



GEOGRAPHIC ATROPHY

# WE CAN'T WAIT AND SEE

THE  
CASE FOR  
ACTION

A SROI report prepared by  
Crash Bang Wallop & HTANALYSTS  
Sponsored by Apellis Australia

## FOREWORD

The title of this report, '**WE CAN'T WAIT AND SEE**,' captures the urgency of addressing geographic atrophy (GA), a progressive eye disease that requires immediate attention.

GA, an advanced form of age-related macular degeneration, can lead to irreversible vision loss and legal blindness. It profoundly affects the independence and quality of life for the estimated 75,000-100,000 Australians living with the condition.

The lack of treatment in Australia and the limited awareness and understanding of GA result in significant challenges for those affected, their carers, and the Australian Government.

This Social Return on Investment (SROI) report, developed in collaboration with leading eye health and vision care organisations, reveals the substantial financial and non-financial benefits of intervening in GA.

It clearly demonstrates that none of us can afford to wait and see: **GA needs to be elevated in the national eye health discussion.**

At the end of this report, you will find key recommendations to drive awareness of GA, provide equitable and timely access to treatment and ensure people living with the condition can access the support services they need, when they need them.

I hope that in reading this report you are compelled to take action in the way that Vision 20/20 Australia, Vision Australia, Retina Australia, Macula Disease Foundation Australia, Optometry Australia and Sight For All have.

We extend our gratitude to all who contributed their time and expertise to this report, including those living with GA, their families and carers, clinicians, and a range of industry and government consultants. Your input has been invaluable.

Kindly,



Carly Iles  
Chief Executive Officer  
Vision 20/20 Australia

## ACKNOWLEDGEMENTS

We would like to thank everyone who kindly contributed their time to help in the development of this report, including the people living with geographic atrophy (GA) and their carers for sharing personal journeys, and the eye health specialists who provided expert opinion.

It is hoped the findings will inform discussions and drive action to better support those impacted by vision loss and blindness in Australia due to GA. When it comes to dealing with this disease, we can't wait and see.

This report was made possible thanks to the collective passion demonstrated by six leading not-for-profit eye health organisations. The Advisory Committee included Vision 20/20, Vision Australia, Retina Australia, Macula Disease Foundation Australia (MDFA), Optometry Australia and Sight For All.

The Advisory Committee provided expert guidance and input into the lived experience of people with vision loss due to GA in Australia. The direction of the research and the findings of this report were guided by the members of the Advisory Committee to make sure the outcomes presented accurately represent their clients and members. The Advisory Committee shaped the recommendations for action on behalf of the communities they support.



### Advisory Committee

This Social Return on Investment study was conducted by HTANALYSTS, a leader in social impact consulting, and sponsored by Apellis Australia, a global biopharmaceutical company focused on the discovery and development of therapeutic compounds for autoimmune and inflammatory diseases.

The design of this communications report, plus development of the content within the featured patient stories, was completed by Crash Bang Wallop, a creative agency bringing global brand experience to ethical pharmaceuticals.



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Contributors

**“When my vision started to deteriorate, my life started to deteriorate. With GA, I can’t do the things I used to do, and I don’t recognise people. It makes life quite unbearable at times.”**

- Colin, living with GA



Scan to watch Colin's GA story



Only through lived experience can we understand the impact of GA-related vision loss on people and their families. Understanding their experience is one of the most important parts of an SROI analysis. Colin, a farmer from rural Victoria, is legally blind due to GA and lost his independence and way of life. This is his journey.



Fig. 1 Journey of Colin, a person living with GA



# EXECUTIVE SUMMARY

## THE IMPORTANCE OF VISION

Vision is one of the most valuable senses a person possesses, and its loss significantly impacts one's ability to interact with the world and participate in daily activities independently. This loss can profoundly affect quality of life and overall wellbeing.<sup>1,2</sup>

When we have the gift of sight, it's easy to take it for granted and not fully comprehend the consequences of losing it. This report features testimonials from patients and carers, detailing their experiences of living with vision loss caused by geographic atrophy (GA) and the profound impact it has on their lives.

This report also presents findings from both a financial impact study and a Social Return on Investment (SROI) analysis to provide an holistic view of the GA burden, and the social value of investing in interventions to delay vision loss and prevent legal blindness.

## GEOGRAPHIC ATROPHY

GA is the dry form of advanced age-related macular degeneration (AMD). This debilitating eye disease progresses over time, typically affecting individuals aged over 65.<sup>3</sup> GA causes the cells in the macula—the part of the eye responsible for central vision—to atrophy or die, leading to patches of missing retina and irreversible vision loss.<sup>3-8</sup>

GA lesions often develop in the outer retina, away from the fovea (non-subfoveal GA), where vision is sharpest.<sup>3</sup> In these early stages, people may find ways to compensate for their vision loss and may not notice significant changes. However, as GA progresses, these lesions grow and eventually cover the fovea (subfoveal GA), leading to more noticeable vision loss.<sup>3</sup> When this occurs, central vision deteriorates and the ability to read, recognise faces, drive, and maintain independence becomes severely compromised, especially when both eyes are affected.<sup>1,2,4</sup> In approximately 20% of cases, GA results in legal blindness.<sup>9</sup>

## DISEASE PROGRESSION

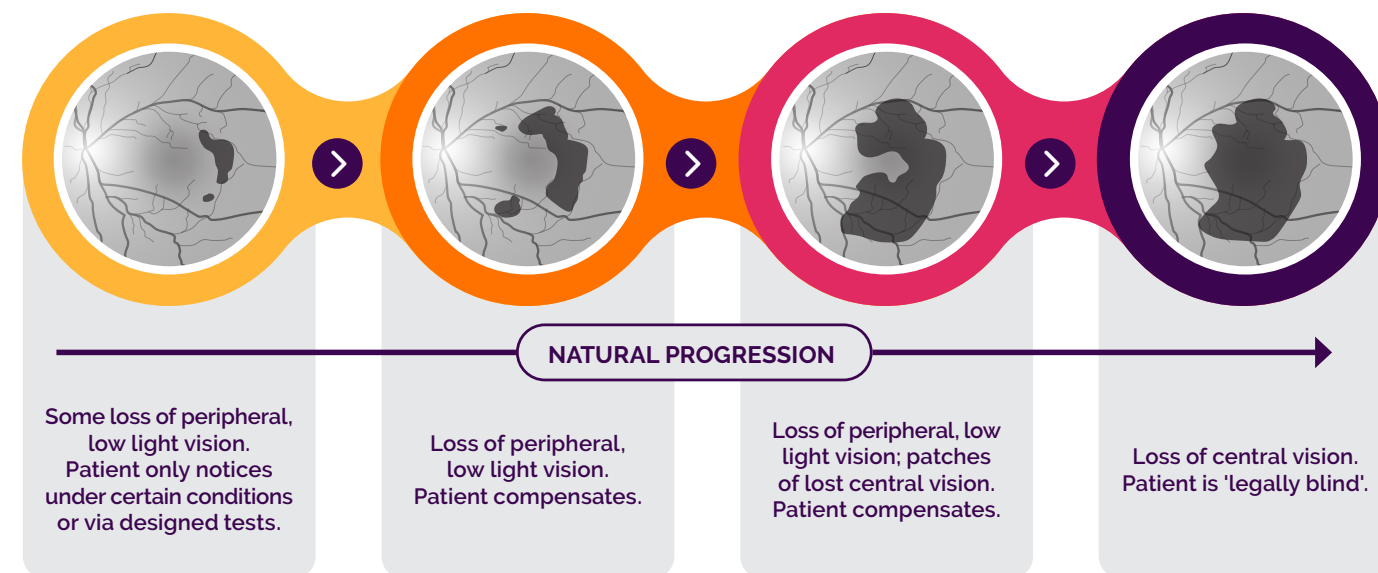
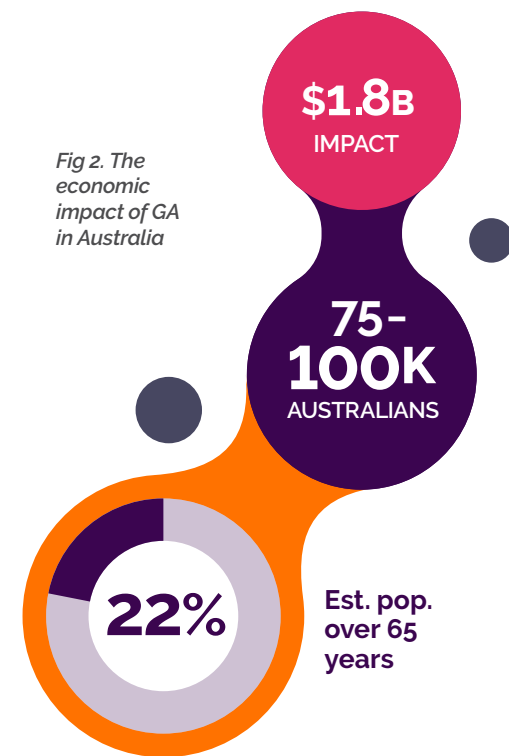


Fig. 3 Stages of typical disease progression



## AN AGEING POPULATION

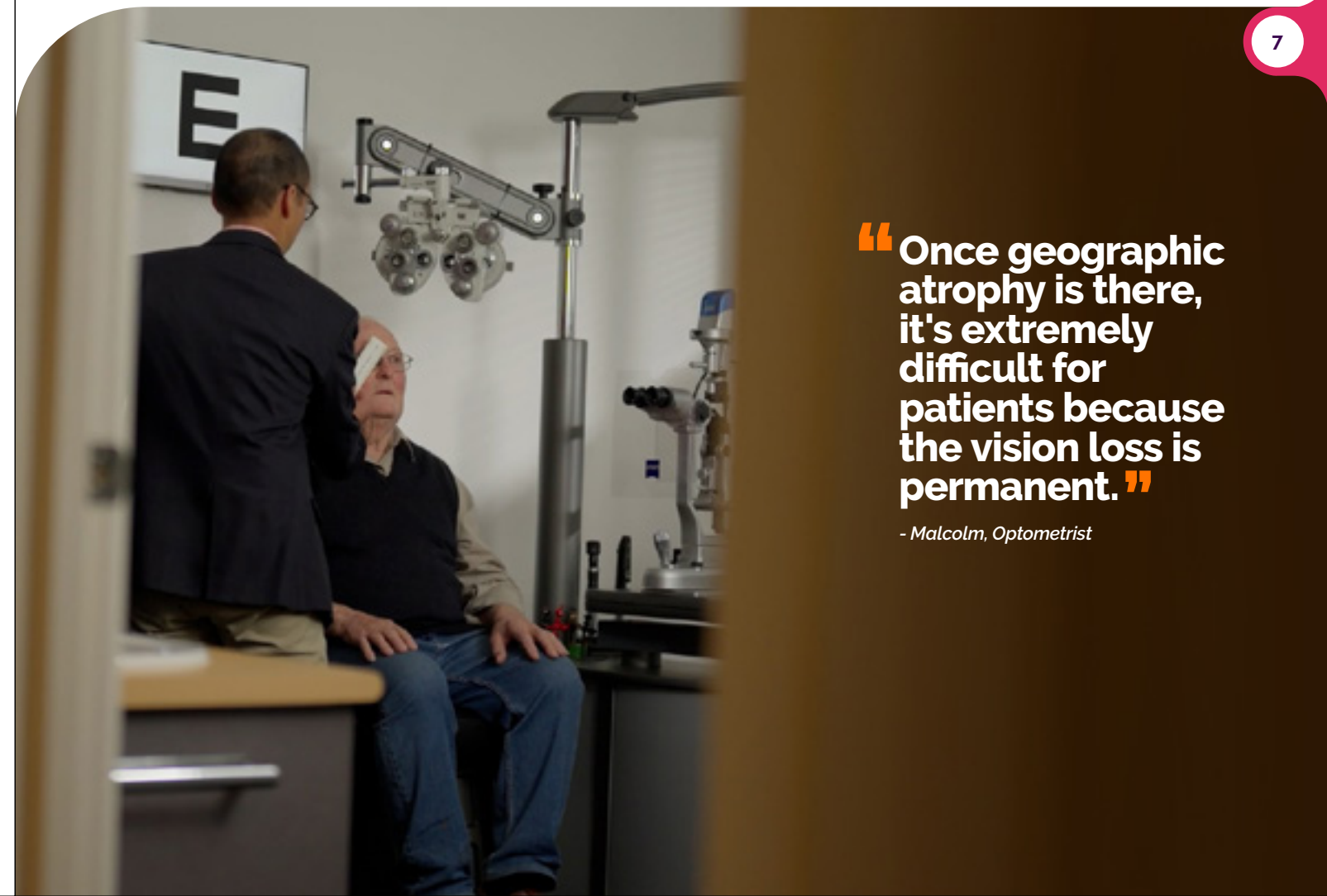
Australia has an ageing population, with 1 in 6 Australians now over the age of 65.<sup>10</sup> As life expectancy continues to rise, it's crucial for older Australians to maintain good health, independence, and social connections. Ensuring healthy ageing is an economic and social imperative. Maintaining vision in people living with GA will support their physical and mental health, independence, and quality of life while reducing the burden on aged care and other government services. An estimated 75,000 to 100,000 Australians are living with GA, but the exact number is difficult to quantify while so many Australians remain undiagnosed or lost to follow up due to the lack of available treatments.<sup>11-13</sup>

Many people with GA believe that declining vision or legal blindness is a natural part of ageing—but it's not.<sup>14</sup> New treatments on the horizon may preserve vision for longer, and we need to be prepared. This involves identifying patients who could benefit from these treatments, assessing their baseline disease characteristics, monitoring disease progression, and understanding the value of preserving vision. Additionally, addressing system gaps that will arise when new treatments become available is essential.

## THE VALUE OF TAKING ACTION

The impact study revealed that the financial cost associated with GA-related vision loss in Australia exceeds \$1.8 billion, including \$377 million in direct health system costs, \$312 million in non-health system costs, and \$1.1 billion in lost wellbeing. Much of this cost is borne by patients, who face high out-of-pocket expenses for specialist appointments, eye imaging, aged care, and wellbeing costs.

The SROI, informed by the lived experience of key stakeholders found that for every \$1 invested in an intervention to delay vision loss and prevent legal blindness due to GA, \$2.21 of social value is created. This value primarily comes from maintained independence (55%) and social and emotional outcomes (45%), with less than 1% of the value being economic in nature. This underscores the limitations of traditional approaches and the importance of innovative methods to capture and measure value. People living with GA experience most of the benefits of the proposed intervention (82%), followed by their carers (17%). The ability to perform tasks such as driving, cooking, and reading is essential for maintaining independence and wellbeing.

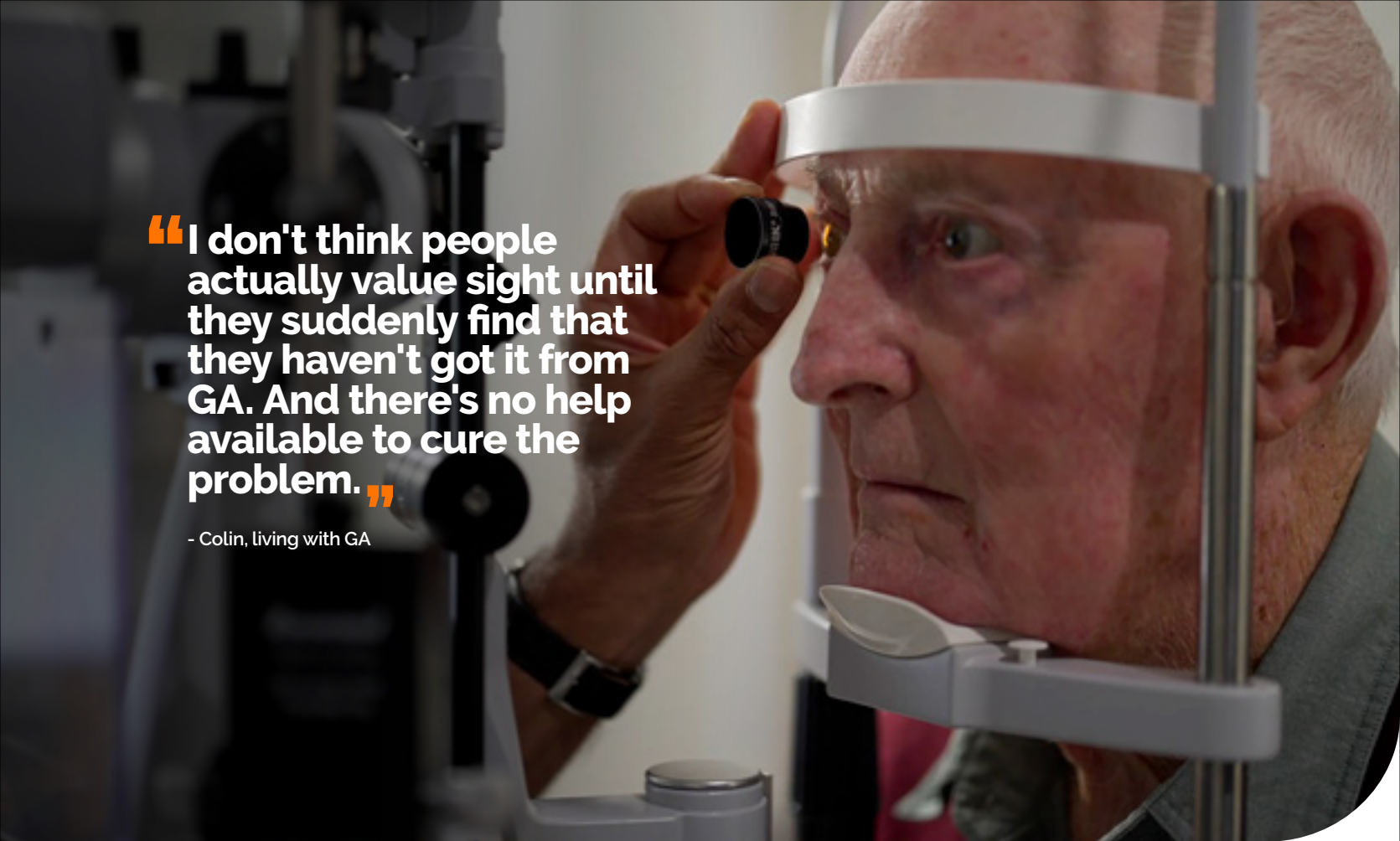


**“Once geographic atrophy is there, it's extremely difficult for patients because the vision loss is permanent.”**

- Malcolm, Optometrist

**“I don't think people actually value sight until they suddenly find that they haven't got it from GA. And there's no help available to cure the problem.”**

- Colin, living with GA



### OBJECTIVES OF THE SROI

As there are currently no disease-modifying treatment options available for people living with GA in Australia, it is not possible to retrospectively evaluate the disease. This forecast SROI was designed to measure the social impact that could be created by investing in an intervention to delay vision loss and prevent legal blindness in people living with GA.

**ASSESS**

To assess the impact of delaying vision loss and preventing legal blindness in people living with GA in Australia

**QUANTIFY**

To quantify the change stakeholders experience as a result of delaying vision loss when preventing legal blindness in people living with GA

**TELL**

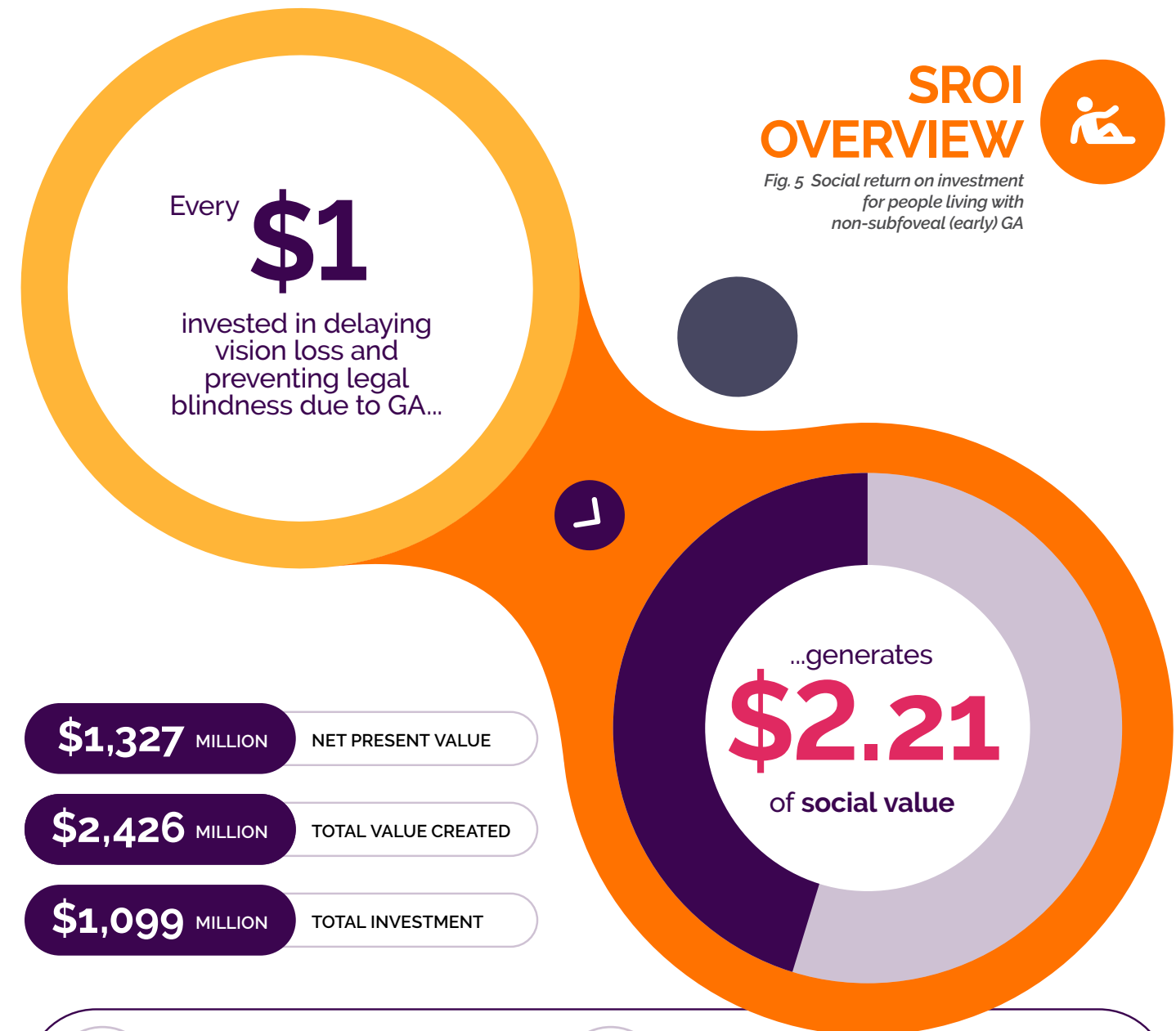
To tell the stories of people living with GA and their families

Fig. 4 Objectives of the SROI

## SROI OVERVIEW



Fig. 5 Social return on investment for people living with non-subfoveal (early) GA



### Outcomes generating social value for stakeholders include:

- Maintained independence
- Maintained mental wellbeing
- Maintained connection to family, friends & community
- Maintained carer wellbeing



# RECOMMENDATIONS

The impacts of vision loss due to geographic atrophy (GA), not only on those with GA but also on their carers, families, and the Australian Government are far reaching. Delaying vision loss, preventing legal blindness and preserving sight for those with GA would support their independence, mental health, and connections with family, friends, and community. The flow-on benefits for carers would include maintained employment and improvement of their own mental wellbeing and social connections. Vision loss is associated with an increased risk of falls, road traffic accidents, burns, and other injuries which put an avoidable strain on healthcare resources. Preserving vision for those with GA would also result in financial savings for the Australian Government.



## WE CAN'T WAIT AND SEE

- 1 Equitably fund vision support services for older Australians
- 2 Fund a national GA awareness campaign
- 3 Public funding for OCT imaging to detect & monitor GA in those at risk
- 4 Fund the creation of a national AMD registry
- 5 Secure dedicated funding for GA research
- 6 Expedite funding for new GA therapies once approved

To fully realise the benefits highlighted by the SROI, we recommend acting in six crucial areas:

### Enhance Support for People Living with Vision Loss:

Australians who have experienced vision loss due to GA need equitable access to support services at the right time to safeguard their independence, dignity and quality of life. Vision support services include information, education, mental health support, practical support aids and modifications around the home, classes to improve confidence in performing activities of daily living such as cooking, and social support groups to reduce social isolation and loneliness. Access to support services should be available at various stages throughout the GA journey.

Cost is another recognised barrier to accessing vision support services.<sup>33</sup> In Australia, those diagnosed with a disability prior to the age of 65 can be eligible to receive funding for supports through the National Disability Insurance Scheme (NDIS) while those diagnosed after the age of 65 cannot—and instead rely on aged care funding.<sup>34</sup> The funding levels offered by these two schemes differ, and as such, some people are disadvantaged.

We need to close the funding gap between NDIS and aged care to ensure that people have equitable access to appropriate vision support services including information, aids and modifications. Maintained independence reduces the need for cared-accommodation and offsets any cost to the at-home aged care system and provides net savings.

**Recommendation One: Equitably fund vision support services for older Australians**

### Drive awareness and Early Detection of GA:

This report demonstrates that GA, and its precursor AMD, is a significant and unaddressed health priority among older Australians. A public awareness campaign conducted by a leading eye health organisation is needed to focus on the importance of regular eye checks in monitoring and assessing GA for the sake of the individual and the community. This would lead to an increase in the number of people actively seeking regular eye checks and reduce vision loss from GA and other eye conditions.

**Recommendation Two: Fund a national GA awareness campaign.**

### Fund OCT Imaging for GA Detection:

It is important to note that currently Optical Coherence Tomography (OCT) imaging, the eye scanning technology required to detect GA, is not publicly funded through the medical benefits schedule (MBS) for conditions where there are no treatments available. Many patients are required to pay an out-of-pocket cost for OCT scans that they simply cannot afford. It is recommended that OCT imaging for diagnosis and monitoring of GA should be publicly funded via the MBS, at least once every 2 years for people over the age of 50, irrespective of treatment availability.<sup>35</sup>

**Recommendation Three: Provide public funding for OCT imaging to detect and monitor GA in those at risk**

### Establish a National AMD Registry:

We need to uncover the true burden of GA, and facilitate evidence-based decision-making. We are unable to accurately quantify the number of Australians living with GA at this time, as many remain undiagnosed or lost to follow-up in the community. Compounded by the fact that many Australians consider vision loss as a normal part of ageing, and that there is no treatment for GA currently available in Australia, many people with the disease are not regularly seeing an eye health professional for eye imaging.<sup>4,36,37</sup>

Although, a private registry called the Fight Retinal Blindness registry has been established however a national AMD registry inclusive of GA is recommended to systemically capture data across the country.

This coordinated approach would enable Australia's eye health community to assess baseline disease characteristics and identify risk factors for disease progression, not mention improve disease monitoring and management, and inform support service delivery.<sup>37</sup>

In collaboration with the existing registries, the GA data captured by the national registry would also provide valuable insight into vision outcomes, and ensure appropriate patients are treatment ready (when GA treatments are available).

**Recommendation Four: Fund the creation of a national AMD registry**

### Invest in GA Research:

Ongoing investment into GA research through programs such as the Medical Research Future Fund (MRFF) and National Health and Medical Research Council (NHMRC) is needed to increase understanding of the disease processes and identify patients most likely to respond to treatment. It is recommended that GA be identified as a priority initiative for investment through the MRFF.

**Recommendation Five: Secure dedicated funding for GA research**

### Ensure Timely Access to New Therapies:

Data shows that patients in Australia experience an extended patient access gap, with an average time of more than a year between registration of medicines by the Therapeutic Goods Administration (TGA) and funding on the Pharmaceutical Benefits Scheme (PBS).<sup>38</sup> This results in delayed access, which for people with GA means declining vision that cannot be reversed and worse quality of life. Furthermore, results from the SROI indicate failure to act leads to greater financial and social costs to society and the government.

While there are currently no registered treatments available in Australia to delay or stop the progression of GA, multiple treatments are currently being considered by the TGA or undergoing clinical trials. When an effective and safe treatment is registered fast track funding is requested.

**Recommendation Six: Expedite funding for new GA therapies once approved**

## SUMMARY

The current burden of geographic atrophy (GA) in Australia is substantial and will continue to grow without intervention. This report not only outlines the burden of GA but also demonstrates the potential benefits of investing in measures to delay vision loss and prevent legal blindness. The six key recommendations—drive awareness and early detection of GA, fund OCT imaging for GA detection, establish a GA registry, invest in GA research, ensure timely access to new therapies, and enhance support for people with vision loss due to GA—identified in this report are essential to improving the quality of life for patients and carers and reducing the burden of GA in Australia.

The authors and Advisory Committee behind this research hope that the introduction of new therapies, along with the implementation of the report's recommendations, will ensure that no Australian has to live with GA without appropriate intervention and support.

**! It is clear that acting today saves sight and money tomorrow, and the cost of doing nothing is too great. When it comes to geographic atrophy, WE CAN'T WAIT AND SEE.**

## CONTACT

### For further support or disease information:

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For further support and information about living with macula disease, Eye Connect offers vital health information, practical advice, and emotional support. Visit: [mdfoundation.com.au/support-me/support-services/eyeconnect](https://mdfoundation.com.au/support-me/support-services/eyeconnect)

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### ADVISORY COMMITTEE

