



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

“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



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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 2020 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

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.^{1,2}

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 65.³ 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.³⁻⁸

GA lesions often develop in the outer retina, away from the fovea (non-subfoveal GA), where vision is sharpest.³ 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.³ 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.^{1,2,4} In approximately 20% of cases, GA results in legal blindness.⁹

AN AGEING POPULATION

Australia has an ageing population, with 1 in 6 Australians now over the age of 65.¹⁰ 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 estimate while so many Australians remain undiagnosed or lost in follow up due to the lack of available treatments.¹¹⁻¹³

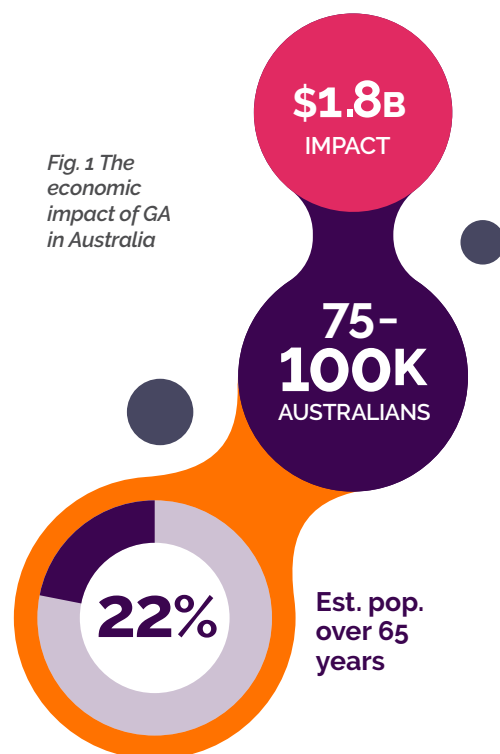
Many people with GA believe that declining vision or legal blindness is a natural part of ageing—but it's not.¹⁴ New treatments on the horizon may preserve vision for longer, and we need to be prepared. This involves identifying patients who could benefit from these treatments, assessing their baseline 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

Fig. 1 The economic impact of GA in Australia



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.

The findings of this report will help decision-makers understand the importance of prioritising GA as a health issue, recognising the value of investing in delaying vision loss and legal blindness associated with this disease.

KEY RECOMMENDATIONS

To fully address the challenges of GA and its impact, action is needed in the following areas:

Enhance Support for People Living with Vision Loss due to AMD:

- People with neovascular AMD and GA need access to information and support services that help maintain their independence and quality of life
- Funding gaps between the National Disability Insurance Scheme (NDIS) and aged care need to be closed to ensure adequate support for those over 65

Recommendation: Equitably fund vision support services for older Australians

Drive Awareness and Early Detection Of GA:

- GA is a significant but under-recognised health issue among older Australians
- A national public awareness campaign is needed to encourage regular eye checks, which can help reduce vision loss from GA

Recommendation: Fund a national GA awareness campaign

Fund OCT Imaging for GA Detection:

- Optical coherence tomography (OCT) is essential for detecting and monitoring GA, but it's not currently covered by the Medicare benefits schedule (MBS) for untreated conditions
- OCT scans should be publicly funded, especially for people over 50, at least once every two years

Recommendation: Provide public funding for OCT imaging to detect GA in those at risk

Establish a National AMD Registry:

- Accurate data on GA prevalence in Australia is lacking, as many cases go undiagnosed
- An AMD registry inclusive of GA would capture high-quality data, improve disease monitoring, and ensure patients are ready for future treatments

Recommendation: Fund the creation of a national AMD registry

Invest in GA Research:

- More research is needed to better understand GA and identify patients who will benefit most from future treatments
- GA should be prioritised in research funding through programs like the Medical Research Future Fund (MRFF) and the National Health and Medical Research Council (NHMRC)

Recommendation: Secure dedicated funding for GA research

Ensure Timely Access to New Therapies:

- There is often a significant delay in making new treatments accessible in Australia after they are approved
- When GA treatments become available, they should be fast-tracked for public funding to prevent further vision loss

Recommendation: Expedite funding for new GA therapies once approved

IMPLEMENTING THE RECOMMENDATIONS

The current burden of 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—are essential to improving the quality of life for patients and carers and reducing the GA burden in Australia.



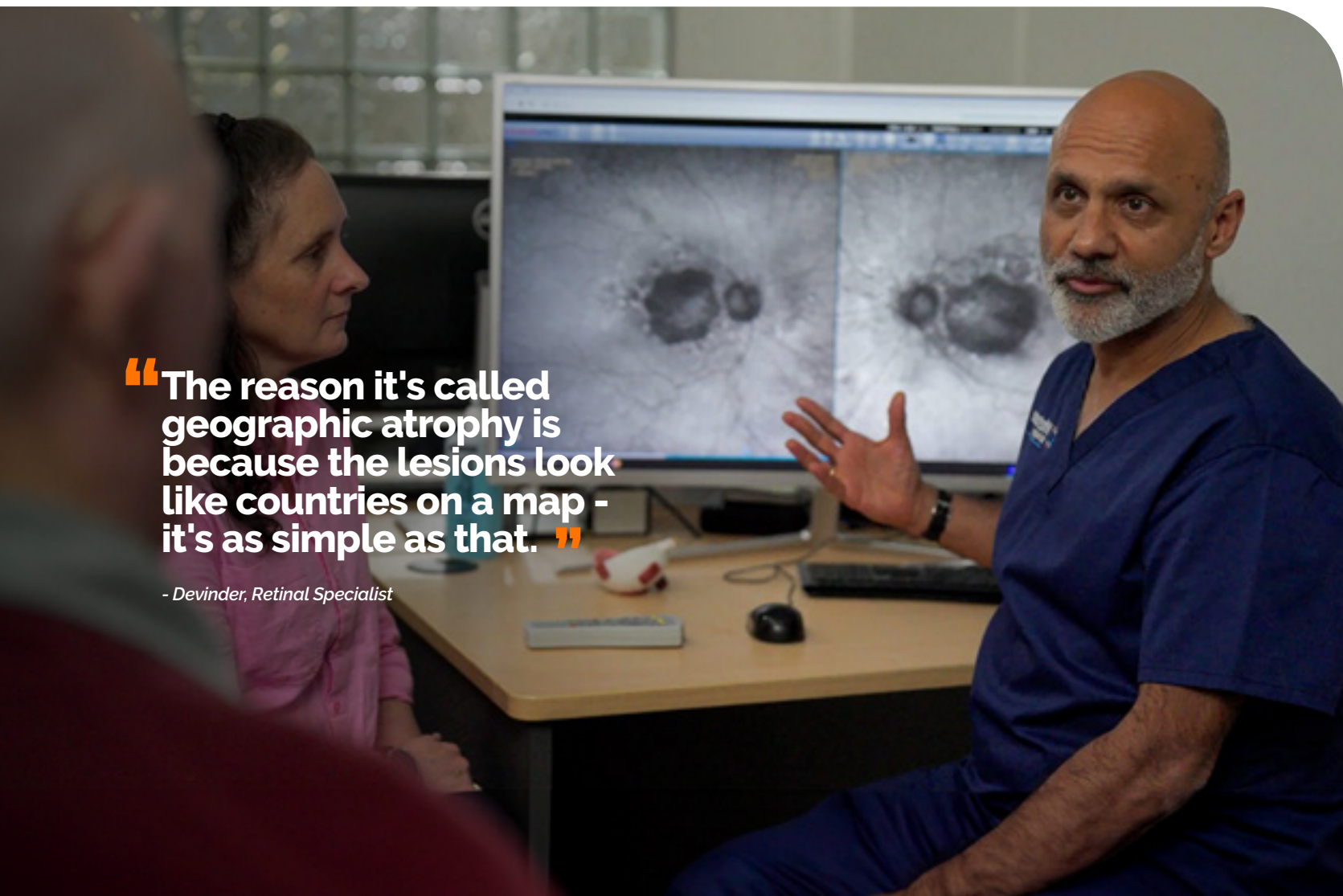
Fig. 2 Stakeholders engaged for the SROI

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 GA, we can't wait and see.

“The reason it's called geographic atrophy is because the lesions look like countries on a map - it's as simple as that.”

- Devinder, Retinal Specialist



THE FINDINGS OF THE SROI

The chart below quantifies the social value created from delaying vision loss and preventing legal blindness in people living with non-subfoveal GA (with vision still to lose).

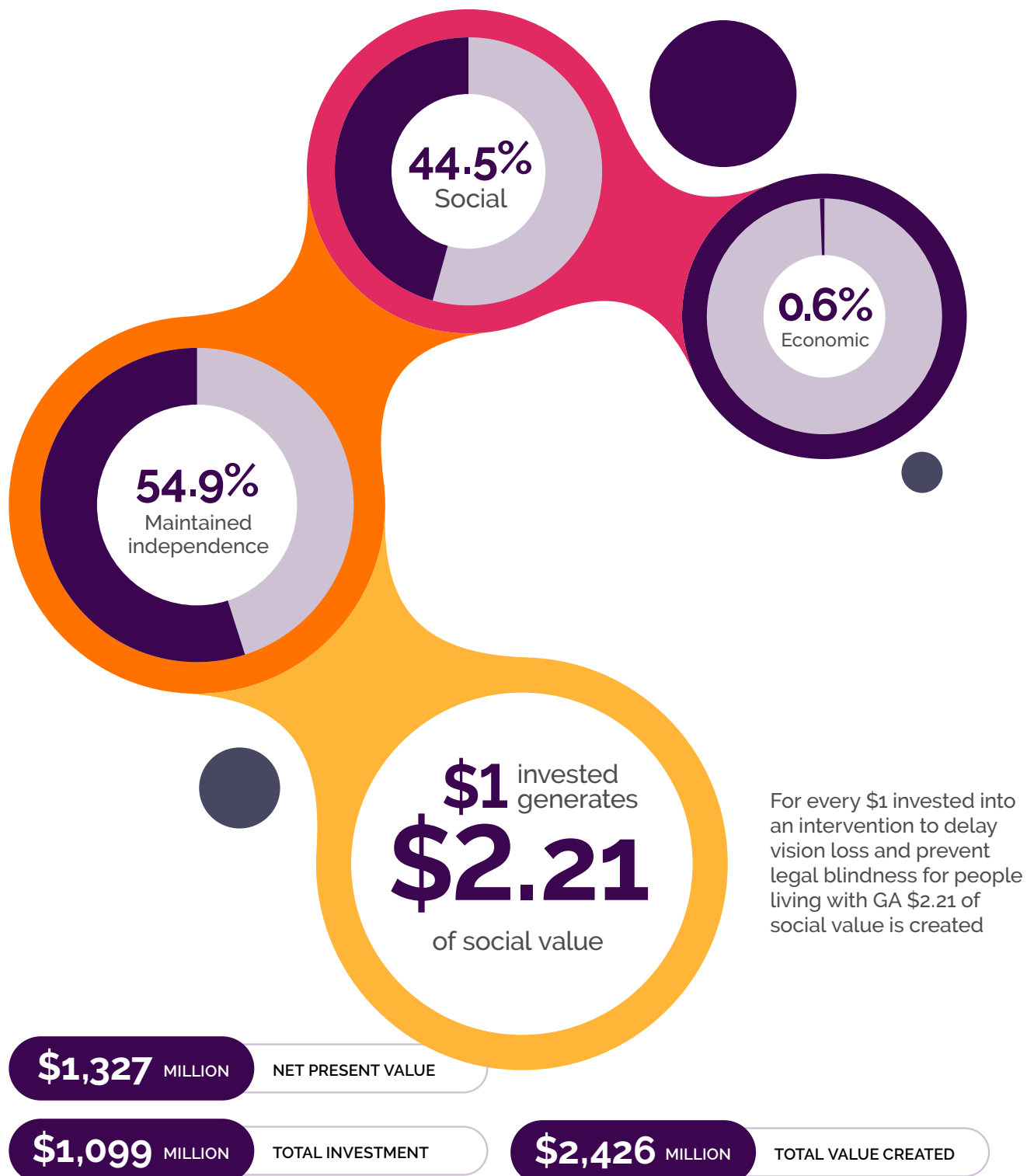


Fig. 3 SROI Findings

PURPOSE OF THIS REPORT

Vision is an invaluable sense, and its loss significantly impacts a person's ability to engage in daily activities, and maintain independence and a sense of wellbeing.^{1,2}

Geographic atrophy (GA) has a profound impact on people's vision. The progressive disease leads to the gradual breakdown of retinal cells, resulting in irreversible vision loss and in approximately 20% of cases, legal blindness.^{3-8,9} GA typically affects those over 65 and can severely impair central vision, affecting activities such as reading, driving, and recognising faces.

This report aims to illuminate the profound effects of GA on individuals' vision and its impact on their lives to emphasise the urgent need for targeted actions to address this growing health challenge. It is a comprehensive overview of GA, detailing how the disease affects vision and quality of life, through data provided by key stakeholders, and patient and caregiver testimonials.

The purpose of this report is four-fold:

Highlight the Human Impact of GA: By sharing personal stories and experiences, the report illustrates the daily struggles faced by those living with GA. It aims to foster a deeper understanding of how vision loss impacts not only the individuals but also their families and carers.

Present Comprehensive Data on GA: The report includes findings from both the financial impact study and Social Return on Investment (SROI) analysis. These insights reveal the significant economic burden of GA-related vision loss, estimated to exceed \$1.8 billion in Australia, and demonstrate the substantial social value of investing in interventions to delay or prevent legal blindness.

Recommend Key Areas for Action: To address the challenges posed by GA, the stakeholders outline six specific recommendations. These include driving awareness and early detection of GA, funding OCT imaging for GA detection and monitoring, establishing a GA registry, investing in GA research, ensuring timely access to new therapies, and enhancing support for people with vision loss due to GA.

Advocate for Policy Changes and Investment: The report calls for policy change and increased funding to support new treatments and improve access to vision care services. It demonstrates the importance of preparing for future treatments and addressing gaps in the current healthcare system to ensure that Australians living with GA receive the care and support they need. By presenting these recommendations and emphasising the urgent need for action, this report seeks to inform decision-makers and stakeholders on the importance of prioritising GA in health policy and resource allocation. The goal is to improve the lives of those affected by GA while reducing the burden on the healthcare system and society.

Apellis Australia Pty Ltd commissioned HTANALYSTS to evaluate the broader social value of preserving vision in people with GA. Social value encompasses the financial, environmental, and wellbeing outcomes that arise when a person's life changes, including benefits not typically measured in health research but significant to GA patients and their families. This research, guided by an Advisory Committee of leading Australian not-for-profit organisations, quantified the SROI of preserving vision in GA patients.

This analysis was informed by stakeholder consultations, secondary research, and verification through the Advisory Committee. The goal was to model the impact of delaying vision loss and preventing legal blindness in GA patients over a three-year period.

WORKING TOGETHER FOR A BETTER OUTCOME

This report brought key stakeholders together to understand the financial and non-financial impact of GA, and to improve outcomes for the people who need it most.

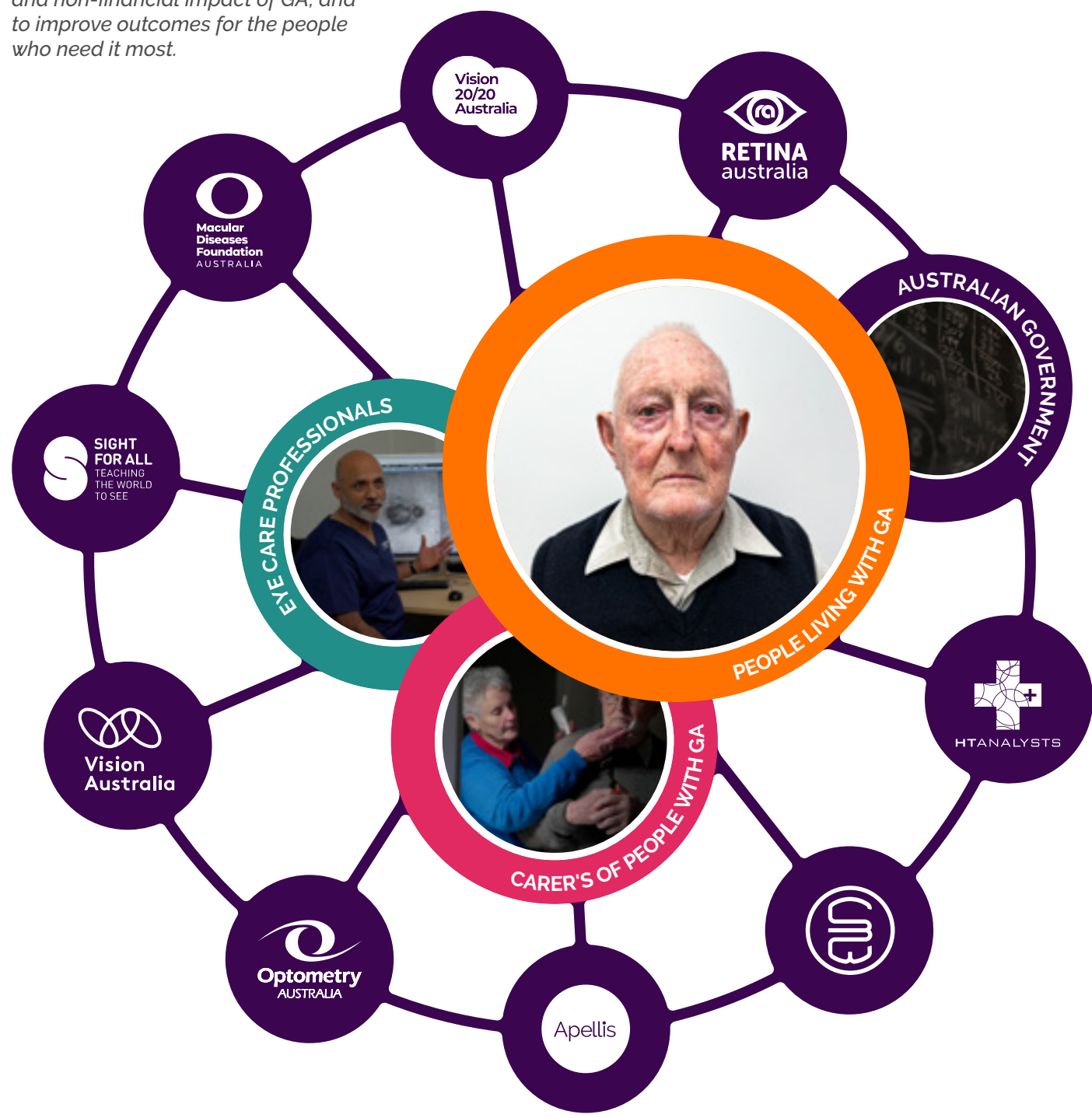


Fig. 4 SROI contributors and stakeholders

GA EXPLAINED

AN ADVANCED FORM OF AMD

Age-related macular degeneration (AMD) is a chronic, progressive eye condition that worsens over time, affecting over 1.5 million Australians. This is more than cardiovascular disease or cancer.^{15,16}

AMD targets the cells in the macula, the part of the eye responsible for central vision, leading to permanent vision loss or legal blindness as the disease progresses through its three stages: early, intermediate, and late.³⁻⁸

There are two types of advanced AMD: neovascular 'wet' AMD and geographic atrophy (GA), also known as 'dry' AMD.¹² In neovascular AMD, abnormal blood vessels grow and can leak fluid, damaging the macula. However, in GA, lesions form in the macula itself, gradually eroding central vision.³

Most Australians living with GA are unaware they have the disease, often incorrectly attributing vision loss to ageing or genetics.

EFFECT ON VISION

GA occurs when certain cells in the retina, the layer of tissue at the back of the eye that helps you see, begin to atrophy or die. This leads to gradual loss of visual function, especially in the central part of your vision, making it harder to see details.¹⁷

From the perspective of the lived experience, GA is like having a slowly expanding blind spot in the middle of your vision. Imagine looking at a photograph of a face as holes appear in the centre. As these holes get bigger, the area you can see clearly gets smaller and you lose the ability to recognise the face.

CHARACTERISTICS

GA can be characterised by the location of lesions within the macula.

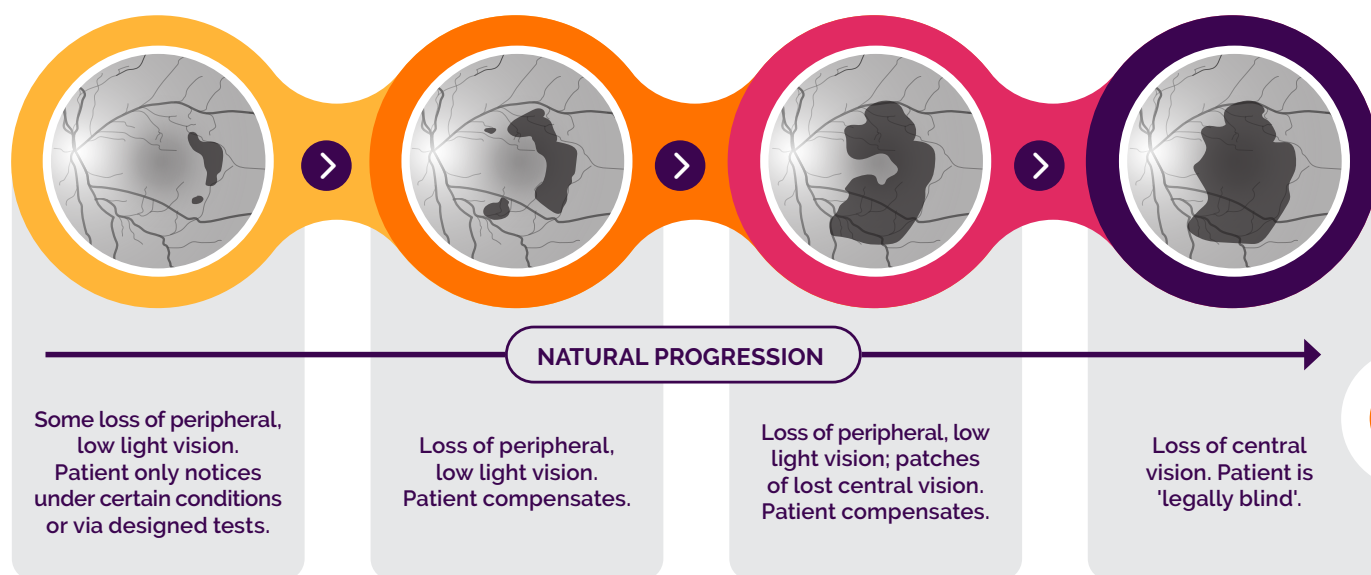
- **Non-subfoveal GA:** Occurs when lesions develop outside of the fovea.³ As these lesions are located away from the central vision area, the impact on sharp vision is less severe and peripheral vision may be unaffected. However, it is possible you may still experience a gradual loss of visual clarity as the disease progresses and damage happens in the surrounding areas.
- **Subfoveal GA:** Occurs when lesions develop or progress to encroach upon the fovea, which is the small part of the retina responsible for your sharpest vision. When GA affects this area, it severely impacts your central vision and makes it very difficult to see fine details, read or recognise faces.³

In both types of GA, loss of visual function progresses over time, but the impact on daily activities can vary depending on which part of the retina is affected.



Fig. 5 GA, the disease

DISEASE PROGRESSION



13

Fig. 6 Stages of typical disease progression³

PREVALENCE

Due to a lack of disease awareness, many Australians may not realise their vision loss is due to GA or that they have the potential to develop the condition. AMD accounts for half of all legal blindness and severe vision loss in Australia, with GA estimated to represent approximately 20% of cases.⁹

Of the 75,000 to 100,000 people living with GA, prevalence significantly increases with age—98% of cases occur in those aged over 65.^{12,13,18} Research specifically focused on GA, particularly in Australia, remains limited.

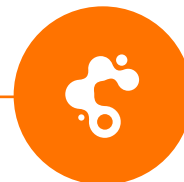
Traditional health economic research often overlooks the broader impacts of vision loss, failing to account for the social value of delaying vision loss and preventing legal blindness in GA patients. The financial and non-financial costs of vision loss due to GA are substantial, exceeding \$1.8 billion a year in Australia, including \$377 million in healthcare expenses, \$312 million in lost productivity, and \$1.1 billion in lost wellbeing.

INTERVENTION

There are no therapies in Australia to slow, halt, or reverse the progression of GA.¹¹ Standard care relies mainly on visual aids, lifestyle modification and rehabilitation services, which offer limited clinical benefits. Without treatment, GA lesions continue to grow, covering the macula and fovea, leading to irreversible vision loss and potential blindness.^{4,6,19,20}

The emergence of new therapies offers hope for GA patients, but much work is needed to prepare for their implementation.

Evidence shows that vision loss impacts many areas of life, including driving, reading, recognising faces, and participating in hobbies, which in turn affects quality of life and social connections.^{1,2} Visual impairment also leads to a loss of independence, increasing reliance on family for support and having significant mental health impacts on patients and carers.²¹



DIAGNOSING & MONITORING GA

Retinal imaging is essential for diagnosing, tracking, and understanding the progression of geographic atrophy (GA). Three main types of imaging are used:

Colour Fundus Photography (CFP): Traditionally, the standard method for capturing images of the retina, particularly to see areas affected by GA. It provides a flat, two-dimensional image that helps doctors observe areas where the retina is thinning or has deteriorated. CFP is still widely used, but has limitations such as lower image contrast. Newer imaging technologies can capture more specific details.

Fundus Autofluorescence (FAF): FAF imaging highlights areas in the retina where certain substances have built up, which can indicate stress or damage. These areas show up as bright spots, while areas where cells have died appear dark. FAF helps measure the size of damaged areas and track how quickly they are growing. It's also useful for showing patients where their vision may be affected, as dark spots on the image correspond to areas of vision loss.

Optical Coherence Tomography (OCT): OCT provides a detailed, cross-sectional view of the retina, allowing doctors to see how the layers have thinned and to measure areas of cell loss. The thinning outer layers of the retina allow the imaging signal to reach deeper layers, making the underlying choroid (a layer of blood vessels) more visible. OCT can also help identify early signs that a patient might develop GA, such as certain patterns or bright spots in the retina.

AN AGEING POPULATION

Australia has an increasingly ageing population, with 1 in 6 Australians over the age of 65.¹⁰ As life expectancy continues to rise, it's crucial for older Australians to maintain good health, independence, and social connections. Ensuring healthy ageing is not only an economic imperative but a social one as well. 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, however this is difficult to quantify while so many Australians remain undiagnosed, or lost to follow-up, due to the lack of available treatments.^{12,13,21} Many people with GA believe that declining vision or legal blindness is a natural part of ageing—when it's not.¹⁴

Almost all people aged 65 and over participate in social activities either at home (97%) or outside their home (94%), including going out with relatives or friends, participating in sport or recreation, or going on holiday.²³ In addition, many older Australians continue to participate in the workforce (both paid and volunteering), especially in regional areas. Older Australians also provide valuable family support, caring for their parents, partners, children, and grandchildren.²³ The value of this unpaid and volunteering work is estimated at almost \$39 billion per year.²⁴

It is estimated that 4.6% of Australians over the age of 65 are currently living in cared-accommodation (including aged care, hospitals, nursing homes, and retirement villages).²⁵ With an ageing population, the total number of Australians requiring aged care supports will increase. Vision loss is also associated with an increased risk of needing aged care supports.²⁵ As a result, aged care is expected to be one of the fastest growing areas of government spending over the coming decades.²⁶

Ensuring the healthy ageing of Australians is not only an economic imperative, but a social one as well. Keeping people healthy, socially connected and living in their own homes will provide social, emotional and economic benefits. Maintaining vision in people living with GA will support their ongoing physical and mental health, independence, and quality of life, while reducing the burden on aged care and other government services.

IMPACT OF GEOGRAPHIC ATROPHY

Vision loss resulting from geographic atrophy (GA) has important impacts on people living with the condition, their families and carers, and the Australian Government. These impacts are both financial and non-financial:

- **Financial impacts** like the cost of seeing a doctor, can be measured using methods such as economic impact assessments.
- **Non-financial impacts** can be harder to measure because they do not have a straightforward economic value or cost. These impacts include difficulty recognising faces, participating in hobbies, maintaining independence and communicating with family and friends.

To measure and understand the true impact of vision loss due to GA, financial and non-financial approaches are required.



Fig. 7 Measuring the impact of GA

ASSESSING THE FINANCIAL COST

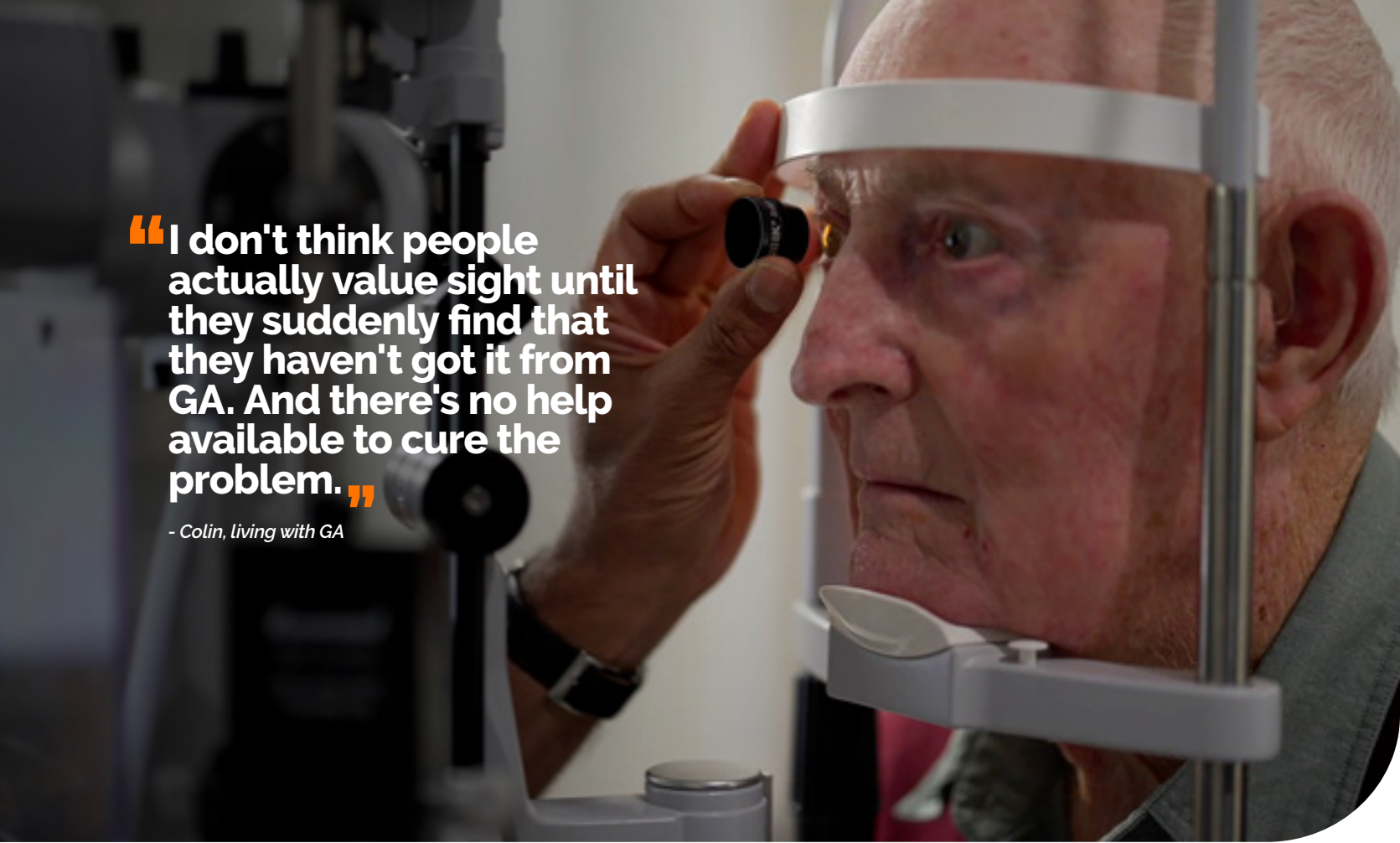
Research has been conducted to calculate the cost of GA in Australia, based on studies that have previously been published. Impact studies measure the financial, health system and non-health system costs of a disease. In some cases, they can also measure the wellbeing cost, which is the cost of lost health. Usually, 'direct' costs are those that relate to the health system, like hospital costs, doctors' appointments, and medical tests. 'Indirect' costs are those that relate to non-health system costs like productivity or welfare payments. This research estimated the total cost of GA in Australia to be more than \$1.8 billion per year, highlighting an urgent and significant need to better support people living with GA.

Direct Costs

Health system costs related to GA include early admission to aged care, imaging and eye exams, specialist appointments, and hospital and emergency department costs. The healthcare system cost of GA is estimated to be over \$377 million per year. This was mostly due to early admission to aged care (62%) and the cost of eye imaging (26%). A large proportion of this cost is paid by people with GA (41%) while the remainder is paid by the Australian Government (59%). Patients pay significant out-of-pocket costs for specialist appointments and eye exams (estimated to be over \$70 million per year). This creates significant barriers to accessing appropriate care.

Indirect Costs

Non-health system costs relating to GA are mostly due to an increased need for government support payments, including the Aged Pension, Disability Support Pension, and Carers Allowance. Lost work for people with GA and their carers also results in lost wages. As their vision gets worse, people with GA might also need to buy vision aids or pay to modify their home to help them remain independent. Overall, the indirect cost of GA was calculated to be over \$312 million per year. This cost was mostly paid by people with GA (65%) and the Australian



“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

Government (34%). The largest indirect cost was due to the Aged Pension, accounting for over \$100 million per year in government costs. While eligibility for the Aged Pension is means tested, this test does not apply when a person is legally blind.

Wellbeing Costs

In addition to financial costs, geographic atrophy (GA) can also have a significant impact on wellbeing. This is often measured using the disability adjusted life year (DALY) which is a measure of years of healthy life lost. This includes illness due to both mental and physical health. The cost of lost wellbeing due to GA was calculated to be over \$1.1 billion. This only includes the cost to people living with GA and does not consider the impact on family or carers.

While the impact of GA based on financial and wellbeing costs is substantial, this approach does not account for the non-financial costs or the burden on carers. Therefore, other methods such as SROI can add to our understanding of the cost of vision loss, and the value of preventing it.



IMPACT STUDY RESULTS

Research on GA is limited, particularly in Australia. Conclusions about its impact are often drawn from studies on vision loss and blindness caused by other conditions, such as diabetic retinopathy or neovascular AMD (nAMD). While these studies may provide some insight into the experience of GA, the specific impact remains underrepresented in the literature.

This research seeks to quantify the direct, indirect, and wellbeing costs of GA in Australia on an annual basis. The cost estimates were derived from secondary research focused on GA in both Australian and international contexts, and these were then applied to current GA prevalence data.

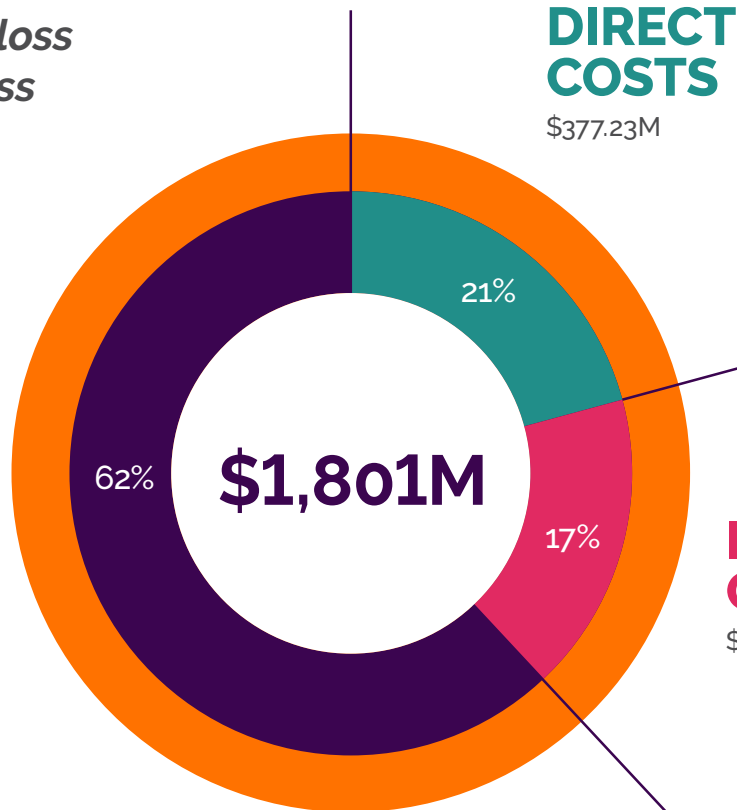
The cost of vision loss and legal blindness as a result of GA

WELLBEING COSTS

\$1,112.49M

75-100K

No. people living with GA in Australia



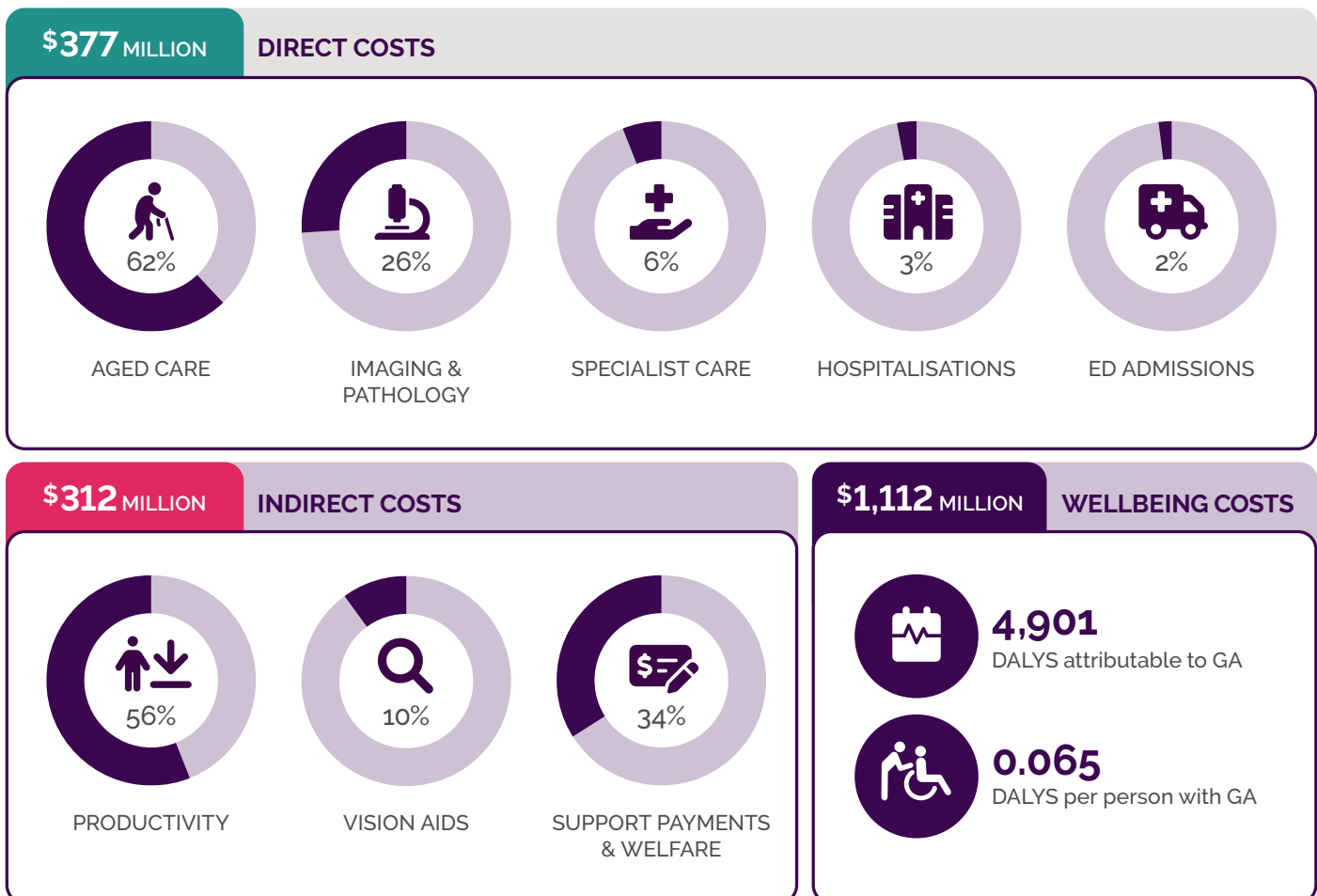
INDIRECT COSTS

\$312.74M

DIRECT COSTS

\$377.23M

Fig. 8 Impact study results



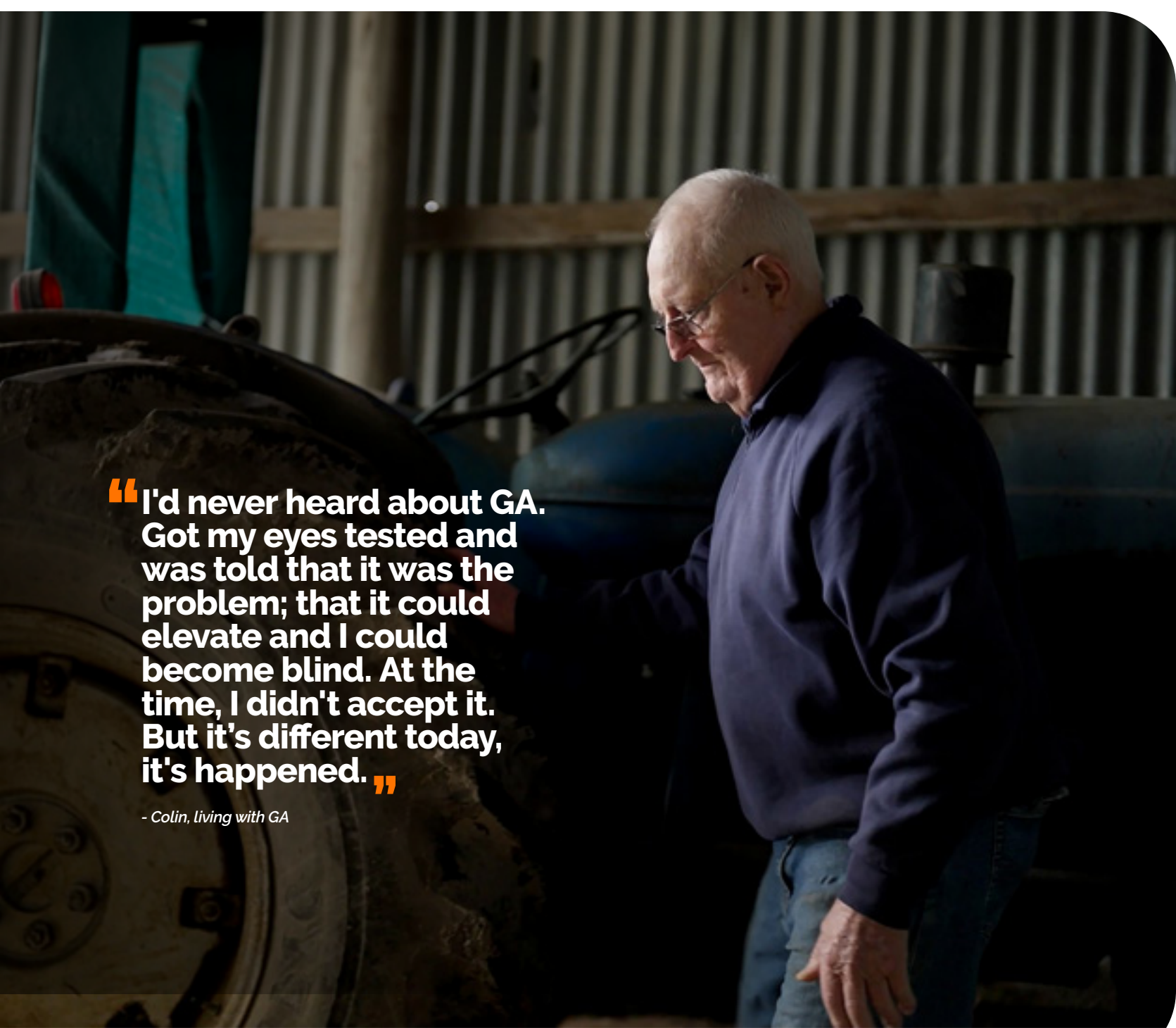
Abbreviations: ED, emergency department, DALYs, Disability adjusted life years

ASSESSING THE HUMAN COST

Only through lived experience are we truly able to 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.

A critical part of the research involved talking to people with GA and their carers, including partners, family members and eye health professionals. Their insights demonstrate the wide-ranging impact of vision loss and legal blindness due to GA, and the importance of taking action to maintain vision.

The following testimonials explore the stories of a rural Australian family impacted by GA. Colin, the father, has become legally blind due to GA and shares his journey, as detailed in the table on the opposite page. Colin's wife Pam also shares the impact of her husband's disease on her family and the family business. Colin's daughter Kerry explains how she and her siblings (in their early 50's and 60's) are showing signs of developing the debilitating disease and are fearful of losing their vision to GA in the future.



“I'd never heard about GA. Got my eyes tested and was told that it was the problem; that it could elevate and I could become blind. At the time, I didn't accept it. But it's different today, it's happened.”

- Colin, living with GA

COLIN'S GA JOURNEY



Fig. 9 Journey of Colin, a person living with GA

PATIENT PERSPECTIVE

COLIN

LIVING WITH GA

A farmer, born and bred, Colin lost his identity and livelihood after developing GA.

'My parents were farmers. Their parents were farmers. Growing up, I considered that's all I wanted to be.'

At the age of 65, the vision in Colin's left eye began to deteriorate due to the disease. Soon after his right eye began to go, too.

'I can remember sitting in the lounge room and looking up to the paddock, it looked like water running over the window, with all these squiggly lines going on down it.'

Characteristic of GA, dry lesions at the back of Colin's eyes were developing and clouding over his fovea, blurring his central vision.

In the space of a few years, Colin lost the ability to read hazardous chemical labels and drive safely. On the farm and on the road he became a danger to himself and others.

'When my vision started to deteriorate, life started to deteriorate. I couldn't do the things I used to do and I didn't recognise people. So I handed in my license. I didn't want to drive the car and be guilty of taking somebody out that deserved to still be about.'

Colin persisted with the farming life as long as he could. However, with fences falling into decline, animals left untended and mounting bills due to rising interest rates, not to mention a family begging him to accept the impact GA was having on his happiness and wellbeing, Colin was forced to accept that going blind from GA was inevitable and irreversible.

'I sold my boat. We ended up getting rid of the caravan. All those sort of things just didn't make me, the wife, or the family, happy any more. We just had to accept the situation as it was.'

By the age of 75, the lesions of Colin's GA had completely covered the fovea of both his left and right eyes, and he was legally blind.

He went from being a self-sufficient man who could turn his hand to anything, not to mention a valued member of the community, to someone wholly dependent on his wife and family for care.

'I considered, once upon a time, a person could have a smile, be happy, have a laugh. Well, that's pretty hard to come by these days.'

In 2009, Colin and his family were forced to sell the family farm and downsize to an acre block in a nearby town.

'People who live in the city, they don't know what it's like to have to give up something that's been a part of you your whole life.'

Unfortunately, after a few years, even this home became too much for Colin, who suffered numerous falls and injuries trying to navigate the block. The family moved to a 600 square metre home in the town around 5 years ago. It's not the life Colin had hoped for his wife and family.

'Having GA, you just can't reverse the situation. It just gets worse and you can't go anywhere. You can't do the things you used to be able to do. And it makes life quite unbearable at times.'

Colin and his wife no longer travel, fish, or pursue any of the interests that used to make them happy.

'I used to dream about the things that we'd be doing when we weren't farming and where we'd be traveling. And these things that just haven't happened because of the problems with my eyes. I feel like I've let the family down and let them down big time. But I had no control over it.'



Scan to watch
Colin's GA story

CARER PERSPECTIVE

KERRY

DAUGHTER OF COLIN, LIVING WITH GA

As the youngest of Colin's daughters, Kerry is uniquely placed in her experience with GA. In addition to watching her father go blind from the disease and seeing her mother's quality-of-life erode, Kerry is now seeing her older sisters enter a phase of life where they too are starting to develop AMD.

'I'm scared of GA, I really am.'

Kerry and her three elder sisters, Sharon, Leesa and Denise, grew up on the farm run by her mum and Dad in the coastal hills of Wonthaggi, Victoria. The property had been in the family for generations.

'That was our life. We grew up there. Had lots of fond memories. Lots of good times. We were a family there.'

Unfortunately, Kerry's parents had to sell the family farm after her father was diagnosed with GA.

'It got to the stage on the farm where he just couldn't do it anymore. It was too dangerous on the motorbike. He lost his license. He even started having trouble with little things like putting a power lead into the socket.'

GA has profoundly affected the lives of everyone in the family.

'Dad's definitely lost his way of life and his identity. Everything that we lived for was there. It's all someone else's now. I don't go back there any more, it's too painful.'

Today, Kerry runs a local cleaning business in a way that enables her to split her time between caring for her own young family and supporting her parents.

'Since Dad's been diagnosed with GA, mum's just beside him all the time. She's lost a lot of her freedom, a lot of her time to just be herself. The irony is that dad's blind, so he can't see Mum struggling.'

Kerry spends at least two days a week at her parent's home, cooking and cleaning. Unfortunately, the greatest burden that Kerry's father's GA has placed on her is the knowledge that she and her children may develop GA, too.

'It's been really hard to watch Dad lose his sight - and get so frustrated with not being able to see and do the things that he used to love doing. [...] And it could happen to me, it could happen to my kids, it could happen to their kids.'

Kerry recently consulted a retinal specialist with the specific intention of looking for signs of GA. Unfortunately the visit confirmed her fears, with scans detecting early signs of AMD - which could become GA.

'It was a bit of a shock to be honest. It really hit home. The potential for me to go blind is definitely there.'

Kerry is now facing an uncertain future and considering her father's advice.

'Dad says that if you've got GA and you've got the funds, go out and travel, see the world because time is limited. One day you'll wake up and you won't be able to see the faces of your grandkids. It's too late to think about going travelling then.'

Kerry's sister, Sharon, has also had signs of AMD detected and has retired early herself. She has dedicated her remaining time with vision to seeing as much of Australia as she can, and tracks the deterioration of her own vision using an Amsler grid.

'Sharon wants to know, Lisa would prefer to bury her head in the sand. I see the struggles dad goes through and I don't want to go through that myself.'

One of Kerry's greatest fears is not recognising her own children. Her father's GA is subfoveal—meaning it has affected his central vision leaving him unable to recognise faces.

'I walk into a room and Dad doesn't even know that I'm there unless I speak to him. He hasn't seen me smile, hasn't seen me cry, hasn't seen me laugh. He's got no idea what I look like these days.'



CARER PERSPECTIVE

PAMELA

SPOUSE OF COLIN, LIVING WITH GA

Pam is the first to admit she grew up in an era when the promise of 'till death do us part' was made as much to your husband's lifestyle as to the man himself. She met and married Colin in her early 20's and takes great pride in the life they forged together on the farm.

'Colin and I did everything together. We milked the cows. We fed the cattle. We did everything together.'

The partnership allowed both Pam and Colin to pursue their individual and shared passions, too. Pam nursed at the local hospital and was active in the Country Women's Association, while Colin played a key role in local charities and building the local sporting club.

'He was an adventurous person. He just loved to try something different and he's been like that all his life... Of course, I love him.'

But Pam's dedication to her husband has been put to the test since his diagnosis with GA. The debilitating eye disease has robbed Colin of his sight and Pam of her independence.

'I thought we would have an independent life. He would do what he wanted to do and I would help him. But the role reversed. Now I do everything to help him.'

Colin first showed signs of GA in 1995, when deteriorating vision in his right eye exposed the fact that he'd been compensating for a lack of vision in his left eye for some time.

'Colin would say to me, 'I can't see... What does this say?', because it was blurry. He was actually already blind in one eye before we realised he had macular degeneration.'

In the years that followed Colin's GA diagnosis by a local optometrist, the dry lesions that characterise the disease continued to develop over both of his foveas. Pam becomes emotional as she recounts how it became hazardous for Colin to drive around the farm or work with his livestock alone.

'It became more difficult for him to read drench packets and see the dosage of the drugs. So I always had to be there to do that.'

Fearing for Colin's safety, Pam found the dynamic of their relationship changing as she struggled to convince him to change his way of life.

'It got to the stage where I would say to him, you can't use the tractor because you might run off the road. You can't see anything coming. And he would get very upset about it. We always had a good, loving relationship and I was becoming the worst person in the world.'

Pam and Colin sold the farm that has been in his family for over 80 years in 2006, and have had to move twice more since, with Colin's desire to be outside and active leading to numerous injuries and falls.

'The hardest thing we had to do was to walk away from the farm and start a new life at 75 years of age. I mean, that's not an easy thing to have to do.'

Today, Colin is legally blind and can't see well enough to plug in a wall socket or shave himself. He relies on Pam to do virtually everything for him.

'It's my responsibility because he's my husband. We've been together for 60 years. We've just been part of one another's life for a long time. That was the commitment I made when we got married.'

Colin's lack of vision means that he can't see how much Pam is struggling.

'Colin's lost his vision. But as a family, we've lost a man who was so independent and able to turn his hand to do anything that he wished and wanted to do. And now he depends on us to do what he can't do.'

Pam has had to give up almost all of her interests and hobbies. Even if she steps away from home, she has to have her phone with her so that Colin can contact her in the event of a fall.

'It's made a lot of extra things for me to do. And if I didn't love the man, I probably would walk away because it's not easy having somebody that is legally blind because of GA. It's very difficult.'



WHY AN SROI?

There is limited understanding of the total impact of geographic atrophy (GA) on society, including people living with the disease, their families and carers, and communities. This leads to a lack of diagnosis and monitoring, which can lead to people with undiagnosed GA dismissing their vision loss as an unavoidable part of ageing. This increases the burden of vision loss, as people do not access the support services that can help them.

This Social Return on Investment (SROI) report aims to measure the social value created from investing in an intervention to delay vision loss and prevent legal blindness due to GA. It considers the impact on people living with GA, their carers, and the Australian Government. The outcomes of this research highlight the importance of awareness, support, and treatment for people living with GA.

SROI analyses generate a monetary result to facilitate communication of impact within existing decision-making frameworks, but the outputs of this research should be interpreted beyond the financial ratio. Investing in interventions to delay vision loss and prevent legal blindness enables people living with GA and their families to access the medical services and support that are critical to their health and wellbeing.

OBJECTIVES OF THE SROI



Fig. 10 SROI objectives

THE DIFFERENCE BETWEEN ECONOMIC IMPACT & SROI

The impact analysis quantifies both the direct and indirect costs associated with GA, such as medical expenses, lost productivity, and support payments. However, a SROI goes beyond traditional financial analyses by capturing the intangible costs and benefits that arise from the lived experiences of individuals affected by GA.

While financial analyses focus on measurable, economic factors like healthcare costs and loss of income, an SROI study aims to provide a more holistic view. It considers non-financial aspects such as the emotional, social, and psychological impacts on individuals, their families, and carers. By assigning value to these often-overlooked areas, SROI provides a comprehensive understanding of the true impact of GA, highlighting the broader social value created by interventions that improve quality of life and well-being.



SROI FRAMEWORK

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. However, a forecast SROI has been 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.

A three-year horizon was chosen for the SROI to capture the short- and medium-term changes in health and social impacts expected to arise from preserving vision in people living with GA. Research suggests the median progression of GA from non-subfoveal to subfoveal occurs over 2.5 years.⁴ Subfoveal involvement is associated with poorer vision in people living with GA.⁶ As such, a three-year horizon is considered reasonable to capture the impact of preventing progression to subfoveal GA, while limiting the uncertainty associated with extrapolating outcomes over a longer time period.

The SROI produces a descriptive (qualitative) and numerical (quantitative) evaluation of social outcomes. Part of this research involved talking to people with GA and their carers about the changes that they experienced due to vision loss. This was expressed visually as a 'Theory of Change', showing how impact is created from the perspective of stakeholders.

One benefit of a SROI is the ability to measure and report non-financial outcomes. While some investments and outcomes have a direct financial value (for example the cost of an appointment with an ophthalmologist), others are less clear. The SROI method allows research to apply representative financial values to each outcome, based on how the outcomes are valued by stakeholders. The SROI approach also considers the real-world context to adjust social values and ensure that value is not overestimated. This process highlights a journey that combines evidence, economics, and real-world experiences to assess how maintaining vision in people living with GA impacts them and in turn, their families & carers, and the Australian Government.

This SROI report has been independently assured by Social Value International (SVI), ensuring that the principles of SROI have been appropriately applied. **This SROI received assurance from SVI in August 2024.**

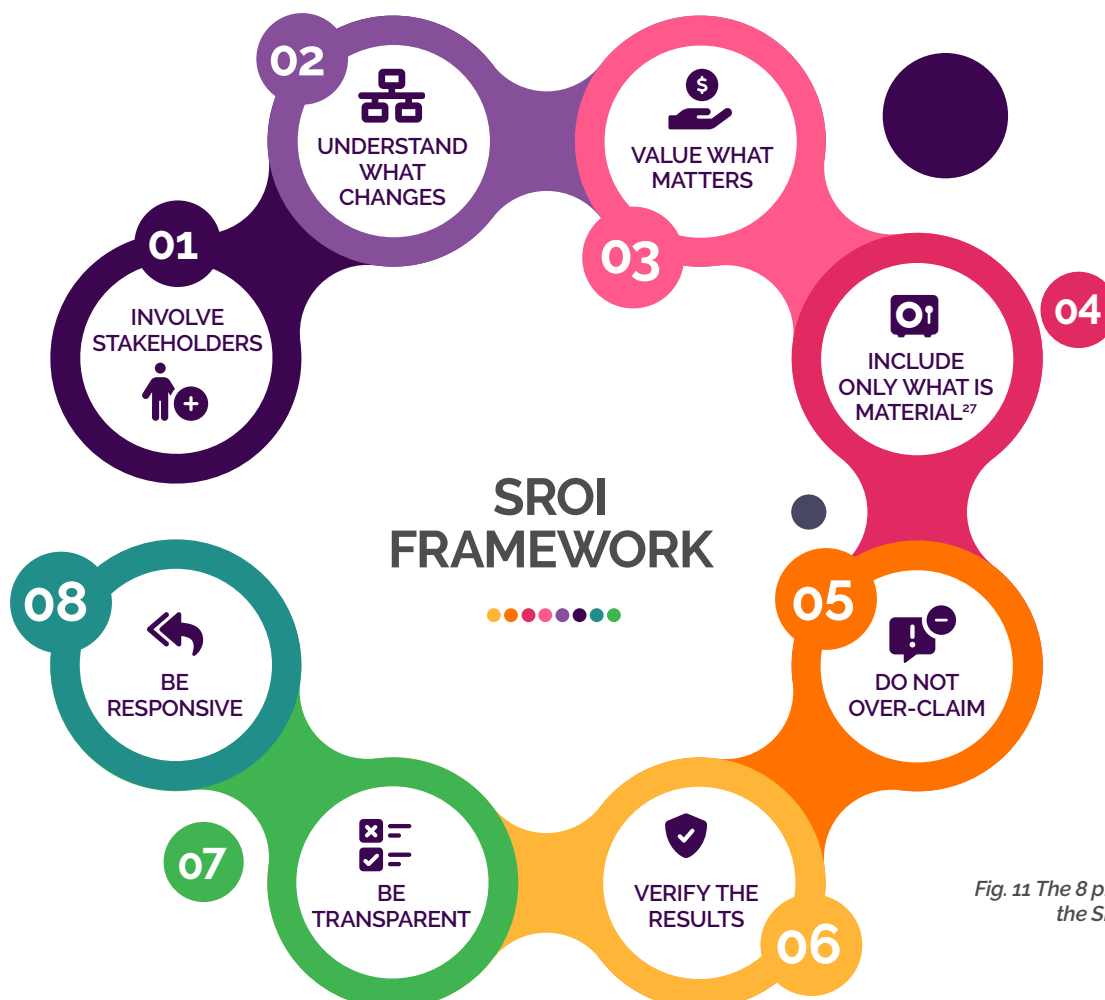


Fig. 11 The 8 principles within the SROI framework

ASSESSING THE SROI

Guided by the principles of SROI, there were six main stages involved in conducting the research into the impact of delaying vision loss and preventing legal blindness due to geographic atrophy (GA). These stages involve talking to stakeholders, identifying and measuring what changes, and applying financial values to each outcome. To obtain the SROI ratio, the overall value created is compared to the investment required to deliver the intervention. This generates a number which shows the social value created by each dollar invested.

ESTABLISH SCOPE & IDENTIFY STAKEHOLDERS

The scope of the analysis is clearly delineated through a road map to ensure a streamlined SROI development process. Stakeholders to be involved are identified as well as the key SROI structural elements, with a particular focus on the research question.

EVIDENCE & EVALUATE IMPACT

Data is gathered through qualitative and quantitative methods to evidence and measure the extent to which outcomes are being achieved and how long they last.

CALCULATE SROI & WRITE THE REPORT

In this stage, the data that has been gathered is expressed in the form of an SROI ratio, ascribing a monetary value to the material outcomes identified through the research phase.



MAPPING OUTCOMES (THEORY OF CHANGE)

This step articulates the program logic, mapping resources (inputs) that would be used to deliver activities (measured as outputs), and how these activities may result in outcomes for stakeholders.

ESTABLISH IMPACT

The extent to which activities contribute to the impact achieved is determined by placing the intervention in context and understanding what would represent material and valuable changes resulting from an intervention, testing the Theory of Change.

REPORTING, USING & EMBEDDING

The SROI report includes qualitative, quantitative and financial findings, to tell the story of change and to provide the reader with information on the social value that could be/has been created by the intervention.

Fig. 12 The 6 main steps of a SROI

STAKEHOLDER ENGAGEMENT

Engaging with people to share their lived experience is a key part of conducting a SROI and makes it different from traditional economic analyses. Stakeholder engagement allows the social value or outcomes to be defined based on the real-life experience of the people who are impacted. For this research, the included stakeholders were people living with geographic atrophy (GA), their carers (including partners, children and other members of their community), and the Australian Government. People living with GA and their carers were invited to participate in interviews and/or a survey about their experience with vision loss due to GA. This stakeholder engagement was supported by secondary research.

METHODS UNDERTAKEN TO GENERATE RESULTS



CONSULTATION PROCESS



Fig. 13 SROI consultation process

STAKEHOLDER GROUP IDENTIFICATION

The comprehensive list of stakeholders for this SROI was developed by considering all those who may impact or be impacted by an intervention to delay vision loss and preventing legal blindness due to geographic atrophy (GA), whether intentional or unintentional, and whether the impact is positive or negative. Some stakeholders who were excluded from a value-gained perspective were still consulted as proxies to gain a complete understanding of the impact of the intervention. The stakeholder list was developed in collaboration with the Advisory Committee, HTANALYSTS and the study sponsor, Apellis.

STAKEHOLDER GROUPS



People Living with GA

The SROI focuses on non-subfoveal (early) GA

People living with GA are expected to be directly impacted by an intervention to delay vision loss and prevent legal blindness. This is the primary stakeholder group for the analysis.

Considering the expected differences in functional vision between people living with non-subfoveal and subfoveal GA, these subgroups were considered as separate stakeholders. The outcomes for these groups may differ materially, owing to expected differences in functional limitations and quality of life associated with vision loss.

People living with non-subfoveal GA may have loss of low light and peripheral vision, but they are often able to compensate for these changes. The proposed intervention will slow the rate of GA lesion progression, preventing the lesion from growing into the fovea and therefore, preventing legal blindness for longer.



OF IMPORTANCE

This SROI was targeted at people living with non-subfoveal GA, as they are the people that still have vision to save. Any reference to 'people living with GA' in relation to this SROI is representative of this population of 50,295 people.



Carers of People Living with GA

Family members including the partners and children of people living with GA were thought to be impacted beyond their role as a carer, given the potential emotional burden of worrying for their loved one or, in the case of children, fear of developing the condition themselves.

It was initially considered that the direct social and emotional burden of GA may differ for partners and children of people living with GA. However, during consultation it was found that the outcomes experienced by these groups related to their role as a carer and were consistent between groups. As such, these groups were consolidated into a single stakeholder group as carers of people living with GA.



Australian Government

The Australian Government is likely to provide investment into the proposed intervention to delay vision loss and prevent legal blindness in people living with GA, as Australia has a single-payer health care system.

Additionally, the Australian Government funds hospital care (including indirectly via state government funding), which may be impacted by preserved vision. As such, the Australian Government is likely to provide an input into the intervention, would be impacted by the outcomes and is therefore included as a stakeholder in this analysis.

PARTICIPANT RECRUITMENT

Ophthalmologists providing medical care to people living with GA were contacted in the first instance. To further support recruitment, a member of the Advisory Committee – Vision Australia – was engaged to contact its clients who had experience with GA. Vision Australia supports over 65,000 Australians living with vision loss, including a number of people living with GA.

ETHICAL CONSIDERATIONS

Ethics approval was not considered necessary for this research, as it was deemed Lower Risk according to the National Statement on Ethical Conduct in Human Research.²⁸ Nevertheless, ethical considerations were included in the design of this research. A Participant Information and Consent Form (PICF) was generated and distributed to all interview and survey participants, either verbally or via email. The PICF aligned with the requirements of the National Statement, providing participants with information regarding risk and benefit, informed consent including withdrawal of consent, privacy and confidentiality, coercion, and the use and management of data and information.

Stakeholder interviews were conducted via telephone from October 2023 to December 2023.

MODE OF ENGAGEMENT

Fig. 14 Stakeholder engagement throughout the SROI process

Stakeholder	Number of stakeholders uniquely engaged ^a	Mode of engagement
People living with GA	17	<ul style="list-style-type: none"> • Interviews (n=17) • Surveys (n=7) • Retina International research²⁹ (surveyed n=57 people living with GA) • Other methods of engagement (e.g. secondary research)
Carers of people living with GA	6	<ul style="list-style-type: none"> • Interviews (n=6) • Retina International research²⁹ (surveyed n=25 carers of people living with GA) • Other methods of engagement (e.g. secondary research)
Clinicians providing medical care to people living with GA (consulted as proxy)	3	<ul style="list-style-type: none"> • Interviews (n=3)
Australian Government	-	<ul style="list-style-type: none"> • Indirectly via interviews with clinicians providing medical care to people living with GA (n=3) • Indirectly via Advisory Committee meetings • Other methods of engagement (e.g. secondary research and authors' experience consulting with Australian Department of Health)

Note: ^a Number of stakeholders uniquely engaged does not include those who provided secondary survey data
 Abbreviations: GA, geographic atrophy; n, number of participants

THEORY OF CHANGE

Understanding the impact of geographic atrophy (GA) on each stakeholder group requires developing a Theory of Change.

The Theory of Change allows us to capture the real-world experience of those affected and map the cascading sequence of events that impact each particular outcome.²⁷ It also specifically identifies what each stakeholder values, and what society could lose without intervention to delay vision loss and prevent legal blindness due to GA. To avoid over-claiming and over-valuation, only final outcomes were valued to assess the social return.

HOW A THEORY OF CHANGE WORKS

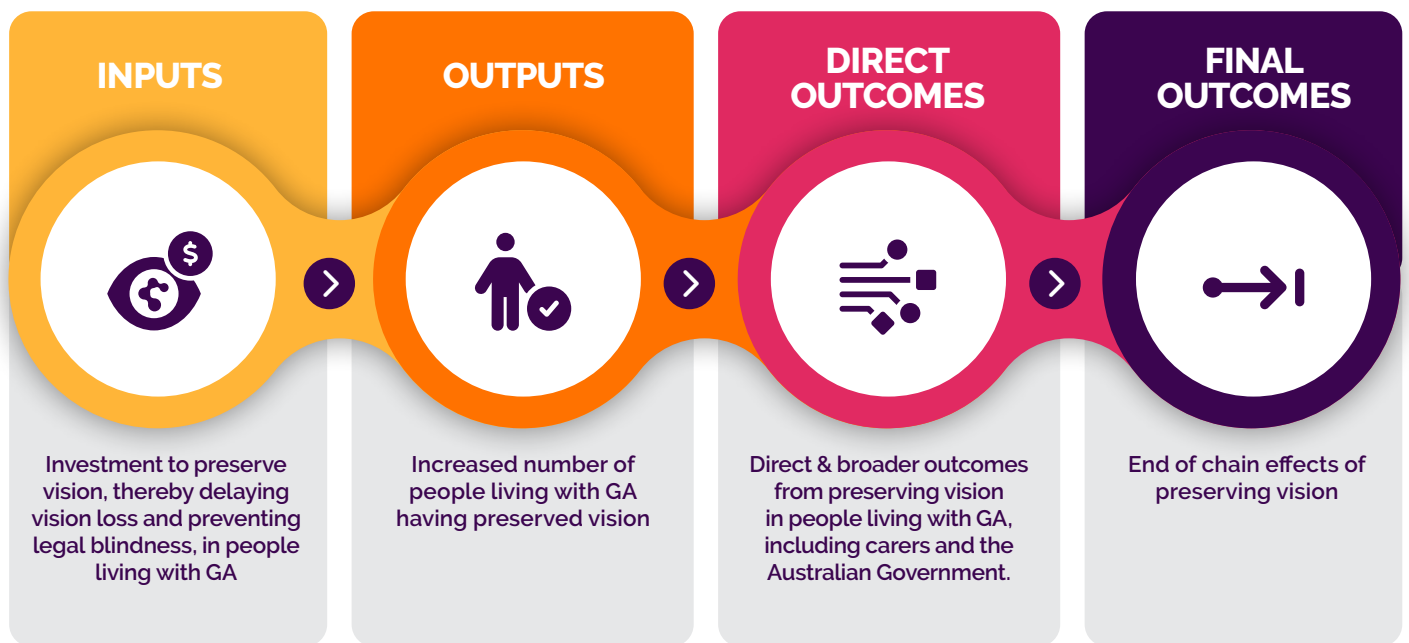



Fig. 15 Theory of Change process

OUTCOMES EXPLORED USING THE THEORY OF CHANGE

Through interviews and surveys, the following outcomes were captured for the three key stakeholders: people living with GA, carers of people living with GA, and the Australian Government.



Fig. 16 Theory of Change outcomes

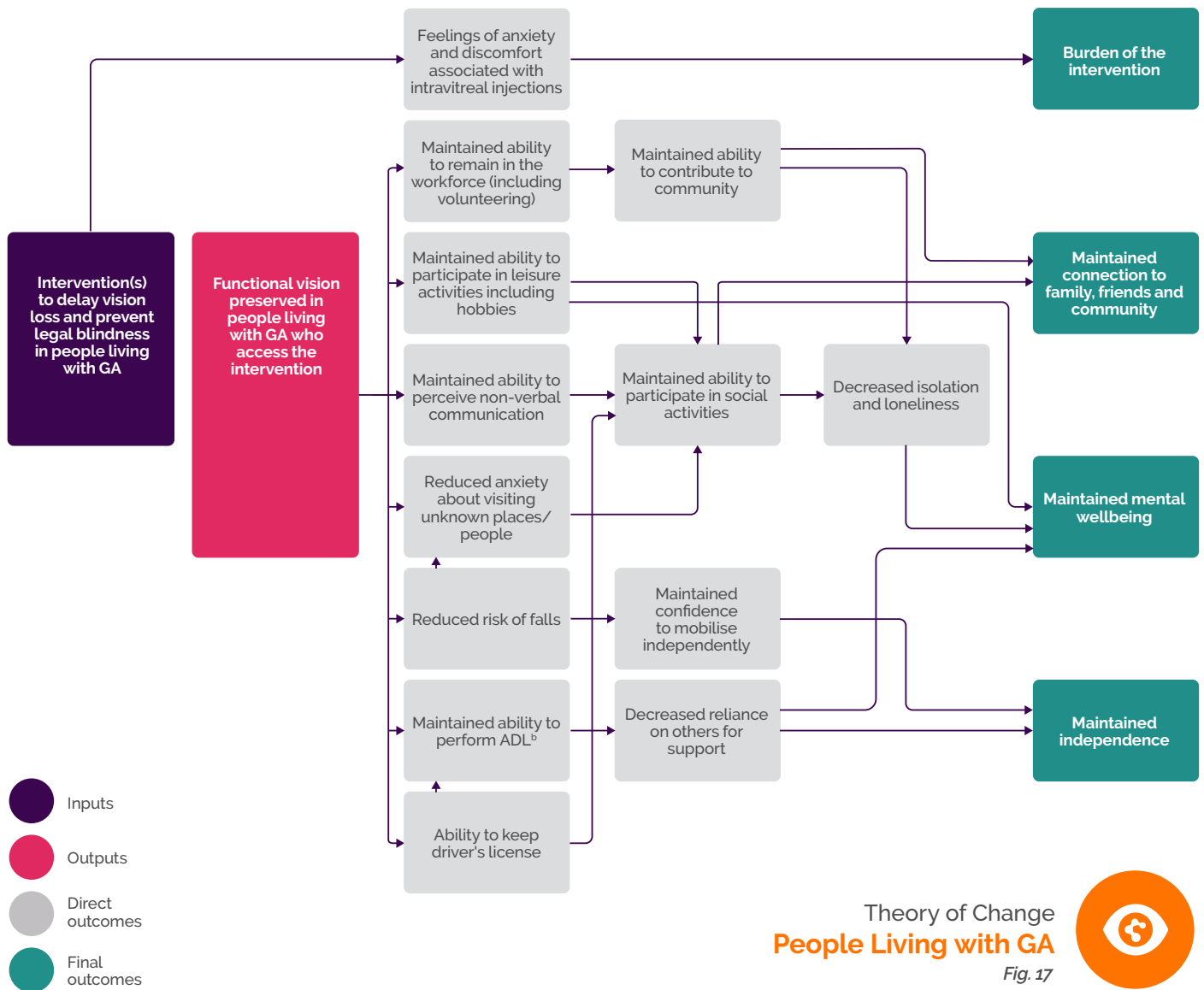


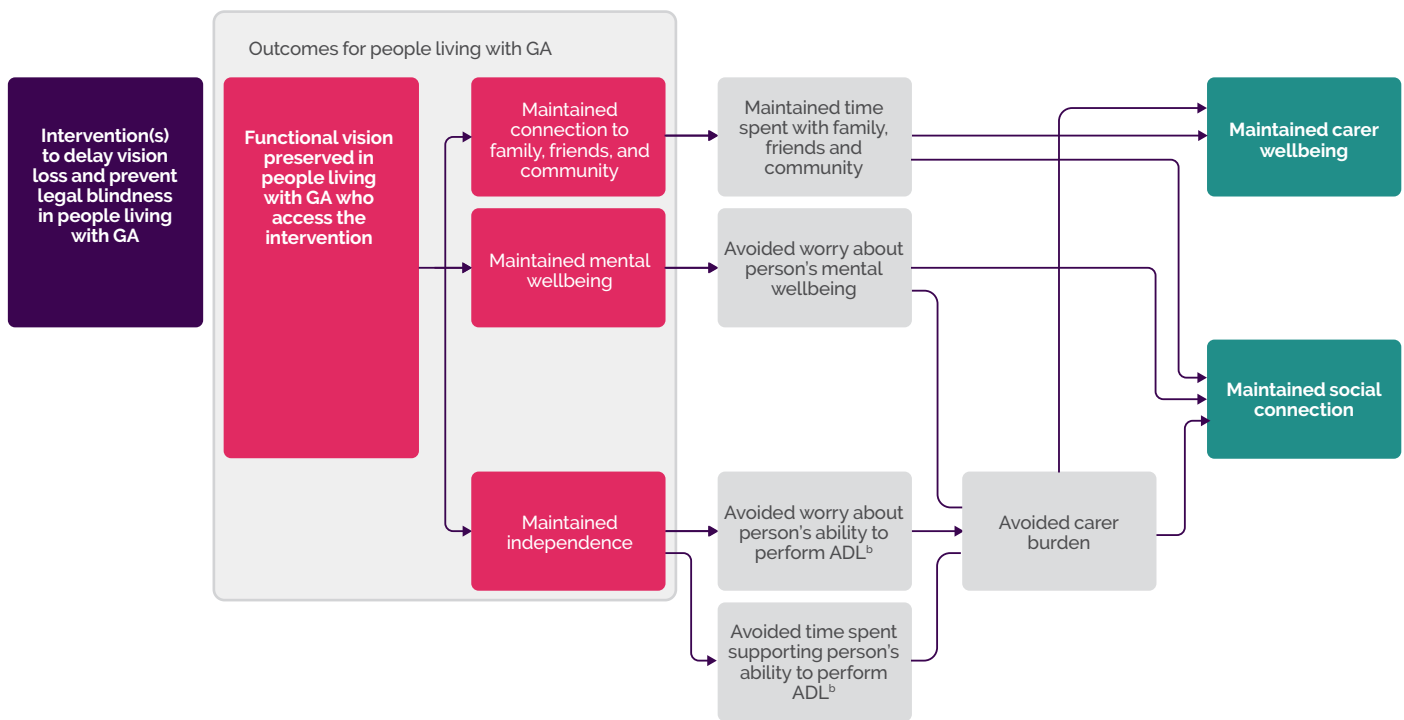
“Dad’s lost his independence completely. We had so much enjoyment out of life doing things together - like fishing. And now it just doesn’t happen because he can’t see.”

- Sharon, daughter of Colin living with GA

THEORY OF CHANGE MAPS FOR EACH STAKEHOLDER

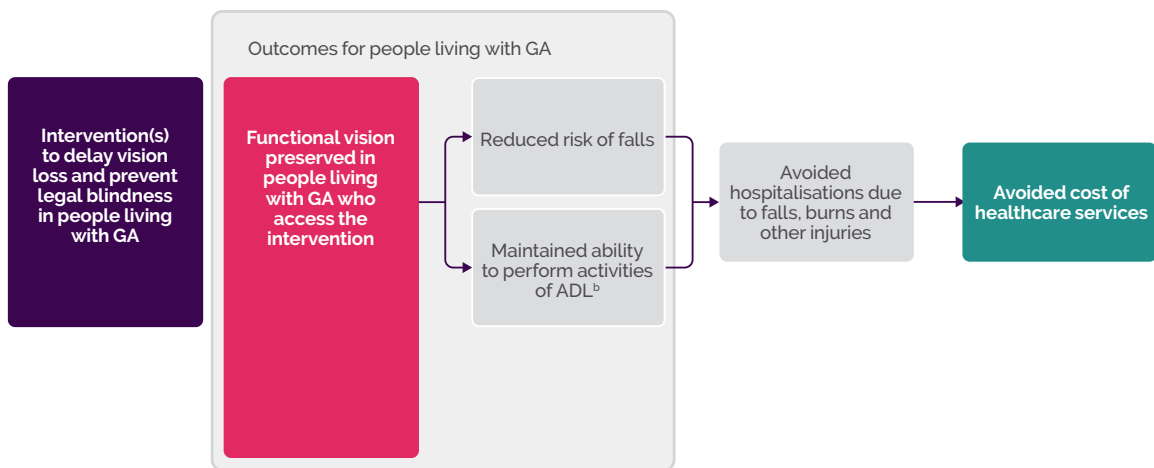
The following Theory of Change maps show the sequence of events forecast to occur when delaying legal blindness and preserving vision in people living with geographic atrophy (GA). They were derived through stakeholder consultation and validated by the Advisory Committee.





Theory of Change
Carers of People Living with GA

Fig. 18



Theory of Change
Australian Government

Fig. 19



^b Activities of daily living (ADL) refers to routine tasks necessary to manage basic needs, such as walking and moving around, eating, dressing, personal hygiene (oral, hair and skincare) and toileting/continence.

FINAL OUTCOMES

The following outcomes have been identified using the Theory of Change to have high relevance and significance to the stakeholder. 'Relevance' implies that the outcome has a clear impact on stakeholders and that stakeholders perceive the outcome as important to them. 'Significance' means the outcome has scale enough to influence decisions and actions, based upon its causality, quantity, and duration.²⁷



PEOPLE LIVING WITH GA

Maintained Independence

When vision is preserved in people living with GA, they can keep doing their normal daily tasks, such as grocery shopping or driving a car, and are less likely to have a fall. Because of this, they need less help from others and are more confident in their ability to move around independently. This supports people living with GA to maintain their independence.

'The saddest day was when I had to hand my driver's license in.' – Person living with GA³⁰

Maintained Mental Wellbeing

When vision is preserved in people living with GA, they are less likely to feel anxious about going to new places or visiting people, and they do not need as much help from others. Because of this, they can continue to participate in social activities and are less likely to experience loneliness. This helps people living with GA to maintain their mental wellbeing.

'[My vision loss] has stopped me doing several things that I used to like to do. I used to do patchwork. I've given that away. It's just too frustrating.' – Person living with GA

Maintained Connection to Family, Friends and Community

When vision is preserved in people living with GA, their ability to participate in leisure activities, including hobbies such as reading groups or sewing clubs, attend social events, and contribute to the community (including volunteering) is maintained. This helps people living with GA to maintain their connection to family, friends and their community.

'They get upset because I can't go to the kids' football...I can't see them when they're out on the field.'
– Person living with GA

Burden of the Intervention

While there is no treatment currently available for GA in Australia, there are a number of treatments for people with neovascular AMD, with each requiring an injection into the eye. As such, this SROI assumed that medical treatment for GA to prevent vision loss and legal blindness due to disease will most likely also require an eye injection.

Burden of intravitreal injections is reported in the literature for both neovascular AMD and GA.^{31,32} Concerns about side effects, costs and the logistical burden of treatment are relatively common, reflecting a potential negative outcome associated with an intervention to preserve vision in people living with GA.



CARERS OF PEOPLE LIVING WITH GA

Maintained Mental Wellbeing

For the carers of people living with GA, there is a clear impact on their mental health as vision declines. Worrying that the person living with GA could experience falls or other injuries if left without support is an emotional burden. The need to be physically present to provide support also leads to a loss of personal time and has a cumulative impact on carer's mental wellbeing. When functional vision is preserved in people living with GA, they rely less on their carers, reducing the physical and emotional burden of care and maintaining carer mental health.

'His world's getting smaller. He doesn't now go anywhere unless I go with him. He gets frustrated about it. And anxious about not being able to do what he could do. And that is very hard, for me, in particular.'

- Carer of a person living with GA

Maintained Social Connection

The SROI research demonstrated that people who provide care for a parent living with GA find it difficult to take holidays due to the need to be physically present. Their social connections are also negatively impacted. After intervention to delay vision loss and prevent legal blindness due to GA, a person living with GA's need for physical care (and carer burden) is reduced and they both maintain the ability to spend more time with family and friends. In turn, this reduces isolation and loneliness.



AUSTRALIAN GOVERNMENT

Avoided Cost of Healthcare Services

When vision loss is delayed and blindness is prevented for people living with GA, they are less likely to experience falls, burns and other injuries. This reduces hospitalisations associated with GA and avoids unnecessary healthcare services costs.

'My vision's been a problem. I've had a number of severe falls over a year or two. And one, which was fairly dramatic.' - Person living with GA



“I hope something will be gained by being involved in this, and that in the future, GA's not a problem like it currently is.”

- Colin, living with GA

VALUING THE OUTCOMES

ASSIGNING VALUES

The monetisation of non-financial outcomes requires the assignment of appropriate financial proxies. To achieve this, stakeholders were consulted to capture and accurately reflect the value of change from the perspective of their lived experience. Each chosen financial proxy was then validated by secondary research and further consultation with stakeholders where possible.

Three main techniques were used to value outcomes:



ECONOMIC VALUATION

Financial value representing the actual savings/cost to the stakeholder



WILLINGNESS TO PAY/ACCEPT

Value of an outcome based on how much stakeholders are willing to pay/accept



REPLACEMENT VALUATION

Cost of other service(s) and/or good(s) that would achieve the same amount of change

“GA is like a car crash happening in slow motion. I've watched too many people go down this path, lose their vision, and there's nothing I can do about it. I've watched too many car crashes.”

- Devinder, Retinal Specialist

CALCULATING VALUES

This report estimates the social value created from delaying vision loss and preventing legal blindness due to geographic atrophy (GA), for people living with GA, their carers, and the Australian Government, over a three-year time frame. Outcomes were based on interviews and surveys with people living with GA and their families, and secondary research. The included outcomes were a result of preserved vision in people living with GA, which allows them to maintain independence, social connections, and mental wellbeing.

The following example shows the process of valuing outcomes in a SROI.

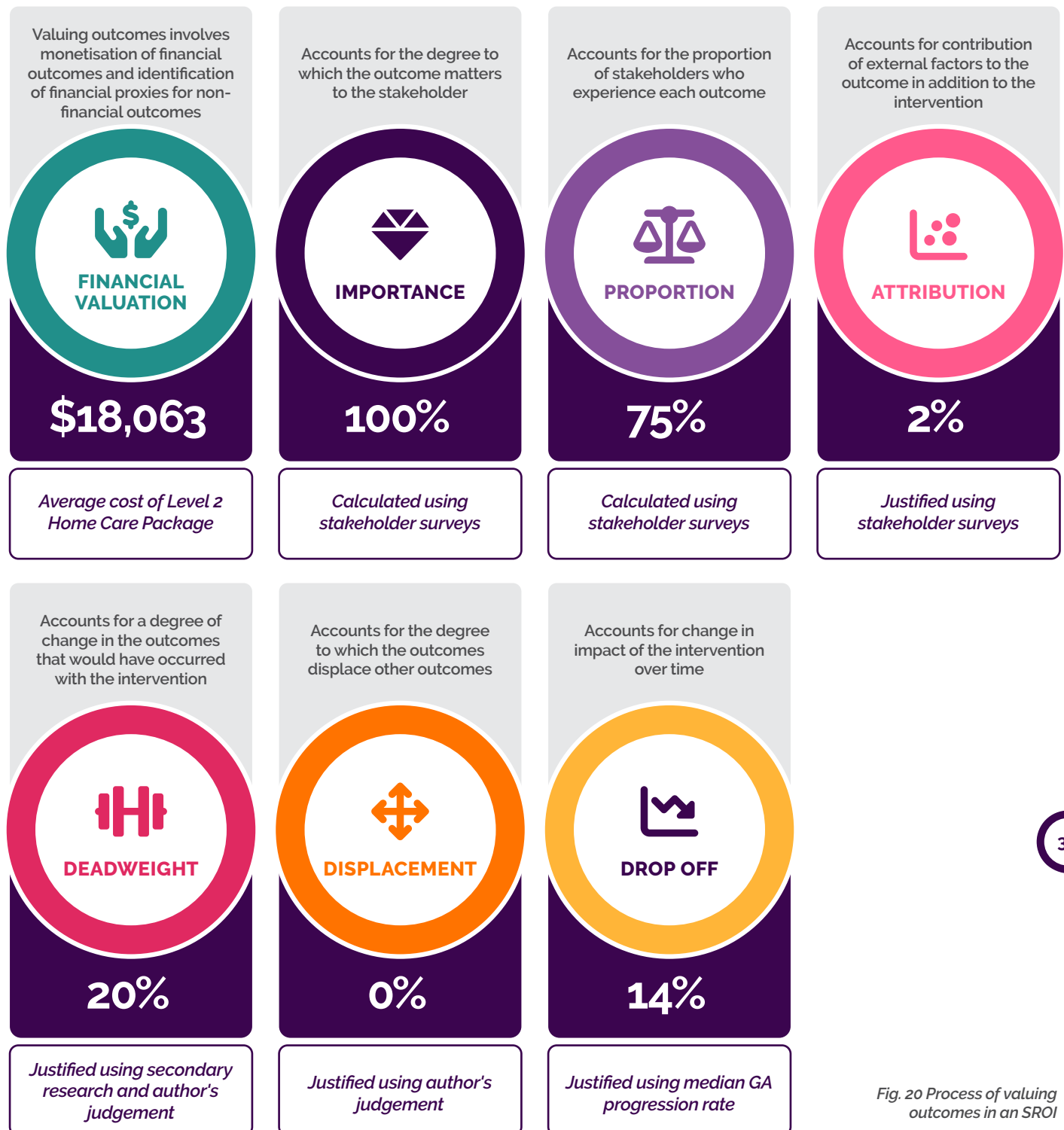


Fig. 20 Process of valuing outcomes in an SROI

VALUE OF THE FINAL OUTCOMES



TOTAL VALUE CREATED FOR PEOPLE LIVING WITH GA

The value of each final outcome for people living with GA was calculated using the methodology explained on the previous page. The total present value created for the entire stakeholder group was **\$39,745 per stakeholder**. The value created from preserving vision is outlined in Figure 21.

Fig. 21 Total present value created for people living with GA

Stakeholder	Outcomes	Total present value for entire stakeholder group	Total present value created per individual stakeholder
People living with GA	Maintained independence	\$1,331,971,715	\$26,483
	Maintained mental wellbeing	\$204,356,462	\$4,063
	Maintained connection to family, friends, and community	\$462,686,804	\$9,199
	Burden of the intervention	-\$27,378	-\$0.54
Total present value created		\$1,998,987,603	\$39,745

Abbreviations: GA, geographic atrophy. NB Rounding applies



TOTAL VALUE CREATED FOR CARERS OF PEOPLE LIVING WITH GA

The total present value created for the carers of people living with GA was **\$13,383**. The value created from preserving vision is outlined in Figure 22.

Fig. 22 Total present value created for carers of people living with GA

Stakeholder	Outcomes	Total present value for entire stakeholder group	Total present value created per individual stakeholder
Carers of people living with GA	Maintained mental wellbeing	\$113,770,381	\$3,684
	Maintained social connection	\$299,525,482	\$9,699
Total present value created		\$413,295,863	\$13,383

Abbreviations: GA, geographic atrophy. NB Rounding applies



TOTAL VALUE CREATED FOR THE AUSTRALIAN GOVERNMENT

The total present value created for the Australian Government was **\$13.57 million**. The value created from preserving vision is outlined in Figure 23.

Fig. 23 Total present value created the Australian Government

Stakeholder	Outcomes	Total present value for entire stakeholder group	Total present value created per individual stakeholder
Australian Government	Avoided cost of healthcare services	\$13,574,978	\$13,574,978
Total present value created		\$13,574,978	\$13,574,978

NB Rounding applies

TOTAL VALUE CREATED FOR ALL STAKEHOLDERS

The summary below presents the value created across all of the stakeholder groups considered in this analysis, with the largest single contributor being maintained independence for people living with GA. During consultation, stakeholders identified independence as a very important outcome, as it facilitated other aspects of life including ability to continue supporting themselves at home, reducing the need to rely on others for support, and social connections.

Fig. 24 Total value created across all stakeholder groups

Stakeholder	Outcomes	Total present value for entire stakeholder group	Total present value created per individual stakeholder
People living with GA	Maintained independence	\$1,331,971,715	\$26,483
	Maintained mental wellbeing	\$204,356,462	\$4,063
	Maintained connection to family, friends, and community	\$462,686,804	\$9,199
	Burden of the intervention	-\$27,378	-\$0.54
Carers of people living with GA	Maintained mental wellbeing	\$113,770,381	\$3,684
	Maintained social connection	\$299,525,482	\$9,699
Australian Government	Avoided cost of healthcare services	\$13,574,978	\$13,574,978
Total present value created		\$2,425,858,444	

THE RESULTS OF THE SROI

As there are currently no treatments available for geographic atrophy (GA) in Australia, the cost of medicines for neovascular AMD was used to represent what an investment into GA might look like. The investment cost included the cost of medicine, ophthalmologist visits, and eye imaging (optical coherence tomography (OCT)).

The investment cost is shared between people living with GA and the Australian Government. People living with GA may need to pay an out-of-pocket cost for some medicines and doctor visits. This is similar to people living with neovascular AMD. The out-of-pocket costs faced by people with neovascular AMD to access treatment is recognised as a significant barrier to continuing treatment, resulting in potentially avoidable vision loss.⁴ This report identifies significant benefits to delaying vision loss and preventing legal blindness in people living with GA. However, these benefits cannot occur if people living with GA cannot afford to access treatment. It is important to make sure that there is sufficient investment into the intervention to allow equitable access.

INVESTING IN MAINTAINING VISION IN NON-SUBFOVEAL GA

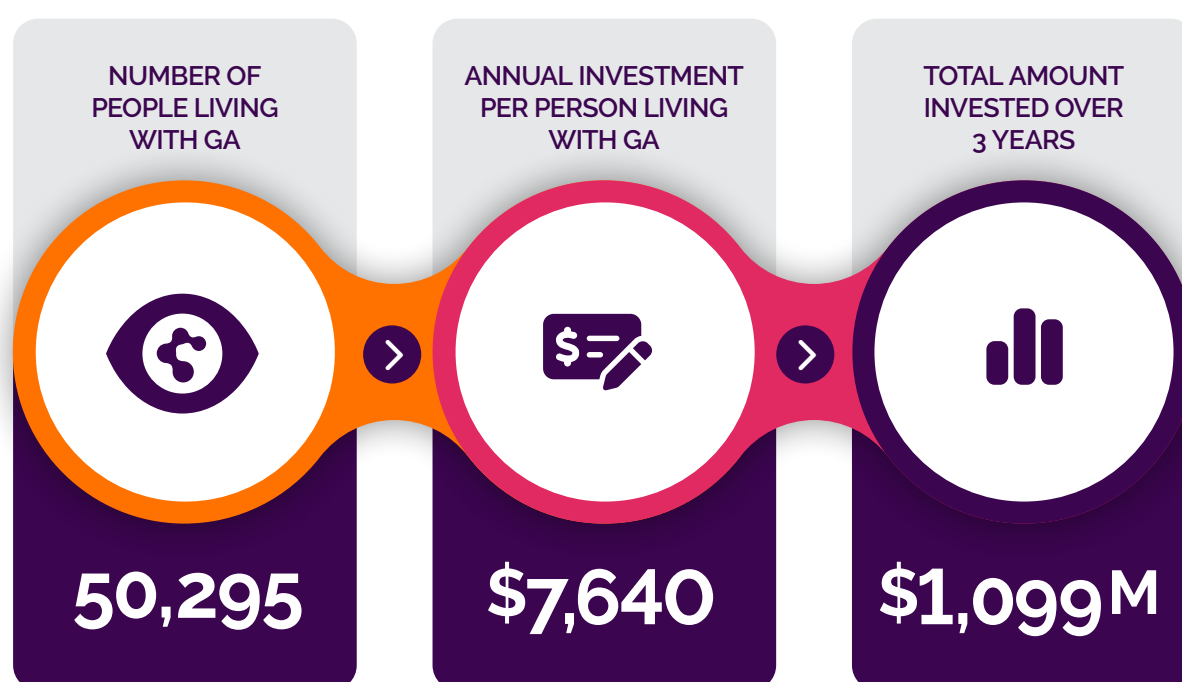


Fig. 25

THE RETURN ON THE INVESTMENT

Informed by the outcomes that matter most to stakeholders, the research reveals 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%). Just under 1% of the value is economic in nature.

People living with GA experience most of the benefits of the proposed intervention (82%), followed by their carers (17%), with the ability to perform tasks such as driving, cooking, and reading being essential for maintaining independence and wellbeing.

While the SROI analysis presented here shows the value of investing in an intervention to delay vision loss and legal blindness in people with non-subfoveal GA (earlier disease), Colin's story demonstrates that subfoveal GA (more advanced GA) has an even more devastating impact on patients and their families. Diagnosing and treating GA early in the disease state is essential to avoid the life changing and irreversible impact of vision loss and legal blindness due to GA.

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

SROI OVERVIEW



Fig. 26 Social return on investment for people living with non-subfoveal (early) GA



\$1,327 MILLION NET PRESENT VALUE

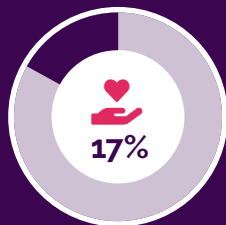
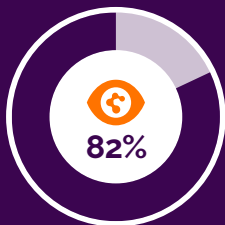
\$2,426 MILLION TOTAL VALUE CREATED

\$1,099 MILLION TOTAL INVESTMENT

50,295 people with non-subfoveal GA expected to be impacted

30,883 carers of people with GA expected to be impacted

The social value created is shared between stakeholders:



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.³³ 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.³⁴ 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.³⁵

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.^{4,36,37}

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.³⁷

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).³⁸ 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, there is the **Eye Connect** service, which offers vital health information, practical advice, and emotional support. Visit: mdfoundation.com.au/support-me/support-services/eyeconnect



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ADVISORY COMMITTEE

