment options.

There is a limited window of opportunity to commence treatment for this disease in order to save sight, and adherence to the ongoing treatment schedule is critical. If people are unable to afford private treatment and have limited access to public care, they may forgo treatment and risk vision loss and possibly blindness at significant cost to the patient, the community and the taxpayer.

Saving a person’s sight from this disease requires ongoing treatment at intervals determined by the ophthalmologist. This may be as often as monthly or in some cases less frequently. Whatever interval is decided upon by the ophthalmologist, it is essential that this time period be observed. Any delay in initiating treatment or providing ongoing treatment risks blindness.
According to a Pharmaceutical Benefits Advisory Committee (PBAC) Drug Utilisation Sub Committee (DUSC) report in 2012, the average patient with 'wet' age-related macular degeneration receives about 7.4 injections in the first year. This declines somewhat in subsequent years, assuming the patient doesn’t stop treatment. It is of note that about 30% of people continue to need monthly injections in order to maintain vision. Furthermore, 22% of people receive injections in both eyes.

Despite the introduction of anti-VEGF treatment in 2007, which revolutionised treatment for ‘wet’ macular degeneration, Australian health and hospital systems have been slow to adapt to the required treatment schedules. Prior to 2007, treatment for ‘wet’ macular degeneration involved infrequent visits to the ophthalmologist for laser treatment in the eye. Since 2007, anti-VEGF treatment has become the global standard of care for ‘wet’ macular degeneration, requiring regular, ongoing visits to the ophthalmologist. However, the provision of outpatient eye treatment services at public hospitals has not kept pace with the substantial increase in demand. Demand for treatment services will only continue to increase due to the ageing population and the availability of new, sight-saving treatments for additional indications such as diabetic macular edema. Adequate treatment equipment and appropriate training levels for medical and allied health staff need to be in place to cope with this increasing demand.

The Commonwealth Government needs adequate sustainable models to fund hospitals to improve accessibility to public hospital outpatient eye treatment for ‘wet’ macular degeneration and other related eye conditions across Australia. Without access to free and timely public outpatient eye treatment, people who cannot afford private treatment can be at risk of permanent vision loss or blindness.

The cost of treatment is significantly less than the economic, social and emotional cost of blindness. In 2010, the direct cost to the health care system (i.e. cost of treatment) was estimated at $359 million. The total cost of vision loss associated with macular degeneration (i.e. cost of blindness) was estimated to be $5.15 billion, of which the financial cost was $748.4 million ($6,982 per person).

Improving access to anti-VEGF treatment in the public system, which serves as a safety net for people with ‘wet’ macular degeneration who cannot afford private treatment, will prevent many from going blind and lower the cost to government.

In NSW and ACT, which have not signed up to the federal PBS agreement, the registered anti-VEGF treatments are typically not available in public hospital formularies.
Recommendation 1:
The Commonwealth Government develop adequate, sustainable funding models to enable state and territory governments to provide appropriate and accessible outpatient eye treatment services for ‘wet’ macular degeneration and other related eye conditions at public hospitals. These services must also include adequate treatment equipment and appropriate training for medical and allied health staff. This must also include a mechanism so that in NSW and ACT (which have not signed up to the federal PBS agreement) public hospitals are able to access federally funded PBS treatments.

b. the impact of additional costs on access to affordable healthcare and the sustainability of Medicare;

b.i) Out-of-pocket costs for treatment

The out-of-pocket costs

People with ‘wet’ age-related macular degeneration can, in addition to the standard co-payments for Pharmaceutical Benefits Scheme (PBS) registered drugs, experience significant out-of-pocket healthcare costs in a number of areas:

1) Gap fees for regular and ongoing private ophthalmologist consultations, diagnostic tests and treatments. In some cases, treatment is required monthly, or if disease is bilateral, even more regularly.

2) Full cost of non-Medicare funded ocular coherence tomogram (OCT) scans, which are universally considered to be essential components for the ongoing management of the disease

3) Full payment for proven Age Related Eye Disease Study (AREDS)\textsuperscript{xii} or AREDS2\textsuperscript{xiii} vitamin supplements which reduce the risk of progression of macular degeneration (except Department of Veteran Affairs Gold Card holders who receive subsidies for AREDS supplements)

The Foundation’s national Macular Disease Helpline is a trusted and highly utilised frontline service that communicates with the macular disease community. In 2013–14, the Foundation received over 13,000 calls on the Helpline, an average of 53 calls a day. The Helpline achieved a 95% approval rating in the Foundation’s latest annual service evaluation survey.

The Foundation's messages and support via the Helpline cover prevention, early detection, timely treatment when indicated and rehabilitation. It actively promotes these messages which are likely to result in the long-term reduction in disease prevalence, morbidity and costs to the health system.
While the vast majority of calls are for extra information, reassurance and support there are also some calls from patients, family members and carers regarding concerns about the out-of-pocket costs for regular anti-VEGF injections, starting necessary treatment schedules and continuation of treatment. Some patients have stated that they had ceased treatment due to the cost. Vision loss or blindness will most likely result if treatment is not undertaken or if ceased prematurely.

It must be emphasised that anti-VEGF injections can save sight, and allow people to maintain independence and quality of life.

For those who call the Helpline, the Foundation will:

1) advise patients on discussing affordable access to treatment with specialists,
   or
2) if necessary, discuss the cost concerns directly with the specialist on behalf of
   individual patients, or
3) arrange alternate, affordable treatment options.

However, the Foundation is concerned for those patients who are unaware of our Helpline support and are at risk of ceasing treatment, which may result in vision loss or blindness.

### Case Study 1
Patient A was diagnosed with ‘wet’ macular degeneration in his right eye about three to four years ago by an ophthalmologist. He was referred to a retinal specialist and had anti-VEGF injections. The patient ceased treatment due to affordability concerns. In late 2013, his vision started to deteriorate.

The patient called the Macular Disease Helpline in February 2014. The Foundation arranged for him to see an alternative ophthalmologist who agreed to bulk bill the patient.

### Case Study 2
Patient B, a part-pensioner, had four anti-VEGF injections between late 2013 and early 2014. He ceased treatment due to affordability concerns.

The patient called the Macular Disease Helpline in May 2014. The Foundation assisted the patient by contacting his ophthalmologist to discuss his circumstances. The ophthalmologist subsequently offered to bulk bill Patient B.
Case Study 3
Patient C was diagnosed with ‘wet’ macular degeneration and was having anti-VEGF injections in her left eye. From the patient’s account of her specialist visit, she stated that she was not advised of the treatment cost or that the treatment was ongoing and for an indefinite period of time. She subsequently ceased treatment due to affordability issues.

The patient called the Macular Disease Helpline in July 2014. On the advice of the Foundation, the patient went back to her ophthalmologist to discuss her affordability issues. Subsequently, Patient C was accommodated by her ophthalmologist through the public hospital system.

The impact of costs

The cost of treatment is significantly less than the economic, social and emotional cost of blindness. In 2010, the direct cost to the health care system (i.e. cost of treatment) was estimated at $359 million. The total cost of vision loss associated with macular degeneration (i.e. cost of blindness) was estimated to be $5.15 billion, of which the financial cost was $748.4 million ($6,982 per person). The largest proportion (85%) of the economic cost of macular degeneration results from the loss of quality of life associated with visual impairment, known as the "burden of disease". The impact of vision loss and blindness on patients is equivalent to stroke, severe cardiovascular disease, coronary artery disease, and cancer.

People who lose sight have triple the rate of depression, double the risk of falls, four to eight times the risk of a hip fracture, an average three years earlier entry into nursing homes and increased social isolation. This places a heavy burden on the individual, their family and carers along with an economic burden for the taxpayer.

The prospect of older Australians losing their vision because they are unable to afford treatment is simply unacceptable.

Where out-of-pocket costs become excessive, older Australians who are still working are unable to afford preventive care, sight saving treatments or rehabilitative support, as they are not eligible for pensioner benefits.

It must also be recognised that due to the advanced age of most people with macular degeneration, they are commonly facing significant out-of-pocket costs due to additional co-morbidities. Some additional issues include:

1) Patients in this age group are likely to have more co-morbidities than other age groups, resulting in more medical expenses;
2) While this may result in these patients reaching the Medicare Safety Net threshold more quickly, they are still required to co-pay 20% of the treatment costs out-of-pocket;
3) Even after these patients become eligible for the Medicare Safety Net, if their ophthalmologist charges fees which exceed the Medicare Safety Net cut-off, these patients will still have to pay the excess cost out-of-pocket; and,
4) Many patients, especially those living in rural, regional or remote areas, have very limited access to alternate treating specialists if the fees are high and the doctor is unwilling to bulk bill.

Recommendation 2:
The Commonwealth Government give consideration to:
   a. Decrease the impact of out-of-pocket costs on patients by addressing the key levers and drivers of cost which include supply factors, such as the number and location of qualified and appropriately trained specialists, and the supply of treatment options in the public system; and
   b. Supporting ophthalmologists to provide bulk billing options when needed, for genuine cases of need.

b.ii) Complexities with the health billing system and subsidy programs
Complexities with the health billing system and subsidy programs make it difficult for older Australians and those with vision loss to receive the benefits to which they are entitled. The Foundation, through the Macular Disease Helpline, has received calls regarding the following:

1) The Extended Medicare Safety Net provides increased subsidies once patients accumulate out-of-pocket expenses that reach the Extended Medicare Safety Net threshold. Couples are required to register for the safety net in order to gain full benefit. There have been awareness issues related to the requirement for couples to register for the safety net to ensure they receive their full entitlements.
2) With the online shift of customer support by various Commonwealth services, older Australians and those with vision loss can be left frustrated. This can make access to Commonwealth services difficult for these groups of people and it is important alternate access options continue to be made available, such as telephone support and physical shop-fronts.

Recommendation 3:
The Commonwealth Government provides ongoing awareness programs for older Australians on the requirements and benefits of the Extended Medicare Safety Net.
Recommendation 4:
The Commonwealth Government is mindful of the accessibility needs of older Australians and those with vision loss when planning customer support for Commonwealth services.

b.iii) Funding OCT scans for ‘wet’ macular degeneration treatment
Australian patients with ‘wet’ macular degeneration are not reimbursed through Medicare for clinically essential optical coherence tomography (OCT) scans that are necessary for the ongoing management of their disease.

OCT is the internationally accepted gold standard diagnostic test for the safe and non-invasive structural assessment of the macula to assess response to treatment, and guide the need for retreatment. Indeed, one of the primary aims of the scan is to assist the ophthalmologist to decide that an injection is not needed at this visit, thereby saving the PBS, Medicare and the patient significant cost. OCT is an essential part of the ongoing management of patients with ‘wet’ macular degeneration. The Foundation is not aware of any ophthalmologist who treats macular degeneration who is not using the technology. It has been utilised in clinical practice in Australia for over nine years. OCT is funded in the health systems of other comparable developed countries. OCT has been funded by the Australian Department of Veterans Affairs since 2005.

In its 2011 evaluation of OCT, the Medical Services Advisory Committee (MSAC) found "insufficient evidence" for the benefit of the test and required a randomised controlled trial to demonstrate benefit over existing technologies.

The reality is that no ethics committee in the world would approve a trial which would involve a control group of patients being denied the use of OCT, potentially resulting in detrimental outcomes for this group.

As such, Medicare funding continues to be denied for this essential, non-invasive diagnostic test. Ophthalmologists universally use the scan as it is the safest and most appropriate way to determine the structural response to treatment and guide the need for further treatment, however patients in Australia are required to pay the full cost.

Recommendation 5:
The Commonwealth Government support the Medicare funding of OCT scans, when performed by an ophthalmologist, as an essential part of the ongoing management of people with neovascular conditions such as ‘wet’ macular degeneration, diabetic macular edema and retinal vein occlusions.
b.iv) Reduced rebate for same day bilateral treatment

About 20% of people with ‘wet’ macular degeneration (and most people with diabetic macular edema) require bilateral treatment (treatment in both eyes), which may result in a doubling of treatment fees.

For people requiring bilateral treatment, where the ophthalmologist charges a treatment fee for the second eye that is similar to the first eye, patients are penalised when the two anti-VEGF intravitreal injections are given on the same day. This is because the Medicare Benefits Scheme (MBS) rebate is reduced to 50% for the second eye injection when performed on the same day. Bilateral, same day treatment is necessary for many people, for example those who need to travel long distances (such as those who live in rural, regional or remote areas), those working or when a patient’s or carer’s commitments do not allow taking additional leave from work. An appointment for ‘wet’ macular degeneration treatment using anti-VEGF injections typically takes several hours, allowing for diagnostics, the injection procedure, post injection monitoring, counselling, and other procedures. Since each eye injection is performed as a totally separate procedure, and the specialist is unlikely to accrue any major savings from performing the two injections on the same day, some doctors do not discount the second injection. It is therefore reasonable that the patient receives a similar rebate for the injection to the second eye, so that the patient does not carry the cost burden.

**Recommendation 6:**
The Medicare rebate for a second intravitreal injection performed on the same day should be increased, ideally to 100%, instead of the current 50% rebate.

b.v) Impact of proposed GP co-payments

The Foundation is concerned that the proposed $7 co-contribution for GP visits could have a number of adverse effects on people with macular degeneration, diabetic eye disease and other eye conditions, and requires further review by Government. It should be noted that:

1) GPs are the cornerstone of diabetes management and hence play a key role in minimising the development of diabetic eye disease.
2) GPs play an important role in educating patients about risk reduction behaviour (such as smoking cessation and dietary modification) for many conditions including macular degeneration.
3) GPs play a role in the monitoring and referral of at-risk people to seek a regular eye examination from an optometrist, which may pick up very early, asymptomatic disease.
4) GPs play a pivotal role in the early detection of symptoms and immediate referral of patients to an optometrist or ophthalmologist.
The introduction of a GP co-contribution may negatively impact the early detection of potentially serious diseases including those that can lead to blindness. The Foundation’s 2013 *Sight Seer 2* study found that the majority (85%) of ‘wet’ macular degeneration patients had co-morbidities, most commonly arthritis (47%), heart disease (25%), or diabetes (12%). A primary concern is that financially vulnerable patients will be discouraged from seeing the GP until symptoms become more severe.

In the case of ‘wet’ macular degeneration, a sudden retinal bleed can occur and cause rapid deterioration in vision. There is a limited window of opportunity to commence treatment. Anti-VEGF treatment should commence as early as possible, ideally within a maximum of two weeks of diagnosis. The GP co-payment may be a disincentive that discourages people from visiting their GP when symptoms initially appear or extend the amount of time between visits to the GP. This may increase the risk of patients delaying diagnosis and treatment until vision loss becomes more severe. By that stage, permanent damage to the macula may have already occurred, resulting in permanent vision loss.

The major preventable risk factors for blinding diseases such as macular degeneration and diabetic retinopathy are smoking and poor diets. These behaviours are over-represented in lower socio-economic groups who will be the most impacted by the proposed GP co-contribution.

**Recommendation 7:**
The Commonwealth Government take into consideration the potential impact of a GP co-payment on prevention, early detection, early referral for diagnosis and possible treatment, and rehabilitation outcomes, especially for patients who are financially vulnerable.

**b.vi) Reforms to Medicare safety nets**
The availability of safety nets is an extremely important mechanism to minimise the impact of out-of-pocket costs. The Foundation supports the Commonwealth Government’s recent amendments, announced in the 2014 Federal Budget, regarding the simplification of the original and extended Medicare safety nets, and the lowering of the thresholds.

However, the Foundation has some reservations regarding the new, lower capping of the total Medicare benefit at 150% of the MBS fee for specialists. If a doctor currently charging above this level does not lower his/her fees, the patient will be required to pay all of the difference. In theory, this measure is aimed at encouraging comparison of costs, but in practice comparing health service costs and changing ophthalmologist is challenging for many patients, especially those who are elderly.
Many patients have limited or no choice of eye specialist, especially in rural, regional and remote communities.

It is critical that any efforts by government to manage health care costs do not result in additional costs being shifted to patients.

**Recommendation 8:**
The Commonwealth Government consider its efforts to ensure the sustainability of Medicare, so that there is no cost shifting to patients as this may result in cessation of treatment and subsequent vision loss, becoming an even greater cost to government.

c. the impact of reduced Commonwealth funding for health promotion, prevention and early intervention;

c.i) Health promotion, prevention and early intervention for macular disease
The Foundation is the national organisation that conducts health promotion, prevention and early intervention programs for macular degeneration in Australia.

Despite the high prevalence of macular degeneration, being four times that of dementia and more than half that of diabetes, and its impact as a chronic disease, the Commonwealth Government does not fund the Foundation’s Macular Disease Helpline and essential awareness, support services, research and representation programs. Presently, the Commonwealth Government provides only limited funding of $147,000 (annual average) for a macular degeneration education program.

This funding is insufficient to adequately support people with macular degeneration, the leading cause of blindness in Australia, and other macular diseases. The Foundation has filled this significant and important gap in public health by using limited donor funds to provide world-recognised prevention and early detection programs.

The Foundation has been recognised globally for this pioneering work in raising awareness of macular degeneration. Australia now leads the world with regard to awareness of this disease and it is this increased awareness that leads to early diagnosis and intervention, improved outcomes and ultimately, saved sight.

Since 2007 the Foundation has conducted a multifaceted public health campaign to increase awareness of macular degeneration, promote symptom recognition and risk reduction measures, and encourage early diagnosis and treatment. Activities have included the annual Macular Degeneration Awareness Week, national TV and radio campaigns, nationwide mobile Vision Van, public education sessions and inserts into
driver's licence renewals (NSW). Tools include the toll-free national Helpline, Foundation website and publications.

Macular Degeneration Awareness Week, held in May each year, is the Foundation's major awareness campaign. As part of this year's activity the Foundation ran a national radio and TV campaign focused on the key message of "have your eyes tested and your macula checked". Australians were asked to contact the Foundation's Helpline to receive a free information kit and Amsler grid - a self-monitoring tool designed to be used at home to detect changes in vision between regular eye examinations. During May, when the campaign was live, the Foundation received almost 4,000 calls to the Helpline.

The Foundation is vigilant in measuring outputs, outcomes and impacts of all activities, including through independent national Galaxy polling, which shows that awareness of macular degeneration in the at-risk population (people aged 50 and over) has increased from just 58% in 2007 to 92% in 2014. This is recognised as an outstanding result for a public health campaign. The Foundation's awareness work was published in the prestigious *American Journal of Public Health* in September 2012.\textsuperscript{xxi}

The Foundation's toll-free Macular Disease Helpline is an essential support service for the Australian community, however it does not receive any Commonwealth funding. It is a frontline service providing callers - Australians at risk of developing or living with macular disease, their carers, family and friends, health professionals and service providers - with information and support on disease prevention, early detection, treatment and rehabilitation. Callers to the Helpline receive appropriate resources that provide important information and contact pathways for service providers and low vision rehabilitation services.

Since the Foundation began collecting statistics on its activities in 2005, over 120,000 calls have been received via the Helpline. A range of calls are received, including calls from people who have been recently diagnosed, their family and carers; callers in need of information or requiring answers to general macular disease-related questions; callers responding to media activity and articles in the Foundation's newsletter. The callers frequently express their thanks and relief that a toll-free Helpline for information and support exists.

Each year the Foundation surveys a sample of its client base. In July 2013, a total of 1999 randomly selected clients were posted an anonymous questionnaire. The sample included people with macular degeneration, family and friends of people with macular degeneration, those with a general interest in macular degeneration and people working in a macular degeneration-related field. Respondents were asked to rate the Helpline; 96% of respondents rated the Helpline as excellent or good.
The Foundation’s highly successful and effective Macular Disease Helpline has been sustained through philanthropic donations and partnerships with the private sector, which is not guaranteed and is vulnerable to external forces. The Commonwealth Government needs to take its fair share of responsibility and adequately fund this already proven and highly cost-effective service to cater for an expected increase in demand, as Australia’s population continues to age and diversify.

Recommendation 9:
The Commonwealth Government adequately fund Macular Disease Foundation Australia’s public health promotion, prevention and early intervention programs for macular disease, including the critical Macular Disease Helpline.

d. the interaction between elements of the health system, including between aged care and health care;

d.i) Eye checks in residential aged care facilities
There is a need to reduce the incidence and impact of macular degeneration in residential aged care facilities.

Residential aged care facilities often do not provide a mechanism for the provision of routine eye examinations. An Australian study found 58% of residents had uncorrected near vision impairment and 29% had not had an eye test within the recommended two years.xxii

The rate of vision loss amongst residential aged care facility residents is significantly higher than older people in the home.xxiii With early detection, many are responsive to intervention, generally with good outcomes.

Once a person notices lost vision, the underlying disease is likely to have progressed significantly with permanent damage. Early detection is essential to prevent vision loss but can only be achieved through regular eye tests, including examination of the macula, by an optometrist or ophthalmologist using specialised equipment.

The impact of macular degeneration on quality of life is wide ranging, affecting not only tasks requiring good vision, such as reading, but also emotional health and a person’s ability to participate in leisure and other activities. Intervention to assess safe mobility should also be considered. Even mild vision loss (visual acuity worse than 6/12) can have a substantial impact on vision-related quality of life. Low vision support and services should be considered for people with even mild vision impairment and worse.xxiv
The causes of vision loss may not be recorded in residential care plans and staff may not feel confident to accurately identify residents with low vision.\textsuperscript{xxv}

Regular vision examinations are more the exception than the rule in most residential aged care facilities. Studies consistently report that most residents have no record of eye care within the previous several years and that clinical data on acuity or causation were rarely present in residents’ records.\textsuperscript{xxvi}

Due to the lack of training and the typically gradual onset of vision impairment, residential aged care facility staff often miss new vision problems.\textsuperscript{xxvii}

Disability and dependency can also be a function of the behaviour and attitudes of well-meaning, but overworked and uninformed staff. When a resident is identified as vision impaired, the fears of staff about the resident’s vulnerability to injury can lead to restrictions in their mobility and self-care activities. For example in the same study, severe vision impairment was a significant factor contributing to whether a resident was wheelchair or bed-bound. Older people may also be inappropriately labelled as mentally impaired and treated as such, as a result of behaviours associated with vision loss. Such restrictions can further add to poor state of mind, while enforced reduction of physical activity negatively impacts general health outcomes.\textsuperscript{xxviii}

To begin to address this problem, the Foundation requested funding from the previous Department of Health and Ageing in 2012 to conduct a pilot eye health and low vision education program. The program would involve eye tests in a residential aged care facility and the establishment of referral pathways with optometry and ophthalmology. Consultation with eye care professionals is a critical primary intervention necessary to reduce morbidity from eye disease. This funding was not approved at the time; this project was recently resubmitted for funding in 2014 to the Department of Social Services under the \textit{Aged Care Service Improvement and Healthy Ageing Grants} program.

**Recommendation 10:**
The Commonwealth Government fund Macular Disease Foundation Australia’s pilot program to reduce the incidence and impact of macular degeneration in residential aged care facilities.
e. improvements in the provision of health services, including Indigenous health and rural health;

e.i) Greater government investment in rural, regional and remote public treatment

While most people see ophthalmologists in their private rooms, it is essential that there is access and affordability of treatment for those who need to access the public hospital system for diagnosis and treatment of eye disease. However, free outpatient eye treatment in public hospitals is extremely limited in rural, regional and remote areas. With the exception of the Gold Coast, Fremantle, Broken Hill and Alice Springs, the Foundation is not aware of any public outpatient eye treatment services for macular degeneration outside the state capital cities. This means that despite the large retired population in regional centres on the east coast, there is no public treatment for macular degeneration available between Sydney and the Gold Coast, between Sydney and Melbourne, or north of Brisbane.

Very few of the public hospitals outside the major capital cities have the necessary equipment and facilities to provide outpatient eye services for macular degeneration, so people with macular degeneration in rural, regional and remote areas are typically dependent on private specialists for diagnosis and treatment, unless they travel large distances to their capital city.

In addition, while some ophthalmologists do provide services in the public sector, the majority of this is for cataract surgery, a procedure which is typically not urgent. There are very few ophthalmologists providing public treatment for ‘wet’ macular degeneration, and as mentioned above, very few public hospitals offer the service.

There are also very few retinal specialists working in rural, regional and remote areas. This problem is exacerbated for patients living in those areas who cannot afford private treatment, putting them at a real risk of vision loss.

The Commonwealth, state and territory governments need to provide greater investment to improve the provision of free public outpatient eye treatment services in rural, regional and remote areas. Currently, some ophthalmologists will travel to rural, regional and remote areas on a periodic basis to provide ophthalmological services in a private capacity. Governments could provide greater incentives, such as additional payments, and use of rural, regional and remote hospital staff and treatment equipment and facilities, to encourage more retinal specialists from the cities to undertake affordable rural, regional and remote outreach programs.
**Recommendation 11:**
The Commonwealth, state and territory governments provide adequate support to improve the provision of free public outpatient eye treatment services in rural, regional and remote areas, including mechanisms to encourage more retinal specialists to undertake rural, regional and remote outreach programs.

e.ii) Rural, regional and remote patients travelling long distances for treatment
People living in rural, regional and remote areas are required to travel to large regional centres or capital cities to receive treatment. Depending on the distance travelled, this may require overnight accommodation, flights, meals, and other transport costs.

For people living in rural, regional and remote areas, travelling long distances to receive ongoing treatment can be challenging, especially in terms of time, costs, and the burden to family members and carers.

The following comments are from people engaged with research undertaken by the Foundation in 2012, who were undergoing treatment and living in rural, regional and remote areas.

**Case Studies**
“I travel about 200km every four weeks for treatment, with all the added costs of transport plus having to ask my sister or daughter to take time off work to accompany me.”
- **Author 4, Eaton WA**

“I have been having injections in my right eye for 'wet' macular degeneration since November 2007 and have now had 50 injections in that eye... I have to travel 250km to receive this medication. There is considerable cost for petrol in the car too.”
- **Author 7, Katanning WA**

“Why does a person 80+ years old have to get up at 4.00am in the morning, travel 17–18kms to catch the Red Cross car to go to his appointment in Melbourne, 300km each way. He gets home anytime between 4–8pm.”
- **Author 1, Paynesville VIC**

“I have 'wet' macular degeneration in both eyes. I have had injections in left eye (26 times) and right eye (14 times) and it is injected every 4 weeks. Doctor found if left longer, I got a new bleed. We live in a small country town and this means a lot of travelling and expense. I am 81 years old and my husband is 86 and it is a great load for him.”
- **Author 33, Euroa VIC**
State and territory governments provide some assistance to rural, regional and remote patients travelling long distances for treatment through patient assisted travel schemes, however the subsidies provided are often inadequate and most patients have to first pay upfront before claiming back the rebate later.

The programs are also inconsistent between states and territories, with different benefits and requirements. As the 2007 Senate Standing Committee on Community Affairs *Highway to health: better access for rural, regional and remote patients* report noted, “Whilst the schemes have some basic features in common, travel assistance arrangements vary across the States and Territories with different eligibility criteria, subsidy levels, requirements for patient contributions and areas of medical care covered”. xxix

Where you live in Australia should not determine how well you can see. The Commonwealth Government needs to provide appropriate review, oversight and intervention when required to ensure equity of access to treatment for patients with macular degeneration in all the states and territories.

However, despite the Senate Committee’s recommendations, many of the issues and discrepancies still exist around these uncoordinated (between states and territories) and underfunded patient assisted travel schemes.

The cost can be high for rural, regional and remote patients to access anti-VEGF treatment due to the long distances they have to travel. Often they have to ask their spouse or children to take time off work to drive them to treatment and back, as vision can be impaired for about 24 hours after treatment.

The following case study demonstrates the same journey, by a rural patient travelling in a private car to treatment, the rebates he would receive under the different patient assisted travel schemes in each respective state and territory and his out-of-pocket costs.

The case study only examines at the cost of travel for the patient for a single day return journey, and does not take in additional cost factors for such trip to treatment, including food, overnight accommodation and the costs for the necessary accompanying person(s).
**Case Study**

James is a 60 year old pensioner who lives in a rural area. He has to be driven 150km (each way) to his eye specialist in a capital city to get his anti-VEGF injections on a four weekly basis.

The following table shows the different subsidies James would receive depending on which state or territory he resided in, under the respective patient assisted travel schemes, and the amount of money he would have to pay out of pocket due to the limited rebates received under these schemes. The cost to James is calculated based on the Australian Tax Office’s business kilometre rate for a medium sized car (1.6L to 2.6L), which is $0.74 per km.

**Table 1: Subsidies for patient assisted travel schemes in different jurisdictions**

<table>
<thead>
<tr>
<th>State / Territory</th>
<th>Private vehicle subsidy</th>
<th>Distance eligibility</th>
<th>Patient Co-contribution (Pension Card Holder)</th>
<th>Subsidy James would receive (300km)</th>
<th>Amount James would have to pay out-of-pocket (est. travel cost: $0.74 per km for 300km)</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW</td>
<td>$0.19 per km</td>
<td>From home: more than 100km one way</td>
<td>N/A</td>
<td>$57</td>
<td>$222 - $57 = $165</td>
</tr>
<tr>
<td>Vic</td>
<td>$0.17 per km</td>
<td>From home: 100km or more one way</td>
<td>N/A</td>
<td>$51</td>
<td>$222 - $51 = $175</td>
</tr>
<tr>
<td>Qld</td>
<td>$0.30 per km</td>
<td>From closest public hospital: more than 50km one way</td>
<td>N/A</td>
<td>Assuming no difference between closest public hospital and home: $90</td>
<td>$222 - $90 = $132</td>
</tr>
<tr>
<td>WA</td>
<td>$0.16 per km</td>
<td>From home: more than 70km one way</td>
<td>N/A</td>
<td>$48</td>
<td>$222 - $48 = $174</td>
</tr>
<tr>
<td>SA</td>
<td>$0.16 per km</td>
<td>From home: more than 100km one way</td>
<td>$30</td>
<td>$48 - $30 = $18</td>
<td>$222 - $18 = $204</td>
</tr>
<tr>
<td>Tas</td>
<td>$0.21 per km</td>
<td>From home: more than 75km one way</td>
<td>$16.50</td>
<td>$63 - $16.50 = $46.50</td>
<td>$222 - $46.50 = $175.50</td>
</tr>
<tr>
<td>ACT</td>
<td>Subsidy based on destination: Sydney - $112.01</td>
<td>Outside the ACT</td>
<td>N/A</td>
<td>Assuming travel from ACT to Sydney for treatment: $112.01</td>
<td>Assuming distance travelled is 300km: $222 - $112.01 = $109.99</td>
</tr>
<tr>
<td>NT</td>
<td>$0.20 per km</td>
<td>From home: more than 200km one way</td>
<td>N/A</td>
<td>Not eligible as journey is under 200km each way</td>
<td>$222 (Not eligible)</td>
</tr>
</tbody>
</table>
**Recommendation 12:**
The Commonwealth Government work with state and territory governments to improve access to and equity of rural, regional and remote patient assisted travel schemes.

f. the better integration and coordination of Medicare services, including access to general practice, specialist medical practitioners, pharmaceuticals, optometry, diagnostic, dental and allied health services;

f.i) Medicare funded comprehensive eye examinations
Australians without any symptoms of eye disease currently receive full MBS coverage for a comprehensive eye examination every two years, which provides a reasonable frequency to enable the detection of early, asymptomatic disease for early intervention in order to reduce the risk of progression to sight-threatening disease.

The 2014–15 Federal Budget proposed the following changes to the frequency of these Medicare funded visits:
1) For asymptomatic people aged 65 and over, the frequency would be increased to annual eye examinations
2) For asymptomatic people aged under 65, the frequency would be reduced to one eye examination every three years

While the Foundation supports the Commonwealth Government’s proposed changes to improve access to eye examinations for people aged 65 and over, the proposed reduction in access to Medicare funded eye examinations for people under the age of 65 is not considered optimal.

The early signs of macular degeneration typically start appearing from about 50 years of age, although people normally do not become symptomatic until their 60s or later. By the time people are symptomatic, irreversible damage could have occurred.

Since the risk of progression of macular degeneration can be significantly reduced by diet and lifestyle modifications, including cessation of smoking, it is critical that people in the at-risk age group (over the age of 50) receive regular checks to ensure the disease is diagnosed at the earliest possible time.

The Foundation has been extremely successful in increasing the awareness of the need for regular eye examinations in at-risk groups, and Australia now leads the world in raising awareness of macular degeneration. This has led to earlier detection of the disease and the ability to intervene earlier to slow down progression of the
disease and implement risk reduction measures. It would be of great concern if the recent gains made in early detection and risk reduction were to be lost by a change in rebates for eye examinations, especially since the budgeted savings are minimal.

The early signs of macular degeneration often appear well before the age of 65 and detecting the disease before the symptoms occur can prevent irreversible vision loss. The Foundation therefore supports the status quo of eye examinations on a two yearly basis for people aged between 45 and 65 who show no symptoms of an eye disease.

In addition, the Foundation supports further modification to allow visually asymptomatic people of any age with diabetes to have an eye examination at least every two years, or at least annually if there is any evidence of retinopathy. In addition, higher-risk patients (longer duration of diabetes, poor glycaemic, blood pressure or blood lipid control) without diabetic retinopathy should be allowed an eye examination at least annually.

The Foundation’s positions on this issue are consistent with the diabetic eye disease treatment guidelines issued by the Australian Diabetes Society and the previous Department of Health and Ageing, and endorsed by the National Health and Medical Research Council (NHMRC) in 2008.

**Recommendation 13:**
The Commonwealth Government maintain the status quo of Medicare funded eye examinations on a two yearly basis for people aged between 45 and 65 who show no symptoms of eye disease.

**Recommendation 14:**
The Commonwealth Government allow people with diabetes of any age to have Medicare funded comprehensive eye examinations on a two yearly basis, or at least annually if there is any evidence of retinopathy.

g. health workforce planning;

g.i) Ophthalmologists
Demand for ophthalmology services is increasing with Australia’s ageing population, as the prevalence of eye diseases correlates strongly with age. Furthermore, the introduction of anti-VEGF treatment for macular degeneration, with the need for regular and ongoing monitoring and treatment, has significantly increased the workload on the profession, especially for those with a retinal sub-specialty. Although changes to injection treatment protocols and the introduction of new, potentially longer lasting drugs will theoretically reduce demand for services (as suggested in
the *Health Workforce 2025* report, in practice, demand continues to increase as most patients will need treatment on an ongoing basis. In addition, more conditions are now able to be effectively treated with the use of injections (e.g. diabetic macular edema, retinal vein occlusions, and many retinal dystrophies). It is also possible that new treatments for previously untreatable diseases such as atrophic ("dry") macular degeneration will require the need for regular injections.

According to the *Health Workforce 2025* report:

1) The Royal Australian and New Zealand College of Ophthalmologists (RANZCO), ophthalmology’s professional college, keeps ophthalmologist training numbers low.

2) There are limited training opportunities in the private sector, which is important as the majority of services are provided privately.

3) Depending on the assumptions/scenarios used, there will be a shortage of up to 204 full time equivalents (FTE) by 2025, representing about 17% of the anticipated demand.

4) RANZCO acknowledges a maldistribution of ophthalmologists, with most practising in metropolitan and urban areas. Only some visit rural, regional and remote areas on a periodic basis.

Although the increased use of telehealth can partially deliver additional capacity in rural, regional and remote areas, especially in the areas of diagnosis, monitoring and follow-up, telehealth cannot deliver essential, sight-saving treatments.

The shortage of ophthalmologists is particularly acute in the public hospital sector for those in need. There is a clear need to expand public treatment and the need to provide more ophthalmologists with specialty training to treat patients with macular degeneration.

**Recommendation 15:**
The Commonwealth Government address the shortage of ophthalmologists in the workforce, especially in rural, regional and remote areas in several ways, including:

a. Continuation and increase of funding for the Medical Specialist Outreach Program.

b. Provision of incentives to encourage specialists to set up in larger regional centres.

c. Work with RANZCO to ensure adequate training places are maintained.

d. Work with RANZCO and the states to address the acute shortage of public outpatient treatment services available, in both metropolitan areas and regional centres.

e. Speedy approval and reimbursement of new technologies and treatments which may reduce treatment burden for patients (and providers).
h. any related matters.

h.i) Access to low vision aids and technologies
The Foundation has been actively advocating the Commonwealth Government to improve access to low vision aids and technologies since it first approached then Prime Minister John Howard in March 2007.

Over the following years, the Foundation constantly drew attention to this critical issue. For people who have permanently lost significant vision, low vision aids and technologies can help the person maintain their independence and quality of life.

During the development of the National Disability Insurance Scheme (NDIS), there were consultations between the Commonwealth Government and stakeholders, and it was indicated that the NDIS would be the solution to the lack of access to low vision aids and technologies.

However, due to adoption of the under 65 years of age requirement to become a participant of the NDIS, there is a disparity in access to low vision aids and technologies based on age.

For people under 65 years of age with significant vision impairment who qualify for the NDIS, such devices can be fully funded for life as a part of their support package. However, almost all people who lose vision from macular degeneration will do so after the age of 65 and therefore will not qualify for the NDIS.

It must be noted that no audit of the cost of existing low vision services within the disability sector, or the costs of duplicating these supports and services in the aged care system, was ever explored by the Productivity Commission or conducted by the Commonwealth Government. This was despite the Foundation’s constant requests to undertake an analysis of the costs on which the decision to exclude people who acquire a disability aged 65 or over was based upon, and the Foundation’s offer to provide expertise and data to assist in making an informed decision.

In November 2013, The Foundation raised this matter in its submission to the National Commission of Audit, stating, “The Foundation is of the strong view that the Productivity Commission should have conducted comprehensive research to identify whether specific disabilities would be better and more economically supported in the aged care system or the disability care system, with appropriate economic modelling.”

The considered view of the Foundation is that the likely costs of including people over 65 who are vision impaired or blind within the NDIS would have been minimal in comparison to accommodation within the aged care sector.
Unlike the NDIS, the aged care system is not powered to care for those with a disability of blindness or severe vision loss, even under the present aged care reform, as it has neither the funding, capacity nor expertise to fully provide necessary services such as low vision aids and mobility training to maintain independence and quality of life.

The Parliamentary Joint Committee on Human Rights acknowledged the Foundation’s concerns in its December 2013 report.\textsuperscript{xli}

It has recently been suggested that limited funds for such devices may be available through the Commonwealth Home Support Programme in the aged care system, however the Department of Social Services recently indicated in the Key Directions for the Commonwealth Home Support Programme Discussion Paper that the cost of funding low vision aids would be capped at only $500 per person per year\textsuperscript{xlii}.

The Foundation’s submission to the Department highlighted that the $500 Goods and Equipment annual cost cap will provide clients with limited low vision aids such as handheld optical magnifiers, which typically cost between $60 and $350.\textsuperscript{1} These aids support reading the mail, newspaper and other printed materials for those who still have some central vision. However, handheld optical magnifiers do not universally cover the needs of all people with vision impairment or blindness. For instance, there are those with less functional vision who require handheld electronic magnifiers, which have different magnification settings and cost between $450 to $2,300.

Older people with low vision may also require a combination of different assistive technologies to assist them with independent daily living, including low vision aids in the kitchen, a white cane and other mobility aids. There are also costs for training clients to appropriately use these aids.

The Foundation demonstrated that the cost of supplying appropriate assistive technologies to people with vision impairment or blindness would exceed the $500 cap, and recommended the Department initially increase the Goods and Equipment annual cost cap to $1,000 as a starting point to accommodate subsidies for low vision and mobility aids.

The Foundation also highlighted that the annual capping mechanism in the Commonwealth Home Support Programme was too restrictive and not cost-effective. People with more severe vision loss may require higher level low vision aids, such reading machines ($2,000 to $4,500) or desktop video magnifiers ($2,500 to $7,000). These aids would not only be more appropriate to the clients’ needs but are also

\textsuperscript{1} The costs of low vision equipment aids quoted in this section were provided by an equipment provider.
potentially one-off costs as they could last for the rest of their lives, or at least many years and when no longer needed could potentially be re-used.

As the annual capped funding was not cumulative, some clients will never be able to access the higher cost assistive technologies they require. A funding mechanism will be needed to offer some flexibility so that clients’ needs can be met even if the cost of the appropriate aid was above the cost cap. In contrast, pensioners with only a moderate hearing impairment can obtain hearing aids at a highly subsidised cost or no cost, as they are rightly supported by the Commonwealth Department of Health’s Hearing Services Program.

Presently, for older Australians who are vision impaired or blind, there is very little access to obtaining low vision aids and technologies from aged care service providers. There is some provision for aged care service providers to use Home and Community Care (HACC) Service Group 5 funding to procure assistive goods and equipment, however very few aged care services actually provided goods and equipment.\textsuperscript{33} Most people with vision loss or blindness have to approach low vision service providers to purchase low vision aids and technologies outright (unless provided through philanthropic means). For many of these people living on the pension, low vision aids and technologies can be costly and unaffordable.

Since 2007, the Foundation has been driving advocacy campaigns to improve access to and affordability of low vision aids and technologies. Over the years, the Foundation has conducted audits of goods and equipment programs provided by state and territory governments and found very limited or no provision of low vision aids and technologies. With the establishment of the NDIS, and the reallocation of state and territory disability funding to the NDIS, the provision of goods and equipment is most likely going to continue under the NDIS.

Since the NDIS excludes people who acquire a disability at the age of 65 or over, low vision aids and technologies need to be accommodated in the aged care system so that there is some support available for those who acquire vision loss or blindness at the age of 65 or over. The provision of low vision aids and technologies is low cost to the Commonwealth Government, yet yields high return for people with vision loss or blindness in terms of improving their quality of life and independence.

Of critical note is the inequity between the aged care system and the NDIS, given there are no cost caps for Goods and Equipment in the NDIS, where participants receive assistive technologies based on their functional needs. This is in addition to the fact that NDIS participants do not have to make any contributions to their cost of care, whereas aged care clients have to pay ongoing fees. The same vision loss in either system deserves the same equitable treatment.
It is also important to note that there will be people with vision loss who are not covered by the NDIS or the aged care system, and there needs to be programs in place to support these people with access to low vision aids and technologies to prevent anyone from falling through the cracks of these two reform agendas.

**Recommendation 16:**
The Commonwealth Government provide equitable access to and affordability of low vision aids and technologies for people with vision loss and blindness, regardless of their age.
End notes

7 Item 7.2 DUSC Agenda Feb 2012.
8 Item 7.2 DUSC Agenda Feb 2012.
9 Item 7.2 DUSC Agenda Feb 2012.
16 DUSC report on ranibizumab, 2011.
23 Hassell J et al, BJO 2006;90:593-596.
24 Hassell J et al, BJO 2006;90:593-596.


