Aust. J. Rural Health (2016) .., ....



# Original Research

# Coordination of diabetic retinopathy screening in the Kimberley region of Western Australia

Verity Moynihan, BMedSci, and Angus Turner, MBBS (Hons), MSc (Oxon), RANZCO

Centre for Ophthalmology & Visual Sciences (incorporating the Lions Eye Institute), The University of Western Australia, Perth, Western Australia, Australia

#### Abstract

Objective: To determine the coverage provided by the Kimberley Diabetic Retinopathy Screening Program and evaluate the impact of the Kimberley Diabetic Eye Health Coordinator position using an evidence-based approach.

Design: Retrospective audit.

Setting: Primary care services in the Kimberley region of Western Australia.

Participants: Individuals with diabetes mellitus who underwent screening for diabetic retinopathy from 1 March 2010 to 28 February 2014.

Interventions: A Kimberley Diabetic Eye Health Coordinator was engaged from February 2012 to provide coordination and support for the diabetic retinopathy screening program.

Main outcome measure(s): Coverage provided by the program for Indigenous Australians with diabetes, as measured against annual projected needs for diabetic eye examinations.

Results: Data were collected for 1247 screening episodes for 947 Indigenous Australian patients. Coverage provided by the program increased from 9.44% in 2010–2011 to 29.8% in 2013–2014 (P < 0.05). The number of sites engaged in screening increased from four in 2010–2011 to 17 in 2013–2014. After the engagement of the Kimberley Diabetic Eye Health Coordinator, significant increases in visual acuity recording and coverage were observed, as well as a non-significant increase in photo quality.

Conclusions: Engagement of the Kimberley Diabetic Eye Health Coordinator was associated with significant increases in program coverage. Despite the observed increase, there were significant shortfalls in

Correspondence: Associate Professor Angus Turner, Centre for Ophthalmology & Visual Science (incorporating the Lions Eye Institute), The University of Western Australia, 2 Verdun Street Nedlands, Perth, Western Australia, 6009, Australia. Email: angus.turner@gmail.com

Accepted for publication 17 January 2016.

the number of Indigenous Australians with diabetes undergoing screening in the Kimberley region. This may be explained by examinations provided by other services in the Kimberley region, namely visiting optometry services, but also highlights a large proportion of the population not undergoing screening.

KEY WORDS: diabetes, Indigenous health, mass screening, ophthalmology, program evaluation.

#### Introduction

The prevalence of diabetes in Indigenous Australians is increasing, with corresponding high rates of diabetic retinopathy-related blindness and vision loss. Diabetic retinopathy (DR) can be prevented with timely diagnosis and treatment, but many Indigenous Australians with diabetes do not undergo regular eye examinations. The provision of eye care services, including DR screening, to Indigenous Australians requires a high level of coordination and partnership between services.

Worldwide, there are many examples of successful and sustained screening initiatives for DR, with a number of these focussing on Indigenous peoples. There are comparatively few sustained screening initiatives in Australia detailed in academic literature, and to date, there has been no national approach to implementing DR screening on a large scale. Coordination has been repeatedly identified as a primary barrier to the provision of eye health services to Indigenous Australians. 6–8

In the Kimberley region of Western Australia – an area twice the size of the state of Victoria (Fig. 1) – screening for DR has been conducted remotely using retinal photography since 1996. The program was proven to be both successful and sustainable in an earlier audit and was able to provide screening services to over 1300 Indigenous Australians with diabetes in the region over 5 years. However, from 2006 onwards, the program suffered several setbacks, most notably the loss of the regional eye health coordinator. After

#### What is already known on this subject

2

- The prevalence of diabetic retinopathy and associated vision loss in Indigenous Australians is rising.
- Although vision loss from diabetic retinopathy is preventable, many do not undergo eye examination which would permit timely intervention and treatment.
- Regional eye health coordinators have been employed in Indigenous eye health programs in various regions of Australia since 1996.

several years of decreasing screening activity, a Kimberley Diabetic Eye Health Coordinator (KDEHC) position was jointly established by the Kimberley Aboriginal Medical Services Council and the Lions Eye Institute. The KDEHC position aims to provide high-



FIGURE 1: Map of Western Australia and the Kimberley region.

#### What this study adds

- The engagement of the Kimberley diabetic eye health coordinator was associated with significant improvements in the Kimberley diabetic retinopathy screening program over a 2-year period.
- The Kimberley DR screening program was able to provide significant coverage for Indigenous Australian patients with diabetes.
- One in five Indigenous Australians who underwent screening during the study period had diabetic retinopathy.

level support and coordination to retinal screening in the Kimberley region and to provide ongoing training for health worker staff.

Qualitative evidence suggests that Regional Eye Health Coordinators (REHC) contribute significantly to the success of Indigenous eye health programs such as diabetic retinopathy screening initiatives. Despite the existence and acknowledgment of REHCs since 1997, there is no formal evidence base to confirm the value of REHCs for eye health programs, including DR screening initiatives. This is the first study that establishes the value of regional coordination, specifically focusing on REHCs, in DR screening. The value of the KDEHC as a regional coordinator will be assessed using an evidence-based approach.

## Methods

#### Service description

In the Kimberley diabetic retinopathy screening program, photographs are sent from 17 sites in the Kimberley region to two Perth-based ophthalmologists. Retinal photography and visual acuity measurements are performed by Aboriginal Health Workers (AHWs), nurses and other clinic staff. One 30° macula-centred image of each eye is taken and photos were graded via a cloud-based eHealth records system using the International Clinical Diabetic Retinopathy Disease Severity Scale with maculopathy being specified as present or absent. 12 The severity of DR present is reported as the greatest severity in either eye, with photos being reported on as pairs for each patient. Photos are reported as inadequate if either photo could not be graded due to media opacity or photographic problems. Based on disease severity and presence of other pathology, recommendations were then made by the trained retinal photo grader with ophthalmologist input for patients to undergo repeat screening, optometry review or ophthalmology review.

The KDEHC is responsible for providing training and upskilling for retinal camera operator staff as well as providing screening services in areas with no permanent retinal camera or camera operator staff. The KDEHC was engaged in December 2011, but for the purposes of the study was considered active from March 2012 to account for time spent learning their role. The Kimberley Eye Health Coordinator position is funded through a partnership between the Lions Eye Institute and the Kimberley Aboriginal Medical Services Council (KAMSC), with significant financial support from the Royal Australian and New Zealand College of Ophthalmologists.

#### Data collection

A retrospective audit of the Kimberley diabetic retinopathy screening program between 1 March 2010 and 28 February 2014 was conducted. The primary aims of the audit were to determine the coverage provided by the screening program and the impact of the KDEHC on program coverage and quality. Data were collected from all referrals in this time period for Indigenous and non-Indigenous Australians with diabetes mellitus. Information was collected on patient characteristics, screening locations, visual acuity and the presence and severity of retinopathy.

The number of screening episodes occurring within the program was compared with projected needs for eye examinations for Indigenous Australians in the Kimberley region to determine the coverage provided. The projected needs for diabetic retinopathy screening in the Kimberley region were determined using population data from the Australian Bureau of Statistics regional profiles and data on diabetes prevalence from the Aboriginal and Torres Strait Islander Health Report: Biomedical Results. 13

## Data analysis

Data were analysed to determine the impact of the Kimberley Diabetic Eye Health Coordinator and the relationship between patient characteristics and different screening outcomes. The number of screening episodes occurring each year was compared with the projected needs for the Kimberley region to give the proportion of coverage provided. Analysis was conducted using SPSS V 22.2. Z tests of population proportion were used to determine the significance (P < 0.05) of changes in program coverage, photo quality and the inclusion of visual acuity in referrals. 95% confidence intervals were calculated for some

patient characteristics and DR. A logistic regression analysis was conducted to determine the relationship between patient characteristics, the engagement of the KDEHC and photo quality (adequate versus inadequate).

#### **Ethics**

Ethical approval was granted for the project by the Western Australian Aboriginal Health Ethics Committee, the University of Western Australia Human Research Ethics Committee and the Kimberley Aboriginal Health Planning Forum.

#### Results

Data were collected for 1349 screening episodes, representing 1029 patients – 916 of whom were Indigenous. Data from 145 screening episodes could not be accessed retrospectively, although the date of receipt of referrals in these cases could still be determined (Fig. 1). The projected number of diabetic eye examinations required annually for Indigenous Australians in the Kimberley region was 1684. <sup>13,14</sup>

# Program coverage

The coverage provided by the program increased from 9.44% to 29.8% in the final year of the audit. Significant increases in coverage were realised over each year of the audit (P < 0.05). The number of sites involved in screening increased from 4 to 17 over the course of the audit. An additional five primary health-care services, five hospitals, one Aboriginal Medical Service and two population health services became involved in screening over the course of the audit period.

#### Effect of KDEHC involvement

There were significant increases in the coverage provided by the program after the engagement of the KDEHC.

The rate of visual acuity (VA) recording prior to the engagement of the KDEHC was 50.7%, compared with 83.9% in the period in which the KDEHC was active. There was a statistically significant association between referrals being sent after the engagement of the KDEHC and vision being included in these referrals ( $x^2(1) = 169.444$ , P = 0) and a very strong relationship between KDEHC engagement and VA recording ( $\phi = 0.354$ , P = 0). The number of screening episodes graded as adequate after the KDEHC was active did not significantly increase (79.3–80.8%, P = 0.61006).

#### Patient characteristics

The average age of Indigenous Australian patients who underwent screening during the audit period was 52.6 (95% CI, 51.7-53.5) (Table 1). Of the 868 Indigenous patients for whom screening data were available, 82.8% had assessable photographs in any screening episode. Second or subsequent screening episodes were more likely to be graded as inadequate than first screening episodes, although the difference in photo quality was not found to be significant (81.3% versus 77.6%, P = 0.17384).

# Diabetic retinopathy severity

Of 64.7% of all Indigenous Australian patients with gradable photos had no DR detected on any screening episode over the audit period (Table 2); 7.6% of Indigenous patients had mild DR not requiring referral. Referrable DR was present in 5.1%; 1.5% had previous laser reported on screening, with no DR grade being specified in 2.3% of all referrals; 19.0% of Indigenous patients who underwent screening over the audit period did not have any adequate screening episodes and so the presence of DR could not be specified for these patients.

# Repeat screening episodes

Of 666 Indigenous patients with an initial screening episode where repeat screening in 12 months was recommended, only 147 (22.1%) underwent repeat screening within the audit period. Of those who underwent repeat screening, 44.3% were re-screened within 9–15 months of the initial screening episode (Table 3).

#### Discussion

This audit is the first study to assess the role and impact of a regional eye health coordinator using

**TABLE 2:** Diabetic retinopathy in Indigenous and non-Indigenous patients (% of assessable patients; 95% CI)

	Indigenous	Non-Indigenous
No diabetic retinopathy	560/723 (77.5%, 74.8–79.9)	64/76 (84.2%, 74.2–90.9)
Diabetic retinopathy (ANY)	163/723 (22.5%, 19.65–25.7)	12/76 (15.8%, 9.1–25.8)
NPDR	123/723 (17.0%, 14.4–19.9)	12/76 (15.8%, 9.1–25.8)
Proliferative DR	3/723 (0.41%, 0.08–1.27)	0

Results reported for individual screening episodes.

evidence-based approach. The Kimberley Diabetic Eye Health Coordinator was associated with improved screening outcomes and expansion of the screening program.

There were observable improvements in multiple areas of the screening program associated with the engagement of the KDEHC. The most notable improvements in the screening program were realised in program coverage and the inclusion of VA recordings with screening referrals. The number of sites involved in screening during this time also increased, and this can be attributed directly to the KDEHC visiting more remote communities and primary health-care services to perform screening on a regular basis.

The coverage provided by the program increased significantly over the audit period, but a projected 70.2% of the Indigenous Australian population did not undergo screening through the program in 2013–2014. This large shortfall is likely accounted for by individuals with diabetes not undergoing regular diabetic retinopathy screening. The shortfall may also be partially explained by the coverage provided by the

TABLE 1: Patient characteristics by Indigenous status

	Indigenous	Non-Indigenous
Total	947	82
Total patients with DOB available	939	81
Age at last screen (mean and 95% CI)	52.6 (51.7–53.5)	57.4 (54.6–60.1)
Age > 40 at last screening episode	788	75
Age $\geq 55$ at last screening episode	414	50
Gender (% female)	55.5	30.5
Total screening episodes	1247	102
Screening episodes where patients age > 40	1045	95
Number of patients with assessable photographs*	719/868 (82.8%)	76/80 (95%)

<sup>\*</sup>Referrals with missing information on photo quality not included in the total patient count for assessable photographs.

TABLE 3: Intervals for repeat screening episodes for Indigenous and non-Indigenous patients where repeat screening was recommended for 12 months after an initial screening episode

	Indigenous	Non-Indigenous
n	147	19
Mean screening interval (months)	14.3	11.8
Minimum screening interval	1	4
Maximum screening interval	39	17
<9 months	32 (26.2%)	1 (5.26%)
9-15 months	66 (44.3%)	16 (84.2%)
>15 months	49 (32.9%)	2 (10.5%)

visiting optometry services in the region. From March 2013 to February 2014, 402 optometry appointments were provided to Indigenous Australians with diabetes in the Kimberley region. <sup>15</sup> There is a potential overlap between those who underwent screening and those who attended optometry appointments, but this cannot be determined due to the existence of multiple separate patient records in the Kimberley region.

In future, the introduction of an integrated eye health record inclusive of DR screening would allow for more comprehensive estimation of coverage provided for patients with diabetes. In Western Australia, an integrated eye health record is being introduced for ophthalmology and optometry services, but this record does not extend to DR screening.

The low rate of DR screening in Indigenous Australians in the Kimberley region is not dissimilar to findings of other studies, such as the National Indigenous Eye Health Survey (NIEHS) and the Melbourne Visual Impairment Project. The NIEHS found that only 20% of Indigenous Australians with diabetes had undergone an eye examination within a year. Despite the shortfall in coverage of the Kimberley DR screening program, the projected coverage of 29.8% is still greater than the recorded 20% of Indigenous Australians who self-reported undergoing an eye examination within a year in the NIEHS.

A low rate of re-engagement with the screening program may also have contributed to the shortfall in coverage. It is, therefore, crucial to continue patient engagement with the screening program through education, ongoing improvement of access to screening and the use of patient recalls and point of care prompts.

The proportion of photos which were graded as inadequate remained high over the audit period, with almost 20% of all screening episodes including inade-

quate photos. A likely contributing factor to poor photo quality is limited use of mydriatic eye drops in retinal photography, where it may be required for many Indigenous patients. It was not possible to assess the impact of mydriasis in this study as this information was not routinely recorded by camera operator staff. The presence of other pathology, such as untreated cataracts, would also contribute to a high ungradeable photo rate.

The Kimberley diabetic retinopathy screening program is an example of a sustained chronic disease care initiative with longstanding partnerships with staff in primary care settings across the Kimberley region. The engagement of the KDEHC was associated with improved screening coverage and outcomes, and efforts to increase coverage and retention of patients within the screening program are ongoing.

# Author contributions

Verity Moynihan (BMedSci) (80%) – study design, literature search, data collection, statistical analysis and manuscript writing. Angus Warwick Turner, FRANZCO (20%) – study design and manuscript review.

# Disclosure statement

No relevant disclosures.

# Acknowledgements

The authors acknowledge the financial support provided by the Alvina King Bachelor of Medical Science Scholarship from the University of Western Australia.

# References

- 1 Wild S, Roglic G, Green A, Sicree R, King H. Global prevalence of diabetes: estimates for the year 2000 and projections for 2030. *Diabetes Care* 2004; 27: 1047–1053.
- 2 Arnold A, Dunn R, Taylor HR, Keeffe J, Fox S, Goujon N, *et al.* National Indigenous Eye Health Survey Full Report. Melbourne, VIC: The University of Melbourne; 2009. [Cited 5 Feb 2014]. Available from URL: http://iehu.unimelb.edu.au/
- 3 Liaw ST, Lau P, Pyett P, Furler J, Burchill M, Rowley K, et al. Successful chronic disease care for Aboriginal Australians requires cultural competence. Australian and New Zealand Journal of Public Health 2011; 35: 238–248.
- 4 Naqshbandi M, Harris SB, Esler JG, Antwi-Nsiah F. Global complication rates of type 2 diabetes in Indigenous peoples: a comprehensive review. *Diabetes Research and Clinical Practice* 2008; **82**: 1–17.

- 5 Maberley D, Walker H, Koushik A, Cruess A. Screening for diabetic retinopathy in James Bay, Ontario: a cost-effectiveness analysis. *CMAI* 2003; **168**: 160–164.
- 6 Durkin SR, Casson R, Newland HS, Selva D. Prevalence of trachoma and diabetes-related eye disease among a cohort of adult Aboriginal patients screened over the period 1999–2004 in remote South Australia. *Clinical and Experimental Ophthalmology* 2006; 34: 329–334.
- 7 Taylor HR, Boudville AI, Anjou MD. The roadmap to close the gap for vision. *Medical Journal of Australia* 2012; 197: 613–615.
- 8 Anjou MD, Boudville AI, Taylor HR. We can see the gap. Regional eye health coordination for Indigenous Australians. *Aboriginal and Islander Health Worker Journal* 2012; 36: 12–16.
- 9 Murray RB, Metcalf SM, Lewis PM, Mein JK, McAllister IL. Sustaining remote-area programs: retinal camera use by Aboriginal health workers and nurses in a Kimberley partnership. *Medical Journal of Australia* 2005; **182**: 520–523.
- 10 Mak DB, Plant AJ, McAllister I. Screening for diabetic retinopathy in remote Australia: a program description

- and evaluation of a devolved model. Australian Journal of Rural Health 2003; 11: 224–230.
- 11 Oh MS, Nelson C, Marley J, Atkinson D, Metcalf S, Lewis P, *et al.* Eye Health in the Kimberley: Plain Language Report 2011. [Internet] Broome, WA: Kimberley Aboriginal Medical Services Council; 2011. [Cited 8 Jul 2014]. Available from URL: http://www.kamsc.org.au/
- 12 Wilkinson CP, Ferris FL 3rd, Klein RE, Lee PP, Agardh CD, Davis M, *et al.* Proposed international clinical diabetic retinopathy and diabetic macular edema disease severity scales. *Ophthalmology* 2003; **110**: 1677–1682.
- 13 Australian Bureau of Statistics. Australian Aboriginal and Torres Strait Islander Health Survey: Biomedical Results, 2012–13 [Internet]. 2014. [Cited 11 Sep 2014]; 4727.0.55.003. Available from URL: http://www.abs.-gov.au/
- 14 Australian Bureau of Statistics. National Regional Profile: Kimberley (SA3) [Internet]. Canberra; 2013. [Cited 29 Apr 2014]. Available from URL: http://www.abs.gov.au/
- 15 Lions Outback Vision. Visiting Optometry Services: Service Provision Data, 01 March 2013 28 February 2014. [Unpublished report].