

Better supporting patients through their glaucoma journey

Glaucoma Australia

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Evaluate

Evaluate was formed in September 2016, to bring fresh thinking to policy and economic questions, particularly those in the social sphere.

Our particular goal is to identify long-term solutions to ensuring the sustainability of Australia's admirable social contract, including universal access to healthcare and education, and the supply of aged care, housing and other social infrastructure.

Our approach is based on a traditional microeconomic toolkit, moderated by the knowledge that social services are accessed by people with a vast variety of experiences, needs and resources. Consequently, we have no bias towards either public or private supply of services, noting that the access and welfare needs of different Australians typically require a mix of both.

The Principals of Evaluate are experienced professionals, and we complement this with external expertise where appropriate.

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<https://glaucoma.org.au/>

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Executive Summary

Glaucoma is one of the leading causes of vision loss and blindness. In Australia, it is estimated that over 300,000 people have glaucoma although only around 50% of those have been diagnosed.¹

Glaucoma is a progressive condition that can affect people across their life span although people aged 70 years and over have an approximately three times greater risk of developing it than people aged 40.²

Glaucoma is a group of eye diseases where damage to the optic nerve leads to people losing their vision. This damage is usually caused by an increase in a person's intraocular pressure (IOP) which then causes irreversible damage to the optic nerve.³ The progression of the disease is usually quite slow and often a person will lose a significant portion of their peripheral, or side, vision before they notice anything is wrong.

Numerous risk factors exist for developing glaucoma, including a family history of glaucoma; high eye pressure; being over 50 years of age; experiencing long or short sightedness; or having had a previous eye injury. People of African and Asian ethnicity also have a higher risk profile.⁴

Managing primary open angle glaucoma – the most prevalent type of glaucoma – cost the health system \$355 million in 2005 and this is estimated to increase to \$784 million in 2025. Total costs, including health system costs, indirect costs and costs or loss of wellbeing, will increase from \$1.9 billion to \$4.3 billion over the same period. This is largely due to increasing prevalence due to Australia's ageing population.⁵

If not treated, people with early primary open angle glaucoma progress more rapidly to advanced stages of the disease. The NHMRC estimates that the average time for a person with primary open angle glaucoma to progress to blindness without treatment is 23 years and, with treatment, 35 years.

There is no cure for glaucoma and people's vision loss is irreversible. Early diagnosis and adherence to a treatment regime – usually involving eye drops – are critical in ensuring that intraocular hypertension is managed and the rate of disease progression slowed. Laser treatment can be used to treat both primary open angle glaucoma and angle-closure glaucoma while other treatments for glaucoma are more invasive

¹ From P. Mitchell et al., 'Prevalence of open-angle glaucoma in Australia. The Blue Mountains Eye Study', *Ophthalmology*, 103 (10) 1996, <https://pubmed.ncbi.nlm.nih.gov/8874440/>; S. Keel et al., 'Prevalence of Glaucoma in the Australian National Eye Health Survey', *British Journal of Ophthalmology*, 103(2) 2019.

[https://pubmed.ncbi.nlm.nih.gov/29699984/#:~:text=Conclusion%3A%20We%20estimate%20that%20198,years%20and%20over%20ave%20glaucoma](https://pubmed.ncbi.nlm.nih.gov/29699984/#:~:text=Conclusion%3A%20We%20estimate%20that%20198,years%20and%20over%20ave%20glaucoma;); and Australian population data Accessed February 2023.

² Quoted in National Health and Medical Research Council, *A Guide to Glaucoma for Primary Health Care Providers: a companion document to NHMRC Guidelines for the screening, prognosis, diagnosis, management and prevention of glaucoma*, 2010. July 2011. https://www.nhmrc.gov.au/sites/default/files/2018-10/cp113_b_glaucoma_guide_healthcare_workers_120404.pdf Accessed December 2022.

³ In addition, there are two groups of people who have either normal eye pressure with glaucoma, known as normal pressure glaucoma, or high eye pressure without glaucoma, simply called ocular hypertension.

⁴ Glaucoma Australia, *Fact Sheet: Glaucoma information and referral*. https://glaucoma.org.au/sites/default/files/2020-08/GA_11299_2019_Information-Referral_16pp_DL_FA-ONLINE.pdf Accessed December 2022.

⁵ M. Dirani, J.G. Crowston, P.S. Taylor, P.T. Moore, S. Rogers, M.L. Pezullo et al, 'Economic Impact of Primary Open-angle Glaucoma in Australia', *Clinical & Experimental Ophthalmology*, 2011. <https://pubmed.ncbi.nlm.nih.gov/21631669/> Accessed December 2022.



and involve surgery. Regardless, while treatment can help prevent additional vision loss, it cannot improve a patient's eyesight or restore lost vision.

Early diagnosis and treatment would support significant reductions in annual healthcare costs.⁶

Impact of glaucoma on patients

Glaucoma significantly impacts patients' lives and often those of their families. Compared to the general population, people with lower vision are at 4-8 times greater risk of breaking or fracturing a hip due to a higher risk of falling; at greater risk of hospitalisations and premature death; and twice as likely to suffer from depression.⁷

Their ability to perform daily activities is often impacted – walking, reading, driving and working can be undermined by their condition and they may become dependent or require financial and/or other support from the welfare system. These impacts often occur shortly after diagnosis, especially if both eyes are affected⁸ and, unsurprisingly, as the rate of vision loss increases, patients' quality of life tends to decrease: especially where their ability to drive and maintain independence is affected. This is also closely associated with increased risk of social isolation, depression and entry into long-term care.⁹ Those who are working often worry about losing their job as their vision declines.

While getting support for glaucoma, and getting that support early, can help support patients through this, few receive appropriate treatment and services sufficiently early and sometimes lose capacity which might otherwise have been supported.¹⁰

Glaucoma Australia's Patient Support Program

Glaucoma Australia is the single, unified voice for all things related to glaucoma. Their expertise is recognised by the National Health and Medical Research Council who, recommend the use of GA's educational resources by healthcare professionals as well as those diagnosed with glaucoma and their families.¹¹

One of the most impactful ways Glaucoma Australia influences the eye health of Australians is via their Patient Support Program. This program is delivered by Glaucoma Australia at no cost to the patient or the

⁶ Quoted in National Health and Medical Research Council, *A Guide to Glaucoma for Primary Health Care Providers*.

⁷ K. Attebo, P. Mitchell and W. Smith, 'Visual Acuity and the Causes of Visual Loss in Australia', *The Blue Mountains Eye Study, Ophthalmology*, 1996. <https://pubmed.ncbi.nlm.nih.gov/8600410/> Accessed December 2022.

⁸ Associate Professor Bang V Bui, Deputy Head, Department of Optometry and Vision Sciences, University of Melbourne, 'The impact of glaucoma on mental health & wellbeing', presentation. https://www.youtube.com/watch?v=NGWCo_ZHpHw Accessed January 2023.

⁹ Felipe A. Medeiros, 'Evaluating Quality of Life in Glaucoma', *Glaucoma Today*, May/June 2016.

<https://glaucomatoday.com/articles/2016-may-june/evaluating-quality-of-life-in-glaucoma#:~:text=Glaucoma%20can%20affect%20patients'%20quality,reading%2C%20walking%2C%20and%20driving.&text=The%20rate%20of%20visual%20decline,if%20the%20loss%20happens%20quickly>. Accessed December 2022.

¹⁰ Associate Professor Bang V Bui 'The impact of glaucoma on mental health & wellbeing', presentation. .

¹¹ National Health and Medicare Research Council, *NHMRC Guidelines for the Screening, Prognosis, Diagnosis, Management and Prevention of Glaucoma 2010*, 2010. https://www.nhmrc.gov.au/sites/default/files/2018-10/cp113_glaucoma_120404.pdf Accessed December 2022.



health system. Glaucoma Australia currently receives no financial or other support from either the State or Federal Government.

The program helps those diagnosed with glaucoma to better understand their disease and make informed decisions to maintain their quality of life; provides one on one emotional support via orthoptist educators to help manage the anxiety experience after receiving a glaucoma diagnosis; plays a facilitation role within each patient's circle of care to maximise rates of appointment and treatment adherence; and supports eye health professionals to 'extend their care' thereby maximising long-term patient treatment outcomes.

The program includes automated email and SMS educational journeys; personalised phone calls – both inbound and outbound; a free support line; webchat on the Glaucoma Australia website during business hours AEST; website resources; social media, including YouTube films and Q&A Live Events; and two online support groups.

The Patient Support Program significantly impacts patients' wellbeing and understanding of their disease. 60% of patients who participate in the program rate their knowledge of glaucoma and how it is treated as above average or excellent compared to 34% of patients when they join the program. Only 20% state that they always or frequently feel anxious about their glaucoma compared to 44% when they first join the program.

Treatment and appointment adherence is also greater for those patients supported by Glaucoma Australia with 85% reporting adherence with their eye drops. This compares to only 50% of patients six months after diagnosis who do not access this support and less than 37% of patients who are compliant three years after their diagnosis.¹² Attendance at recommended appointments to review their glaucoma status or treatment is also much higher for patients supported by Glaucoma Australia at 91% compared to only 14% generally.

Despite the significant impact the Patient Support Program delivers and its low cost of \$150 per patient per year, **it is accessed by only 1% of new glaucoma patients**. The principal constraint on access is availability of the program, which would be assisted by modest public investment.

Economics

The principal costs involved with glaucoma include direct medical costs; costs associated with aids and compensation for low vision; rehabilitation services; paid caregiving; and lost income.¹³ As patients' glaucoma worsens, costs increase and this is impacted by factors such as underdiagnosis; underestimates of the severity of damage; insufficient reduction of IOP; inadequate assessment of peaks and means of IOP;

¹² R. Bansal and J. Tsai, 'Medical Treatment: Compliance/Adherence to Glaucoma Medication – A Challenges', *Journal of Current Glaucoma Practice*, 2007.

https://www.researchgate.net/publication/244952732_Medical_Treatment_ComplianceAdherence_to_Glaucoma_Medications_-_A_Challenge Accessed December 2022.

¹³ Jordana K Schmier et al, "The Economic Implications of Glaucoma: A Literature Review", *Pharmacoeconomics*, 2007: 25(4). <https://pubmed.ncbi.nlm.nih.gov/17402803/> Accessed January 2023.



and difficulty in evaluating the rate of progression.¹⁴ Greater compliance with IOP-lowering medications and regular appointments should reduce the impact of these factors.

Before considering the savings case for investment in compliance, it is worth considering the increased cost in testing. On face value, this represents a potential cost to the Government due to use of Medicare for testing people. However, there are clear benefits from getting diagnosed as early as possible and the potential for early arrest of disease progression would deliver both system savings and better quality of life for the patient. However, increased testing is recommended only for those with assessed risk factors.

Potential Savings

This paper considers in detail four sets of potential savings that might be delivered from better compliance with glaucoma treatment. These are reduction in avoidable acute hospital services, for which the previously cited 4-8 times greater risk of hip fracture is used; simple reduction in the rate of demand for increased treatment services and medicines for the disease; reduction in demand for residential aged care, or other aged care services; and the costs of vision-related disability services under the NDIS. These are compared to Glaucoma Australia's Patient Support Program which costs \$150 per person.

Hip Fracture - In Australia, 93.2% of hip fractures are caused by falls¹⁵ and the average cost of a hip fracture to the health system is approximately \$16,666.67.¹⁶ This means that, across the general population, the mean individual cost (incidence by price) in a given year is \$33.16, but, for those with vision impairment from glaucoma, at a four times rate, this would be a mean of \$132.67 and, at an eight times rate, it would be a mean of \$265.33. Clearly, if the Glaucoma Australia Patient Support Program expenditure could be targeted only to those at risk, these data alone would make the program fiscally attractive.

Ongoing Treatment Costs - The inflated mean treatment costs of only glaucoma-related medicines and interventions is \$8,115.97. Of this total, \$1,990.47 is for medicine costs and the remainder \$5,290.04 for other glaucoma-related interventions. Studies suggest that the worsening of glaucoma is associated with at least a doubling of the annual eye-related outpatient costs¹⁷ which indicates a mean cost in Australia for severe glaucoma of \$16,231.94 *per annum*. If the incremental difference is applied *only* to the 9.5% of glaucoma patients who experience avoidable residual vision loss, then the average increase in cost over the entire glaucoma population would be some \$771 *per annum*. This clearly outstrips any cost associated with the Patient Support Program.

Aged Care - The expected increased cost of aged care for a person with substantial vision loss due to glaucoma is some \$117,026.10. Accounting for the 9.04% of patients who could avoid progression to

¹⁴ Remo Susanna Jr et al, "Why Do People (Still) Go Blind from Glaucoma?", *Translational Vision Science and Technology*, March 2015. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4354096/> Accessed January 2023.

¹⁵ = $\frac{16,300}{17,493}$ AIHW, "Hip fracture incidence and hospitalisations in Australia 2015–16", 2018, p.13.

<https://www.aihw.gov.au/reports/injury/hip-fracture-incidence-in-australia-2015-16/summary> Accessed January 2023.

¹⁶ = $\frac{\$350,000,000}{21,000}$ Australian Commission on Quality and Safety in Healthcare & IHPA, "Best practice pricing and clinical quality information on hip fracture care" https://www.safetyandquality.gov.au/sites/default/files/migrated/Best-practice-pricing-and-clinical-quality-information-on-hip-fracture-care-report_April-2016.pdf Accessed February 2023.

¹⁷ Vanessa Shih et al, "Clinical and Economic Burden of Glaucoma by Disease Severity: A United States Claims-Based Analysis", *Ophthalmology Glaucoma*, 2021. <https://pubmed.ncbi.nlm.nih.gov/33352292/> Accessed January 2023.



serious vision loss, this would be distributed across all persons with glaucoma as \$10,579.15 across their post-65 years' life. As noted in the paper, these are blunt calculations but potential aged care costs dwarf the proposed expenditure on Glaucoma Australia's Patient Support Program.

Comparison with disability funding - The mean cost of an NDIS package where vision loss is the primary source of disability is \$46,800. While this is lower than the average across all packages of \$72,000,¹⁸ this is an annual cost for what is expected to be many years in most cases and certainly for substantially longer than the average stay in residential aged care.

While glaucoma is predominantly a disease experienced by those aged over 65 who are excluded from NDIS entry, what would be funded where a person experiences earlier vision loss is substantially greater than any combination of aged care or carer benefits available in later life.

The point here is that there is a comparative standard for funding the relief of vision loss which makes the cost of avoiding it – at \$150 per person – completely trivial. This is a strong argument for further investment for glaucoma education and compliance.

Conclusion and recommendations

While the data discussed above do not deliver a neat single return on investment for Glaucoma Australia's Patient Support Program, and some of the data and calculations are relatively makeshift, what can be concluded is that on each of the four comparators – hip fracture, ongoing treatment costs, aged care and disability funding – expenditure on the Patient Support Program would be significantly outstripped by expected savings. Even if the data are somewhat unclear, the scale of the costs which may be addressed by such modest expenditure easily justifies the investment. And again, given the scale differences, proposing a substantial increase in public expenditure in Glaucoma Australia's Patient Support Program to increase compliance rates would still be cost-effective.

The driver of all this is the significant reduction in non-adherence within the Program by a factor of more than 80%. Consequently, increased investment in this program is recommended as the Glaucoma Australia Patient Support program represents strong value on multiple fronts and expansion of its funding will have a positive return to Government, patients and the broader economy.

In addition, Evaluate recommends that a more detailed study of compliance investment in glaucoma in Australia should be undertaken to obtain data to permit a detailed cost-benefit analysis. Evaluate would also recommend that ways to capture more reliable data about the prevalence of glaucoma in Australia be explored and implemented.

¹⁸ NDIS-sourced data.



Glaucoma in Australia

Glaucoma is one of the leading causes of vision loss and blindness. In Australia, it is estimated that over 300,000 people have glaucoma although only around 50% of those have been diagnosed.¹⁹

Glaucoma is a progressive condition that can affect people across their life span although people aged 70 years and over have an approximately three times greater risk of developing it than people aged 40.²⁰

There are numerous risk factors for developing glaucoma. A family history of glaucoma, especially in first degree relatives, is a key risk factor with people with a direct family member with glaucoma being 10 times more likely to develop the condition.

Other risk factors include having high eye pressure, being over 50 years of age, experiencing long or short sightedness or having had a previous eye injury. In addition, the likelihood of developing glaucoma is higher for those people who suffer from migraines, high or low blood pressure, obstructive sleep apnoea or have used cortisone medications for any prolonged period of time. People of African and Asian ethnicity also have a higher risk profile.²¹

Sadly, there is no cure for glaucoma and people's vision loss is irreversible. Early diagnosis and adherence to a treatment regime are critical to help slow the progression of glaucoma. In addition, early diagnosis and treatment would support significant reductions in annual healthcare costs.²²

What is glaucoma?

The term glaucoma encompasses a group of eye diseases where damage to the optic nerve leads to people losing their vision. The progression of the disease is usually quite slow and often a person will lose a significant portion of their peripheral, or side, vision before they notice anything is wrong.

¹⁹ From P. Mitchell et al., 'Prevalence of open-angle glaucoma in Australia. The Blue Mountains Eye Study', *Ophthalmology*, 103 (10) 1996, <https://pubmed.ncbi.nlm.nih.gov/8874440/>; S. Keel et al., 'Prevalence of Glaucoma in the Australian National Eye Health Survey', *British Journal of Ophthalmology*, 103(2) 2019.

[https://pubmed.ncbi.nlm.nih.gov/29699984/#:~:text=Conclusion%3A%20We%20estimate%20that%20198,years%20and%20over%20ave%20glaucoma](https://pubmed.ncbi.nlm.nih.gov/29699984/#:~:text=Conclusion%3A%20We%20estimate%20that%20198,years%20and%20over%20ave%20glaucoma;); and Australian population data Accessed February 2023.

²⁰ Quoted in National Health and Medical Research Council, *A Guide to Glaucoma for Primary Health Care Providers: a companion document to NHMRC Guidelines for the screening, prognosis, diagnosis, management and prevention of glaucoma*, 2010. July 2011. https://www.nhmrc.gov.au/sites/default/files/2018-10/cp113_b_glaucoma_guide_healthcare_workers_120404.pdf Accessed December 2022.

²¹ Glaucoma Australia, *Fact Sheet: Glaucoma information and referral*. https://glaucoma.org.au/sites/default/files/2020-08/GA_11299_2019_Information-Referral_16pp_DL_FA-ONLINE.pdf Accessed December 2022.

²² Quoted in National Health and Medical Research Council, *A Guide to Glaucoma for Primary Health Care Providers: a companion document to NHMRC Guidelines for the screening, prognosis, diagnosis, management and prevention of glaucoma*, 2010. July 2011. https://www.nhmrc.gov.au/sites/default/files/2018-10/cp113_b_glaucoma_guide_healthcare_workers_120404.pdf Accessed December 2022.



While there is no definitive definition of glaucoma due to the number of separate types and classifications of it, broad agreement exists to it being a “progressive optic neuropathy with characteristic visual field loss, optic disc and nerve fibre degeneration”.²³

Glaucoma is usually caused by an increase in a person’s intraocular eye pressure (IOP) which then causes damage to the optic nerve. The amount of pressure which causes this progressive damage varies between people and it is not possible to predict a person’s risk of progression or vision-threatening glaucoma with precision.

In addition, there are two groups of people who have either normal eye pressure with glaucoma, known as normal pressure glaucoma, or high eye pressure without glaucoma, simply called ocular hypertension.

Our eyes constantly generate a clear fluid which it secretes into itself. This is known as aqueous humour and it holds our eyes in shape whilst simultaneously nourishing them. The fluid drains from our eyes through an area called the drainage angle or anterior chamber angle. Any damage to the drainage angle means that the rate at which our eyes create aqueous humor can become greater than the rate at which it is drained away, causing high intraocular pressure in the eye.

It is this increased eye pressure that begins to cause damage to the optic nerve. The optic nerve is at the back of the eye and is made up of around one million nerve fibres connecting the back of the eye to the brain. Damage to the optic nerve cells causes irreversible damage to our vision.

Types of glaucoma

There are four main ways to classify glaucoma as follows:

- The mechanism by which an individual’s aqueous flow is impaired as discussed below – open or closed;
- The causes and presence of associated factors with the impairment – primary or secondary;
- The age of the person with glaucoma, i.e., childhood glaucoma – congenital or juvenile; and
- The temporal nature of symptoms i.e., whether they are acute or chronic.²⁴

The most common types of glaucoma are primary open-angle glaucoma (POAG) and primary angle-closure glaucoma (PACG).

Primary open-angle glaucoma

²³ National Health and Medical Research Council, *A Guide to Glaucoma for Primary Health Care Providers: a companion document to NHMRC Guidelines for the screening, prognosis, diagnosis, management and prevention of glaucoma, 2010*. July 2011. https://www.nhmrc.gov.au/sites/default/files/2018-10/cp113_b_glaucoma_guide_healthcare_workers_120404.pdf Accessed December 2022.

²⁴ National Health and Medical Research Council, *A Guide to Glaucoma for Primary Health Care Providers: a companion document to NHMRC Guidelines for the screening, prognosis, diagnosis, management and prevention of glaucoma, 2010*. July 2011. https://www.nhmrc.gov.au/sites/default/files/2018-10/cp113_b_glaucoma_guide_healthcare_workers_120404.pdf Accessed December 2022.



Primary open-angle glaucoma is the most common form of glaucoma experienced by Australians with around 90% of people experiencing this type of glaucoma.

In primary open-angle glaucoma, the drainage angle in the eye is wide or 'open' and cannot drain the fluid out of the eye sufficiently. This leads to increased eye pressure which then causes gradual damage to the optic nerve and, often time, loss of peripheral vision and then blindness.

There are no obvious symptoms of primary open angle glaucoma until it is quite advanced which means that it can be quite progressed before many people receive a diagnosis.

If not treated, people with early primary open angle glaucoma will progress more rapidly to advanced stages of the disease. 10% of patients with ocular hypertension progress to primary open angle glaucoma within five years.²⁵

The NHMRC estimates that the average time for a person with primary open angle glaucoma to progress to blindness without treatment is 23 years and, with treatment, 35 years.

Primary angle-closure glaucoma

This is the second most common form of glaucoma in Australia with around 10% of cases being attributed to it. As the name suggests, this type of glaucoma occurs when the drainage angle becomes narrow. This is often due to the iris being too close to the drainage angle and, as a result, blocking the space for the fluid to drain through.

If the drainage angle narrows suddenly, which can happen, a person's intraocular eye pressure will rise rapidly which causes an acute attack of angle-closure glaucoma. This is a medical emergency and needs immediate and urgent treatment.

Symptoms of acute angle-closure glaucoma include severe eye pain often combined with vomiting and nausea, headache, watery eyes and a sudden onset of seeing 'halos' around light or having blurred vision.

Other types of glaucoma

While open angle glaucoma and angle-closure glaucoma are the most common types of glaucoma, there are other types.

These include childhood (congenital) glaucoma which is a potentially blinding condition associated with raised intraocular pressure, specific visual field defects and optic disc changes. This is usually found in infants, including babies of only a few days, and its signs include tearing of the eye with significant photophobia; enlargement of the eyeballs and corneal haze.

²⁵ National Health and Medical Research Council, *A Guide to Glaucoma for Primary Health Care Providers: a companion document to NHMRC Guidelines for the screening, prognosis, diagnosis, management and prevention of glaucoma, 2010*. July 2011. https://www.nhmrc.gov.au/sites/default/files/2018-10/cp113_b_glaucoma_guide_healthcare_workers_120404.pdf Accessed December 2022.



Other types of glaucoma include mixed mechanism glaucoma; traumatic glaucoma; Iridocorneal Endothelial Syndrome; steroid induced glaucoma; uveitic glaucoma; pseudoexfoliation glaucoma, pigmentary glaucoma and neovascular glaucoma. The last two of these present very similarly to primary open angle glaucoma with some additional and specific key signs.

Getting a diagnosis

It is not possible to self-diagnose glaucoma and in fact there is no single test that allows an accurate diagnosis.

The initial signs of glaucoma may be identified by an optometrist or other eye health professional during a regular eye check-up. The optometrist may then diagnose the patient's glaucoma before referring them to an ophthalmologist for confirmation and treatment.

An ophthalmologist will undertake numerous tests as part of making a diagnosis and closely examine the eye and the optic nerve. The eye's pressure will be tested, the drainage angle of the eye measured through a gonioscopy and the optic nerve examined to identify any damage. A person's vision – both peripheral and central – will be tested and the thickness of their cornea measured.

Other tests might include optical coherence tomography, which looks at the retina and for which there is currently no Medicare rebate and a dilated fundus examination to help see the back of the eye.

These tests will be repeated throughout the patient's journey with glaucoma. While these tests can be performed by optometrists, who may also bulk bill, the involvement of an ophthalmologist is required in treatment and diagnosis. How often tests are performed depends on the individual and their progress with some people being tested every few weeks and some only every eighteen to twenty-four months. Most commonly, however, patients see their ophthalmologist every six to twelve months.

Treatment of glaucoma

Topical intraocular pressure lowering treatment, or eye drops, are effective for most individuals with primary open angle glaucoma as it slows the rate of progress of the disease.²⁶ This occurs as eye drops can reduce the amount of aqueous fluid that is secreted into the eye or help the fluid drain more effectively through the drainage angle.

Adherence to a patient's medication regime is critical however in ensuring that intraocular hypertension is managed and the rate of disease progression slowed.

²⁶ National Health and Medical Research Council, *A Guide to Glaucoma for Primary Health Care Providers: a companion document to NHMRC Guidelines for the screening, prognosis, diagnosis, management and prevention of glaucoma, 2010*. July 2011. https://www.nhmrc.gov.au/sites/default/files/2018-10/cp113_b_glaucoma_guide_healthcare_workers_120404.pdf Accessed December 2022.



Laser treatment can be used to treat both primary open angle glaucoma and angle-closure glaucoma. Selective laser trabeculoplasty, which treats primary open angle glaucoma, uses low energy light pulses on the drainage angle to help better flow of the aqueous fluid while, in a peripheral iridotomy, a laser creates a hole in the edge of the iris to support the fluid draining out better. Cyclo diode and argon laser treatment may also be used.

Other treatments for glaucoma are more invasive and involve surgery. Surgical trabeculectomy lowers the intraocular pressure by creating a filtration bleb, like a little pocket, under the conjunctiva. A tiny flap is also created in the white part of the eye and aqueous fluid flows through the flap into the filtration bleb where it can be absorbed. Glaucoma drainage devices may also be utilised.

Minimally invasive glaucoma surgery, commonly known as MIGS, works by helping the aqueous fluid leave the eye by different means, effectively bypassing the blockage in the drainage angle. Different types of MIGS involve devices such as iStent inject W, Hydrus, XEN Gel Stent, iTrack and PRESERFLO MicroShunt.

Regardless, while treatment can help prevent additional vision loss, it cannot improve a patient's eye sight or restore vision lost as a result of optic nerve damage.

Economic impacts of glaucoma in Australia

A study into the economic impact of primary open angle glaucoma in Australia found that costs to the health system from the management of glaucoma were \$355 million in 2005 and are estimated to increase to \$784 million in 2025.

Total costs, including health system costs, indirect costs and costs or loss of wellbeing, will increase from \$1.9 billion to \$4.3 billion over the same period. This is largely due to increasing prevalence due to Australia's ageing population.²⁷

Impact of glaucoma on patients

There are many impacts on people as a result of having their vision impaired and these are well documented.

Compared to the general population, people with lower vision are:

- At 4-8 times greater risk of breaking or fracturing a hip due to a higher risk of falling;
- At greater risk of hospitalisations and premature death; and
- Twice as likely to suffer from depression.²⁸

²⁷ M. Dirani, J.G. Crowston, P.S. Taylor, P.T. Moore, S. Rogers, M.L. Pezullo et al, 'Economic Impact of Primary Open-angle Glaucoma in Australia', *Clinical & Experimental Ophthalmology*, 2011. <https://pubmed.ncbi.nlm.nih.gov/21631669/> Accessed December 2022.

²⁸ K. Attebo, P. Mitchell and W. Smith, 'Visual Acuity and the Causes of Visual Loss in Australia', *The Blue Mountains Eye Study, Ophthalmology*, 1996. <https://pubmed.ncbi.nlm.nih.gov/8600410/> Accessed December 2022.



Glaucoma can and does impact many aspects of a patients' quality of life as well as those of their carers. The way they experience the world can be impacted and their capacity to perform a wide range of activities of daily living, such as walking, reading, driving and even working, can be undermined by their condition and they may become dependent or require financial and/or other support from the welfare system. In addition, the risk of injury to themselves and others is also significantly increased.

Interestingly, while it is usually assumed that the impact on patients' quality of life occurs quite late in their experience with the disease, quality of life can be impacted very early, especially if both eyes are affected.²⁹ Unsurprisingly however, as the rate of vision decline increases, patients' quality of life tends to decrease.

The possibility of losing the ability to drive and the independence associated with this is a major concern for people with glaucoma. In many locations, driving is central to the capacity to maintain independent living and ceasing driving is closely associated with increased risk of social isolation, depression and entry into long-term care.³⁰ Having to stop driving has particularly significant impact on people living in regional and rural areas.

Glaucoma has been directly implicated as a risk in people falling. The disease impairs people's balance, depth perception and walking ability and patients with bilateral vision loss more frequently bump into things, including around their own houses. Many patients with glaucoma report concern about walking up and down stairs and studies show that people with glaucoma are two to four times more likely to experience a fall than people who do not have glaucoma.³¹

It is not surprising therefore that studies find that patients with advanced glaucoma undertake limited physical activity and that levels of physical activity decline as patients' glaucoma progresses.³²

Glaucoma is also associated with the disruption of patients' circadian rhythms and patients with glaucoma often experience decreased quality of sleep. In addition, patients may sleep up to one hour less a day,³³ again with implications for their mental wellbeing and confidence in their physical environment.

²⁹ Associate Professor Bang V Bui, Deputy Head, Department of Optometry and Vision Sciences, University of Melbourne, 'The impact of glaucoma on mental health & wellbeing', presentation. https://www.youtube.com/watch?v=NGWCo_ZHpHw Accessed January 2023.

³⁰ Felipe A. Medeiros, 'Evaluating Quality of Life in Glaucoma', *Glaucoma Today*, May/June 2016. <https://glaucomatoday.com/articles/2016-may-june/evaluating-quality-of-life-in-glaucoma#:~:text=Glaucoma%20can%20affect%20patients'%20quality,reading%2C%20walking%2C%20and%20driving.&text=The%20rate%20of%20visual%20decline,if%20the%20loss%20happens%20quickly.> Accessed December 2022.

³¹ Felipe A. Medeiros, 'Evaluating Quality of Life in Glaucoma', *Glaucoma Today*, May/June 2016. <https://glaucomatoday.com/articles/2016-may-june/evaluating-quality-of-life-in-glaucoma#:~:text=Glaucoma%20can%20affect%20patients'%20quality,reading%2C%20walking%2C%20and%20driving.&text=The%20rate%20of%20visual%20decline,if%20the%20loss%20happens%20quickly.> Accessed December 2022.

³² W. Huang, K. Gao, Y. Liu, M. Liang and X. Zhang, 'The Adverse Impact of Glaucoma on Psychological Function and Daily Physical Activity', *Journal of Ophthalmology*, April 2020. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7191398/> Accessed December 2022.

³³ Associate Professor Bang V Bui, Deputy Head, Department of Optometry and Vision Sciences, University of Melbourne, 'The impact of glaucoma on mental health & wellbeing', presentation. https://www.youtube.com/watch?v=NGWCo_ZHpHw Accessed January 2023.



The impact of glaucoma on people's ability to adjust to different levels of light is well recorded. Patients find adjusting to both glaring light and dimly lit conditions difficult. This impacts their confidence in undertaking numerous daily tasks, including driving.

Glaucoma also impacts people's capacity to read for sustained periods as their condition changes the way in which they read characters on a page and they read much more slowly. This can impact their capacity to work as well as their independence as they may struggle to read and manage financial materials, such as bills and other financial statements.

Concern about progression of their disease

The uncertainty and lack of predictability about how their glaucoma will progress is also a psychological burden for many patients. Patients vary in their responses to being diagnosed with glaucoma with some people reporting 'going to pieces' even when they are usually not like that at all. Individuals report that they are more worried about their glaucoma than other medical conditions they have, even when those conditions are quite serious, "because you can't cure it [the glaucoma], you can only hope it doesn't get worse".³⁴

The uncertainty certainly plays on people's mind with a lack of information in some instances causing greater concern. One patient reported "you can't find anywhere how it will manifest itself. Maybe...this [is] going to be so ghastly nobody dare say what it is".

There is also significant concern about being a burden. Patients often realise that they need help, either with tasks of daily living like being driven somewhere or needing help to find objects around the house but are deeply worried about becoming a burden to family or friends or asking too often for assistance. Many people also worry about losing their job, particularly if it relies on their capacity to drive or hold a licence.

There is social embarrassment in many instances when people start to not be able to identify people easily. Patients also report not being able to watch the television very well as their disease progresses as they can't see the people's faces and therefore can't follow a plot as easily as before.³⁵

Sadly many patients give up activities that they had previously enjoyed or limited their participation due to the challenges and risks it now poses for them. In many instances, this leads to feelings of frustration and even resentment. In turn, it also often leads to people becoming increasingly isolated with the associated psychological impacts of that.

³⁴ F.C. Glen and D.P. Crabb, 'Living with glaucoma: a qualitative study of functional implications and patients' coping behaviours, *BMC Ophthalmology*, 15:128 2015. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4596492/> Accessed December 2022.

³⁵ F.C. Glen and D.P. Crabb, 'Living with glaucoma: a qualitative study of functional implications and patients' coping behaviours, *BMC Ophthalmology*, 15:128 2015. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4596492/> Accessed December 2022.



While getting help for glaucoma, and getting that help early, can help support patients through these experiences and impacts, few are directed to appropriate treatment and services sufficiently early as would be ideal and therefore sometimes lose capacity which might otherwise have been supported.³⁶

Shannon's story – a shock diagnosis

A partner in a leading professional services firm, Shannon had always been healthy – he watched what he ate, worked out regularly, visited his dentist the regulation two times a year and even ran half-marathons.

In 2020 at the age of 43, Shannon realised that his two sisters both wore glasses and so did many people he knew who were the same age as him. He had no family history of glaucoma that he knew of and no apparent problems with his own vision but decided maybe he'd have his eyes checked.

After browsing the frames in his local optometry practice, Shannon had his eyes examined by the optometrist who also did an intraocular pressure (IOP) test.

The next few moments changed his life and those of his family forever.

Shannon was told he had IOP in the high 40s – normal is between 10 and 21 – and, worse, his optic nerve had sustained progressive and permanent damage.

At the ophthalmologist's, the news got worse. Shannon was told that his glaucoma was at the 'end stage' of its progression, he had very little vision left and was declared legally blind. Relying as is normal for day-to-day life on his central vision, Shannon had simply not noticed the progressive loss of his peripheral vision.

His shock diagnosis forced him to make significant changes in his life. He lost his driver's licence which meant that his wife became the family's sole driver, a challenging situation with two small children. He needed to take two different types of eye drops four times a day which, given the time needed for infusion, took up to an hour and a half every day.

Problems with light and glare, with contrast and with stairs and walking on uneven surfaces became increasingly difficult and spending time on a computer or other screens made him increasingly tired. Recognising or reading people's face became challenging and Shannon found himself responding strangely during conversations or, one time, greeting a stranger thinking it was a friend.

Shannon was assessed as being totally and permanently disabled and had to step back from his job.

After multiple laser procedures, Shannon's glaucoma continued to progress and a double trabeculectomy was recommended. Initially Shannon decided to have surgery on his right eye first, hoping that it might help maintain the existing sight in his better eye before surgery on the left.

³⁶ Associate Professor Bang V Bui, Deputy Head, Department of Optometry and Vision Sciences, University of Melbourne, 'The impact of glaucoma on mental health & wellbeing', presentation. https://www.youtube.com/watch?v=NGWCo_ZHpHw Accessed January 2023.



The decision was harrowing and the 10% possibility of losing some or all of his vision due to the operation was devastating.

Throughout it all though Glaucoma Australia supported Shannon. He received regular calls from their orthoptists or ophthalmology registrars and had the opportunity to ask all the questions he had. The level of care and attention he received made him assume, from his corporate work, that they were a large organisation and he was amazed to discover that they had only eight employees and few resources, supported by volunteers.

Shannon is now focused on maximising his remaining sighted time with his wife and sons. He's also adapting his house and learning new technologies that help maintain his independence.

He's also become one of Glaucoma Australia's Ambassadors, together with media personality David Koch and former Senator John Faulkner. Shannon is focused on helping raise awareness of glaucoma, mentoring people who have been recently diagnosed and talking about his experience. He believes firmly that, given the benefits of early diagnosis of glaucoma, that the community should be badgered to see their optometrist and have their vision checked, just like we are encouraged to see the dentist. "The cost of having [their eyes] reviewed and managed early is far less than the cost to families and the economy of managing blindness down the track", he says.

Susan's story – reacting to a diagnosis

Susan was in her forties when she went to her optometrist for her annual check-up. They'd done the normal tests before concluding with the visual fields test which she hated.

The optometrist looked at the results and then looked at Susan's results on another machine, one she hadn't seen before. She was studying them very carefully and asked Susan to come and have a look. There were pictures, graphs and lots of words with funny symbols. The optometrist explained that this was a picture of Susan's optic nerve and part of it was thinner than elsewhere.

Susan joked that it was the only part of her that was getting thinner, a joke the optometrist didn't seem to appreciate before then telling Susan that she might have glaucoma. Susan was horrified – all she knew about glaucoma is that it causes blindness.

The optometrist made a phone call for Susan to make an appointment with a specialist ophthalmologist – two weeks later. It felt like a lifetime away.

Two weeks later, the ophthalmologist confirmed that Susan had glaucoma. She was shattered.

As the carer, driver and vision support for her husband who has significant vision loss due to illness, Susan was frightened about the future. Also she was frightened for her children, her sister and her brother because she knew glaucoma is genetic and runs in families.

Susan cried when she told her daughter and spent the rest of the day in a grief-filled daze. She wanted to keep busy and think of other things but with little success. She was so frightened about the future and what the rest of her life might look like. What if her children have it? What if she's passed it on?



Eventually, when she was all cried out, she remembered the ophthalmologist's words "We've got it early. That's good and offers the best outcomes. You will not go blind in your lifetime."

There is hope and Susan holds onto it with all her might.

Sarah's story – long term experience with glaucoma³⁷

Sarah lives in a remote mining town in the Northern Territory and, four years after a total "burn out", she noticed she was having problems with her vision. She and her GP put it down to her antidepressant medication.

Given her location, there were no specialists nearby and so Sarah and her GP left things as they were in order to avoid having to travel to Darwin or Cairns.

Then Sarah visited her children in Cairns and, playing tennis, noticed that she often simply didn't see the ball. She also noticed that she had challenges walking up and down steps and stairs.

One of Sarah's children took her to Brisbane to see an eye specialist. He told her she had glaucoma but she was not too worried because she thought he said trachoma, which is quite common in the Aboriginal population in Arnhem Land.

The specialist then explained how serious glaucoma was and that Sarah had probably lost around 50% of total vision in both eyes. He advised her to consult another specialist back in the Northern Territory which she did. Unfortunately, as the new specialist was in Darwin, Sarah had to wait three months.

After her eventual appointment with the specialist, Sarah tried various eye drops to relieve her eye pressure but they did not work. She then had a trabeculectomy in both eyes, which helped control the pressure. Ongoing problems though led to a partial corneal transplant in Sarah's left eye and a stent being implanted in her right one. All this has involved significant amount of time, effort and money spent in travelling to Darwin.

Two of Sarah's three brothers have also now been diagnosed with glaucoma.

Katie's story – being a kid with congenital glaucoma

Katie was born with congenital glaucoma, one of the 1 in 750,000 children in Australia born with the condition.

Being born in Melbourne, Katie was lucky as she was quickly diagnosed and could access care at the Melbourne Children's Eye Clinic and the Royal Children's Hospital.

³⁷ Names of patient participants have been changed. Sapna is the lead Orthoptist Educator at Glaucoma Australia and has agreed for her real name to be used.



Katie was given eye medications straight away and, at nine days old, had her first operation to relieve the pressure in her eyes. Over the next four months, the surgeons tried different procedures on Katie's eyes but, after five operations, ended up with tube shunts in both her eyes and an iridectomy in her right eye.

Now five years old, Katie's glaucoma is considered stable and treated with daily eye drops. Her eyes have some complex issues though – she has significant scarring, her pupils are strangely shaped and misaligned (aniridia) and her eyes “dance” due to nystagmus. She is quite short sighted and she suffers from an intermittent eye turn which actually switches from one eye to the other.

Most of her challenges relate to depth perception and adjusting to light glare and Katie trips and stumbles into obstacles quite often. Her sunglass prescription is still being finetuned and her future is unclear.

Glaucoma Australia support program – overview

Glaucoma Australia was established in 1986 by ophthalmologist Clinical Professor Ivan Goldberg AM and his patient Miss Kathleen Holmes OAM to support the needs of glaucoma patients across Australia. The organisation was registered as a charity and incorporated in 1988 and, in March 1999, renamed as Glaucoma Australia Incorporated.

Glaucoma Australia is the single, unified voice for all things related to glaucoma because of their expertise, credibility, and partnerships. The value of Glaucoma Australia's tailored information, including videos and literature, is recognised by the National Health and Medical Research Council who, in their *Guidelines for the Screening, Prognosis, Diagnosis, Management and Prevention of Glaucoma*, recommends these educational resources to healthcare providers to assist patients and their families understand and manage their disease.³⁸

Glaucoma Australia Patient Support Program

One of the most impactful ways Glaucoma Australia influences the eye health of Australians is via their Patient Support Program. This program is delivered by Glaucoma Australia at no cost to the patient or the health system and is instead funded from funding received from donors and bequests to Glaucoma Australia and, to a lesser extent, corporate partners.

Glaucoma Australia currently receives no financial or other support from either the State or Federal Government.

The objectives of the program are as follows:

- Empower those who have been diagnosed with glaucoma to understand their disease and make informed decisions to maintain their quality of life;

³⁸ National Health and Medicare Research Council, *NHMRC Guidelines for the Screening, Prognosis, Diagnosis, Management and Prevention of Glaucoma 2010*, 2010. https://www.nhmrc.gov.au/sites/default/files/2018-10/cp113_glaucoma_120404.pdf Accessed December 2022.



- Provide one on one emotional support via orthoptists educators to help manage the anxiety experience after receiving a glaucoma diagnosis.
- Play a facilitation role within each patient’s circle of care to maximise rates of appointment and treatment adherence; and
- Support eye health professionals to ‘extend their care’ thereby maximising long-term patient treatment outcomes.

Program Features (Maybe as a graphic?)

- Automated email and SMS educational journeys
- Personalised phone calls – both inbound and outbound
- Free support line: 1800 500 880
- 24-hour webchat on the Glaucoma Australia website
- Website: www.glaucoma.org.au
- Social media: Facebook and Instagram
- You Tube educational films + Q&A Live Events
- 2 online support groups (General and Congenital)

There is also a clear referral pathway as outlined in Figure Two.

Figure Two: Patient referral pathway

One of the most impactful elements of this program are Glaucoma Australia’s orthoptist clinical educators, who provide one on one emotional support to help people manage the anxiety normally associated with receiving a diagnosis of glaucoma and also play a facilitation role, supporting patients to maximise their attendance at appointments and their adherence to their treatment regimen. Patients are also assisted in practical ways to reduce risks and advised on matters of wellness and lifestyle.

In addition, the Patient Support Program aims to support eye health professionals to ‘extend their care’ beyond their practice, thereby maximising long-term patient treatment outcomes. This includes working with them to drive referrals to Glaucoma Australia’s Program.

The Program has numerous features and can be tailored to support each patient according to their circumstances, needs and preferences. Education and support are at the heart of the program and online resources, automated emails and SMS provide trusted, authoritative educational materials and information. Patients receive and, critically, can make personalised phone calls to the orthoptist educators



via a free support line. Live webchat is available during office hours from the Glaucoma Australia website and the website has numerous additional resources, including videos, for example, demonstrating how to properly instill eye drops and on other issues such as lifestyle, diet and exercises beneficial to glaucoma management.

There are two online support groups, one focusing on general glaucoma and the other on congenital glaucoma. The online support groups are regulated by Glaucoma Australia's Orthoptist Educators and Social Media Manager to ensure the information discussed are clinically correct. The support groups act as a platform that provides glaucoma education and emotional support to Australian's with glaucoma. The groups are private and provide a safe and empathetic place for patients and their loved ones to interact.

The Glaucoma Australia team host various Q&A Live Events featuring eye health experts on YouTube and the channel also holds educational films on a regular basis.

Patients greatly appreciate the support provided by the educators and Glaucoma Australia as demonstrated in the case studies below and demand for the program is growing with new patient referrals now over 500 per quarter. While positive, this represents only 1% of all newly diagnosed glaucoma patients in Australia which, considering the benefits delivered to patients, offers significant opportunity to grow the Program offering multilingual clinical educators and optimise its impact in future as more Australians are diagnosed with glaucoma. As this is a chronic disease, the needs of glaucoma patients is constantly evolving and many patients consider GA as an integral part of their decision making and glaucoma journey.

Glaucoma Australia support program – benefits

There are clear benefits to the Patient Support Program as demonstrated by the Patient Impact Measurement Survey that Glaucoma Australia undertook in 2022.

Participation in the Program significantly impacts patients' understanding of their disease and, importantly, helps reduce their anxiety levels over time through ongoing support calls and contacts to check in with them. 60% of patients who participate in the program rate their knowledge of glaucoma and how it is treated as above average or excellent compared to 34% of patients when they join the program. Only 20% of them state that they always or frequently feel anxious about their glaucoma compared to 44% when they first join the program.

Treatment adherence is also greater for those patients supported by Glaucoma Australia with 85% reporting adherence with their eye drops. This compares to only 50% of patients six months after diagnosis who do not access this support and less than 37% of patients who are compliant three years after their diagnosis.³⁹

³⁹ R. Bansal and J. Tsai, 'Medical Treatment: Compliance/Adherence to Glaucoma Medication – A Challenges', *Journal of Current Glaucoma Practice*, 2007.
https://www.researchgate.net/publication/244952732_Medical_Treatment_ComplianceAdherence_to_Glaucoma_Medications_-_A_Challenge Accessed December 2022.



Attendance at recommended appointments to review their glaucoma status or treatment is also much higher for patients supported by Glaucoma Australia. 91% of patients in the Patient Support Program report that they attend their appointments whilst only 14% of unsupported patients do so.⁴⁰

Considering the nature of glaucoma and its familial association, critically, 88% of those responding to the patient impact survey have informed their relatives of their diagnosis and urged them to get tested themselves.

Tom story's – getting help with crippling anxiety

Tom had long been a participant of GA's Patient Support Program and regularly watched information videos from the website and accessed various other literature to better understand his condition.

Describing the videos as “excellent and...reassuring”, leading up to his regular six monthly appointment with his ophthalmologist, Tom emailed Sapna – GA's lead Orthoptist Educator who supports patients and is trained in clinical counselling – due to his generalised anxiety level which he said had increased significantly. His fear was about the future should his glaucoma progress, despite the fact that he strictly adhered to his daily eye drop routine.

Tom wondered whether he should raise his anxiety with his ophthalmologist and asked Sapna's advice. She reassured him that, given he had been compliant with his eye drop treatment, he was doing the best he possibly could to manage his glaucoma and preserve his vision. She explained that, if there were any changes to his glaucoma, his ophthalmologist would take action to change his treatment plan to minimise progression of his glaucoma and indicated that, at present, his ophthalmologist was confident that monitoring his condition every six months was sufficient.

Sapna also suggested that, if Tom experienced any changes with his eye health or vision between visits to his eye specialist, he could always visit his optometrist for a check up. Doing this might provide additional reassurance and relieve some of Tom's anxiety. She offered to talk with him directly either before or after his appointment if that would help and also suggested he join the private Glaucoma Australia Support Group online.

Tom really appreciated Sapna's response and support, thanking her for her “kind and understanding response to my anxiety episode” and commenting that he liked her suggestion of visiting the optometrist. After his appointment, he contacted her again, thanking her for her “wonderful support over the last week” and commenting that her suggestions had proven a “great way of reducing my levels of anxiety”. He had a plan to manage his glaucoma and again felt in control.

⁴⁰ A.T. Do, M.R. Pillai, V. Balakrishnan et al., 'Effectiveness of Glaucoma Counselling on Rates of Follow-up and Glaucoma Knowledge in a South Indian Population', *American Journal of Ophthalmology*, 2016. <https://pubmed.ncbi.nlm.nih.gov/26705095/> Accessed December 2022.



Glaucoma Australia support program – moving forward

In the last financial year, Glaucoma Australia has hired another qualified orthoptist to support their 1800 helpline on a part time basis. Patient education and support options have been expanded to include webchat, face-to-face live presentations and the online live Q&A sessions between experts and the patient community mentioned above.

Glaucoma Australia's lead orthoptist, Sapna, has also been supported to obtain a formal patient counselling qualification to enable her to provide the comprehensive mental health support needed by many patients who are distressed and concerned about their diagnosis, state of their eye health and the future.

While the Patient Support Program has proven highly effective in supporting patients to adhere to their treatment regimen, attend their appointments and encourage their family members to get tested for glaucoma, **it is still being accessed by only 1% of new glaucoma patients.**

Glaucoma Australia is working to raise awareness of the Patient Support Program and its effectiveness with optometrists and ophthalmologists and is collaborating on a trial with Specsavers to roll the program out to their customers. While referral numbers naturally dropped during COVID, Glaucoma Australia is working with Specsavers to return referrals to at least a pre-pandemic baseline of around 380 per month. Specsavers is the principal referrer, accounting for 60% of these referrals.

At the same time, due to the pandemic, the avoidance of routine eye check-ups coupled with a backlog in follow-up appointments and eye operations is transferring into a worrying number of later diagnoses of glaucoma and an associated increase in patients' anxiety levels. This is driving an urgent need for mental health support and regular patient follow-up to ensure people are attending their appointments and adhering to their treatment.

Glaucoma Australia's educators are increasingly busy and, while the organisation also has 125 active clinical volunteers – eye health and medical students and qualified eyecare professionals – there is a lack of sufficient resources to train and use them to their full potential. Clinical volunteers increasingly need formal training in counselling and mental health support skills in order to support patients and reduce the high anxiety levels patients are experiencing. Recruiting more volunteers across the country to facilitate extending the hours of service beyond the current 9am-5pm AEST Monday – Friday would also be beneficial for the patient community who usually prefer to have these conversations outside working hours.

Many elderly and vulnerable patients also require their support to be delivered face-to-face or, at the very least, via the telephone as often they do not use digital channels. More face-to-face education sessions, presentation at wellness meetings and visits to nursing homes and retirement villages are needed to support high risk communities such as seniors, CALD groups, people living in regional and rural communities and families with congenital glaucoma. Translating existing materials into multiple languages is also becoming more important, particularly amongst high-risk communities such as those of Asian and African descent. This is particularly relevant given Australia's multicultural community has significant cohorts from these regions.



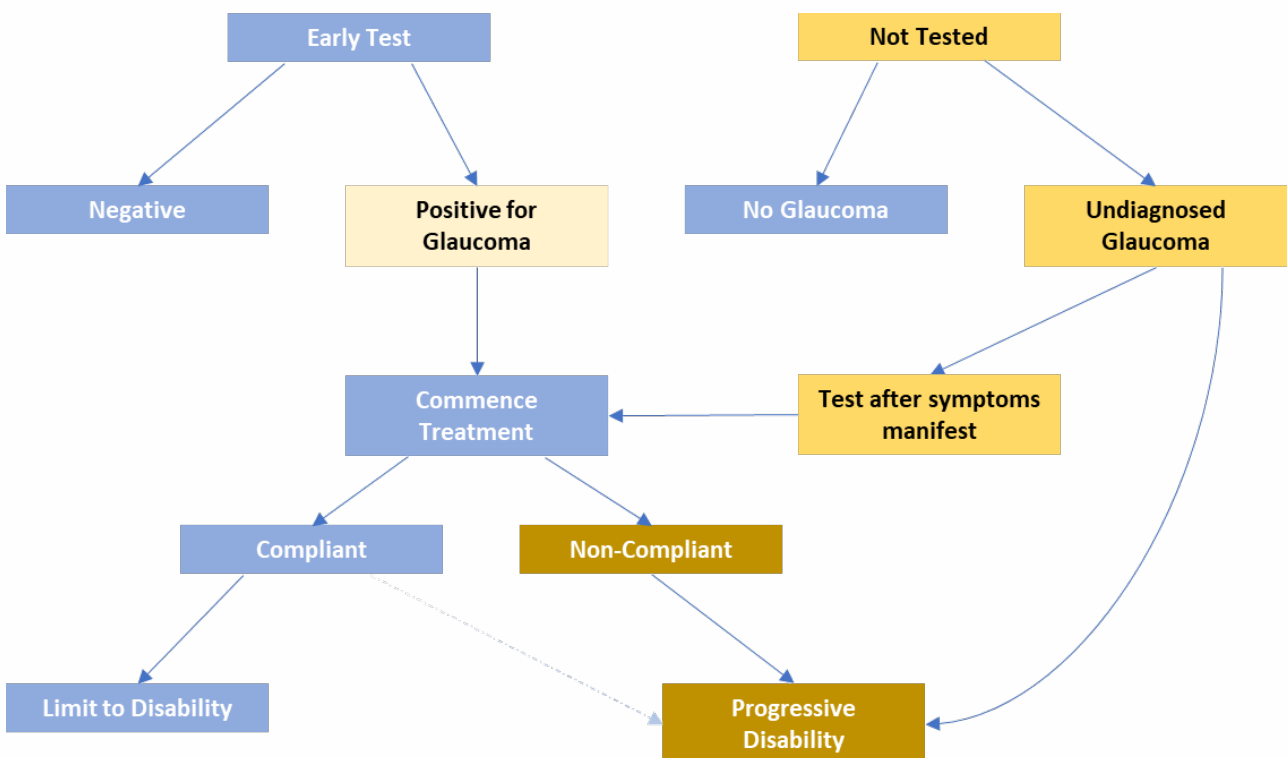
Economics

The economic questions posed by glaucoma are well summarised in Schmier et al (2007) who identify the principal costs as:

- Direct medical costs;
- Costs associated with aids and compensation for low vision;
- Rehabilitation services;
- Paid caregiving; and
- Lost income.⁴¹

Each of these is valued in the literature as part of the overall cost of glaucoma, particularly in Dirani et al. However, prior to consideration of individual impacts, it is useful to consider the directional effects of various events in the diagnosis and treatment of glaucoma. This is illustrated in Figure One.

Figure 1: Glaucoma Diagnosis and Treatment Pathways



⁴¹ Jordana K Schmier et al, "The Economic Implications of Glaucoma: A Literature Review", *Pharmacoeconomics*, 2007: 25(4). <https://pubmed.ncbi.nlm.nih.gov/17402803/> Accessed January 2023.



In many ways, this figure simply recapitulates the arguments outlined above in support of Glaucoma Australia's proposed management strategy. The key to the illustration is:

1. Blue boxes indicate nett savings or zero costs (the latter where there is no glaucoma);
2. Mustard boxes of various degrees illustrate costs, in which:
 - a. The simple diagnosis of glaucoma presents an unavoidable cost as there is no preventive measure;
 - b. Darker boxes show costs which are avoidable and exacerbate burden of the disease to an increasing degree;
3. The pathway from earliest diagnosis to compliant treatment is the best predictor of limited disability:
 - a. Notwithstanding – per the dotted line – that a given percentage of patients (perhaps 10%)⁴² will experience progressive disability despite best practice treatment; and,
 - b. On the reverse, late diagnoses and poor compliance result in the poorest outcome.

This provides the basis for some basic cost-benefit comparisons. While there are significant limitations in the Australian data to this, published literature is helpful in providing parameters for calculation.

The chart above is of course a substantial over-simplification, with multiple variations to pathways, and different consequences from minor variations in diagnosis and treatment. It is noted in a recent US study that as well as underdiagnosis, progression to severe visual disability is exacerbated by such factors as:

- Underestimates of the severity of damage;
- Insufficient reduction of IOP;
- Inadequate assessment of peaks and means of IOP; and
- Difficulty in evaluating the rate of progression.⁴³

What may be said here though is that greater compliance with IOP-lowering medications and regular appointments should reduce the impact of these factors.

The Glaucoma Australia Patient Support Program is particularly focused on the bottom left of Figure One, i.e., compliance, with the identified benefits of:

⁴² Glaucoma Australia, "Glaucoma facts and stats", February 2022. <https://glaucoma.org/glaucoma-facts-and-stats/> Accessed February 2023

⁴³ Remo Susanna Jr et al, "Why Do People (Still) Go Blind from Glaucoma?", *Translational Vision Science and Technology*, March 2015. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4354096/> Accessed January 2023.



- 85% of those in the program being compliant with their medication regimes after three years compared to 37% of patients in the general community;
- 91% of participants attending their glaucoma-related appointments compared to only 14% generally; and,
- 88% of participants informing familial relatives who are at greater risk of glaucoma than the general population.⁴⁴

Before looking at the general savings case for investment in compliance, it is worth considering the impact of the third datum above compared to the increased cost in testing.

On the face of it, this represents a potential cost to the Government. Presuming an optometrist bulk-bills, this is an increased cost of \$60 per patient to the Commonwealth (either annually or three-yearly), based on MBS items 10910, 10911 and 10912 depending on the age of the patient and the circumstances of the consultation. However, there are definite benefits from getting diagnosed as early as possible.

As these are comprehensive consultation payments, diseases and conditions other than glaucoma may be identified, with the potential for early arrest of disease progression leading to both system savings and better quality of life for the patient. These potential benefits are broad and outside the scope of this paper but may be regarded as additional benefits from early testing.

It is noted here that increased testing should be focused on at-risk groups. General evidence for screening as an alternative remains decidedly ambiguous.⁴⁵

Estimates of glaucoma prevalence and under-diagnosis vary. Dirani et al (2011) estimate that the number of patients with glaucoma will rise from 208,000 in 2005 to 379,000 in 2025.⁴⁶ In contrast, Keel et al (2019) estimate 198,923 non-Indigenous and 2139 Indigenous people have glaucoma: a total of 201,052 Australians.⁴⁷ This indicates a weighted prevalence of 1.5% of the population with definite glaucoma and 3.4% with probable glaucoma.⁴⁸

There is considerable ambiguity in the data regarding the prevalence of reported glaucoma with significant variations in reported incidence over the past 15 or so years as demonstrated in Figure Two.

⁴⁴ For a discussion of at-risk criteria for glaucoma, see: Lindsay A Rhodes et al, "Eye Care Quality and Accessibility Improvement in the Community (EQUALITY): impact of an eye health education program on patient knowledge about glaucoma and attitudes about eye care", *Patient Related Outcome Measures*, 2016. <https://www.dovepress.com/eye-care-quality-and-accessibility-improvement-in-the-community-equali-peer-reviewed-fulltext-article-PROM> Accessed January 2023.

⁴⁵ Nicholas Y Q Tan et al, "Glaucoma screening: where are we and where do we need to go?", *Current Opinion in Ophthalmology*, March 2020. https://www.researchgate.net/publication/338398173_Glaucoma_screening_Where_are_we_and_where_do_we_need_to_go Accessed January 2023.

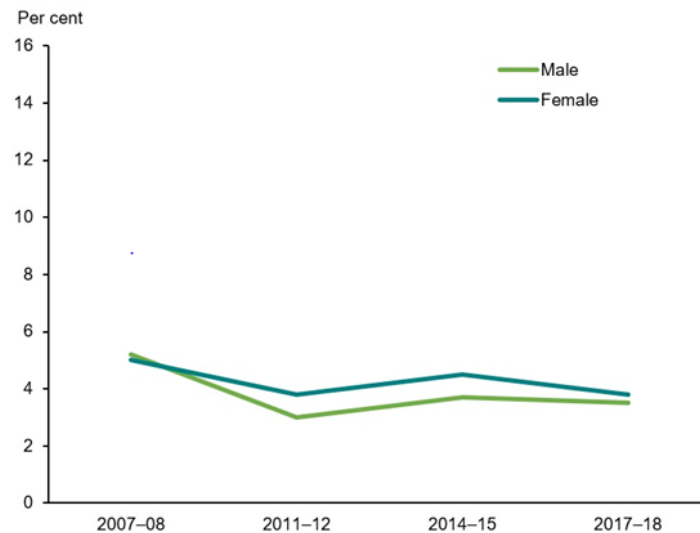
⁴⁶ Dirani et al, "Economic impact of primary open-angle glaucoma in Australia", 2011.

⁴⁷ Stuart Keel et al, "Prevalence of Glaucoma in the Australian National Eye Health Survey", *British Journal of Ophthalmology*, 2019.

⁴⁸ Keel et al, "Prevalence of Glaucoma", 2019. <https://pubmed.ncbi.nlm.nih.gov/29699984/> Accessed January 2023.



Figure Two: Percentage of the Australian Over-65 Population with Glaucoma, by Sex⁴⁹



Source: ABS 2009, ABS 2013, ABS 2016, ABS 2019a (Table 1.6).

Nonetheless, even if the rate of prevalence itself is not changing, the simple ageing of the population will lead to a peak number of patients with glaucoma in coming years.

From the latter study cited above – looking at the non-Indigenous community – a combined 53.4% of definite and probable glaucoma cases were previously diagnosed although only 7.4% of those undiagnosed met the threshold glaucoma indication of an intraocular pressure (IOP) of 21mm Hg and 50% had visited an optometrists or ophthalmologist in the past 12 months.⁵⁰ While the prevalence of glaucoma in Australia’s Aboriginal and Torres Strait Islander population is overall lower – potentially in part due to lower life expectancy and consequent ageing rates⁵¹ – the rate of underdiagnosis is greater, which indicates that solutions specific to this community are needed.

Even if delayed diagnosis is limited to the 7.4% of cases, this represents some 14,720 Australians who will have poorer outcomes from their glaucoma than they otherwise need to. In practice, the impact of this should be the same as diagnosis followed by non-compliance, which is discussed below.

⁴⁹ AIHW, “Eye Health”, February 2021, Figure 6.

⁵⁰ Australian Institute of Health and Welfare (AIHW), “Eye Health”, February 2021, Figure 6. <https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths/eye-health/overview> Accessed January 2023.

⁵¹ Australian Bureau of Statistics, “Aboriginal and Torres Strait Islander life expectancy lowest in remote and very remote areas”, 2018. <https://www.abs.gov.au/articles/aboriginal-and-torres-strait-islander-life-expectancy-lowest-remote-and-very-remote-areas> Accessed February 2023.



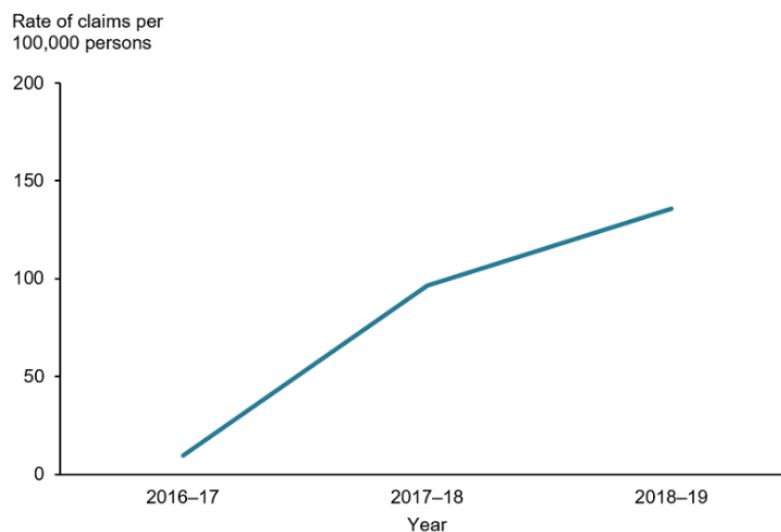
Direct Costs

Dirani et al estimated a series of costs to the health system from open-angle glaucoma in Australia. If the most common of these – topical eye medication – is considered, taking the median cost for a male aged 65-74 in 2011, the 2005 observed annual cost of \$1,297.40⁵² inflates to \$1,990.47 at end-2022.⁵³

If the observed 2005 costs of trabeculectomy at \$556.15 and trabeculectomy at \$3,436.39 are added to this, then the total 2005 per-patient cost of \$5,290.04 would have inflated to \$8,115.97 by 2022. This presumes no change in compliance, which would increase uptake of all treatments and increase costs.

Further, recent innovations show rapid uptake in the treatment of glaucoma, including in combination surgery in which cataracts are treated simultaneously with insertion of a trans-trabecular drainage device for patients who are either intolerant of or unresponsive to topical medication. This growth is demonstrated in Figure Three.

Figure Three: Incidence of Combination Cataract-Glaucoma Surgery⁵⁴



This treatment is covered by MBS item 42075 which has a standard benefit of \$722.40 and a bulk-billed benefit of \$870. Out-of-pocket fees charged to patients may increase this total cost.

What is important to note in relation to all direct health system costs is that these are priced on a ‘capacity to pay’ basis. This is where the Government compares potential expenditures to a standard measure – typically a quality-adjusted life year (QALY) – which values an extra year of normal life without disability or

⁵² Dirani et al, “Economic impact of primary open-angle glaucoma”.

⁵³ Reserve Bank of Australia, “Inflation Calculator”. <https://www.rba.gov.au/calculator/annualDecimal.html> Accessed February 2023.

⁵⁴ AIHW, “Eye Health”, February 2021.



debility at around \$50,000. This is called a ‘capacity to pay’ approach because it roughly equates to mean economic contribution across the population.⁵⁵

Whether this is the most appropriate measure for glaucoma is discussed below. However, the critical takeout is that any increase in direct health expenditure flowing from compliance is already nominally priced as fair value within the health system and is therefore at least a zero sum benefit. It is not a discount to any observed benefits from Glaucoma Australia’s Patient Support Program.

While an Australian cost per QALY gained is not available, evidence from the US is of USD29,600 per QALY gained for glaucoma patients who comply with their treatment.⁵⁶ This equates to AUD42,898⁵⁷ which is well within Australian QALY values and, given the relatively high cost of US healthcare compared to Australia, is likely an overestimate. This suggests room for greater investment in all areas of glaucoma treatment, including in supporting patients.

Sources of Benefit: Evidence

With an annual referral to the Patient Support Program of around 2,000 new patients, and at a total current expenditure of \$300,000, the nominal mean cost per patient is \$150. This reflects the value of capital already sunk into resource development. The question is whether this represents good value or, in other words, whether the benefits of increased compliance are greater than this.

The first thing to be said here is that there is a variety of evidence on the impact of compliance. Most positively, the Early Manifest Glaucoma Trial (2003) which included both topical treatment and trabeculoplasty showed 50% reduction in progression of the disease where patients were compliant with their treatment compared to the control.⁵⁸

Adding to this, direct comparison of treatment versus no treatment, there is evidence that even slightly attenuated compliance leads to poor outcomes. For example, Sleath et al (2011) showed that, in a randomised controlled trial of glaucoma sufferers – 93.1% of whom had bilateral glaucoma – even a 20% reduction in compliance led to more severe vision impairment for patients.⁵⁹ This study underscores the particular value of good early education on compliance and technique, which are key elements of Glaucoma Australia’s Patient Support Program. Similarly, other research shows that the greatest increase in adherence lies with reducing the difficulty patients experience with their eye drop regime.⁶⁰

⁵⁵ In practice, the continuing use of a \$50,000 QALY has not kept pace with growth in GDP per capita, even discounted for deadweight losses.

⁵⁶ Paula Anne Newman-Casey et al, “Cost Utility Analysis of Glaucoma Medication Adherence”, *Ophthalmology*, 2020. <https://pubmed.ncbi.nlm.nih.gov/31767436/> Accessed January 2023.

⁵⁷ AUD1 = USD0.69.

⁵⁸ M Christina Leske et al, “Factors for Glaucoma Progression and the Effect of Treatment: The Early Manifest Glaucoma Trial”, *JAMA Ophthalmology*, January 2003. <https://pubmed.ncbi.nlm.nih.gov/12523884/> Accessed January 2023.

⁵⁹ Betsy Sleath et al, “The Relationship between Glaucoma Medication Adherence, Eye Drop Technique, and Visual Field Defect Severity”, *Ophthalmology*, December 2012. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3223548/> Accessed January 2023.

⁶⁰ Julie F McClelland, Lynne Bodle & Julie-Anne Little, “Investigation of medication adherence and reasons for poor adherence in patients on long-term glaucoma treatment regimes”, *Patient Preference and Adherence*, 2019. <https://pubmed.ncbi.nlm.nih.gov/31496662/> Accessed January 2023.



The importance of technique should not be underestimated and studies demonstrate the value of having the treating specialist show correct application of eye drops.⁶¹ A key element of the Glaucoma Australia program is the provision of resources such as videos to support patients in the correct application of their topical treatments.

The psychology of this is fairly predictable. There is a strong correlation between not recognising the fact that reduced compliance leads to reduced vision over time and failing to comply with treatment. Better education and communication support patients in adherence.⁶²

This is complemented by evidence which shows the association between better patient education and reduced anxiety,⁶³ which suggests that understanding the benefits of compliance in reducing risk will lead to greater compliance. Better understanding of the condition is also associated with increased quality of life (QoL) relative to those with poorer engagement with the disease.⁶⁴

Early arrest of progression will help with compounding psychological effects of reduced vision. Not surprisingly, more severe vision impairment is associated with a higher incidence of depression.⁶⁵ Notably this is subjective as, particularly with newly-diagnosed patients, depression symptoms correlate with self-reported vision loss as opposed to clinically-measured reduction in sight.⁶⁶ It is only in severe glaucoma that deficits in self-perceived QoL more clearly align with reduced visual acuity.⁶⁷ This disparity appears to reflect a greater fear of blindness, which leads to further reduced QoL, and may be assisted through appropriate counseling and education.

The evidence from a Glaucoma Australia questionnaire, which shows that only 20% of patients have high anxiety after the Patient Support Program – compared to 44% without support – shows the valuable pathway to better engagement and compliance which the Program provides.

⁶¹ Betsy Sleath et al, "Ophthalmologist-Patient Communication, Self-efficacy, and Glaucoma Medication Adherence", *Ophthalmology*, April 2015. <https://pubmed.ncbi.nlm.nih.gov/25542521/> Accessed January 2023.

⁶² David S Friedman et al, "Doctor-Patient Communication, Health-Related Beliefs, and Adherence in Glaucoma: Results from the Glaucoma Adherence and Persistency Study", *Ophthalmology*, August 2008. <https://pubmed.ncbi.nlm.nih.gov/18321582/> Accessed January 2023.

⁶³ Simon E Skalicky et al, "Glaucoma Australia educational impact study: a randomized short-term clinical trial evaluating the association between glaucoma education and patient knowledge, anxiety and treatment satisfaction", *Clinical and Experimental Ophthalmology*, 2018. https://www.researchgate.net/publication/318320783_Glaucoma_Australia_educational_impact_study_a_randomized_short-term_clinical_trial_evaluating_the_association_between_glaucoma_education_and_patient_knowledge_anxiety_and_treatment_satisfaction_Glauco Accessed January 2023.

⁶⁴ Xiang Mei Kong et al, "Is glaucoma comprehension associated with psychological disturbance and vision-related quality of life for patients with glaucoma? A cross-sectional study", *BMJ Open*, May 24, 2014. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4039808/> Accessed January 2023.

⁶⁵ Simon Skalicky & Ivan Goldberg, "Depression and quality of life in patients with glaucoma: a cross-sectional analysis using the Geriatric Depression Scale-15, assessment of function related to vision, and the Glaucoma Quality of Life-15", *Journal of Glaucoma*, 2008. <https://pubmed.ncbi.nlm.nih.gov/18854731/> Accessed January 2023.

⁶⁶ Henry D Jampel et al, "Depression and mood indicators in newly diagnosed glaucoma patients", *American Journal of Ophthalmology*, August 2007. <https://pubmed.ncbi.nlm.nih.gov/17560843/> Accessed January 2023.

⁶⁷ Ivan Goldberg et al, "Assessing quality of life in patients with glaucoma using the Glaucoma Quality of Life-15 (GQL-15) questionnaire", *Journal of Glaucoma*, 2009. <https://pubmed.ncbi.nlm.nih.gov/19142128/> Accessed January 2023.



Importantly, a review of different approaches found that effective support should initially involve face-to-face education and counselling as the key to successful interventions that improve compliance.⁶⁸ However, studies have also shown that, without reinforcement, knowledge and engagement will be transitory⁶⁹ which is where the ongoing telephone, online and video services provided by Glaucoma Australia will support persistent, knowledge-based compliance.

Potential Savings

Estimating the potential savings from better compliance with glaucoma treatment is a complex challenge and depends on assumptions about the role of treatment compliance in arresting visual losses.

There are four sets of potential savings which are discussed below as follows:

1. Reduction in avoidable acute hospital services, for which the previously-cited 4-8 times greater risk of hip fracture is used as an exemplar;
2. Simple reduction in the rate of demand for increased treatment services and medicines for the disease;
3. Reduction in demand for residential aged care, or other aged care services; and
4. As a comparator, the costs of vision-related disability services under the NDIS.

These are all potentially avoidable costs to the health, ageing and disability care systems. They do not capture the total impact on the individual nor do they capture all economic losses, such as welfare payments for carers, or lost taxes through reduced employment.

These are discussed individually below.

Hip Fracture

In Australia, 93.2% of hip fractures are caused by falls.⁷⁰ It is axiomatic that significant reduction in vision will lead to an increase in the rate of falls thus the observed higher incidence of 4-8 times risk. While the absolute relative risk of hip fracture for patients with glaucoma is only 1.49,⁷¹ the following considers the risk for those with poorer visual acuity due to non-compliance with their treatment.

⁶⁸ Paula Anne Newman-Casey, Megan Dayno & Alan L Robin, "Systematic Review of Educational Interventions to Improve Glaucoma Medication Adherence: an update in 2015", *Expert Review in Ophthalmology*, 2016. <https://pubmed.ncbi.nlm.nih.gov/27134639/> Accessed January 2023.

⁶⁹ Anna T. Do et al, "Effectiveness of Glaucoma Counselling on Rates of Follow-up and Glaucoma Knowledge in a South Indian Population", *American Journal of Ophthalmology*, March 2016. <https://pubmed.ncbi.nlm.nih.gov/26705095/> Accessed January 2023.

⁷⁰ $\frac{16,300}{17,493}$ AIHW, "Hip fracture incidence and hospitalisations in Australia 2015–16", 2018, p.13.

<https://www.aihw.gov.au/reports/injury/hip-fracture-incidence-in-australia-2015-16/summary> Accessed January 2023.

⁷¹ Dirani et al, "Economic Impact of Open-Angle Glaucoma", p.626



The crude incidence of hip fracture in Australia for all persons over 45 is 199 per 100,000 (0.199%) although the rate increases with age to 1,800 per 100,000 persons by age 85.⁷²

The average cost of a hip fracture to the health system is approximately \$16,666.67.⁷³ This means that:

- Across the general population, the mean individual cost (incidence by price) in a given year is \$33.16; but,
- For those with vision impairment from glaucoma:
 - At a four times rate, this would be a mean of \$132.67; and,
 - At an eight times rate, it would be a mean of \$265.33.

Clearly, if the Glaucoma Australia Patient Support Program expenditure could be targeted only to those at risk, these data alone would make the program fiscally attractive.

In 2005, the estimated rate of visual impairment due to glaucoma as a primary cause in Australians over 55 years was 13.17%.⁷⁴ There is no clarity around duration of glaucoma here, but this figure can be nominally discounted by 10% to reflect an assumption about inevitable vision loss regardless of treatment. This leaves a residual of 11.86%. The question posed at this point is how much of this might be avoided by utilising the Patient Support Program. Here it is worth noting both that:

- Some patients, typically with higher levels of education and socio-economic circumstances, are likely to be fully compliant regardless of the program; whereas,
- Some patients, despite extensive investments in education and treatment will remain non-compliant. This particularly includes those with complex comorbidities such as dementia, mental illness and Parkinson's Disease. There are also non-compliance biases towards people of lower socio-economic status, and non-English speakers.

The difficulty here is in assessing how much incremental benefit accrues from education. Key data here are that participants in the Program have 85% medication adherence compared to 37% in the broader community of glaucoma patients. The counterpoint to this is non-adherence rates of 15% compared to 63%, which is a ratio of a little over 1:4.

The implication is that over 75% of non-adherence can be removed through programs such as Glaucoma Australia's Patient Support Program.

⁷² AIHW, "Hip fracture", p.9.

⁷³ = $\frac{\$350,000,000}{21,000}$ Australian Commission on Quality and Safety in Healthcare & IHPA, "Best practice pricing and clinical quality information on hip fracture care" https://www.safetyandquality.gov.au/sites/default/files/migrated/Best-practice-pricing-and-clinical-quality-information-on-hip-fracture-care-report_April-2016.pdf Accessed February 2023.

⁷⁴ = $\frac{14,400}{109,300}$ AIHW, "Vision problems among older Australians", July 2005, pp.1,13. <https://www.aihw.gov.au/reports/eye-health/vision-problems-in-older-australians/summary> Accessed January 2023.



What this suggests in terms of avoidable costs is that if non-adherence is regarded as the principal contributor to residual vision loss, this suggests that 9.04% of the total population of patients with glaucoma could have avoided their vision loss through accessing better counseling and support.

Compared to the risk of hip fracture:

- At the lower bound of four times, this gives predicted savings of \$11.99 *per annum*; and,
- At the upper bound, this doubles to \$23.98 each year.

It is important to note here that the price being used for Glaucoma Australia's Patient Support Program of \$150 is only for *newly-diagnosed* glaucoma patients. Longevity with the disease is important. While there is a range of data, one quoted conclusion is that average life expectancy after initial glaucoma diagnosis (all causes mortality for over-65s) is 12.8 years.⁷⁵ This would indicate respectively:

- An undiscounted value of \$153.45 at the lower bound for increased incidence; and,
- Again doubling, \$306.90 at eight times the average population rate.

Given the increase in incidence of both glaucoma and falls/hip fracture with age, these may well be underestimates of benefit.

Nonetheless these are very rough calculations and Evaluate notes that they are highly sensitive to the various assumptions made above. This section is principally offered as an illustration of what value might be available in only a single disease category from better management of glaucoma.

Ongoing Treatment Costs

Above, the inflated mean treatment costs of only glaucoma-related medicines and interventions is given as \$8,115.97. Of this total, \$1,990.47 is for medicine costs and the remainder \$5,290.04 for other glaucoma-related interventions.

A recent US study concludes that, in comparing mild to severe glaucoma:

- Pharmacy costs at the median were \$493 vs. \$139 or a factor of 3.55; and,
- Worsening of disease was associated with at least a doubling of the annual eye-related outpatient costs.⁷⁶

A note of caution is required here insofar as these are US claims costs and, as such, reflect a significantly different payment environment from that in Australia. Equally, some of the lower expenditure on mild glaucoma may reflect under-treatment or poor compliance, which would lead to progression in some cases.

⁷⁵ Tarun Sharma & John F Salmon, "Ten-year outcomes in newly diagnosed glaucoma patients: mortality and visual function", *British Journal of Ophthalmology*, 2007. <https://pubmed.ncbi.nlm.nih.gov/17475705/> Accessed January 2023.

⁷⁶ Vanessa Shih et al, "Clinical and Economic Burden of Glaucoma by Disease Severity: A United States Claims-Based Analysis", *Ophthalmology Glaucoma*, 2021. <https://pubmed.ncbi.nlm.nih.gov/33352292/> Accessed January 2023.



Nonetheless, if the real cost factor for progressed disease is presumed to be at least a doubling of costs, this indicates a mean cost in Australia for severe glaucoma of \$16,231.94 *per annum*. If the incremental difference is applied *only* to the 9.5% of glaucoma patients who experience avoidable residual vision loss, then the average increase in cost over the entire glaucoma population would be some \$771 *per annum*.

This clearly outstrips any cost associated with the Patient Support Program.

Again, there are significant data limits here and a detailed sample of expenditure data across Australian glaucoma patients would be required to comprehensively assess benefits in terms of avoided treatment costs.

Aged Care

The relative risk for nursing home – residential aged care placement – for older Australians with vision impairment is 1.8,⁷⁷ or 80% higher than for persons of similar age and circumstance who are not visually impaired.

The over-65 population lifetime risk of ever entering aged care significantly exceeds 50% at 50.5% for men and 58.0% for women⁷⁸ with an average duration of three years. Assuming that current pressures to expand home care reduce demand for residential care, it might be conservatively estimated that future demand will be 50% for people over 65.

If the relative risk for those with visual impairment is 1.8, then the incremental risk of aged care is 40% (total 90%) of three years. A modal annual cost of aged care of \$97,521.75 can be used, which represents the typical price of quartile 2 entry to a small facility.⁷⁹

This would make the expected increased cost of aged care for a person whose glaucoma has led to substantial vision loss of some \$117,026.10. Accounting for the 9.04% of patients who could avoid progression to serious vision loss, this would be distributed across all persons with glaucoma as \$10,579.15 across their post-65 years' life.

Again, these are blunt calculations but potential aged care costs dwarf the proposed expenditure on Glaucoma Australia's Patient Support Program.

⁷⁷ Jie Jin Wang et al, "Visual impairment and nursing home placement in older Australians: the Blue Mountains Eye Study", *Ophthalmic Epidemiology*, 2003. <https://www.tandfonline.com/doi/abs/10.1076/oep.10.1.3.13773> Accessed January 2023.

⁷⁸ Royal Commission into Aged Care Quality and Safety, "MEDIUM- AND LONG-TERM PRESSURES ON THE SYSTEM: THE CHANGING DEMOGRAPHICS AND DYNAMICS OF AGED CARE", 2019, p.21. <https://agedcare.royalcommission.gov.au/publications/background-paper-2-medium-and-long-term-pressures-system-changing-demographics-and-dynamics-aged-care> Accessed January 2023.

⁷⁹ Royal Commission Research Paper No.9 (University of Queensland), "The cost of residential aged care", August 2020, p.4. https://agedcare.royalcommission.gov.au/sites/default/files/2020-08/01_research_paper_9_-_cost_of_residential_aged_care.pdf Accessed January 2023.



Comparison with disability funding

Earlier in this paper, looking at direct healthcare costs, the principle of capacity to pay and the QALY were introduced. However, with the emergence of the NDIS, an alternative principle of willingness to pay has been embedded into the Australian health system.

This means that the NDIS, rather than comparing costs to alternative expenditures, simply enters the market to purchase what is required to meet the needs and wants of Australians with disabilities. Leaving aside emerging concerns about the fiscal impact of the NDIS, it is a strong expression of community willingness to tackle serious disability.

The mean cost of an NDIS package where vision loss is the primary source of disability is \$46,800. While this is lower than the average across all packages of \$72,000,⁸⁰ it is worth noting that this is an annual cost for what is expected to be many years in most cases and certainly for substantially longer than the average stay in residential aged care.

While glaucoma is predominantly a disease experienced by those aged over 65 and who are excluded from NDIS entry, what would have been funded where a person experiences earlier vision loss is substantially greater than any combination of aged care or carer benefits which would be available in later life.

The point here is that there is a comparative standard for funding the relief of vision loss which makes the cost of avoiding it – at \$150 per person – completely trivial. This is a strong argument for further investment for glaucoma education and compliance.

Conclusion and recommendations

While the data discussed above do not deliver a neat single return on investment for Glaucoma Australia's Patient Support Program, and some of the data and calculations are relatively makeshift, what can be concluded is:

1. On each of the four above comparators – hip fracture, ongoing treatment costs, aged care and disability funding – the expenditure significantly outstrips expected savings;
2. Even if the data are somewhat unclear, the scale of the costs which may be addressed by such modest expenditure easily justifies the investment; and
3. Again, given the scale differences, proposing a substantial increase in public expenditure in Glaucoma Australia's Patient Support Program to increase compliance rates would still be cost-effective.

The driver of all this is the significant reduction in non-adherence within the Program by a factor of marginally over 80%.

⁸⁰ NDIS-sourced data.



Consequently, increased investment in this program is recommended.

Finally, Evaluate would strongly recommend that a more detailed study of compliance investment in glaucoma in Australia be undertaken to obtain linear data to permit a proper cost-benefit analysis in the future. This would accord with similar efforts in other jurisdictions, to better identify the costs and benefits of various pathways to improvement.⁸¹ Evaluate would also recommend that ways to capture more reliable data about the prevalence of glaucoma in Australia be explored and implemented.

In particular, it is recommended that a forward study that track the following data points over one, five and 10 years:

- The baseline condition of entrants into the Glaucoma Australia program (current progression and estimated prior duration of the disease at referral);
- Comparative compliance rates between the GA referral group and a control sample of the Australian newly-diagnosed population at one and three years;
- Outcomes in terms of disease progression; and,
- Specific events, including hospital admissions and aged care referrals.

This will require detailed design as well as a comprehensive ethics approval. It will provide substantially more robust data than is currently available to this study.

Nonetheless, it remains clear that the Glaucoma Australia Patient Support program represents strong value on multiple fronts and expansion of its funding will have a positive return to Government, patients and the broader economy.

⁸¹ Inhae Park, Jesse Gale & Simon E Skalicky, "Health Economic Analysis in Glaucoma", *Journal of Glaucoma*, 2020.