

# Identifying best-practice features of diabetic retinopathy treatment models for Aboriginal and Torres Strait Islander Australians

Rosamond Gilden MPH<sup>1</sup>  | Rosemary McKenzie PhD<sup>2</sup> |  
Mitchell D. Anjou MScOptom<sup>1</sup>

<sup>1</sup>Indigenous Eye Health, The University of Melbourne, Carlton, Victoria, Australia

<sup>2</sup>Melbourne School of Population and Global Health, The University of Melbourne, Carlton, Victoria, Australia

## Correspondence

Rosamond Gilden, South Australian Health & Medical Research Institute (SAHMRI – North Terrace), Adelaide SA 5000, South Australia, Australia.  
Email: [rosamond.gilden@outlook.com](mailto:rosamond.gilden@outlook.com)

## Present address

Rosamond Gilden, South Australian Health & Medical Research Institute (SAHMRI – North Terrace), Adelaide, South Australia, Australia.

## Abstract

**Objective:** Indigenous Australians are nearly three times more likely to have diabetes than non-Indigenous Australians. The prevalence of diabetes-related vision impairment for Indigenous Australians is 5.5% compared to 1.5% for non-Indigenous Australians, and treatment rates are lower for Indigenous Australians. Despite this situation, there is limited evidence on effective service delivery models for diabetic retinopathy care and treatment. This study seeks to identify best-practice features of diabetic retinopathy care that could be used to inform current and future service delivery models for Indigenous Australians with diabetic retinopathy.

**Setting:** All states, territories and geographic remoteness categories in Australia.

**Participants:** Eight ophthalmologists engaged in providing eye healthcare to Indigenous Australians.

**Design:** Semi-structured interviews were conducted. The Framework Approach was used to conduct a thematic analysis of the interviews to facilitate identification of key themes and issues that emerged from these discussions.

**Results:** Seven best-practice features for service delivery of diabetic retinopathy treatment for Indigenous Australians were identified. These were: cultural safety, affordability and accessibility, partnerships with key stakeholders, timeliness, integration with primary care, clarity of guidelines, and clinician attitude and motivation.

**Conclusion:** The findings from this study identified seven best-practice features for diabetic retinopathy treatment. These have the potential to inform and influence how care is delivered to Indigenous Australians. Although further research is warranted to capture other service provider inputs and Indigenous end-user perspectives, these features in the meantime can begin to inform the decisions of the Indigenous eyecare sector on policy reforms and best-practice diabetic retinopathy treatment approaches.

## KEYWORDS

aboriginal health, diabetes, diabetic retinopathy, diabetic retinopathy treatment, eye care

## 1 | INTRODUCTION

Diabetic retinopathy (DR) is a progressive eye disease that impacts the retinal microvasculature.<sup>1</sup> The direct cause of DR is diabetes.<sup>2</sup> In 2017, the International Diabetes Federation (IDF) estimated that 451 million people had diabetes globally.<sup>3</sup> In Australia, the self-reported data from the Australian Bureau of Statistics (ABS) 2017–18 National Health Survey, estimated that 1.2 million Australians (4.9% of the overall population) had diabetes.<sup>4</sup> For Aboriginal and Torres Strait Islander Australians (hereafter respectfully referred to as Indigenous Australians), the self-reported data from the ABS National Aboriginal and Torres Strait Islander Health Survey (2018–19) estimated 64 100 (7.9% of Indigenous Australians) had diabetes.<sup>4</sup> After factoring in age structure differences between Indigenous and non-Indigenous populations that were based on measured and self-reported results, the prevalence of diabetes was nearly three times more likely for Indigenous Australians compared to non-Indigenous Australians (12.6% vs 4.3%).<sup>4</sup>

Diabetic Retinopathy has been referred to as a ‘silent disease’. In the early stages of non-proliferative DR, it typically produces no visual symptoms, and signs of DR observed in the retina are minimal.<sup>5</sup> The prevalence of diabetes-related vision loss in Indigenous Australians is 5.5% higher than the non-Indigenous prevalence of 1.5%.<sup>6</sup>

As the disease progresses to proliferative DR, visual symptoms are noticeable,<sup>7</sup> and if left untreated, DR pathology can cause permanent vision loss.<sup>1</sup> Through early detection and timely treatment, almost all diabetic vision loss is preventable.<sup>8</sup>

Screening is an important preventative measure in detecting DR early to prevent permanent vision loss.<sup>1</sup> In Australia, the National Health and Medical Research Council (NHMRC) guidelines recommend biennial screening for non-Indigenous Australians with diabetes and annual screening for Indigenous Australians.<sup>9,10</sup> For cases where mild or moderate non-proliferative DR is detected, monitoring is required.<sup>9</sup> When individuals are detected with sight-threatening DR, two treatment modalities exist. The traditional treatment approach to DR and diabetic maculopathy (DM) has been the episodic use of retinal lasers – including panretinal photocoagulation (PRP). The delivery of treatment with laser ranges from two to three treatment sessions in the first year.<sup>11</sup> The current first-line treatment of DR is now anti-vascular endothelial growth factor (anti-VEGF) injections.<sup>12</sup> The delivery of this treatment is every four to six weeks.<sup>13</sup> In

### What is already known on this subject:

- The literature reports that the prevalence of diabetes-related vision impairment for Indigenous Australians is 5.5% compared to 1.5% for non-Indigenous Australians, and treatment rates are lower for Indigenous Australians
- There is no current literature on suitable service delivery models, specific clinical guidelines, or funding models of diabetic retinopathy treatment specific for Indigenous Australians

### What the paper adds:

- This paper identifies seven best-practice features for diabetic retinopathy treatment of Indigenous Australians
- These features have the potential to influence and inform suitable service delivery models, funding models and specific clinical guidelines for delivering diabetic retinopathy treatment that is specific for Indigenous Australians

the advanced stages of DR, surgical management is warranted, and a vitrectomy may be performed.<sup>14</sup>

Whilst issues surrounding the prevalence and appropriate treatment for Indigenous Australians in other conditions such as mental health and cancer have been well documented<sup>15,16</sup> with recommendations provided on how to assess and treat in a culturally appropriate manner,<sup>17–19</sup> there is no current literature on suitable service delivery models, specific clinical guidelines, or funding models of DR treatment for Indigenous Australians. This is despite the known barriers to accessing ophthalmology in general for Indigenous Australians, including longer waiting times, affordability, unclear referral processes, complex socioeconomic determinants, acceptability of service, and barriers of distance to care.<sup>20–22</sup>

The aim of this study was to identify and consider the features of a best-practice DR service delivery model for Indigenous Australians.

## 2 | METHODS

Key informant interviews were conducted with a convenience sample of ophthalmologists with specialist

skills, knowledge and experience in treatment of DR for Indigenous Australians. The semi-structured interviews were designed to explore current practices and perspectives of treatment of DR in Australia.

## 2.1 | Recruitment

The participants were purposefully recruited from a stakeholder register that resides with the Indigenous Eye Health Unit (IEHU) at the University of Melbourne. The register lists organisation, position, state or territory, region, postcode, and a contact email address. The list was initially filtered to sixteen ophthalmologists known to be involved in the provision of care in Indigenous communities. The list was then further reduced to eight clinicians based on the criteria of having representation from all states and territories and geographic remoteness areas. Two additional ophthalmologists were identified in the event that the contacts on the primary list could not be reached. An information sheet and plain language statement was sent to the eight identified ophthalmologists, explaining the purpose of the research project, its relevance to Indigenous eye health, expected tasks of participants and inviting them to participate. A reminder email was sent a week later to the potential participants who were yet to respond. Seven of the eight confirmed their involvement by responding to the email. One of the additional ophthalmologists was contacted and agreed to participate. Verbal consent was obtained over Zoom prior to conducting each interview.

## 2.2 | Semi-structured interviews

A semi-structured interview guide was developed that used open-ended questions to facilitate discussion with participants being interviewed (refer to [Appendix 1](#)). Interviews were conducted via Zoom or by telephone and were recorded with the participant's permission and were transcribed verbatim. Thematic analysis was conducted using the 'Framework Approach' which has five stages in analysing data. These were: (1) Familiarisation (2) Identifying a thematic framework (3) Indexing (4) Charting and; (5) Mapping and interpretation.<sup>23</sup> The first author conducted thematic analysis which was reviewed and refined with the second author. The eight ophthalmologists were each interviewed for up to 45–60 min.

Research ethics approval was obtained from the University of Melbourne, School of Population and Global Health Human Ethics Advisory Group on 9 April 2020 ID: 2056644.1.

## 3 | RESULTS

### 3.1 | Participants

The participants selected worked in all states and territories of Australia, and the eye care they provided represented all geographic remoteness categories of urban (4), regional (3) and remote (3). All participants were male, with the mean number of years practicing as an ophthalmologist at 17 years. The mean number of years treating Indigenous patients was 14 years. No participants were Indigenous. The participants practiced in a range of clinical settings. Six of the eight ophthalmologists worked in private practice, seven of the eight worked in public hospitals, and five of the eight provided outreach services. The clinical services provided by participants included general ophthalmology, cataract, diabetic eye disease, macular degeneration, and other retinal disease, to both Indigenous and non-Indigenous patients. All participants provided DR treatment to Indigenous Australians in either their private clinics, public hospitals or during their outreach visits.

### 3.2 | Best-practice features of a DR service delivery model

The thematic analysis of the interviews identified seven features that could contribute to best-practice DR care to Indigenous Australians. A feature is included in the list and discussed below if it was raised by two or more participants. [Table 1](#) presents a summary of these features.

#### 3.2.1 | Cultural safety

Two ophthalmologists referred to delivering culturally safe services. Terms used to describe this were 'culturally appropriate care' and 'make it safe'. One ophthalmologist expanded on this by stating that this improves Indigenous access to eyecare services.

#### 3.2.2 | Affordability and accessibility

Most ophthalmologists mentioned that affordability of care was a key feature. Affordability was described as bulk-billed care or a service that posed no financial barriers. However, one ophthalmologist did not consider cost as a factor to inform DR treatment options. He mentioned that 'cost can be neutralised'. There was no elaboration of what this means or how this could be achieved.

TABLE 1 Best-practice features of a DR treatment service delivery model of Indigenous Australians

Key features of best-practice models	Explanation and details
Cultural Safety	Services are provided within a culturally safe and appropriate environment, as considered by community
Affordability and Accessibility	There are no cost or financial barriers to patients to receive care with services publicly funded or subsidised to a level that is effectively publicly funded
Partnerships with Key Stakeholders	Relationships are important to support integrating and linking patients in the pathway of care and creating system changes/reforms (e.g., AMS, optometrist, ophthalmologist, hospital, AHLO)
Timeliness	Refers to: <ul style="list-style-type: none"> <li>• Patients receiving DR screening on regular basis</li> <li>• Patients referred for DR treatment within appropriate time frame</li> <li>• Travel time and distance to receive care is as close to home as possible such that care is delivered locally</li> </ul>
Integration with Primary Care	Primary care providers understand and are engaged in the pathway of eye care (i.e., diabetic retinopathy screening) and referral pathways to secondary and tertiary care
Clarity of Guidelines	Clinicians refer to and follow the established guidelines so as to provide consistent and agreed standards of care
Clinician Attitude and Motivation	Ophthalmologists involved are willing and committed to improving diabetic retinopathy outcomes for Indigenous client

One ophthalmologist linked affordability with accessibility. The ophthalmologist argued that for the service to be accessible it needs to be either publicly funded or subsidised to a level that it is effectively publicly funded.

A different ophthalmologist mentioned that the issue of accessibility needs to be sorted. The ophthalmologist said that if you 'start with accessibility, everything else will follow'. This was based on his own experience where he would ensure access to his private clinics by providing a bulk-billed service.

Another ophthalmologist discussed treatment options and its relationship to the issue of accessibility. The ophthalmologist said, 'although outcomes are better for anti-VEGF, costs have gone up and accessibility has reduced'. This ophthalmologist discussed how there was an upshot with services that were inundated with demand for anti-VEGF injections. The result was a progressively heavier clinical load.

Another ophthalmologist discussed the importance of providing care within an Aboriginal Medical Service (AMS) setting to avoid the local hospital city barriers. These barriers related to the difficulty in navigating the complex pathway of hospitals and a less personalised service.

Teleophthalmology was also discussed by this same ophthalmologist. This was linked to the visiting optometry service (VOS) whereby the client had been seen by the optometrist and then a video call was made to the ophthalmologist. This ophthalmologist reported that Aboriginal clients find this much easier when the ophthalmology call is made at the end of their optometry appointment.

This call was used as an opportunity for the client to meet the ophthalmologist, discuss treatment options and next steps.

### 3.2.3 | Partnerships with key stakeholders

Most ophthalmologists said that the 'key is trying to develop partnerships with the local Aboriginal Community Controlled Health Organisation (ACCHO) and the Aboriginal Liaison Officer (ALO)'. One ophthalmologist described his relationship with the ACCHO and ALO as useful in following up with clients who were hard to reach and coordinating care. Other ophthalmologists discussed the benefit of partnerships with key stakeholders in relation to referral pathways. Working with the ACCHO, the visiting optometrists and personnel at the hospital, helped to facilitate the establishment of clear referral pathways and familiarity of local providers within and outside of the ACCHO.

### 3.2.4 | Timeliness

Two ophthalmologists mentioned 'timely detection' and 'early detection' as a key feature. One ophthalmologist stated 'by screening early, you diagnose the disease early and that can lead to early treatment and better outcomes'.

One ophthalmologist mentioned 'timely referral' as a key feature in providing best-practice DR treatment of Indigenous Australians.

One ophthalmologist mentioned providing treatment to clients in a timely manner. This ophthalmologist suggested that ‘treatment be available there and then’ in remote communities visited. Another ophthalmologist described the challenge of seeing clients within the right timeframe – ‘[we] can deliver [treatment] but need the resources and facilities to be able to deliver it sooner’.

In relation to the issue of timeliness, one ophthalmologist said that ‘care delivered as close to home as possible’ was a key factor to inform DR treatment options. To ensure this was the case, distance was considered when deciding on treatment options.

### 3.2.5 | Integration with primary care

Several ophthalmologists mentioned integrating care into existing primary care services. One ophthalmologist described his own process of integration into primary care when providing outreach. Junior medical staff or registrar clinics would operate from an AMS. This would enable patients to be seen opportunistically. An advantage of integration within the AMS setting mentioned by this ophthalmologist is direct contact and familiarity with local primary care physicians – ‘they know you, the service and what can be done’. However, one ophthalmologist identified the concern with focusing only on integration at an ACCHO level. This ophthalmologist mentioned that most Indigenous clients, particularly in areas of concern – the metropolitan areas – are not seen within an ACCHO setting. He stated that ‘[mainstream] primary care providers need to be integrated into this process [but it is] not happening’.

Further to this, one ophthalmologist also mentioned that General Practitioners (GPs) need to have an increased awareness of clients who have diabetes to have regular diabetic eye checks. The ophthalmologist believed achieving this requires getting GPs to feel confident and have the skills to detect the eye problems in the first place. To encourage this, the ophthalmologist suggested the following: (1) Incorporate eye health at the undergraduate medical level and; (2) Increase the medical education work with GPs on eye health.

### 3.2.6 | Clarity of guidelines

Ophthalmologists mentioned [DRCR.net](#) protocols, NHMRC guidelines and reading of literature informed their decision regarding best DR treatment options for Indigenous clients. One ophthalmologist also commented that these guidelines need to be clear and followed.

### 3.2.7 | Clinician attitude and motivation

There was general motivation and willingness of the participants interviewed to develop and adapt service models to meet community and client need. The ophthalmologists participating wanted to contribute to better eye health outcomes in Indigenous Australians. This was reflected in the type of changes made to their private practice to provide bulk-billed care, introducing priority pathways at hospitals to improve accessibility, and participating in outreach work.

## 4 | DISCUSSION

There is no current published evidence about suitable service delivery models, specific clinical guidelines or funding models to provide appropriate and best-practice DR care to Indigenous Australians. From the interviews conducted with ophthalmologists in this study, we were able to identify seven best-practice features that could be used as a basis to develop recommendations to inform best-practice DR care. The seven features identified were not mentioned by all the ophthalmologists interviewed, although there was a high degree of agreement around certain key features of timeliness, partnerships with key stakeholders and affordability and accessibility. The features emerged from the respondents’ reflections on their own professional experience of what worked well when managing and treating Indigenous clients.

A key feature identified by the ophthalmologists was that guidelines for DR care need to be clear and followed. Reference was made to [DRCR.net](#) protocols and the NHMRC guidelines to inform treatment options. At the time of conducting these interviews, the NHMRC guidelines were available. These guidelines recommended differences in DR screening timeframes for Indigenous clients with diabetes, as these clients have a higher risk of DR.<sup>9</sup> The guidelines also acknowledged the cultural and geographical challenges related to treatment and follow-up in Indigenous communities.<sup>9</sup> The document did not contain specific information on providing appropriate DR treatment care to Indigenous communities considering the differences and barriers faced to accessing care. As the guidelines were published in 2008 and have since been removed from the NHMRC site, there is an opportunity for the Indigenous eyecare sector to provide input and recommendations regarding best-practice DR care to Indigenous Australians.

For the best-practice feature of affordability and accessibility, the importance of provision of medical outreach services (supported by Commonwealth program funding) was commonly raised amongst the ophthalmologists

interviewed for this study. Where the interviewee provided outreach service support at the local ACCHO or within another local community facility, the services were bulk-billed, leaving no out-of-pocket costs for Indigenous clients. By providing care that was as close to home as possible, affordable, and accessible, clients in these areas were able to obtain the DR care required. However, the no-cost ophthalmology model for Indigenous clients under medical outreach is not a mandatory requirement of those programs, particularly under the Commonwealth Rural Health Outreach Fund, and is not universal amongst outreach ophthalmology.<sup>24</sup> Future recommendations for reform could consider amendment to the outreach service delivery standards to enable this.

Given the observation around the motivation and willingness of the participants to develop and adapt their models of care based on Indigenous community and client need, there is potential to further research and analyse the traits and the backgrounds of service providers involved in the provision of eye care in Indigenous communities to influence ophthalmology training, recruitment and distribution into the future.

All seven best-practice features respond to the barriers Indigenous Australians encounter in accessing ophthalmology services.<sup>20–22</sup> Respondents' reflections on challenges faced by Indigenous Australians in accessing appropriate specialist care concur with the published literature. The subsequent strategies devised demonstrate the respondents' direct efforts to overcome known barriers and improve access to DR treatment.

Limitations of this study are the selection bias of informants as all participants were male and all practicing ophthalmologists. A further limitation was our small sample size of eight participants. Due to time limitations and the commencement of COVID-19, we did not have time or scope to seek the perspectives of secondary care providers (for example, optometrists) and primary care providers (including ACCHOs and other AMSs). Our study did not include perspectives from the Indigenous end-user or the Indigenous community. It would be key to contrast our findings with beneficiary groups to understand the current barriers and enablers to culturally appropriate and accessible DR care, and design patient-centred services. Further research of this kind would also greatly contribute towards the development of final recommendations for DR treatment reform in Indigenous Australia.

## 5 | CONCLUSION

This study has provided best-practice features from the ophthalmologists' perspectives that can inform DR service

provision to Indigenous Australians and contribute to the design of future care delivery models. Further research is required to capture other service providers and Indigenous end-user perspectives on appropriate DR models of care. In the meantime, this paper can position the Indigenous eyecare sector to advocate on further research, policy reform, and patient-centred approaches in providing care to Indigenous Australians with DR.

## AUTHOR CONTRIBUTIONS

RG: conceptualisation, data curation, formal analysis, investigation, methodology, project administration, visualisation, writing – original draft preparation, writing – review & editing. RM: conceptualisation, formal analysis, methodology, supervision, visualisation, writing – review & editing. MA: conceptualisation, formal analysis, methodology, supervision, visualisation, writing – review & editing.

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## CONFLICT OF INTEREST

Nil.

## ETHICAL APPROVAL

Research ethics approval was obtained from the University of Melbourne, School of Population and Global Health (MSPGH) Human Ethics Advisory Group (HEAG) on 9 April 2020. Ethics ID: 2056644.1.

## ORCID

Rosamond Gildea  <https://orcid.org/0000-0002-9416-3817>

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## APPENDIX 1: Interview guide for semi-structured interviews

Date of Interview: day/month/year

Participant Unique ID: MPH01

### 1. Participant professional profile

- a. What and where are the places that you work at?  
**Prompt:** outreach services, visiting services, hospital, private clinic
- b. What are your main patient groups?
- c. Are Aboriginal and Torres Strait Islander people within your patient group?
- d. How long have you worked as an ophthalmologist? (text in years)
- e. Of those years, how many of them were seeing Aboriginal and Torres Strait Islander patients?

### 2. Clinical practice and treatment

- a. Do you provide diabetic retinopathy treatment? (Y/N)  
**Prompt:** more than assessment/examination
- b. What treatment options do you provide for diabetic retinopathy?  
**Prompt:** laser, injections, combination
- c. What informs your decision regarding diabetic retinopathy treatment options for particular patients including Aboriginal and Torres Strait Islander patients?  
**Prompt:** drivers, barriers for selecting different treatment modalities; what changes have you observed in treatment preferences across the profession since you commenced practice; to what extent do patient factors such as ability to pay; convenience, time commitment, or other personal

preferences such as comfort, influence your treatment choices?

- d. What is the service model you use when working with Aboriginal and Torres Strait Islander patients requiring diabetic retinopathy treatment (i.e., from consults to treatment)?  
**Prompt:** consult, OCT scans, treatment (laser or injections or both); does it differ from treatment pathways and modalities that you use for non-Indigenous patients?
- e. What would you say are the barriers for Aboriginal patients receiving diabetic retinopathy treatment?  
**Prompt:** access and geographic location cost, availability of bulk-billing, other factors such as cultural or family preferences around treatment?
- f. How would you describe 'leading-practice' (best practice) approach to care for Aboriginal patients with diabetic retinopathy? And what would you say are the key features of a 'leading-practice' (best practice) service delivery model for Indigenous patients with diabetic retinopathy?
- g. What policies, systems and supports are required to deliver this?  
**Prompt:** workforce, equipment, Medicare item for OCT, remuneration, transport, site of treatment
- h. What else needs to be done to improve the care of diabetic retinopathy treatment for Aboriginal and Torres Strait Islander Australians?
- i. How many Aboriginal or Torres Strait Islander patients (estimate) did you provide diabetic retinopathy treatment for in 2019?
  - (i) Of this number how many were laser? What number were injections?  
Alternative is proportion of patients treated with laser/injections.