the Australia and New Zealand School of Government

ANZSOG Case Program

Overturning a blind eye: closing the vision gap for Indigenous Australia (B)

2015-100.2

Proor Hugh Taylor, head of the Centre for Eye Research Australia (CERA), returned to Melbourne from his sabbatical in the UK in 2006, determined to target the eradication of trachoma from Australia's Indigenous populations. The infection, causing blindness at six times the rate of mainstream Australia, had resisted numerous reports, action plans and strategies aimed at eliminating it. Recent advances, including the 'SAFE' treatment strategy[1] developed by Taylor himself, now gave a realistic chance of beating an intractable problem exclusively affecting Australia's Indigenous population. By also improving Indigenous eye health in general, it could 'close the vision gap' with mainstream Australia.

With 2007 an election year and Indigenous issues at the fore, Taylor intended to ensure that trachoma stayed squarely in the sights of decision-makers. His plan was to replicate the process CERA had applied to mainstream eye health: get robust data to (1) establish the national burden, causes and distribution of eye disease; (2) document the gaps in existing eye health services; (3) cost the impact of vision loss; (4) conduct a cost-benefit analysis of a defined set of interventions; and (5) build momentum for implementation.

Prime Minister Howard had launched the Northern Territory Intervention, formally named the Northern Territory National Emergency Response. Though it contained a series of measures around child health and welfare, the Intervention did not look specifically at trachoma in childhood health.

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.

[1] The SAFE acronym refers to Surgery, Antibiotics, Facial cleanliness and Environmental improvement, the four interlocking components in a strategy to deal with the different stages of trachoma.

In the run-up to the election, Taylor spent time with politicians from both main parties, especially federal Labor Members Jenny Macklin and Nicola Roxon, who went on to become the Ministers for Indigenous Affairs and Health and Ageing respectively, as well as Senator Trish Crossin, who was a strong advocate for reform through the Senate Estimate Committee process.

Taylor explained:

> We had the data from the National Trachoma Surveillance and Reporting Unit from 2006 that showed that there was still trachoma across Australia, and the 2007 National Indigenous Eye Health Survey which showed that 60% of [Indigenous] communities were affected by trachoma and that it was the fourth leading cause of blindness in adults.

Indigenous Australians exclusively bore the brunt of trachoma.

The survey, conducted by CERA, was funded by the Vision Cooperative Research Centre and the Royal Australian and New Zealand College of Ophthalmologists with money from the Federal Department of Health and Ageing. It examined 1,700 Indigenous children (aged 5-15 years) and 1,200 adults (aged 40 years and over). Indigenous children, the data showed, had better vision than their mainstream peers, with only 20% of the rate of vision loss. Indigenous adults, on the other hand, had over six times the rates of blindness of mainstream Australian adults, and almost three times the rate of vision loss.

The critical finding was that this dramatic 'vision gap' could be almost completely closed. Nearly all vision loss in Indigenous people – some 94% – could be prevented or treated.[2] Part of the problem was that 35% of Indigenous adults had never had their eyes examined. Surprisingly, vision loss was similar for all Indigenous Australians, whether they lived in cities, rural areas, or in remote settings, and despite eye care services being more common in urban environments. Additionally, the waiting times for cataract surgery were twice as long for Indigenous patients as for mainstream ones.

The CERA survey concluded by the end of 2007, and in 2008 Hugh Taylor led the analysis from his new professorial position as the Harold Mitchell Chair of Indigenous Eye Health at Melbourne University's School of Population Health.

The Indigenous Eye Health Unit

The establishment of the Indigenous Eye Health Unit (IEHU) in 2008 introduced a new 'independent and fearless' advocate for action to improve Indigenous eye health; it was also a voice with the authority of an increasingly strong evidence base. Unusually for such an entity in Australia, it was substantially funded by private donors.

The idea of the IEHU arose after CERA board member Professor John Funder, also on the board of the Harold Mitchell Foundation, discussed Taylor's work and aspirations with Harold Mitchell. Mitchell, a successful Australian media businessman and philanthropist supporting health, education and the arts, was passionate about Indigenous issues. When Funder and Mitchell met with Melbourne University's Vice Chancellor and Dean of Medical School, Mitchell said he would give $1 million over five years for an Indigenous eye health unit, if the University would match it. The University agreed to match funding and to house the unit; it also supported Taylor's applications for further funds from the Ian Potter Foundation[3] and private philanthropists such as Greg Poche.[4]

---

[2] The major causes of blindness in Indigenous adults include: cataract (32%), optic atrophy (14%), refractive error (14%), diabetic eye disease (9%) and trachoma (9%).

[3] A major philanthropic foundation in Australia supporting health and medical research as well as a wide range of other causes.

[4] A freight company founder, one of Australia's 40 richest people, who by 2015 had donated $60 million to Indigenous health and skin cancer causes. See http://www.forbes.com/lists/2012/78/australia-billionaires-12_Greg-Poche_B308.html.

The largely private and independent funding gave the IEHU team an unusual degree of flexibility, allowing it to build on the surveys of the National Trachoma Surveillance Research Unit (which it housed in 2009-2010), and also extend into health economics and health systems planning. As Taylor related:

> I only needed a small team, so I was looking for just the funds that we needed to do what we wanted. The private philanthropy meant that we didn't need to worry about traditional research funding from say the Australian Research Council or National Health and Medical Research Council. They gave three to five year grants for a fixed project that would have been no use to us, as we needed the flexibility to evolve the program. Also you'd spend six or twelve months writing grants with only a twenty per cent chance of getting them funded, when time is precious. And importantly, with our private funding base, we could be confidently independent in expressing views to government.

Taylor invited four of CERA's board members (John Funder, Barry Jones, Terry Nolan and Michael Wooldridge) to form an advisory board for the IEHU. They brought a unique combination of medical, political and fundraising expertise.[5] He also invited representatives of the donor organisations to sit on the Board, as well as Indigenous representatives from the University, and Indigenous colleagues with whom he had worked previously (including in the 1970s with Fred Hollows) (see *Exhibit 2*). The Board advised Taylor, raised donors' interests, and provided a voice for key stakeholders. As Wooldridge explained: 'An advisory board helps facilitate things and keep people informed. It is extremely important for a sensitive political issue like Indigenous health.'

At its first meeting in June 2008, the Board considered proposals for a series of research projects to build a case for comprehensive action on Indigenous eye health. The three initial projects were to identify the underlying reasons why existing and appropriate eye care services did not reach Indigenous Australians; to assess the available evidence base that could inform policy and practice for the treatment of trachoma; and to critically review the policy history of Indigenous eye health interventions and their lack of impact.

Taylor proposed to build on this initial set of analyses to estimate the economic losses to Australia resulting from inadequate eye care for the Indigenous population. Additionally, Taylor presented a plan for an in-depth mapping of the current and optimal eye health workforce, to inform future policy recommendations. The findings would all feed into a comprehensive plan to 'Close the Vision Gap' between Indigenous and mainstream Australia.

Finally Taylor proposed, with separately sourced private funding,[6] a demonstration project against trachoma in the Katherine Region of Western Australia. Given the relatively advanced state of technical knowledge of trachoma, he proposed to 'fast-track' implementation to show governments what could be accomplished on a national scale for eye health, applying a comprehensive approach and appropriate resources.

The IEHU made what was then ground-breaking use of health economics for a 'business case' to combat trachoma. The case was built on findings that the antibiotic azithromycin treatment of trachoma cost between $0.47 and $7.50 per Disability Averted Life Years, and that eyelash surgery to prevent blindness cost $13 per Disability Averted Life Year averted – both extremely cost-effective interventions. To eliminate trachoma in Indigenous Australia, the IEHU prepared a plan costing $25 million over four years to set up regional implementation teams, with national coordination, monitoring and support.

---

[5] Professor Terry Nolan was the head of the School of Population Health at the University of Melbourne. Dr Barry Jones AO was a Labor Member of the House of Representatives (federal) from 1977 to 1998, and served as a minister in the Hawke Government 1983-90. Dr Michael Wooldridge was the Minister of Health in the Howard Coalition Government who had commissioned the follow up review.

[6] Donors included the Christian Blind Mission Australia, and private philanthropists David Middleton and (later) Greg Poche.

At the same time the IEHU stepped up its advocacy efforts, working closely with other entities, notably the Fred Hollows Foundation (FHF).[7] Part of the messaging was to point to Australia's supportive advocacy role in the 2003 World Health Organisation resolution to eliminate avoidable blindness (including trachoma) by 2020. Another message was to contrast the experience and success of much poorer countries like Morocco and Ghana in eliminating their trachoma burden – and in essence asking why Australia had not done the same. The report of the National Indigenous Eye Health Survey, showing trachoma as the fourth most significant cause of blindness in Australia and afflicting 60% of Indigenous communities, would dramatically demonstrate what was urgently needed. The report, already in draft, was due for publication in 2009.

'Evidence alone is not sufficient…'

Even at their first meeting, Board members had raised the importance of building a systematic lobbying and communications strategy to prepare the political environment for CERA results and recommendations (*Exhibit 3*). Board member and Harold Mitchell Foundation representative Ian Roberts proposed that the Foundation leverage its privileged relations with Haystac, a public relations firm owned by Mitchell, to develop a media plan around the launch of the report of the National Indigenous Eye Health Survey.

The new Rudd Labor Government, elected in November 2007, had maintained many of the initiatives of its predecessor and brought a renewed focus on Indigenous issues. It had committed an additional $25 million for health services in the Northern Territory, and initiated an early childhood development program ('An Equal Start in Life for Indigenous Children'). Trachoma, however, was not recognised as a priority. The disease had been dropped from the Government's Indigenous health priorities, while rheumatic heart disease remained.

In April 2008, Prime Minister Rudd convened the Australia 2020 Summit to 'help shape a long term strategy for the nation's future'. Although not an invited participant, the IEHU made a submission arguing that the eradication of trachoma was now an achievable goal, which Australia should take on, if only to salvage its international reputation. The resulting report contained two mentions of trachoma in its wide-ranging recommendations.[8]

Around this time, Hugh Taylor had approached the Federal Ministers of Health and Indigenous Health Nicola Roxon and Warren Snowdon, asking for a new $25 million over four years for trachoma programs. This was in line with its previous election commitments, and could demonstrate what was possible at scale with adequate resources. He had been told, however, that they preferred to maintain current allocations, citing the three years of funding from 2006 for the National Trachoma Surveillance and Reporting Unit. They would await the Unit's results before making further commitments.

As IEHU Advisory Council member and former Minister of Health Michael Wooldridge commented: 'This is an example that gets to a truth of the evidence-based policy process: evidence alone is not sufficient. There are always unique complexities that mean you can't replicate successes across issues.'

[7] The FHF was established in 1992. Despite being named for Professor Fred Hollows AC, the notable ophthalmologist and advocate who had led the first survey of Indigenous eye health, the FHF's work in vision predominantly focused on developing countries, with only a limited amount of activity in Indigenous eye health.

8 '7.22 Eradicate trachoma amongst Indigenous children within five years through a comprehensive health strategy, at a cost of possibly less than $25 million' and 'Attend to chronic health conditions for which early intervention and prevention are crucial – for example, trachoma, rheumatic fever and foetal alcohol syndrome.' *Australia 2020 Summit: Final report*. Commonwealth of Australia 2008. Available from: http://apo.org.au/sites/default/files/2020_summit_report_full.pdf Accessed 9 April 2013.

Frustrated with his failure to garner government support, Taylor remarked to his friend and IEHU Advisory Council member Barry Jones that he needed to talk directly to the Prime Minister, Kevin Rudd. Jones chaired the Port Arthur Historic Site Management Authority in Tasmania, where Prime Minister Rudd was to open the newly restored prison site in August. 'I thought that if Hugh joined me at the site, there would be enough gaps in the PM's schedule to fit in a serious talk about trachoma,' Jones later recalled. Taylor and his team put together a 20-page outline of the $25 million proposal for a concentrated effort at eradicating trachoma from Australia.

With amusement, Taylor later recollected: 'I got about three minutes standing in the freezing rain with Rudd. It was about as far removed from the deserts where trachoma is a problem as you could possibly be. But we also got to meet with Rudd's Chief of Staff and really start a conversation'. As Jones remembered: 'The PM grasped at once the severity of the disease and Australia's isolation in being the only OECD nation where trachoma survived.'

Taylor and his team made repeated trips to Canberra in the subsequent months, redoubling efforts to cultivate awareness and support across the political spectrum. He was now working with a political advisor, Emma Stanford, who had previously worked for two Australian health ministers and a medical research institute. As he explained: 'Politicians don't want problems – there are more than enough of those – what they want is solutions. So we tried to present trachoma as low hanging fruit, something that could concretely be done to help "close the gap".' By December 2008, Taylor was able to tell the Board of a positive response to the proposal.

On 13 February 2009, the first anniversary of his historic apology to the Stolen Generations, Prime Minister Rudd announced $58.3 million for Indigenous eye and ear programs over four years, of which $16 million was allocated to the elimination of trachoma. This money was confirmed with the Federal Budget announcement in May 2009, and became available at the beginning of July.

The announcement marked a major step forward in the fight against trachoma. By then, Hugh Taylor and the IEHU team were already considering how to galvanise support for an estimated $70 million in public funding needed to implement the plan over four years – soon to be named the 'Road Map to Close the Vision Gap'. However, other developments were casting a long shadow, most prominently the widening budgetary impacts of the Global Financial Crisis. Implementation was again looking under threat.

Exhibit 1 Indigenous eye health timeline continued

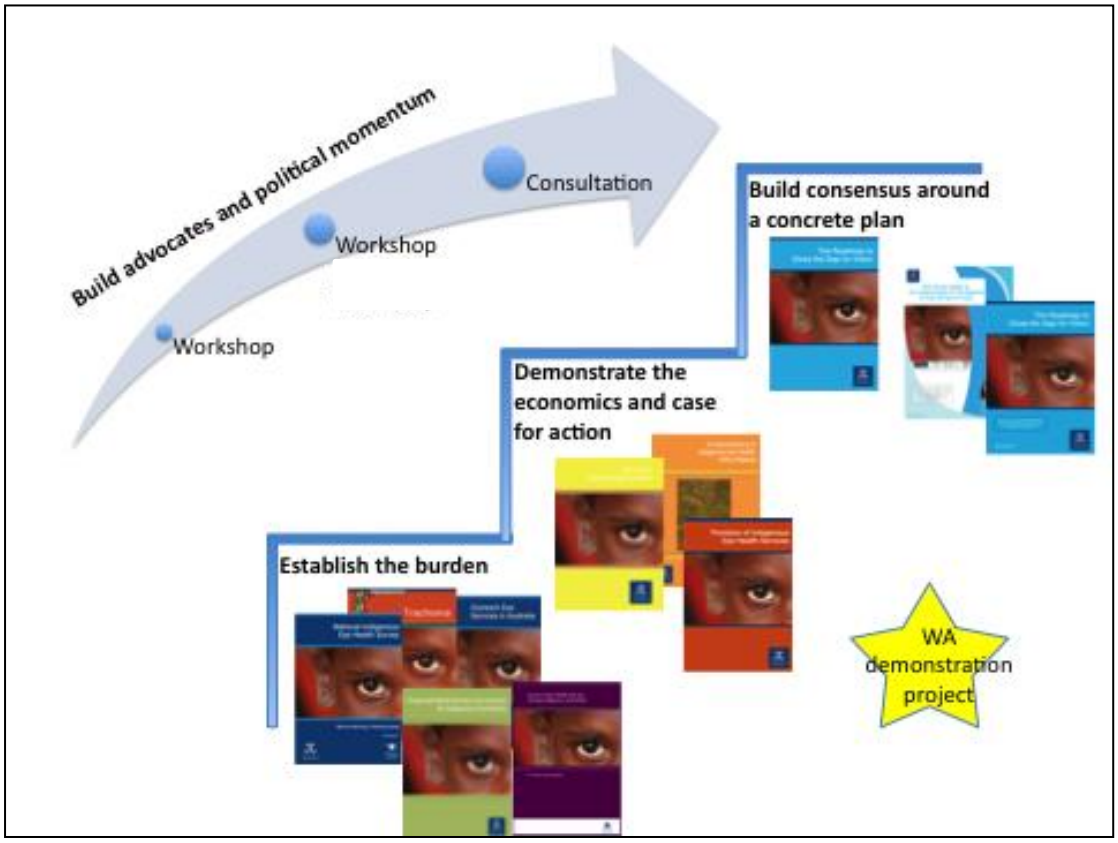
2007	• Commonwealth Government launches the Northern Territory Emergency Response (commonly referred to as 'the Intervention'). • Taylor conducts trachoma survey in Katherine region. • Taylor initiates National Indigenous Eye Health Survey (2007-2008). • Labor Government led by Kevin Rudd elected in November.
2008	• Taylor founds Indigenous Eye Health Unit (IEHU) with funding from Harold Mitchell, University of Melbourne and other private donors. • Taylor initiates trachoma program in Katherine region. • Prime Minister Rudd convenes Australia 2020 Summit in April which called for action on trachoma. • Taylor asks Federal Ministers for $25 million. • Taylor meets with Prime Minister Rudd in Port Arthur in August to ask for funding to eliminate trachoma.
2009	• Prime Minister Rudd announces $58.3 million for Indigenous eye and ear programming, including $16 million against trachoma. • Launch of report on National Indigenous Eye Health Survey, by Governor-General, HE Quentin Bryce, at Koori National Heritage Centre, Melbourne (September). • Global Financial Crisis impacts on funding requests.
2010	• Approaches to media, targeted outreach to experts and decision-makers, including leaders of the Indigenous community-controlled health sector. • Draft, then final development of the Road Map to Close the Vision Gap. • Launch of government-funded, IEHU-developed trachoma story kits at Katherine.
2011	• Road Map complete, with initial state and federal commitment to implement. • Successful application to federal government for $750,000 over three years.
2012	• Active trachoma eliminated in three out of eight communities in Northern Territory; reduction in others to 20% or below.
2013	• Five-year initial funding of IEHU to expire.

Exhibit 2: IEHU Advisory Board (2008-2011)

The role of the Advisory Board is to provide overarching advice, direction on work, guidance on funding, and advice as to how data collected can be used to implement policy change. Below is a list of its membership over time.

Name	Affiliation	Tenure	Illustrative contributions
Prof Ian Anderson	University of Melbourne	2008-2012	• Indigenous perspective, contributed to the historical review of policy
Prof John Funder	Harold Mitchell Foundation	2008-	• Used network, e.g. outreach to Access Economics, Harold Mitchell Foundation, Governor General
Mrs Jan Hirst	Potter Foundation	2008-	• Donor
Ms Jilpia Jones		2008-	• Indigenous perspective, contributed to the historical review of policy
Prof Terry Nolan	School of Population Health, University of Melbourne	2008-	• Hosted the IEHU
Mr Ian Roberts	Harold Mitchell Foundation	2008-2011	• Represented founding donor • Brought connections to Haystac for PR support
Prof Hugh Taylor	IEHU, School of Population Health, University of Melbourne	2008-	• IEHU
Mr Trevor Buzzacott	South Australian State Government	2008-	• Indigenous perspective
Hon Dr Barry Jones	University of Melbourne	2008-	• Political perspective
Hon Prof Michael Wooldridge	University of Melbourne	2008-	• Political perspective
Assoc Prof David Middleton		2009-2013	• Donor
Mr Reg Richardson	Greg Poche Foundation	2009-2011	• Donor
Mr Peter Anastasiou		2011	• Donor

Exhibit 3: Building momentum



Source: Dr Kate Taylor

Exhibit 4: December 2009 consultations

Prior to the launch of the National Indigenous Eye Health Survey in December 2009, Prof Hugh Taylor and Emma Stanford met with the following people to brief them on the national survey results and work of the IEHU.

Stakeholders	Briefings conducted
Federal Ministers	• Minister for Indigenous Health, Warren Snowdon • Minister Roxon's office (Dr Meredith Arkus) • Parliamentary Secretary Mark Butler MP
Federal Departments	• Ms Mary Murnane (Department of Health and Ageing - Dep Sec) • Office for Aboriginal and Torres Strait Islander Health (Rajan Martin, Tarja Saastamoein and Naomi Poole) • Rural Health MSOAP, Anne Lambie
State / Territory Health Ministers	• Northern Territory Minister Kon Vatskalis • Queensland Deputy Premier and Minister for Health the Hon Paul Lucas • Western Australia Deputy Premier and Minister for Health Dr Kim Hames • South Australia Minister John Hill • Tasmania – Margot Dawson Adviser to Minister Lara Giddings • Victoria – Minister Daniel Andrews
State / Territory Departments	• Northern Territory Dr David Ashbridge CEO, Department of Health and Community Services • QLD Health – Prof Andrew Wilson (Deputy Director General Policy, Planning and Resourcing) and Haylene Grogan (Senior Director, A&TSI Health Branch) • NSW Health – Dr Kerry Chant Deputy Director General, Population Health, Chief Health officer and colleagues • Victoria DHS – Vicky Mason and Jim Hyde • WA – Dr Peter Flett, Director General • SA Health – Dr Tony Sherborn, Chief Executive and Country Health SA • Tasmania – Jeanette James, Policy Officer Aboriginal Health DHHS
National Aboriginal Community Controlled Health Organisation 'NACCHO' and affiliates	• Aboriginal Medical Services Alliance Northern Territory - Dr Andrew Bell, Dr Tanya Davies, Dr Liz Moore • NT Central Australian Aboriginal Congress Alice Springs • NACCHO – Dea Thiele • Queensland Aboriginal and Island Health Council - Clint Arizmendi and Dr Katie Panaretto • NSW Aboriginal Health & Medical Research Council - Dr Sandra Bailey (CEO), Dr Jenny Hunt (Public Health Medical Officer) and Sally Cairnduff (Public Health Program Manager) • Victorian Aboriginal Health Service and Victorian Aboriginal Community Controlled Health Organisation Inc • Aboriginal Health Council of Western Australia and Kimberly Aboriginal Medical Service Dr Carmel Nelson • Aboriginal Health Council of South Australia - Mary Bucksin and colleagues
Other organisations	• Telethon Institute for Child Health Research – Prof Fiona Stanley • Vision 2020 Australia • Vision Cooperative Research Centre • The Royal Australian and New Zealand College of Ophthalmologists • Optometrists Association • Fred Hollows Foundation