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## Original Research

# Understanding Indigenous patient attendance: A qualitative study

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### **Abstract**

Objective: To better understand Indigenous patient non-attendance at medical specialty appointments by learning from the patients attending their scheduled outreach ophthalmology clinic appointment.

Design, setting and participants: A qualitative study using face-to-face, semi-structured interviews with 69 Indigenous Australian ophthalmology patients and 8 clinic workers at one urban and one rural Aboriginal Medical Service (AMS) over the period from April 2015 to November 2015.

Main outcome measures: Explored motivations and enablers for attending patients to guide best practice for specialist outreach clinics.

Results: The main themes emerging from the interviews included: clinic staff are persistent in their efforts to organise outreach ophthalmology clinics; both motivated and reluctant patients attend medical appointments; and reluctant patients are more likely to be unaware of their referral pathway. Health literacy and clinic staff triggered the reluctant patient to attend.

Conclusion: Indigenous patients attend their outreach ophthalmology appointments based on various motivations. Clinic staff who recognise reluctant patients can communicate through a sensitive, patient-centred approach that helps the patient realise the importance of the appointment thus creating motivation and promoting attendance. The efforts of the clinic staff, through their patient reminding, transport provision and patient-centred communication suggest that they are the enablers of Indigenous patient attendance at AMS outreach ophthalmology clinics.

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### Introduction

Patient non-attendance rates are a significant and persistent problem for health clinics worldwide. Reported rates of non-attendance ranging from 5% in some family practice clinics<sup>1</sup> to 55% in US primary care settings<sup>2</sup> impact the efficiency of health care delivery both in terms of dollar-cost and health-cost measures.<sup>3,4</sup>

Non-attendance rates are also notable in Australia<sup>5</sup> with some population groups being over-represented. Indigenous Australians, for example, are three times more likely to miss a scheduled medical appointment compared to non-Indigenous Australians.<sup>6</sup>

Most non-attendance studies use structured telephone-administered questionnaires to identify the reasons why people fail to attend. The main reported reasons are: forgetfulness and/or unawareness;<sup>7–12</sup> administrative errors or problems with scheduling and communications;<sup>12,13</sup> and financial and transport issues.<sup>7</sup>

Simply replicating a structured questionnaire targeting non-attending Indigenous patients is unlikely to further advance our understanding of non-attendance involving this demographic. Additionally, such an approach would be logistically difficult as many Indigenous patients living in regional and remote areas are not accessible by telephone and the approach might be considered culturally inappropriate as it may inadvertently assign 'blame' for not attending. Hence, the researchers in this study sought an alternative approach to explore this issue by focusing on how Aboriginal Medical Services (AMS) establish a culture of attendance. This was achieved by conducting interviews with Indigenous patients attending their appointments and the AMS clinic staff. By focussing on attenders, the study aims to identify the motivating and enabling factors that help promote attendance rates and inform best practice.

### What is already known on this subject:

- In Australia, Indigenous patients are three times more likely than non-Indigenous patients to not attend a scheduled medical appointment.
- Literature on this topic concentrates on the non-attender.

# Study context – Why is Indigenous patient non-attendance at outreach ophthalmology appointments so important?

Lions Outback Vision attempts to reduce the barriers faced by regional, remote and Indigenous Communities in accessing specialist care by delivering regular outreach ophthalmology clinics across Western Australia. However, an internal audit of its outreach ophthalmology clinics conducted at 17 AMS throughout the State uncovered an average non-attendance rate of 51% (with rates ranging from 39% to 63%).

Behind refractive error and cataract, the third most common cause of vision impairment in Australian Indigenous populations is diabetic retinopathy.<sup>14</sup>

In Australia, 32% of Indigenous adults have diabetes and about one-third of these people have diabetic retinopathy. Such individuals will not necessarily be aware of their vision-threatening diabetic eye change until permanent vision loss occurs. Current National Health and Medical Research Council guidelines recommend that Indigenous Australian diabetics undergo an eye examination annually. 16

The implementation of the 'Roadmap to Close the Gap of Vision' requires the assessment of eye health, detection of vision debilitating conditions and subsequent management.<sup>17</sup>

Outreach services at many Indigenous Communities are limited and therefore attendance rates are an important factor to achieve guideline targets.

### Methods

### Design

In the development of an alternative approach to explore the complex issue of non-attendance, two criteria were prioritised: the respectful treatment of interview data to ensure that the voices of Indigenous patients were paramount; and a transparent and rigorous approach to qualitative analysis.

A qualitative design was used to explore the issue of non-attendance from the attending patient's

### What does this study adds:

- Through appropriate clinic staff patient communication, reluctant patients can become motivated outreach medical appointment attenders.
- Through their patient reminding, transport provision and ability to detect reluctant attenders, Aboriginal Medical Service clinic staff appear to be the enablers of Indigenous patient attendance at ophthalmology outreach appointments.

perspective. Face-to-face, semi-structured interviews with 69 Indigenous patients and eight clinic staff were conducted so that participants could express themselves and their points-of-view freely, in a way that a structured questionnaire would not allow.

Table 1 displays the characteristics of the interviewed patients according to their location, gender, age and diabetes status, and appointment type. Of the 35 urban participants, nine were rural patients temporarily residing at an urban health hostel.

The interview schedule was developed in an iterative process with reference to the predictors of non-attendance as detailed in the literature. For patients, the interview schedule covered their knowledge of the referral process and appointment notification, appointment motivations, factors affecting attending, previous non-attendance history and eye health literacy. The final interview schedule was prepared after a short-list of open and closed questions was developed, peerreviewed and piloted. For clinic staff, the interview schedule was adapted to suit clinic coordinators, transport officers and reception staff involved in the delivery or coordination of the ophthalmology clinics.

All interviews were digitally audio-recorded and transcribed verbatim. The accuracy of the transcripts was checked by a second researcher. All but four patients consented to participate in the study, with another consenting to the interview but not the

**TABLE 1:** Patient participant characteristics (n = 69)

Characteristic	Description
Urban:Rural	35:34
Gender (M:F)	26:43
Age range (years)	30-82
Appointment type (initial : review)	23:46
Number of diabetics	61

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recording of it. In this instance, the interview was transcribed contemporaneously.

Research participants were recruited from patients attending Lions Outback Vision's ophthalmology appointments in two outreach clinic locations – one urban and one remote.

In line with the guidelines for the ethical conduct of research in Aboriginal and Torres Strait Islander health contexts<sup>18</sup> key staff at the health clinics were contacted for input and feedback into the design and delivery of the research. Support letters for the research were received from the two sites. Ethics approval was obtained from the Western Australian Aboriginal Health Ethics Committee (approval no:605) and reciprocal approval was acknowledged by the University of Western Australia.

Interviews were conducted over an 8 month period, allowing for data collection from four clinic sessions in the urban location and three clinic sessions in the remote location to ensure theoretical saturation was met.<sup>19</sup>

### **Analysis**

An inductive analytical approach was used, enabling the data itself to drive the structure of analysis.<sup>20</sup> The process involved analysing the transcripts, identifying key themes within the data and categorising the emergent themes. Coding was done manually and organised into emergent themes with the assistance of NVivo (version 10.0; QSR International Australia, Victoria, Australia). Following this, the coding framework was verified and confirmed by a second researcher and the list of themes was workshopped with peers to ensure transparency of the method.

### Results

## Patient awareness about the referral pathway and their appointment

About one quarter of patients (18/69) recalled a doctor or optometrist having told them that they needed to see an ophthalmologist. One half (33/69) recalled someone from the AMS telling them about needing to see the ophthalmologist, while the remaining patients (18/69) could not recall who advised them about the need to see the ophthalmologist. The majority of attenders (63/69) learned about their appointment inside a week of their appointment.

### **Transport**

Almost two-thirds of patients (42/69) reported relying on the provision of transport to enable them to attend their ophthalmology appointment. Half of these patients indicated that they would not have attended if it wasn't for this provided transport.

#### Patient motivations

The majority of the participating patients in the present study were motivated to attend (65/69) with some offering multiple motivations to attend. These could be classified into one of seven categories which are provided in Figure 1.

### Previous non-attendance

Thirty-five patients recalled missing previous medical appointments. The three most common reasons for this were: other commitments (out of town, at work, other appointments; 14/35); lacked transport (7/35); or that they forgot or were unaware (7/35). Figure 2 displays all categorised explanations offered.

### **Enabling strategies**

Further insights into patient attendance were elicited through the patient and staff interviews. It was apparent that clinics deliberately give little notice about upcoming scheduled ophthalmology appointments, as evidenced by the following quote:

Sometimes it's one day out, so sometimes it might even be the day before. Cause, our patients, if we tell them a week before they won't remember to come. (Rural staff, #2)

While this is effective in minimising forgetfulness, those who have advanced plans to be 'out of town', 'at work' or planning 'other appointments' might miss these appointment opportunities as reflected here:

And being told on that day, or the day before, which is very, to me, is not good enough... That's it, not enough notice, because, especially people who work, they have to notify the workers. (Rural patient, #28)

The methods of receiving notification about the appointment include email, phone call, mail-out, in person reminders and hand-delivered appointment cards. More than one method of contact is employed. Clinic staff have learned to be persistent in contacting patients to inform and remind them about upcoming appointments. The examples below showcase this:

And we've also found giving people things in envelopes, they don't open envelopes. So that's why we now have a little card that we've made up and hand deliver and they can see it as soon as they get it. (Rural staff, #2)

- 1. curiosity, or looking for reassurance regarding their eyes (23 references). "Cause when they took my photo the last time they said it had changed slightly, so yeah, bit concerned about that. I just want to know if it's something I should be really worried about or if it's just something that happens over time". Rural patient, #9.
- 2. being symptomatic (22 references). "I did, yes, ahh, because my vision is not a hundred percent, I know that." (Urban patient #35)
- 3. recognition of the consultation being part of a preventative medicine approach (17); "... It's ahh, your eyesight is something you don't muck around with. It's very important, you know you lose your eyes you virtually become very, very incapcitated." (Rural patient, #10),
- 4. an expectation that they would receive glasses (7); "Yeah, they going to see me for my eyes and they going to give me eye glasses. Before I asked them for eye glasses." (Urban patient #5)
- 5. having missed previous opportunities to have the consultation (6); "... well, I have been seeing Dr X, but I haven't, um, kept up with that last appointment so I thought I'd better make sure I get back and see him..." (Urban patient, #29)
- 6. being adherent (6);
  "Well, I told one of the clinic in Karratha, who look after me for diabetic side. And she said 'you got to go and see a specialist.' That's why I decide to come." (Urban patient, #23)
  "Well I suppose I had no choice did I?" (Rural patient, #28)
- 7. that they had no other conflicting engagements or commitments at the time of the appointment (3). "Oh well. Nothing else to do at home." (Urban patient, #24)

FIGURE 1: Motivations for attendance, in order of frequency.

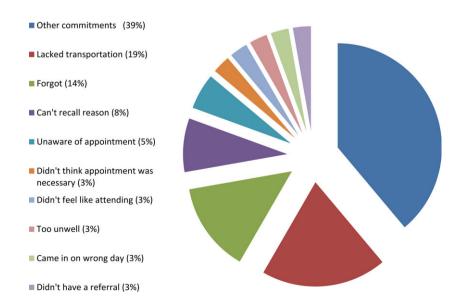


FIGURE 2: Prevalence of reasons for previous medical appointment non-attendance recalled by Indigenous patients.

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So we call them, send a card out, send a message and, yeah, the three main things, that's what we do. (Rural staff, #3).

Clinic staff utilise the local knowledge of transport officers, crediting them with much success in enabling patient attendance.

...our transport being local and grew up here they pretty much know where to go and how to find them...They know all people. ...Without them, we wouldn't be able to get our patients. (Rural staff, #3).

Staff reveal that they contribute to patient attendance in three ways: reducing patient barriers to make it as easy as possible to attend; being persuasive without being forceful; and by appealing to the patients' values and linking how preserving their vision will preserve what is dear to them. The pitch to patient values is exemplified in the following quote:

I look what's on their walls, in their space, see what's close and important to them. I ask about who's this, their pictures, their writing. The main thing is their kids and grandkid photos. I tell them if you don't get your eyes checked you won't be able to see them. An example today was JL. He wanted to go banking. I said, if you don't come in, in a couple of months you won't be able to see your banking. You need to see eye doctor for your eyes. (Urban staff, #5)

### Combatting reluctance

During the interviews, four patients admitted that they did not really wish to be at the ophthalmology appointment. The patients were 'reluctant attenders' despite the fact that they knew diabetes could cause blindness. Among this group, one patient recalled that it was a doctor or a nurse that advised him about the need for his ophthalmology appointment saying: 'They were worry about everything.' This same patient drove himself to the appointment and demonstrated his diabetic health literacy in this quote:

Try to eat traditional food when I can... It's taking tablets regularly, morning and, you know. It depends on what doctor describes, description and yeah, what sort of food you eat, sort of.

He expressed his reluctance to attend because he knew, from previous experience, that the eye drops burn and that the appointment can be lengthy. Triggering him to attend was his own realisation about the benefit of the ophthalmology appointment:

But in a way it's good for me keep a, you know, keep a check on my eyes and saying what's happening you know

The other three reluctant attenders were hostel residents who were completely dependent on clinic transport, lacked awareness about who had referred them and were generally perplexed about why they were at the clinic for the appointment:

No, they didn't say about my appointment. Only they told me to jump on. (Urban patient, #32)

I thought we were going up to the bank. (Urban patient, #4)

Their reluctance relates to their belief that the appointment was unnecessary or they were feeling too poorly to prioritise it. The strongest statement against attendance was demonstrated by an urban patient who said:

I don't know these, you know, really business about appointment and everything. I say to myself, I'm all right, what the heck I don't want to go and get it checked out or do anything. I'm all right going with my own life. It's my life, that I'm thinking about, it's not theirs. Why the heck do I want to waste time going up to appointment? (Urban patient, #4)

### Discussion

Interviews with the attending patients in this study revealed that the majority were in fact motivated to attend. In most cases, patients prioritised attendance because they perceived the appointments to be of value to them either because they were symptomatic, concerned or recognised the need for regular checkups. The most telling finding that emerged from the interview data was that a number of patients were 'reluctant attenders' and could quite easily have become non-attenders. The fact that they attended despite their reluctance makes their perspectives particularly valuable and worthy of discussion.

Lack of referral awareness and understanding about the need for the ophthalmology appointment was common amongst the reluctant attenders. This suggests that effort is required to inform patients prior to their appointment about what has led to the need for ophthalmology attention. Similarly, if the specialist wishes to review the patient they should communicate in language that reinforces why this is important. Such an approach will promote health literacy. After all, it was health literacy that self-triggered Rural patient #13 to overcome his initial reluctance to attend.

Clinic staff interviews revealed that they invest a lot of effort into the organisation and running of outreach clinics. Through experience they acknowledge the disablers to attendance being patient forgetfulness, transport difficulties and the mobile nature of patients. Clinic protocols currently attempt to neutralise these attendance barriers by using timely and varied communication methods and employing local transport officers to locate patients. Additionally, it was revealed that staff can often recognise patients who are reluctant to attend and how they attempt to quell this reluctance by informing patients about how the appointment is linked to vision preservation and what this means for the individual's values and priorities. This is an example of a patient-centred approach.<sup>2</sup> It emphasises the importance of the clinic-patient interaction prior to an appointment and suggests that the clinic is the enabler of patient attendance.

The issues identified in this paper are unlikely to be unique to ophthalmology clinics. Other health services have similar concerns regarding attendance rates.<sup>21</sup> Information sharing with clinic staff, especially around enabling strategies highlighted here, is needed to support and facilitate a culture of attendance in outreach clinics.

In conclusion, Indigenous patients attend their outreach ophthalmology appointments based on various motivations. Reluctant attenders are enabled to attend with the help of clinic staff who recognise this reluctance and communicate with these patients using a sensitive, patient-centred approach that helps the patient realise the importance of the appointment thus creating motivation. The efforts of the clinic staff, through their patient reminding, transport provision and patient-centred communication suggest that they are the enablers of Indigenous patient attendance at AMS outreach ophthalmology clinics.

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### Author contributions

Study conception and design: SC. Data analysis and interpretation: SC, JM. Manuscript preparation and critical revision: SC, JM, AT.

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