



The Fred Hollows  
Foundation

THE INDIGENOUS AUSTRALIA PROGRAM'S  
**CASE STUDY**

**Intensive Eye Surgery Week**

**“The tyranny of distance –  
The family in this case study  
traveled over 2000 kilometers  
to receive treatment and  
return home”**

In June 2015, a 3-year old boy from a remote community in Central Australia received sight-saving eye surgery during an Intensive Eye Surgery Week in Alice Springs. There were numerous barriers that almost prevented this surgery from going ahead; the family moved to a different remote community, the boy's father possibly had a negative experience with eye surgery in childhood, the patient transport system did not allow two carers to travel with one patient and cultural and language barriers prevented the father from accessing information in order to provide informed consent. Thanks to the dedication of the Indigenous Australia Program (IAP) staff members, there was a happy ending to this story. This story highlights a number of barriers that are common to Aboriginal and Torres Strait Islander people receiving eye surgery. There is a need to develop and advocate for solutions to minimise these barriers.

## 2 MONTHS PRIOR TO SURGERY

IAP was notified of the boy's need for surgery as he was placed on the waiting list provided by Alice Springs Hospital (ASH) Eye Clinic. Through the community clinic the boy was offered surgery to correct dislocated lenses in both eyes, brought about by a co-morbid chronic health condition.

Soon after this, IAP utilised existing contacts and relationships to discover that the boy and his family had moved to another community (880 km away), so IAP contacted the community clinic in this community, whilst keeping the first community clinic updated.

Aboriginal people are generally mobile and often travel to different communities throughout the NT. This is attributed to the various cultural and traditional ties that are shared between clans, which criss-cross the NT and communities over the WA, SA and QLD borders.



## 1 WEEK PRIOR TO SURGERY

IAP staff members travelled to the patient's community and met with the family and staff at the local clinic. It was discovered that although the boy's mother was willing to consent to the surgery, his father was very apprehensive. This was due to the young age of his son, who was born with a life-threatening chronic health condition that affects his heart. The father was fearful about how the bilateral procedure might impact his health. It was later discovered that the father had a similar operation when he was young, as it was a hereditary condition. It was highly possible that this surgery had been a negative experience for this man.

The boy's father refused to give consent for surgery, however, he did agree for the mother and child to travel to ASH during the Intensive Eye Surgery Week for an ophthalmologist review. He felt that the boy was too young for the surgery and had a fear that he would not survive, due to his chronic health issues. The father expressed his intention not to travel to Alice Springs with the boy and his mother. The Patient Assisted Travel Scheme (PATS) policy is that only one escort/carer may travel with the patient, so the father would not be covered for travel and accommodation for the journey.

Alice Springs is 640 km away from the community. IAP managed to negotiate for a larger charter flight to be booked, in a shared arrangement with PATS Alice Springs, and asked the community clinic staff to convey to the family that there was an opportunity for the father to travel in to Alice Springs, if desired. The IAP offered to cover the associated expenses of accommodating the additional parent and travel costs, in order to assist in providing every opportunity to support and encourage him to be part of the patient's journey.

The offer of surgery and booking date were kept open on the theatre schedule, with the understanding that there would be more opportunity to provide further information, with the hope, that the father may reconsider and consent to surgery.

## TRAVELLING TO ALICE SPRINGS

On the scheduled day of the charter flight from the remote community to Alice Springs, IAP were advised by the community clinic staff that both parents had boarded the flight with the boy. This enabled an opportunity to further engage with the parents on appointment day.

IAP arranged for the Ophthalmologist to brief a male Aboriginal Liaison Officer (ALO) from ASH on the boy's condition and procedure. This particular ALO was specifically identified for involvement, in keeping with cultural safety and observation of strict kinship rules in Central Australia. These measures are crucial, in supporting the patients to navigate through the mainstream health system.

The complex kinship system in Central Australia strongly influences how people relate to each other and determines behaviour patterns and the level of social interaction with other kin. Gender is also a major factor of the social organisation under the kinship system. It is more preferable in Aboriginal society for men to confer with other men. In this case, the ALO had the appropriate kinship relationship and key language skills required, to directly support the parent. In turn, the parent was able to participate more comfortably in the decision making process, leading up to the surgery. The fact that he was a male was also very important to ensure the father felt comfortable with this interaction, and be able to ask the questions he needed to ask.

When the family arrived in Alice Springs there was an issue regarding the accommodation for the father that was related to the PATS guidelines. This was resolved by the IAP by negotiating with the hostel.

The ALO was unavailable to attend the initial review appointment so IAP arranged for the appointment to be rescheduled so that the ophthalmology team, the parents and the ALO could meet and provide as much information as possible to the parents for them to make an informed decision in relation to their son receiving surgery.

## AT THE REVIEW APPOINTMENT

Before the meeting, IAP staff and the ALO asked the parents if they had any questions or concerns. The father had a number of relatively basic but significant questions which were written down for the ALO to ask the ophthalmologists. The questions related to the duration of the surgery, whether they could accompany their child into theatre, whether admission overnight was required, the length of time required in Alice Springs and whether the surgery would be on one or both eyes. There was a perception that these questions had not been properly answered or addressed with the family since the patient's referral and likely contributed to the father not giving consent.

The second meeting occurred, with further reassurance and discussion from the ophthalmology team, and support from the ALO. Information was able to be effectively communicated between all parties at this stage. However, at this point, there was still no indication of informed consent being given for the child to have surgery, and IAP staff took the family back to their accommodation.

## DAY OF THE BOOKED SURGERY

On the day of the booked surgery appointment, IAP staff went to the accommodation to pick up patients and transport them to Alice Springs Hospital for their respective appointments. The boy and his parents were waiting with the group. They were transferred to the hospital, and on arrival, the parents asked for assistance to book the boy in for surgery.

The patient had his surgery successfully completed.

# PATIENT JOURNEY



# BARRIERS TO EYE HEALTH CARE

This case study demonstrates a number of the barriers that Aboriginal and Torres Strait Islander people can face on the eye health care patient journey. These, and other barriers identified through IAP projects and the literature, are summarised below:

Barriers to Eye Health Care for Aboriginal and Torres Strait Islander People	Example of this barrier in the Case Study	How barrier was overcome in this Case Study – Solutions
Differing perceptions and understandings of health and illness, including the way health and illness are conceptualised and expressed within Aboriginal and non-Aboriginal contexts.	In initial stages of referral, limited support mechanisms for cultural safety and consideration of the Aboriginal 'world-view' of health and illness, were considered along the patient journey.	As determined through cultural protocol, a male ALO, who shared the appropriate kinship and cultural ties was engaged. He assisted with explaining the procedure and answered the father's questions. Assisted with explaining the procedure and allowing the father's questions to be answered.
Systemic communication barrier between Aboriginal Australians and health professionals, which may lead to feelings of fear and anxiety regarding treatment.	Information about the procedure was not explained in a way that the boy's father was able to understand.	A male ALO assisted with explaining the procedure and answered the father's questions.
Lack of cultural competency amongst health professionals, leading to poor communication with patients and a lack of regard for patient's particular needs.	It is not sure whether there was a lack of cultural awareness amongst the health staff in this particular case study.	The presence of the male ALO could have assisted with this. IAP involvement, knowledge and ensuring access to the ALO for this patient-centred approach contributed to a successful outcome.
Dominance of the Western Biomedical approach, which leads to treatment interactions involving the use of unfamiliar clinical terms.	The boy's father was not able to understand unfamiliar clinical terms relating to his son's surgery. Considerations not given to father's background, ie - not in his 'home' community, difference in language groups and mainly being addressed by female clinic staff.	A male ALO assisted with explaining the procedure and answered the father's questions.
Issues associated with relocation for treatment, including long distances, foreign environments, and restrictive patient travel policies.	Both parents were initially unable to travel with their son for surgery, due to restrictive patient travel policies. There was also issues with the accommodation booking for the father.	IAP was able to facilitate the booking of a larger plane, and assisted with the cost, to allow both parents to travel. IAP also sorted out the accommodation issue.
Distrust due to negative experiences, including negative experiences of others, sometimes resulting in fear and communication issues.	It was likely the father had a negative experience as a boy undergoing a similar surgery.	A male ALO assisted with explaining the procedure and answered the father's questions.
Competing priorities and obligations, including family, social and cultural obligations which may be prioritised over individual needs such as engaging with treatment.	It can be assumed that this was not a barrier in this case.	

# IMPLICATIONS FOR IAP

The IAP was able to assist this family to successfully navigate the barriers to access eye care. However, IAP is aware that there are potentially many other cases where Aboriginal and Torres Strait Islander people are facing similar barriers to eye health care.

Identification of some of these barriers has been an important exercise for IAP, and potential solutions for some of these barriers have been considered in 2016 programs. This includes the development of a health literacy research project to investigate barriers to access to eye health care, as well as working on developing indicators to measure factors that may impact on these barriers to eye health care.

**“Through anticipating as many factors as possible and removing as many barriers as we could (within reason and scope), facilitating an opportunity to enable the father to voice his concerns and questions was immensely beneficial for the family, as he was able to then make an informed decision and consequently consented.**

**This seemed to have a flow-on effect, as a result of the open communications, including having things explained to him in his own language and by someone who shared a level of kinship with him in the region.”**

IAP Staff member

