



# **Submission to the Productivity Commission**

## **Reforms to Human Services Issues Paper**

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**OUR VISION**

**To reduce the incidence and impact of macular disease in Australia**

## **Improving public patient access to sight-saving injections**

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Macular Disease Foundation Australia's response to the Reform to Human Services Issues Paper focuses on the issues surrounding patient access to public hospital outpatient ophthalmology services for diagnosis, provision of treatment (especially sight-saving eye injections) and the ongoing provision of care for people with macular disease.

The Foundation highlights that currently, ophthalmology outpatient injection services are simply not available in most public hospitals to even consider any potential benefits of competition and contestability. In addition, the establishment of standards of care for ophthalmology services in public hospitals would be more suitable than introducing competition and contestability initiatives.

### **Macular disease**

Macular disease is the greatest contributor to chronic eye disease in Australia. It is estimated that there are approximately 8.5 million people at risk of macular disease and over 1.6 million Australians with some evidence of macular disease.<sup>1,8</sup>

Macular disease is a large group of sight-threatening conditions that affect the central retina at the back of the eye, which is responsible for detailed, central vision. These diseases include age-related macular degeneration, diabetic retinopathy, retinal vein occlusions and numerous macular dystrophies.

The treatment of 'wet' age-related macular degeneration was transformed in 2007 with the registration and Pharmaceutical Benefits Scheme (PBS) listing of the first anti-vascular endothelial growth factor (anti-VEGF) drug for this condition.<sup>2</sup> For the first time, the vision of people with this macular disease could not only be preserved, but in many cases, vision already lost could actually be improved or restored using ongoing, regular anti-VEGF injections into the eye. Registration and PBS reimbursement for other similar conditions and a second drug followed in later years.

Critically, good outcomes are highly dependent on early diagnosis, the immediate commencement of injections when indicated, and regular ongoing injections at a frequency depending on individual response. For about 30% of people, injections must continue to be given every four weeks, although the majority of people can gradually have the gap between injections increased, up to 12-weekly in some cases.

### **Hospital treatment**

While the majority of injections are provided in private ophthalmology rooms, only about 17% of injections are bulk billed. As a result, some people are unable to afford the ongoing out-of-pocket costs for private care and are dependent on a public outpatient service to receive these sight-saving injections. It therefore remains of great concern that the vast majority of public hospitals, and almost all public hospitals in regional and remote locations do not provide an outpatient injection service.

The Foundation is aware that many patients find it financially challenging to meet the cost of ongoing anti-VEGF treatment, but continue to pay in order to retain their vision. As indicated by one client, "It's a very difficult decision - go blind or broke."<sup>3</sup> For patients who are unable to pay, public ophthalmology services need to be available to save their vision.

Currently, people who encounter difficulty paying for these injections given in private ophthalmologists' rooms have to seek treatment in one of a limited number of public outpatient ophthalmology clinics. However, these are typically found in only two or three of the major teaching hospitals in state capital cities.

These clinics invariably have long waiting lists to receive treatment, highlighting the level of demand from people who cannot afford private care. Treatment for 'wet' age-related macular degeneration and similar conditions cannot wait and a delay longer than a few weeks can result

in significant and irreversible vision loss. Public outpatient ophthalmology clinics providing sight saving injections are underfunded, under-resourced and in very limited supply.

The Foundation is aware that some public outpatient ophthalmology injection clinics are now in a position of being unable to accept new cases or treat people within the recommended time as they have little or no further capacity, while others are treating people for two or three months and are then moving patients to the private sector for maintenance of treatment. Details on the follow up of these patients, once exiting the public system, are difficult to obtain.

Public outpatient ophthalmology clinics are in short supply across the country and are virtually non-existent in regional and remote areas, despite high patient need and demand - there are almost no public hospitals providing injections for macular disease away from capital cities. Regional and remote areas have little or no availability of treating specialists, public or private, and therefore patient choice is very limited.

Without access to public care, some people with limited income have essentially no affordable option available for ongoing sight-saving injections.

**It is the Foundation's position that in the case of outpatient ophthalmology services in the public hospital system, increasing competition and contestability is not the answer to providing a better public hospital system for the patient.**

**Increasing patient access to outpatient ophthalmological services in a wider range of public hospitals across Australia must be the priority.**

**Once sufficient services are actually in place, competition and contestability is not the key to improved services. Establishing appropriate standards of care, training, supply of ophthalmologists and the appropriate resources are the priorities. This is not driven by competition, but by the provision of resources at a level that provides for the needs of the community.**

## About Macular Disease Foundation Australia

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Macular Disease Foundation Australia is a national body representing the macular disease community, and was established in 2001:

- Its vision is to reduce the incidence and impact of macular disease in Australia.
- Recognised nationally and internationally as the Australian peak body for macular disease.
- The Foundation is a robust organisation with a strong governance model:
  - An experienced Board of Directors set the strategic direction of the organisation
  - Four expert Committees including a Medical Committee, comprising 11 of Australia's leading retinal specialists who provide expertise across all macular diseases, guiding the Foundation on major matters related to prevention, treatment and patient outcomes.
  - National Research Advisor, Professor Paul Mitchell, Professor of Ophthalmology University of Sydney: World expert on macular disease.
  - Experienced senior staff: Backgrounds in science, education, communications, pharmaceutical and medical industries, government policy, media and business.
- Has a national client base of over 53,000 people, across all states and territories, comprising: those at risk of developing, or living with macular disease, their family and carers; eye care and allied health professionals including optometrists, ophthalmologists, orthoptists, occupational therapists, dietitians, pharmacists, GPs, diabetes organisations, residential aged care facilities, university faculties and students, low vision rehabilitation providers; CALD communities; industry groups, key interest and advocacy groups.
- Its work in education, awareness and support services directly correlates to and supports the *National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness in Australia*.
- Has a highly regarded position in representing the views of the macular disease community to government in a collaborative environment in order to make a positive impact on the health of the community. This is evident in the marked improvements in access to treatment and rehabilitation, support and subsidies for patients, families and carers. Given government's emphasis on chronic disease and improving health outcomes, the Foundation, as a peak body and in its advisory roles, can continue to play a significant role in reducing the incidence and impact of Australia's leading cause of blindness.
- Has a powerful voice in the eye health sector for its clients, and has developed tools and expertise to ensure it effectively communicates and represents the views of clients.
- A proven track record of outcomes for public health in Australia which has been recognised on the world stage, with the publication of its work in leading international, peer-reviewed journals.<sup>4,5,6,7,8</sup>
- Regularly invited to share its outstanding achievements in local and international forums, including at major international conferences and events in Europe, South America and Asia Pacific.

## About macular disease in Australia

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- Macular disease is a large group of sight-threatening conditions that affect the central retina at the back of the eye, which is responsible for detailed central vision. These diseases include age-related macular degeneration, diabetic retinopathy, retinal vein occlusions and numerous macular dystrophies.
- Age-related macular degeneration and diabetic retinopathy have been categorised as priority eye diseases for the prevention of blindness and vision impairment by the World Health Organization.
- It is estimated that there are approximately 8.5 million people at risk of macular disease and over 1.6 million Australians with some evidence of macular disease.<sup>9,8</sup>
- Macular disease is the greatest contributor to chronic eye disease in Australia.<sup>9</sup>
- Early detection of macular disease is vital. Diet and lifestyle measures can slow progression of macular disease and where indicated, treatment can save sight.<sup>9,8</sup>
- Age-related macular degeneration is the most common macular disease in Australia:
  - Age-related macular degeneration is a chronic disease with no cure.
  - It is the leading cause of blindness and severe vision loss in Australia and is the cause of 50% of blindness in Australia.<sup>9</sup>
  - 1 in 7 (1.25 million) people over the age of 50 years have some evidence of age-related macular degeneration.<sup>9</sup>
  - This is estimated to increase to 1.7 million by 2030, in the absence of adequate treatment and prevention measures.<sup>9</sup>
  - It primarily affects those over the age of 50 and the incidence increases with age.<sup>9</sup>
  - Age-related macular degeneration is a major chronic disease with prevalence 50 times that of multiple sclerosis and 4 times that of dementia.<sup>9</sup>
  - The impact of age-related macular degeneration on quality of life is equivalent to cancer or coronary heart disease.<sup>10</sup>
  - Smoking is a key risk factor as it increases the risk of developing age-related macular degeneration by 3 to 4 times and smokers, on average, develop age-related macular degeneration 5 to 10 years earlier than non-smokers<sup>9</sup>.
- Diabetic eye disease is the leading cause of blindness among working age adults in Australia:<sup>11</sup>
  - Almost 1.1 million Australians have diagnosed diabetes. Of these, over 300,000 have some degree of diabetic retinopathy and about 65,000 have progressed to sight-threatening eye disease.
  - The longer one has diabetes, the greater the likelihood of sight threatening eye disease.
  - One in three people over the age of 50 with diabetes has diabetic retinopathy.
  - The expected growth in the number of Australians living with diabetes will lead to a corresponding rise in diabetic eye disease and vision loss – numbers are expected to at least double between 2004 and 2024.

- Almost everyone with type 1 diabetes and more than 60% of those with type 2 diabetes will develop some form of diabetic eye disease within 20 years of diagnosis. Significantly, many people with diabetes are diagnosed late, by which time retinopathy may already be present.
- Almost all cases of vision loss from diabetic retinopathy can be prevented with regular eye tests, careful management of diabetes, the use of certain medications, and in some cases, treatment with anti-VEGF agents and/or laser and/or steroids.

### **Socio-economic costs of vision loss in Australia**

- **There is a high cost of vision loss from macular disease to government. Even a modest reduction in the proportion of people who progress to vision loss will generate significant savings.**
- Visual impairment prevents healthy and independent ageing and is associated with<sup>6</sup>:
  - Risk of falls increased by two times.
  - Risk of depression increased by three times.
  - Risk of hip fracture increased by four to eight times.
  - Admission to nursing home three years earlier.
  - Social independence decreased by two times.
- Vision loss from age-related macular degeneration:
  - In 2010, the total cost of vision loss, including direct and indirect costs, associated with age-related macular degeneration was estimated at \$5.15 billion, of which the financial cost was \$748.4 million (\$6,982 per person).<sup>9</sup>
  - The socio-economic impacts of age-related macular degeneration include:
    - Lower employment rates.
    - Higher use of services.
    - Social isolation.
    - Emotional distress.
    - An earlier need for nursing home care.
- Vision loss from diabetic retinopathy:
  - As diabetic retinopathy frequently affects people of working age, the social and economic impact of vision loss can be dramatic and long-lasting. People with vision loss from diabetic retinopathy experience higher rates of unemployment and underemployment, reduced safety in the workplace and home, increased rates of depression and greater dependence on carers due to an inability to drive, mobilise independently and undertake common activities. It is clear that even modest reductions in the proportion of people who progress to vision loss will generate significant savings to government.<sup>8</sup>
  - Vision loss from diabetic retinopathy is nearly always preventable, however thousands of Australians continue to lose vision from the disease. Awareness of the risk of blindness from diabetes is low, and compliance to recommended testing regimens, risk reduction strategies and treatment protocols remains unacceptably poor.<sup>8</sup>

- Vision loss in patients with diabetes also directly interferes with essential tasks to manage diabetes such as insulin administration, glucose monitoring, and exercise, making diabetes progression and other complications more likely.<sup>12</sup>

## References

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- <sup>4</sup> Heraghty J et al, Am J Public Health, 2012;102:1655.
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- <sup>6</sup> Varano M et al, Clin Ophthalmology 2015;9:2243.
- <sup>7</sup> Vukicevic M et al, Eye (Lond) 2015 online Nov 27.
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- <sup>12</sup> Leksell JK, Wikblad KF, Sandberg GE. *Sense of coherence and power among people with blindness caused by diabetes*. Diabetes Res Clin Pract. 2005;67:124-129.