



ANZSOG Case Program

Overturing a blind eye: closing the vision gap for Indigenous Australia (A)

2015-100.1

In 2008, Australia was the only OECD country where the preventable eye disease trachoma remained active in its population. Australia had been a leading player in the World Health Organization's successful campaign to eliminate trachoma around the world by 2020, and it was a hundred years since the disease had been seen in mainstream Australia. Yet in Aboriginal communities, children were still being infected, and adults blinded, at rates equal to the worst in the world. Numerous reports and governmental reviews had made little difference. But now Prime Minister Kevin Rudd had just made his historic apology in Parliament.¹ A new national agreement to improve Indigenous health outcomes, largely prompted by the 'Close the Gap' campaign, was pending. How could Hugh Taylor, Professor of Indigenous Eye Health at the University of Melbourne, capitalise on this political momentum to get the resources to eradicate trachoma in Australia, when so many eye health advocates (himself included) had failed before?

The persistent gap

Overall, Australia was a relatively healthy and wealthy country. In 2008, Australia's per capita Gross Domestic Product (GDP) ranked eighth in the world (2005 data), and it ranked fourth in the United Nation's Human Development Report. Seventy per cent of its population of 21 million lived in urban

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¹ One of Rudd's first major policy statements was to issue an official national apology in Parliament for the historical removal of Aboriginal children from their families, the so-called 'Stolen Generations'. See also ANZSOG case study 2009-104.1 *The road to sorry: Kevin Rudd's apology to the Stolen Generations*.

centres, mostly on the coast. The 2007 census identified 2.5% of Australians as Indigenous, approximately 520,000 people, of whom nearly 70% lived outside the capital cities (with 25% in remote areas).

The 'gap' to be closed between Aboriginal and mainstream Australians could be described in a number of ways. Many of them were detailed in the 2008 report *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples*.² Disparities between Indigenous and mainstream Australians could be found in average income (60% less), unemployment (three times higher) and earnings when employed (only 72% of the mainstream average). Indigenous people comprised 24% of the total Australian prisoner population, with incarceration rates thirteen times higher than mainstream Australians (up to twenty-one times higher in Western Australia, from 2007 data). Indigenous children were six times more likely to be involved with the child protection system. Their families were more likely to be living in overcrowded conditions, with poor access to services.

Among the most dramatic disparities were in health indicators and outcomes. The average Australian, with a life expectancy of 81.4 years, would be outlived only by the Japanese. By contrast, the life span of Indigenous Australian men was 67 years, 11.5 years less than mainstream males, and for Indigenous women 73 years, a gap of 9.7 years. These gaps were growing wider. Indigenous infants and children up to 14 years were twice as likely to die, although this gap was closing.³ Indigenous Australians were three times more likely to have diabetes, twice as likely to smoke, and twice as likely to be obese if female. They were hospitalised for potentially preventable illnesses at five times the rate of the mainstream population.

Yet they lived in a country that spent 9% of its GDP (\$86.9 billion per annum⁴) on health, compared to the 2005 OECD average of 8.4%.⁵ Australia's health system comprised funding, technical and implementation agencies across the nine federal, state and territory governments. It assured universal coverage or access to affordable health services, including subsidised pharmaceuticals.⁶ Almost all Indigenous health care was publicly funded through a complex range of multi-governmental channels, and delivered through 151 Aboriginal and Torres Strait Islander primary health care services.⁷

For every dollar spent on mainstream individuals, \$1.31 was spent on Indigenous Australians, and in total Indigenous health care consumed 3.3% of the national health budget. For governmental community support and welfare, 8.5% of total national spending went to Indigenous Australians. These figures lay against a backdrop of successive government policies, from the National Aboriginal Health Strategy of 1989 to the National Strategic Framework for Aboriginal and Torres Strait Islander Health 2003-2013 (*Exhibit 1* is a timeline).

In 2005, Aboriginal and Torres Strait Islander Social Justice Commissioner Tom Calma forcefully pointed out these differences. He initiated the 'Close the Gap' campaign, calling for all levels of Government to commit to achieving equality in Indigenous Australians' health and life expectancy by 2030. Only in 2008 did the Council of Australian Governments (COAG, the peak policy forum comprising federal, state and territory governments) endorse a National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes.

² Unless otherwise indicated, all statistical information is from Pink, B. and Albon, P. *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples*: 2008. Australian Bureau of Statistics and Australian Institute of Health and Welfare (hereafter Pink and Albon). Available from <http://www.aihw.gov.au/>

³ Pink and Albon.

⁴ All currency in Australian dollars (\$A).

⁵ OECD, *Society at a Glance: OECD Social Indicators*, OECD, Paris, 2005, pp75-76. Figures are based on 2002 data.

⁶ Pink and Albon.

⁷ Ibid.

Trachoma, a blinding disease of poverty

In some remote Aboriginal communities in 2008, rates of the treatable disease trachoma were equal to the worst in the developing world, with over 50% of children infected and 10% of adults blind, or at risk of going blind. Trachoma, caused by infection with *Chlamydia trachomatis*, was an ancient disease that remained the leading cause of infectious blindness globally. It was considered a disease of poverty, as it occurred in settings of poor access to water, poor hygiene, and overcrowding. Children typically carried active infection, which was transmitted to their carers, meaning that women suffered greater frequencies of blindness from repeated infections than men. Trachoma had been rife in the urban slums of Europe during the Industrial Revolution, and was probably introduced to Australia by early European settlers. Improved standards of living meant that trachoma disappeared from Australian cities and towns in the early 1900s. But as early as the 1950s, a pioneering English ophthalmologist Ida Mann identified that it had not been eradicated from Indigenous Australian populations, and argued that improved sanitation and housing was important to control it.

In 1999, the World Health Organization (WHO) launched the Vision 2020 campaign, its target the global elimination of trachoma using the 'SAFE Strategy'. The SAFE strategy had four interlocking components to deal with the different stages of trachoma: **S**urgery to correct eyelashes that scarred and blinded the eye; **A**ntibiotics (specifically azithromycin); **F**acial cleanliness; and **E**nvironmental improvement (to enhance access to water, hygiene, and living conditions) to interrupt the cycle of infection. Using the SAFE strategy, reinforced with funding and political support, countries such as Iran and Morocco had been able to eliminate the disease within seven years.

One of the designers of the SAFE strategy was Australian ophthalmologist Hugh Taylor, based at Johns Hopkins University in Baltimore, USA. Taylor was a globally recognised expert in public health ophthalmology, making contributions in trachoma, as well as the link between sunlight (UV-B light) and cataracts. He demonstrated that a drug could eradicate river blindness, a disease that afflicted over 100 million people in Africa and Latin America.

Superior sight but ten times the rate of blindness

As a trainee, working with famed ophthalmologist Fred Hollows, Hugh Taylor had taken part in Australia's first national survey of Indigenous eye health in the mid-1970s. The Commonwealth-funded National Trachoma and Eye Health Program examined over 100,000 Australians. The results, published in 1980, showed that Indigenous people had ten times the rates of blindness than the mainstream population, despite the fact that the best-ever recorded visual acuities were in healthy Aboriginal people without eye disease.^{8;9}

Hugh Taylor moved to the USA in 1977. The irascible Fred Hollows,¹⁰ a 'very noisy and prominent person', turned the findings of the national trachoma survey into hard-hitting television and newspaper articles: 'Even years later people remembered Fred.' Hollows called for a national body to coordinate activities. Facing opposition from the state governments, the Commonwealth eventually agreed to fund state trachoma committees. But political commitment and resources did not follow.

There were almost insurmountable problems, including a lack of technical knowledge about how to properly treat trachoma in the community. Available antibiotics were only partially effective, and

⁸ Royal Australian College of Ophthalmologists, *The National Trachoma and Eye Health Program of the Royal Australian College of Ophthalmologists*, Sydney, Royal Australian College of Ophthalmologists, 1980.

⁹ Taylor, HR, Prevalence and causes of blindness in Australian Aborigines, *Med J Aust* 1980, 1:71-76.

¹⁰ New Zealand-born and educated, graduate trained in the UK and then Professor of Ophthalmology at the University of New South Wales, Fred Hollows was the 1990 Australian of the Year, by which time most of his work was conducted overseas in developing countries. He died in 1993, still a vocal advocate for Indigenous eye health.

there were difficulties in getting people to use them twice-daily over three weeks. In addition, Hugh Taylor recalled:

The programs were rapidly devolved to the states, so the responses varied a lot and no one was held accountable. They put trachoma people or trachoma teams in place until 1997, but these were just visiting people with inadequate resources, no oversight and no real skills in terms of a systems approach. In the end, they were actually a block for taking activities to scale.

Taylor returned to Australia in 1989 to head the department of ophthalmology at the Royal Victorian Eye and Ear Hospital and University of Melbourne, where he had trained 20 years earlier. There he established the Centre for Eye Research Australia (CERA) as an independent medical research institute with an Australia-wide focus on population health and clinical epidemiology.

In 1997, 17 years after the National Trachoma and Eye Health Program report, the then Federal Minister of Health Dr Michael Wooldridge commissioned CERA to do a review of Indigenous eye health. In response to its findings, he promised to do 'whatever it takes'. Taylor's report opened by saying:

Despite the hard work and commitment of a number of individuals and organisations over the past ten to twenty years, the standards of Aboriginal eye health in some areas of our country remain appalling, and this seems inexcusable.

Rates of trachoma and blindness were essentially unchanged in remote communities, although they had improved in urban settings.

In 1998, Prime Minister John Howard announced that azithromycin (the antibiotic needed to treat trachoma) would be made available for children, although no provisions were made to identify needy communities, distribute the drug, or treat adults. As a result, there was negligible impact. The same year, the federal government initiated the National Aboriginal and Torres Strait Islander Eye Health Program to increase the available workforce and to enhance the necessary infrastructure. Regional Eye Health Coordinators were funded in primary health care settings, as was some ophthalmic equipment.

Again, an impossible task

Regional Eye Health Co-ordinators faced an impossible task. As a single person they were responsible for coordinating with hospitals, managing private ophthalmologists, and tracking patients through the clinic: all the many different tasks involved in a patient's journey to getting appropriate eye care.

Policy changes introduced in 1996 allowed Aboriginal medical services to bill through Medicare directly. This led to a significant increase in the resources flowing to them – approximately a three-fold increase over two years – but did not translate to enhanced eye care largely because there was no clear plan against which to work. Hugh Taylor recalled:

There was lots of competition between [Indigenous] health priorities – especially diabetes and chronic renal failure, but also otitis media and rheumatic heart disease. At the same time, primary health care people were pushing for a greater focus on primary health care – and they didn't see how eyes – or especially how trachoma – fitted in. We heard lots of what we came to call the 'False Reasons' (*Exhibit 4*) why trachoma wasn't a priority.

By 2003, even while Australia was championing the Vision2020 action plan against trachoma internationally at the World Health Assembly, domestically the situation for Aboriginal eye health showed no significant improvement. A review of the program called for changes in funding and better integration of eye care in primary health care services. As Taylor described it, the review 'gave Aboriginal medical services global budgets to use at their discretion. Some centres kept an eye health role, but many redirected funds so there was no longer formalised eye care coordination.'

During the 2004 election, the opposition Labor Party had pledged to fund a program against trachoma as part of its unsuccessful election campaign. Whilst the Liberal National Coalition government made no commitments on Indigenous health, after the election the Federal Minister of Health Tony Abbott allocated \$940,000 over three years for trachoma. Half of this was to establish a National Trachoma Surveillance and Reporting Unit (NTSRU, launched in 2006) and the rest to the three most affected states and territory for implementation (effectively \$50,000 per jurisdiction per annum).

Even after this, only fragmented regional programs against trachoma were being conducted by publicly funded public health services and Aboriginal controlled health services. Different jurisdictions had different programs, despite national treatment guidelines.

It was now clear how difficult it could be, even for mainstream eye health, to get political sights set on an effective program, with resources and accountability. CERA had conducted the first representative epidemiological survey of the burden of eye disease and its distribution across Australia. In partnership with consulting firm Access Economics, CERA developed what was at the time a ground-breaking analysis of the cost to society of preventable vision loss: \$9.85 billion annually.

An eye health framework for all Australians

The CERA/Access Economics partnership developed a framework to strengthen eye health care. This was estimated to potentially save over \$650 million, for the cost of only \$1.9 million over two years. With the support of key stakeholders, CERA presented a case for action. The federal and state governments adopted a National Eye Health Framework in 2005 to improve eye health in mainstream communities.¹¹ The Framework provided a precedent for nationally coordinated action to promote eye health, but lacked plans for implementation or accountability targets beyond annual reporting. The Framework would be cut short following the 2007 change of government.

Overall, some progress was being made, as Taylor observed:

Most of the costs from vision loss were indirect costs, and the benefits came from downstream savings through increasing access to and use of services. That was enough to get us on the political agenda, but not enough to get a program with teeth.

In 2006 Hugh Taylor took a sabbatical at Cambridge University to research and write a definitive textbook on trachoma.¹² The pause gave him time to reflect on what he hoped to achieve next:

I thought we had mainstream eye health on the right track. For international prevention of blindness there were lots of people who were doing a good job. But looking at Indigenous eye health in Australia, it was essentially going nowhere – so that's where I could make a real difference.

¹¹ The Framework's full title was the National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss.

¹² Taylor, HR, *Trachoma: A Blinding Scourge from the Bronze Age to the Twenty-first Century*, Haddington Press, 2008.

Exhibit 1: Eye Health Timeline to 2006

Further detail is available in Jones J, Henderson G, Poroch N, et al. 'A Critical History of Indigenous Eye Health Policy-Making Towards Effective System Reform'. IEHU 2011. Available:

http://iehu.unimelb.edu.au/publications/iehu_reports/a_critical_history

Year	Event
1971	First Aboriginal Community Controlled Health Service established in Redfern in Sydney.
1974	Australia introduces universal health coverage, initially through Medibank and from 1983 expanded under Medicare.
1975	Visiting Optometrists Scheme launched to provide optometric services to rural and remote Indigenous communities.
1976-1979	National Trachoma and Eye Health Program (NTEHP) led by Fred Hollows conducts first national survey of Indigenous eye health.
1980	NTEHP launches its report.
1989	National Aboriginal Health Strategy (NAHS) calls for Indigenous community control and participation of Indigenous medical services.
1992	Hugh Taylor initiates Melbourne Visual Impairment Program (1992-1996). Fred Hollows Foundation (FHF) established.
1993	Fred Hollows dies.
1994	Commonwealth review finds that NAHS was not effectively implemented.
1996	Aboriginal medical services allowed to bulk bill through Medicare.
1997	Taylor conducts National Review of Indigenous Eye Health for Minister of Health, Michael Woolridge.
1998	Howard Government approves Azithromycin to treat trachoma in children and launches National Aboriginal and Torres Strait Inlander Eye Health Program with funding for Regional Eye Health Coordinators. World Health Organisation (WHO) adopts Global Elimination of Trachoma (GET), including 'SAFE' strategy to combat trachoma and commits to eliminate blinding trachoma by 2020. Taylor initiates SAFE strategy trial in Central Australia Lands (1998-2001).
1999	WHO launches Vision 2020 globally.
2000	Vision 2020 Australia launched to advocate for improved eye health nationwide.
2003	WHO World Health Assembly, with strong advocacy from Australia, endorses VISION 2020 action plan to eliminate avoidable blindness (including trachoma) by 2020. Review of Aboriginal medical services.
2004	Minister of Health, Tony Abbott allocates \$940,000 for National Trachoma Surveillance and Research Unit and eye health programs in States/Territories.
2005	National Framework for Action to Promote Eye Health and prevent Avoidable Blindness and Vision Loss adopted by Commonwealth and States.

Exhibit 2: Key background

Current Status of Indigenous Eye Health

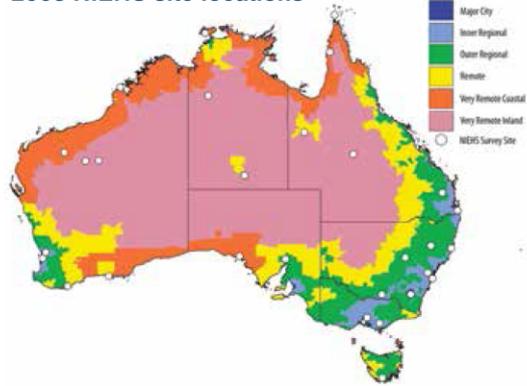
The 2008 National Indigenous Eye Health Survey determined the magnitude, distribution and causes of vision loss in Aboriginal and Torres Strait Islander people.

It examined 1694 children (5 – 15 years) and 1189 adults (40 years and over) in 30 sites across the country.

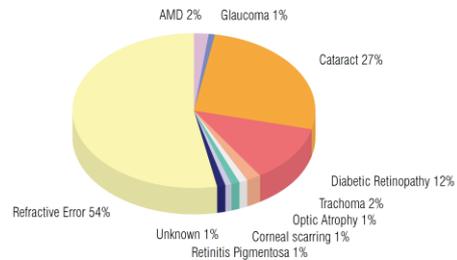
Indigenous children
> better vision than mainstream

Indigenous adults
> 6 times as much blindness
> 94% of vision loss was unnecessary and is preventable or treatable

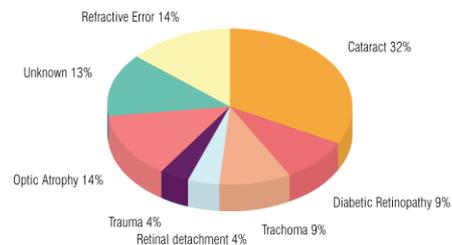
2008 NIEHS site locations



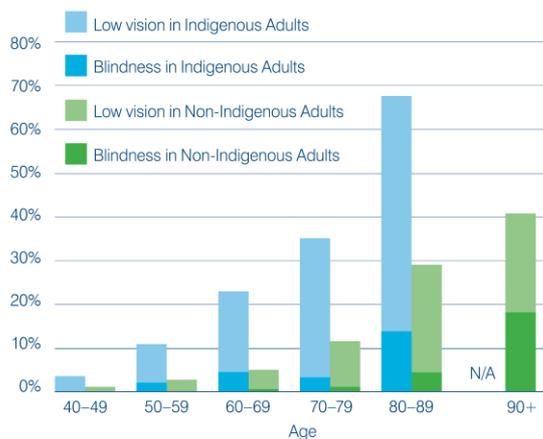
Low Vision (<6/12) in Indigenous Adults



Blindness (<6/60) in Indigenous Adults



Vision Loss in Adults



Crude Prevalence Rates of Vision Loss in Indigenous Australians

State	Children		Adults		Regions	Children		Adults	
	Low Vision	Blindness	Low Vision	Blindness		Low Vision	Blindness	Low Vision	Blindness
NSW	3.3%	0.4%	5.7%	2.4%	Major City	4.5%	0.6%	7.7%	2.6%
NT	0.8%	0%	9.1%	3%	Inner Regional	2.6%	0%	7.8%	2.4%
QLD	0.9%	0.3%	11.6%	0.4%	Outer Regional	1.5%	0%	6.6%	0.6%
SA	0%	0%	9.3%	1.6%	Remote	0.9%	0%	10.2%	0.8%
TAS	0%	0%	4.7%	0%	Very Remote Coastal	1.1%	0.3%	9.5%	1.1%
VIC	0%	0%	6.9%	6.9%	Very Remote Inland	0.3%	0.3%	12.7%	3.9%
WA	1.9%	0.2%	12%	1.8%	TOTAL	1.5%	0.2%	9.4%	1.9%

Rates of vision loss do not show significant jurisdictional or regional variation – the need for eye care is nationwide

Source: University of Melbourne, April 2013, *The Roadmap to Close the Gap for Vision – Summary Report 2013 April* (page 2), accessed 17 June 2015

[http://iehu.unimelb.edu.au/_data/assets/pdf_file/0003/783912/The Roadmap to Close the Gap for Vision - Summary Report 2013 April.pdf](http://iehu.unimelb.edu.au/_data/assets/pdf_file/0003/783912/The_Roadmap_to_Close_the_Gap_for_Vision_-_Summary_Report_2013_April.pdf)

Exhibit 3:

Trachoma

- > Trachoma is a major blinding infectious eye disease
- > It occurs in areas with poor hygiene and living conditions
- > Australia is the only developed country to still have Trachoma
- > Blinding endemic Trachoma occurs in 60% of outback communities
- > Late scarring and in-turned eyelashes (trichiasis) affects 1.4% of older Indigenous people across the country
- > Trachoma is still the fourth leading cause of blindness

The National Trachoma Surveillance and Reporting Unit (NTSRU) has collected data since 2006

Data collection is still far from complete
 Not all at-risk communities have been examined
 Endemic areas need to be mapped fully

The SAFE Strategy is not fully implemented

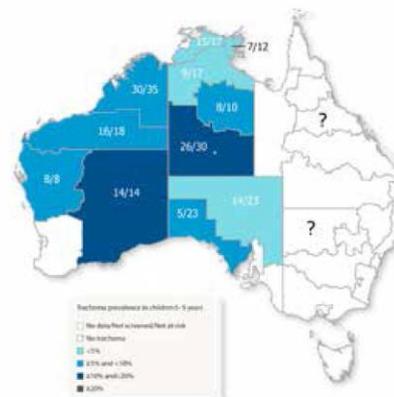
Trachoma screening is often incomplete
 Trichiasis screening is often forgotten
 Treatment is often not given
 Clean faces campaign and health promotion is incomplete

Trachoma can be prevented with WHO's SAFE Strategy:

- S**urgery for trichiasis
- A**ntibiotic (Azithromycin) treatment
- F**acial cleanliness and
- E**nvironmental improvements

WHO and all Governments including Australia have committed to the Global Elimination of Trachoma by 2020 (GET 2020).

Trachoma Prevalence in Indigenous Children



Trachoma prevalence in children aged 5-9 years and number of communities screened/ number of at risk communities in 2011

Reprinted from 2011 Report of NTSRU



Regional education and health promotion material

Source: University of Melbourne, April 2013, *The Roadmap to Close the Gap for Vision – Summary Report 2013 April* (page 6), accessed 17 June 2015

[http://iehu.unimelb.edu.au/_data/assets/pdf_file/0003/783912/The Roadmap to Close the Gap for Vision - Summary Report 2013 April.pdf](http://iehu.unimelb.edu.au/_data/assets/pdf_file/0003/783912/The_Roadmap_to_Close_the_Gap_for_Vision_-_Summary_Report_2013_April.pdf)

Exhibit 4:

Nine False Reasons for Not Addressing Blindness

Vision loss is not important in Indigenous communities:

- > Vision loss is the equal third leading cause of the Gap in health after heart disease and diabetes but ahead of trauma, stroke and alcoholism. Indigenous adults have six times more blindness than mainstream.

Blindness does not kill people – we need to address the life threatening things:

- > Even mild vision loss (<6/12) increases the risk of dying 2.6 times in mainstream Australia. Vision loss from Trachoma in African communities increases the risk of dying by 6.8 times. Mild vision loss prevents independent healthy living.

Eye care is body part medicine, it is not holistic:

- > The patient's journey for eye care starts in properly developed, comprehensive primary health care and requires seamless linkage with specialist services. Lessons learnt from integrating specialist eye care visits will inform ways to improve the linkage of primary care and specialist care.

There are many other more pressing priorities than eye care:

- > It is true that there are many health priority areas but 94% of vision loss is unnecessary and much of it can be rapidly reversed. A pair of glasses or Cataract surgery can eliminate vision loss overnight, whereas other chronic diseases (diabetes, heart disease, alcoholism) cannot be reversed overnight.

It is not worth spending the money on eye care, it is too expensive:

- > In fact, eye care is extraordinarily cost effective, for example Cataract surgery costs \$3,000 per QALY and Diabetic Retinopathy examinations \$15,000 per QALY. In Australia, each \$1 spent on eye care yields a \$5 return.

We are already spending too much on Aboriginal health and the money is wasted:

- > It is true we now spend \$1.39 on Indigenous health for each \$1 spent on mainstream. (A decade ago it was \$0.80 for Indigenous health). As there is three times the morbidity (and vision loss), one would expect to spend at least three times as much even if delivery costs to remote areas were not higher than urban areas. In terms of Cataract surgery, seven times less surgery is done for Indigenous people.

There are not enough specialists to provide the care required:

- > The actual increase in the number of optometric and ophthalmic services required is quite small and with the appropriate co-ordination and resources, many specialists are willing to take on this work.

This plan or roadmap is too complex, it is not all necessary:

- > Over the last 30 or so years multiple proposals have been made to address Indigenous eye health. None have worked properly as they overlooked different criteria. This roadmap has been based on a careful review, new evidence and wide consultations. Each element is interlocked forming an integral chain. It will also provide a template for the delivery of other specialist services to primary care services.

There is no more money to spend on Indigenous health:

- > With a relatively small increase in expenditure, there will be a huge increase in efficiency and reduction in waste for Indigenous eye health services. A doubling in funding will increase glasses use by 2.5 times, diabetes eye exams by 5 times and Cataract surgery by 7 times.

Source: University of Melbourne, April 2013, *The Roadmap to Close the Gap for Vision – Summary Report 2013 April* (page 9), accessed 17 June 2015

http://iehu.unimelb.edu.au/_data/assets/pdf_file/0003/783912/The_Roadmap_to_Close_the_Gap_for_Vision_-_Summary_Report_2013_April.pdf