



ANZSOG Case Program

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

2015-100.3

In February 2011, three years into the five-year life of the Indigenous Eye Health Unit (IEHU), Professor Hugh Taylor could report significant progress with its mandate to close one of the most significant gaps between Indigenous and mainstream Australians – eye health, especially the incidence of preventable blindness. As he told the IEHU advisory board, the unit's research had identified and mapped out the weaknesses in the health system that compromised Indigenous eye health services.

Drilling down to the needs of individual communities, they documented:

- the existing burden of eye disease;
- the current levels of access to eye health services;
- the projected needs to achieve adequate service delivery;
- the costs of eye health systems strengthening; and
- a comprehensive implementation plan with identified roles, responsibilities and accountabilities over time (now officially known as the *Road Map to Close the Vision Gap*) (see *Exhibits* for key results). The plan had gained broad-based support through the advocacy efforts of the IEHU.

The IEHU had identified 42 steps where patients could 'leak' from services (*Exhibit 1*). Reducing the risk of losing touch with patients during their eye care pathways would require significantly better coordination across primary to tertiary levels of eye services, across Commonwealth and state

This case has been written by Dr Kate Taylor, University of Melbourne for Professor Rob Moodie, University of Melbourne, with editorial assistance from Janet Tyson, Australia and New Zealand School of Government. It has been prepared as a basis for class discussion rather than to illustrate either effective or ineffective handling of a managerial situation. The assistance of Professor Hugh Taylor and board members of the Indigenous Eye Health Unit is greatly appreciated, but responsibility for the final content rests with ANZSOG. Version 17-06-2015.

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delivery systems, and across different eye-related specialities and other clinical settings. Full implementation of these goals, along with evaluation and the application of the research to other areas, would likely be costly and take a number of years – well beyond Taylor’s initial five years of funding.

The next hurdle approached: at least three or four years’ new funding would be needed, and there was no obvious source. The IEHU had been established when philanthropist Harold Mitchell challenged the University of Melbourne to match his donation of \$1 million a year for five years. The University not only took up the challenge but also housed the new unit, enabling the IEHU to quickly become active, and to attract additional donations. The key issues now were deciding between continuity in private philanthropy or seeking out new public funds. How to make the case to potential donors? Just as importantly, could the IEHU continue to serve as an effective advocate for action and accountability if it took government money?

Arguably, the IEHU had been able to achieve as much as it had because it had benefited from significant private funding. As well as enabling the unit to be an outspoken advocate for eye health, the flexibility of private funding had allowed the IEHU to shape and refine the implementation plan as new findings and evidence emerged.

Taylor and his board had always drawn a clear distinction between the funding of the Unit’s activities and programmatic funding to be sought from the government. They agreed that private donations couldn’t – and shouldn’t – be sought for implementation of a national program. This was seen as important both for sustainability and recognising the government’s moral responsibility to make health care available for all of its citizens. As Taylor explained: ‘Sustainable funding means it has to come from the usual budgets. Also, the scale of a national program requires the support of government – not only for funding but to ensure adoption’.

The Federal Government, and to a lesser extent the state governments, funded the vast majority of biomedical and public health research in Australia. However, there had also had been a history of significant private benefaction, predominantly towards hospital and research facilities, with buildings and even entire institutes bearing the names of donors.

The impact of private financing and philanthropy in Australia

With the recent success of the Australian economy, Australia’s wealthiest people had grown significantly richer. From the most recent statistics, the wealthiest 200 Australians had seen their worth increase by nearly 30% to \$128.6 billion between 2006 and 2007. The top 200 families had an average net worth of over \$600 million each.¹

Overall, however, wealthy Australians gave significantly less than their well-off peers in other OECD countries. In their 2007 World Wealth Report, financial consultants Merrill Lynch/CapGemini estimated that globally, high net worth individuals typically donated between 3% and 12% of their wealth annually.² Billionaires such as Bill and Melinda Gates and Warren Buffett were building on Buffett’s \$31 billion commitment to the Gates Foundation in 2006 by calling for the Giving Pledge in 2010. The Giving Pledge was a public commitment made by the world’s wealthiest people to give the majority of their riches to philanthropy, either before or after their deaths.³

¹ Madden, K. and Scaife W. *Good Times and Philanthropy: Giving by Australia’s Affluent*, Australia Centre for Philanthropy and Nonprofit Studies, 2008. (hereafter Madden and Scaife) Available from: http://www.petrefoundation.org.au/docs/CPNS_Good_Times_and_Philanthropy_Report.pdf accessed 15 May 2013.

² Merrill Lynch/CapGemini 2007.

³ For more information, see <http://givingpledge.org/>

In contrast, statistics from the Australian Tax Office showed that of the 8000 Australians who earned over \$1 million per year, over a third did not make a claim for tax deduction for charitable giving.⁴ While 87% of Australians reported making a donation, the majority were small donations, with an average value of in 2004 of \$424.⁵ In 2005, the donations of the 4500 highest net worth Australians with taxable incomes over \$1 million gave \$177 million, averaging about \$59,350 per person or 1.98% of their taxable income (*Exhibit 2*).⁶

Even in Australia, it was recognised that when donors did give, they could make a significant impact: 'Above others, the affluent hold the key to non-profit ventures that really make a difference in the wider community. They have the wealth to make transformational donations. However, their influence exceeds financial support. They are opinion leaders and trend-setters for the rest of the community.'⁷

IEHU Advisory Board member Prof John Funder described Harold Mitchell's donation as 'a classic case of enlightened investment by a philanthropist - his million dollars over five years triggered another twenty million'.

Hugh Taylor felt many aspects of the current governance and funding arrangements had contributed to the effectiveness of the IEHU. This included not only medical, political and fundraising expertise, but also contacts with key stakeholders. Building on relationships that were forged in the 1970s while working with Fred Hollows, there was extensive consultation with leaders from the Indigenous community-controlled health sector whose support was critical.

Governor-General Quentin Bryce gave the project further momentum when she agreed to launch the report of the National Indigenous Eye Health Survey, which took place in September 2009 at the Koori National Heritage Centre, Melbourne.⁸ The communications strategy developed between public relations firm Haystac and Melbourne University (referred to in *Part B* of this case) worked well, generating extensive television, radio and newspaper coverage.

Communication about the plan to close the Vision Gap was further backed up with targeted outreach to experts and decision makers. A series of three large consultations were planned for 2010, as well as scores of meetings with bureaucrats, politicians and technical experts at local, state and federal levels.

Despite these successes, bigger picture issues had impeded momentum. In principle, national health reform proposals to have primary care and hospitals better linked at the regional level should have been entirely consistent with what the IEHU was proposing for eye health services. Taylor reflected:

It should have been an opportunity to get things implemented, but [the political stalemate that developed] intervened. The hung Parliament⁹ also brought so many distractions; it made it really hard for people to focus on issues, even those with bipartisan support. But it was the GFC [Global Financial Crisis] that really screwed up everything. We hoped for \$70 million to implement the Indigenous Eye Health Roadmap – but the Government was trying to cut money from everything.

⁴ <http://www.smh.com.au/business/philanthropy-is-big-business--except-in-corporate-australia-20110603-1fktm.html#ixzz2Qm4ShiuE>

⁵ Madden and Scaife, op cit.

⁶ McGregor-Lowndes and Newton (2007) cited in Madden and Scaife.

⁷ Madden and Scaife, p. 1.

⁸ <http://www.abc.net.au/news/2009-09-29/scandalous-blindness-rates-can-be-reduced/1445854>

⁹ The 2010 Australian federal election resulted in a 'hung parliament', where none of the major parties had an absolute majority to form a government. The minority Gillard Labor Government was subsequently formed with the support of the Australian Greens and three independents.

Trachoma treatment trial shows the way

Another IEHU project that had secured private funding was a demonstration that the SAFE strategy for treatment and prevention of trachoma could be effectively implemented at scale with appropriate funding and resources; not only for trachoma but for Indigenous eye health in general. The trial, funded by the Christian Blind Mission and philanthropists David Middleton and (later) Greg Poche, began in 2009 and almost immediately had an impact. Operating at five sites in the Katherine region of remote Western Australia, the trial showed that the treatment strategy was highly effective in significantly reducing the incidence of the disease.

In August 2010, the Minister for Indigenous Health, Warren Snowdon, visited the settlement of Katherine to launch the IEHU-developed Trachoma Story kits. These were funded under the Federal Government's \$16 million Trachoma program announced in 2009. The kits included technical information, posters, flip charts, DVDs and other materials.¹⁰ 'Stars' of the program included Milpa, the trachoma goanna (*Exhibit 4*), and Imparja, the Aboriginal Television station in Alice Springs. After several approaches by Taylor to the leadership of the Melbourne Football Club, further celebrity support was secured in 2010 with their assistance. By September, leading Aboriginal players Liam Jurrah and Aaron Davey had filmed a promotional message to accompany the trachoma kits and made various appearances in communities.

By 2011, Taylor had established the evidence base and case for action, not only for trachoma, but for Indigenous eye health in general. He had *The Roadmap to Close the Gap for Vision*, with broad based technical, implementer and political support, and had some initial commitment at state and federal levels to implement it. But the IEHU's funding would expire before the work could be achieved. He explained:

I thought we were doing such a good job that we would get more money from our existing donors. Our plan was to continue business as usual. We were worried that without continued support and pressure, implementation would falter. But the Harold Mitchell Foundation and Poche Foundation understandably wanted to move on to other priorities, to other projects. They offered to help us with introductions to other donors, if we wanted. So we had to rethink.

¹⁰ Available on the website www.iehu.unimelb.edu.au.

Postscript

Taylor successfully raised funds to continue the activities of the IEHU from a range of sources. His original donors, especially Harold Mitchell and his Foundation's Executive Director Stephanie Copus-Campbell, were active in making introductions to new private philanthropists. As a result, two new supporters came on board (an anonymous donor and Gandel Philanthropy). Two existing donors, the Potter Foundation and Christian Blind Mission, contributed additional funds.

Taylor also applied for \$750,000 over three years from the Commonwealth Government and was successful. He explains: 'It was the right time for the Federal Government to come on board – while their financial support is important, their imprimatur and the access to people inside key government departments would really boost implementation'.

There remained more to be done, however. The IEHU's 2013 update identified a number of issues including:

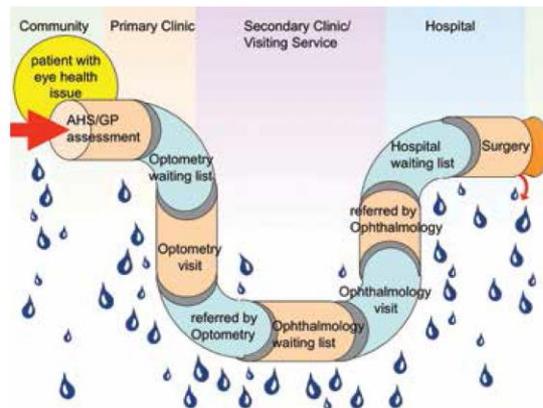
- Commonwealth funding was committed only through mid-2013.
- \$17.4 million was required to continue the implementation of the SAFE strategy against trachoma through 2016.
- \$5.4 million in additional funding was required for surveillance for 2017-2020 to demonstrate the elimination of trachoma from Australia.

Exhibit 1: the Patient Journey

The Patient Journey

Successful eye health outcomes involve co-ordination of both eye care services and the patient journey

The referral pathway is a leaky pipe with a blockage at its end
 It is often very inefficient and wasteful of services
 Many people drop out
 Because of this, others do not enter



Levels of Co-ordination

Community

- > Community liaison provides a vital link between individual community members, their families and the clinic and its services
- > This may include identification, transport, interpretation, translation and moral support

Clinic, Primary Eye Care

- > Referral of more complex cases to visiting eye team
- > Maintenance of patient records and referral lists for visiting eye team
- > Scheduling of visits by visiting eye teams
- > Co-ordination with other visiting specialists
- > Co-ordination of exam rooms, accommodation, equipment and local staff
- > Make arrangements for referrals to Regional Hospital
- > Schedule follow up visits as required

Eye Team, Secondary Eye Care

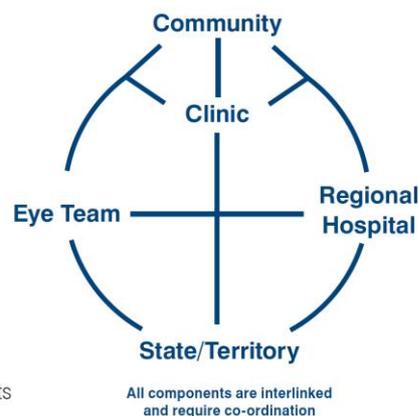
- > Co-ordination of visits with clinic and community
- > Update patient records as necessary
- > Communication and co-ordination between visiting optometrists and ophthalmologists
- > Mechanism for communication and co-ordination with other visiting specialists
- > Specific equipment items brought with team (e.g. lasers, slit lamp)
- > Organise a list/ information about patients waiting to be seen
- > Assistance with patient identification, transport, translation, explanation and support
- > Clerical support for forms and paper work
- > Referral systems for further management or surgery

Regional Hospital, Tertiary Eye Care

- > Organisation of the clinic space, theatre time, staff, accommodation, travel and surgical supplies for the visiting eye teams
- > Co-ordination with other visiting specialists
- > Organisation and supply of surgical equipment
- > Co-ordination of patients who require surgery with community and clinic
- > Organisation of travel and other arrangements for patients

National/State/Territory

- > Co-ordination of other specialist and allied health visits with the visiting eye team
- > Oversight of co-ordination performed at different levels, recruitment, training and support
- > Oversight of distribution of visiting eye teams (and other specialists) including ratio of optometric and ophthalmic visits and frequency of visits

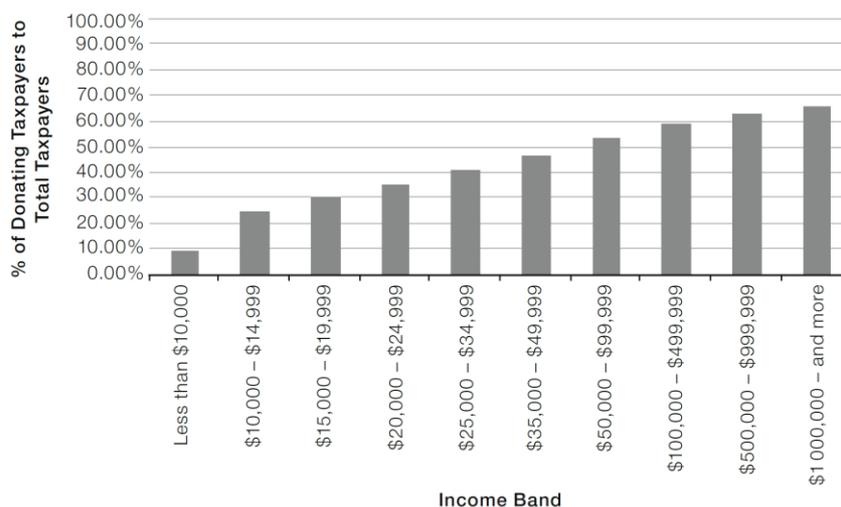


Source: University of Melbourne, April 2013, *The Roadmap to Close the Gap for Vision – Summary Report 2013 April* (page 5), accessed 17 June 2015

[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 2:

CHART 8: PERCENTAGE OF DONATING TAXPAYERS TO TOTAL TAXPAYERS BY INCOME BAND IN AUSTRALIA 2004-05



Source: McGregor-Lowndes & Newton, 2007

TABLE 4: BLACKSPOTS IN GIVING BY AUSTRALIA'S AFFLUENT POPULATION

Taxable Income	Non Donor Rate (% of total affluent group not claiming charitable donations)	Donor Level (% taxable income claimed as donations)
Upper (\$1m+)	Almost 30%	–
Mid (\$500k+)	Almost 40%	0.78%
Lower (\$100k+)	Over 40%	0.45%

Source: Developed for this report drawing on ATO tax statistics for 2005-06

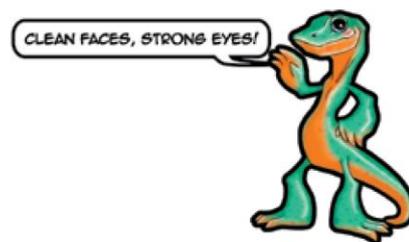
Source: Queensland University of Technology, March 2008, *Good times and Philanthropy* (pages 27 and 11 respectively), accessed 17 June 2015

[http://eprints.qut.edu.au/27262/1/Good Times and Philanthropy Giving By Australias Affluent March 2008.pdf](http://eprints.qut.edu.au/27262/1/Good_Times_and_Philanthropy_Giving_By_Australias_Affluent_March_2008.pdf)

Exhibit 3: IEHU's donors

Year of first donation	Donor	Amount (\$)	Purpose
2008	Harold Mitchell Foundation	200,000 per annum (p.a.) over 2008-12	Harold Mitchell Chair in Indigenous Eye Health
2008	University of Melbourne	200,000 p.a. over 2008-12 then 200,000 p.a. for 2013-15	Operations of the IEHU
2008	Ian Potter Foundation	200,000 p.a. over 2008-12 then 200,000 p.a. over 2013-16	IEHU activities: mapping eye health service utilisation; GEM; policy history of Indigenous eye health
2008	Private donors	<ul style="list-style-type: none"> • 50,000 p.a. over 2008-10 then 10,000 in 2011 • 50,000 p.a. over 2009-11 • 40,000 p.a. over 2008-11 • and others 	Trachoma elimination activities
2009	Greg Poche	500,00 p.a. over 2009-10	Four Poche Fellows to support research activities
2008	Cybec Foundation	30,000 p.a. over 2008-9 then 50,000 p.a. over 2013-15	Support of IEHU researchers
2011	Anonymous donor	900,000	IEHU operations
2012	Vision Cooperative Research Centre	120,000 p.a. over 2012-13	Roadmap implementation
2013	Christian Blind Mission Australia	25,000 in 2009 then 60,000 p.a. for 5 years	Trachoma elimination and health promotion programs
2013	Commonwealth Department of Health and Ageing	923,000	Roadmap implementation and trachoma health promotion
2013	Gandel Philanthropy	100,000	IEHU operations
2013	Anonymous donor	500,000	IEHU operations

Exhibit 4: 'Clean faces, strong eyes'



Milpa
The Trachoma Goanna

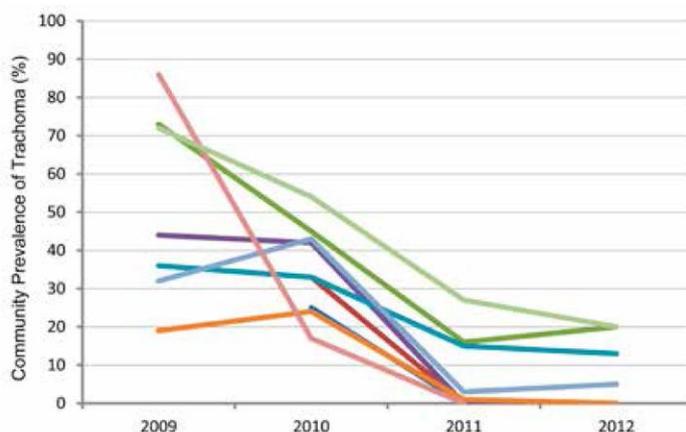
In 2009 the Australian Government committed to eliminate Trachoma in Australia

Current Activities:

- > Prime Minister Rudd committed \$16m (2009-2013) to start the elimination of Trachoma
- > Implementation could have been faster, but once started great progress has been made, especially in the Northern Territory and Western Australia
- > More communities have been screened
- > More children have been examined
- > Treatment coverage has improved
- > Health education materials have been widely used
- > "Clean faces, strong eyes" campaign is underway
- > AND Trachoma rates are starting to fall

When the SAFE Strategy is properly implemented Trachoma rates show marked declines

Community prevalence of active trachoma in one region in the Northern Territory (de-identified data; each coloured line represents a separate community)



What is needed now:

- > Funds to finish the job and eliminate Trachoma
- > Current Commonwealth funding ends in mid-2013 and continued funding is required
- > \$17.4m is required to continue the SAFE program 2013-2016
- > A further \$5.4m is required for surveillance 2017-2020

Source: University of Melbourne, April 2013, *The Roadmap to Close the Gap for Vision – Summary Report 2013 April* (page 7), 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

Exhibit 5: A comprehensive five-year costing

The total cost: \$45 million a year or an additional \$140 million.

- Current spending: \$18 million a year.
- Added cost to Close the Gap for Vision: \$28 million a year, or \$140 million over 5 years.
- 46% of the additional cost is for implementing the necessary co-ordination workforce within the eye health care system.

Executive Summary Table 1: Annual Costs by Uncapped Commonwealth, Uncapped State, Capped and Co-ordination Costs; and also by Current, Additional and Total Costs

	Commonwealth		Co-ordination Cost	State/ Territory		Total
	Uncapped Cost	Capped Cost		Uncapped Cost	Capped Cost	
CURRENT	\$4,759,837	\$991,102	\$8,012,408	\$1,682,982	\$1,958,089	\$17,404,418
ADDITIONAL	\$5,109,859	\$2,910,654	\$13,324,604	\$4,710,672	\$2,007,014	\$28,062,803
TOTAL	\$9,869,696	\$3,901,756	\$21,337,012	\$6,393,654	\$3,965,103	\$45,467,221
5 YEAR ADDITIONAL	\$25,549,295	\$14,553,270	\$66,623,018	\$23,553,362	\$10,035,070	\$140,314,015
5 YEAR TOTAL	\$49,348,480	\$19,508,780	\$106,685,058	\$31,968,270	\$19,825,515	\$227,336,103

Source: University of Melbourne, August 2011, *The Cost to Close the Gap for Vision* (page 2), accessed 17 June 2015 http://iehu.unimelb.edu.au/data/assets/pdf_file/0003/514452/cost_to_close_gap_for_vision.pdf

Exhibit 6: A set of 42 interlocking recommendations was proposed

Recommendation Heat Map

to illustrate the relative contribution of recommendations to guiding principles and reinforce the interdependence between components of the Roadmap

	Evidence based	Engage community	Integrated with primary health care	Access in mainstream	Population based	Appropriate and quality services	Accountability	Efficient use of resources
1 PRIMARY EYE CARE AS PART OF COMPREHENSIVE PRIMARY HEALTH CARE								
1.1 Enhancing eye health capacity in primary health services	1	1	3	2	1	3	1	2
1.2 Health assessment items include eye health	2	1	3	2	1	3	1	3
1.3 Diabetic Retinopathy detection	3	1	3	2	1	3	2	3
1.4 Eye health inclusion in clinical software	3	1	3	2	1	1	2	2
2 INDIGENOUS ACCESS TO EYE HEALTH SERVICES								
2.1 Aboriginal Health Services and eye health	3	3	3	2	2	3	2	3
2.2 Cultural safety in mainstream services	1	3	1	3	1	3	1	2
2.3 Low cost spectacles	2	1	2	2	1	3	1	3
2.4 Hospital surgery prioritisation	1	1	1	3	1	3	1	3
3 CO-ORDINATION AND CASE MANAGEMENT								
3.1 Local eye care co-ordination	3	3	3	3	3	3	3	3
3.2 Clear pathways of care	2	2	2	3	1	3	1	3
3.3 Workforce identification and roles	1	1	3	3	2	3	2	3
3.4 Eye care support workforce	2	2	3	1	2	3	1	3
3.5 Case management	2	2	3	2	2	3	1	3
3.6 Partnerships and agreements	1	2	2	2	1	3	3	3
4 EYE HEALTH WORKFORCE								
4.1 Provide eye health workforce to meet population needs	3	2	2	3	3	3	2	2
4.2 Improve contracting and management of visiting services	1	2	1	3	2	3	3	3
4.3 Appropriate resources for eye care in rural and remote areas	2	1	2	3	3	3	2	3
4.4 Increase utilisation of services in urban areas	3	3	2	3	3	2	1	2
4.5 Billing for visiting MSOAP supported services	1	2	1	3	1	3	3	3
4.6 Rural education and training of eye health workforce	1	2	1	2	1	2	1	1
5 ELIMINATION OF TRACHOMA								
5.1 Definition of areas of risk	2	3	2	1	3	3	1	1
5.2 Effective interventions	3	3	3	3	3	3	1	3
5.3 Surveillance and evaluation	3	2	1	1	3	2	3	2
5.4 Certification of elimination	2	1	1	1	3	1	3	1
6 MONITORING AND EVALUATION								
6.1 Managing local eye service performance	3	1	2	2	3	1	3	3
6.2 State and National performance	3	1	2	3	3	2	3	3
6.3 Collating existing eye data sources	3	1	1	1	3	1	3	2
6.4 National benchmarks	2	2	3	3	1	2	2	3
6.5 Quality assurance	3	2	2	2	1	2	3	3
6.6 Primary health service self-audit in eye health	2	2	3	3	2	3	2	2
6.7 Program evaluation	3	1	2	2	3	2	3	3
7 GOVERNANCE								
7.1 Community engagement	3	3	2	1	2	3	3	3
7.2 Local Hospital Networks and Medicare Locals	2	3	3	2	1	3	3	3
7.3 State/Territory management	3	1	2	1	2	1	3	3
7.4 National oversight	3	1	2	1	2	1	3	3
7.5 Program interdependence	2	1	1	2	3	2	3	1
8 HEALTH PROMOTION AND AWARENESS								
8.1 Eye health promotion	1	3	3	2	1	2	1	3
8.2 Social marketing eye care services	1	3	3	2	1	2	1	3
9 HEALTH FINANCING								
9.1 Current spending on Indigenous eye health (non Trachoma)	3	1	1	1	1	3	2	1
9.2 Current spending on Trachoma	3	2	2	1	3	3	3	1
9.3 Full additional annual capped funding required	3	1	1	1	3	3	2	3
9.4 Cost to 'Close the Gap for Vision' funded for 5 years	3	1	1	1	3	3	2	3

Highest relative contribution to guiding principles **3**
 Significant relative contribution to guiding principles **2**
 Contribution to guiding principles **1**

Source: University of Melbourne, September 2011, *The Roadmap to Close the Gap for Vision* (page 11), accessed 17 June 2015
http://iehu.unimelb.edu.au/_data/assets/pdf_file/0007/536803/roadmap_to_close_the_gap_for_vision_summary.pdf.