New South Wales

Special Commission of Inquiry into Healthcare Funding

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Name: Macular Disease Foundation Australia

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Mr Richard Beasley SC
Commissioner
The Special Commission of Inquiry into Healthcare Funding
Via email - submissions.hfi@specialcommission.nsw.gov.au

Dear Commissioner,

Macular Disease Foundation Australia appreciates the opportunity to raise our concerns about the **absence of treatment for people with macular disease in NSW public hospitals.**

The crux of this longstanding issue is that NSW has not signed the Pharmaceutical Reform Agreements. If this does not occur, there will remain **no** public hospital treatment for these conditions, which if left untreated will inevitably lead to irreversible vision loss or blindness.

This submission addresses the following Terms of Reference from the Inquiry:

A. The funding of health services provided in NSW and how the funding can most effectively support the safe delivery of high quality, timely, equitable and accessible patient-centred care and health services to the people of NSW, now and into the future;

B. The existing governance and accountability structure of NSW Health:

iv. including the impact of privatisation and outsourcing on the delivery of health services and health outcomes to the people of NSW; and

C. The way NSW Health funds health services delivered in public hospitals and community settings, and the extent to which this allocation of resources supports or obstructs access to preventative and community health initiatives and overall optimal health outcomes for all people across NSW.

About Macular Disease

Macular disease is the collective term used for eye diseases and conditions affecting the macula, which is the part of the retina responsible for central vision. **Macular disease is the leading cause of blindness and severe vision loss in Australia.**[1] There are over 1.9 million Australians living with some evidence of macular disease.[1,2]

Age-related macular degeneration (AMD) is the most common type of macular disease, which is the primary cause of irreversible vision loss and blindness among older Australians.[3,4] There are 1.5 million Australians with some evidence of AMD, of whom 466,000 people live in NSW.[2,5]

Anti-vascular endothelial growth factor (anti-VEGF) eye injections are the sight-saving treatment available for people with the neovascular form of AMD (also known as wet AMD) and other macular diseases, including diabetic macular oedema and retinal vein occlusion. The injections are typically delivered by an ophthalmologist in an outpatient clinic setting.

People receive eye injection treatment for neovascular AMD every 4 to 12 weeks for an indefinite period in order to maintain their vision, but there is no definitive cure. **Without treatment, people with neovascular AMD will progressively develop severe vision loss and blindness.**[6]

For people living with diabetic macular oedema and retinal vein occlusion, eye injection treatment can prevent further vision loss or even improve vision, and in many cases, treatment may safely be suspended once expected outcomes have been achieved.

In NSW, there are 28,000 people with neovascular AMD, 4,500 with diabetic macular oedema and 2,500 with retinal vein occlusion who receive eye injection treatments.[7,8]

Impact on people living with macular disease

Deteriorating vision significantly impacts a person's quality of life, including loss of the ability to drive, difficulty maintaining employment, and challenges in living independently. This in turn significantly increases the need for costly health, aged care and disability support services.[9,10,11]

Whilst eye injection treatments for neovascular AMD are available, which slow or prevent vision loss, there is limited access to this sight-saving eye injection treatment within the public hospital system across Australia. As a result, the vast majority of people have to pay out-of-pocket costs to receive treatment in the clinics of private ophthalmologists.

Even with the Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) safety nets, eye injection treatment is a financial challenge to the most financially vulnerable Australians as it consumes a significant proportion of their income, such as those who rely on the Age Pension for their everyday needs.

The cost of treatment is significant, with out-of-pocket costs estimated at approximately $1,900 per year based on an average of seven treatments a year, which includes factoring in the additional rebates from reaching the Extended Medicare Safety Net Threshold.[12,7] Many people will require treatment to both eyes, further increasing out-of-pocket costs.

Unlike some macular diseases where treatment may be safely suspended once the expected outcomes are achieved, people with neovascular AMD need to receive eye injection treatment every 4 to 12 weeks for an indefinite period in order to maintain vision.

Unfortunately, 20% of people with neovascular AMD will stop treatment in their first year, and 50% of people will stop their eye injections within 5 years,[7] putting them at risk of severe vision loss or blindness. **This low persistence with treatment is highly concerning for Macular Disease Foundation Australia, and should be an area of priority for NSW Health.**

There are several factors that result in people with neovascular AMD stopping treatment against the advice of their ophthalmologist, including the financial burden of treatment. A 2020 survey undertaken by Macular Disease Foundation Australia on barriers to accessing treatment found:[13]

- **78% of people paid some out-of-pockets costs (after rebates)**, and only 17% of people did not pay any out-of-pocket costs.
    - For those who paid out-of-pocket costs, 69% paid up to $299 per treatment (after rebates), 20% paid between $300 to $599, and 6% paid over $600.
- 69% of people had some difficulty paying their ophthalmologists' fees.
    - 29% of people considered **delaying or stopping treatment due to cost**, and of these 6% actually delayed or stopped treatment.

People who delay or stop treatment risk irreversible vision loss or blindness.[6] This should not be happening in a country like Australia, where we expect to have a world-class health system.

The survey also found that 51% of respondents did not feel comfortable asking their ophthalmologist to reduce their fees; and only 21% asked their ophthalmologist for a fee reduction when it was a challenge to pay for treatment.[13]

Importantly, approximately 29% of people reported that they had been forced to cut back on other expenses, including basics such as food and groceries, to be able to afford treatment costs.

The lack of public treatment for neovascular AMD in NSW

There is **no** treatment in NSW public hospital clinics for neovascular AMD.

As NSW is the only State that is not a signatory to the Pharmaceutical Reform Agreements,[14] NSW public hospitals do not have access to Pharmaceutical Benefits Scheme (PBS) listed medicines for neovascular AMD eye injection treatment.

Therefore, in NSW, unlike all the other States, treatment is only available through Medicare and PBS funded services. Only a few treatment clinics in the entire State offer routine bulk billing to eye injection patients. To our knowledge, only 3 of these clinics are located on the grounds of public hospitals and are Medicare/PBS funded but are not part of the public hospital system.

All other treatment clinics are in the private sector where the vast majority of people pay out-of-pocket costs. Private ophthalmologists set their own treatment fees and only 18% to 23% of them offer bulk billing to some patients.[12]

Macular Disease Foundation Australia has raised our concerns with NSW Health and recommended establishing oversight over the allocation of resources and funding, as well as centrally collecting data, for neovascular AMD eye injection treatment.

There appears to be an expectation that NSW Local Health Districts and public hospitals may individually collaborate with ophthalmologists to make their own decisions about providing and facilitating access to this treatment. However, as a result of this lack of central oversight and limited service provision, people with neovascular AMD experience challenges in accessing affordable treatment, and treatment data are unavailable for analysis.

Financial impact of macular disease on government

The total annual economic cost of vision loss in Australia is estimated to be $16.6 billion or $29,000 per person with vision loss aged over 40.[3] The total annual economic cost of vision loss associated with AMD was estimated at $5.15 billion, of which the direct cost was $748.4 million ($6,982 per person).[2] In addition, these costs are likely to be an under-estimate, given they are from 2010 and have not been adjusted for inflation.

People with low vision incur significantly higher direct heath care costs than fully sighted people. In addition, the loss of wellbeing is the greatest single contributor to the overall cost of vision loss. These costs are associated with the increased morbidity and mortality from vision loss and include a higher risk of depression, falls and hip fractures, and increased admission to nursing homes or health services.[15]

Helping Australians to stay on eye injection treatment and maintain their vision is also a win for government in terms of the long-term net savings. Based on a recent economic modelling study, investment that increases eye injection treatment persistence by 25% will result in saving the sight of an additional 22,000 vulnerable Australians, adding up to $2 billion over 10 years to the government's bottom line.[16]

Mandating NSW Health's responsibility over public treatment

We hope this Special Commission of Inquiry into Healthcare Funding will recommend that the NSW Government signs the Pharmaceutical Reform Agreements. This would allow NSW Health to be involved with leadership and oversight and become actively involved in the provision of public eye injection treatment for neovascular AMD.

Without proper resourcing and planning around public treatment, the current limited number of bulk billing treatment services will be unsustainable in the long term. And without public treatment to serve as a safety net for people who are unable to afford the out-of-pocket

costs for private treatment, financially vulnerable people with neovascular AMD will unnecessarily go blind.

Macular Disease Foundation Australia believes the NSW Government needs to uphold the key principle of universal healthcare, and priority needs to be given to the equity of eye injection treatment in the NSW public health system for people with neovascular AMD.

Recommendation

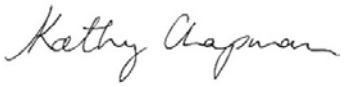
Given the absence of NSW Health's involvement in the treatment of people with neovascular AMD in NSW public hospitals, there is a critical need for NSW Health to sustainably, effectively and efficiently provide outpatient neovascular AMD eye injection treatment with no out-of-pocket costs in NSW public hospitals, with a centralised collection of treatment data for analysis and benchmarking.

This is only possible if the NSW Government signs the Pharmaceutical Reform Agreements.

Macular Disease Foundation Australia appreciates the opportunity to input into the Special Commission of Inquiry into Healthcare Funding, and we are happy to provide further information.

Should you have any questions, please do not hesitate to contact me at [redacted]. We look forward to the outcomes of this Inquiry and wish the Commission great success in facilitating genuine systemic change.

Yours sincerely,



Dr Kathy Chapman
CEO

About Macular Disease Foundation Australia

Macular Disease Foundation Australia is the national peak body representing people living with macular disease and their carers. Our purpose is to reduce the impact of macular disease through our four pillars of work – community awareness and early detection; support for people living with macular disease; advocacy; and research. We work with multiple partners in eye health and low vision sectors, and government to improve patient outcomes. We currently directly engage with 75,000 members of the community nationally, including 33,000 NSW residents.

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