

# **Line of Sight**

**Evaluating the Impact of the Lions Outback Vision Program** 

Research Report | 2017

## 1 Introduction

## 1.1 Project Objectives

People living in regional, remote and Aboriginal communities of Australia face significant health disadvantage. Generally, they have a higher prevalence of risk factors and disease, and poorer access to health providers and services compared with other Australians<sup>1</sup>. Furthermore, the differing social and economic circumstances of these communities can greatly influence and perpetuate this disadvantage. Outreach service delivery is key to bridging this gap and has been endorsed as an important global strategy to promote equitable access to health care<sup>2</sup>.

In Australia, outreach is an integral part of national eye health policy and service delivery. Pioneered by the professional interest and personal commitment of Ida Mann, Frank Flynn and Fred Hollows among others, outreach eye services exist in all states and territories, though the models of service delivery vary.

While it is generally accepted that outreach visits are an important and appropriate part of delivering efficient, equitable and effective eye health services<sup>3,4</sup>, there is limited evidence substantiating the long-term health and social impact of such programs, and no agreed methodology that allows for the comparison of differing service models.

This report presents the findings of a project to evaluate the effectiveness and impact of the Lions Outback Vision (LOV) Program. It focuses on understanding whether, and how, health and social change has occurred, and seeks to identify a range of appropriate indicators to measure the extent of this change.

## **1.2** Approach to Measurement

To fully assess the importance, effect or value of a program, numerical data must be presented alongside other information such as the story of how change is being created. As such, organisations and decision-makers are increasingly looking toward social impact assessment to understand if they are making a difference and guide the allocation of scarce resources. Determining and measuring this impact is challenging, largely because of the multifaceted nature of outreach activities and outcomes that are difficult to apportion. One approach that has become increasingly popular is Social Return on Investment (SROI).

SROI is an internationally recognised methodology used to understand, measure and value the impact of a program or organisation. It is a form of cost-benefit analysis that examines the social, economic, cultural and environmental outcomes created and the costs of creating them<sup>5</sup>.

A modified SROI methodology was determined to be the most appropriate approach for this project, as informed by the following tasks:

- A review of national and international outreach literature to identify relevant methodologies.
- The collation of existing eye health program measures and national benchmarks.
- An analysis of available LOV Program monitoring data to determine the feasibility and reliability of measures.
- Consultation with subject experts, such as the Centre for Social Impact UWA, for advice and guidance.
- Consideration of the cultural context and applicability of approach.

The benefits of this approach are:

- It takes an equity focused approach in that it is patient-centred and participatory which is in line with the approach of the LOV Program.
- It can incorporate a holistic Aboriginal perspective on the health and wider benefits of service delivery, rather than being confined to Western biomedical definition of health benefits.
- Reporting using SROI requires the inclusion of both monetised values as well as qualitative information, which contextualises and validates both the cost and benefits. This approach enables a

deeper understanding of the operating context as well as the benefits of service delivery from Aboriginal perspectives.

- It utilises existing data already collected for the program.
- It takes an outcomes-orientated approach that is compatible with the existing program model.
- It aligns better with the design of the program and the requirements for the analysis than other methods considered.
- The method could be adapted and replicated in other outreach settings.

Broadly speaking, the approach chosen articulates and links inputs (the resources that go into a program), activities (what the program does), outputs (the number of people, places supports and activities the program has produced), outcomes (what changes have occurred) and impact (long term change).

Figure 1. Steps in SROI Process



#### 1.3 Data Sources and Methods

Data in this report has been sourced from a wide range of datasets, including quantitative and qualitative. All quantitative program data was collected by retrospective audit. Input, activity, output and outcome data measures were obtained from statement of accounts, funding agreements, billing and clinical record systems, and independent analysis of published and unpublished LOV literature, reports and documentation.

To supplement these measures, the report incorporates the findings from a qualitative study completed in the Pilbara investigating patient and health worker perspectives on LOV Program impact. The qualitative study sought to provide a richness and depth to the data that is not always easily identifiable in quantitative data collection. An independent research consultant and LOV's Aboriginal Eye Health Coordinator conducted the study over a two-day visit to Karratha and Roebourne, arranged to coincide with a scheduled LOV outreach ophthalmology service to maximise participant recruitment and engagement. Feedback was gathered by 'clinical yarning' - a culturally meaningful communication style characterised by relaxed, open-style conversation with storytelling as the medium to discuss health issues.

## 1.4 Scope and Limitations

To adequately assess the impact of the LOV Program, the project area was encapsulated in the Pilbara region of Western Australia. This allowed data to be assessed over a six-year fiscal period from 2011 to 2017 without introducing variables that would exist if the study was completed over several regions.

In reviewing the information within this report, it is important to note the considerable limitations in data collection, synthesis and analysis including:

- The variation in LOV data collection tools and data entry personnel over time affecting data comparability.
- Under-identification of Aboriginal people in the available data sets.
- The lack of more granular level data available for analysis, particularly in earlier years.
- Incomplete data sets data items not recorded at certain points in time or recorded inconsistently thus impacting on the validity of the data.
- Unknown activity of other service providers, making it difficult to provide an accurate reflection of LOV contribution and whole region activity.
- Qualitative study recruitment was limited to ethics approved locations.

Whilst the opinions of qualitative study participants cannot be considered representative of all stakeholders in the region, many of the study's key findings have also been drawn in similar bodies of previous LOV research.

This suggests the findings could potentially resonate across the regions, and can be reliably used to support the analyses.

While this report describes the input, activity, output, outcome and impact of the LOV Program, it recognises many benefits cannot be reliably quantified and may be culturally inappropriate to monetise. Acknowledging these sensitivities and limitations, the modified approach follows the SROI methodology, presenting the underpinning steps of the research process, but stops short of attributing value to all measures and calculating a SROI ratio.

## 1.5 Structure of the Report

The report is divided into four chapters. Chapter 1 introduces the purpose of this report. Chapter 2 provides a snapshot of eye health inequities, the Pilbara region and the Lions Outback Vision Program as background for the analysis. Chapter 3 examines the findings of the modified SROI analysis. It provides insight to the critical success factors of the LOV Program, highlighted in patent and provider stories from the field. Finally, Chapter 4 reflects on the broader impacts and opportunities to achieve improved eye health outcomes, and presents recommendations for action.

## 2 Background

## 2.1 The Great Inequity

The persistence of avoidable blindness among regional, remote and Aboriginal people is largely a problem of unequal access <sup>6</sup>. Despite the existence of effective treatments, overall service provision is constrained by financial and physical resources, which disproportionately affect the disadvantaged and most vulnerable.

90% of vision impairment and blindness in Australia is preventable or treatable  $^{7}$ .

Regional and remote residents needlessly suffer higher rates of blinding eye diseases, as well as conditions that have gone undiagnosed due to a lack of eye care services<sup>8</sup>. Moreover, Aboriginal children are born with better vision than their non-Aboriginal peers however by the time they reach adulthood, they are 3 times more likely to be blind or have low vision; 12 times more likely to have cataract related blindness and 14 times more likely to have diabetes related blindness. Despite this, regional and remote populations are less likely to have seen an eye care provider compared to urban populations, and an alarming 35% of Aboriginal adults have never had an eye examination <sup>9</sup>

Access to comprehensive eye health care services is critical to early detection and treatment, but specialist eye services are up to 19 times less available in regional WA than the Australian average<sup>10</sup>. Currently demand for specialist eye services in WA is met by transferring 4,800 patients per year to urban ophthalmologists and providing periodic outreach services by visiting specialists to rural areas, at a total cost of over \$3 million per year<sup>8</sup>. The effectiveness of such approaches however is limited because many Aboriginal patients are unwilling to move 'off country', and a more regular specialist presence is required in the regions to meet service demand.

## 2.2 Understanding the Community: Pilbara at a Glance

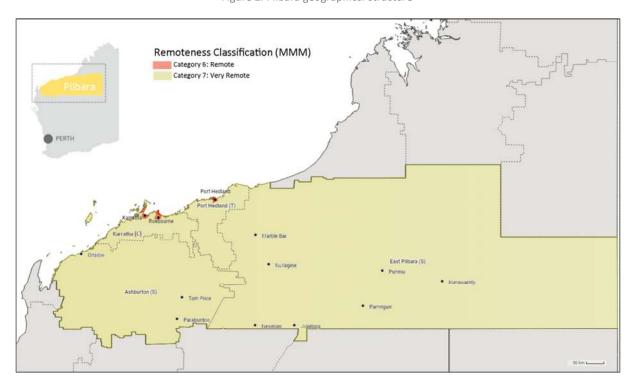
The Pilbara is one of the largest regions in Western Australia (WA) accounting for 20% of the state's total land mass. Its vast 507,896 square kilometres comprises two Health Districts (West and East Pilbara) or four Local Government Areas (the shires of Ashburton, East Pilbara, Town of Port Hedland and City of Karratha <sup>1</sup>).

Approximately 1200km north of Perth, most of the region is classified <sup>2</sup> as very remote (Figure 2). Accessibility to and from smaller towns and communities is often only possible with 4WD vehicles and light aircraft, and this too is subject to the volatile extreme weather conditions particularly during the wet season (October to March). Subsequently the region is largely reliant on visiting services, digital health technologies and travelling great distances to regional hubs and Perth for care. This involves the inconvenience of time away from family and employment, which is often associated with further emotional and financial impacts.

<sup>&</sup>lt;sup>1</sup> Formerly known as the Shire of Roebourne but renamed and granted city status on 1 July 2014.

<sup>&</sup>lt;sup>2</sup> As defined by the Modified Monash Model (MMM), a newer classification system that better categorises metropolitan, regional, rural and remote areas according to both geographical remoteness and population size.

Figure 2. Pilbara geographical structure



#### 2.2.1 Who Lives in the Pilbara?

Pilbara's demographic profile is strongly linked to the region's economic activity. Boasting a wealth of natural resource assets dominated by iron ore and natural gas, the region is known as the economic powerhouse of Australia. The 2008-2012 mining boom saw an influx of fly-in fly-out (FIFO) workers and the largest resident population growth of anywhere in Australia. In this period of unprecedented growth, regional infrastructure and services lagged as living and business costs soared.

Today 59,552 people call the Pilbara home<sup>3</sup>, in addition to an estimated 20,000-strong FIFO workforce<sup>12</sup> and seasonal visitors. Compared with WA as a whole, the Pilbara resident population is younger (median age 33 Pilbara, 36 WA) and made up of a significantly higher proportion of males (61% Pilbara, 50% WA)<sup>13</sup>.

Aboriginal persons account for 14% of Pilbara's population (n. 8313), significantly greater than the 3% state average. Most (70%) reside in the larger regional centres and towns, with others living across the 8 town-based reserves and 16 remote communities. Compared to the non-Aboriginal population, the Pilbara Aboriginal population is considerably younger but more gender balanced (median age 26, 52% male)<sup>13</sup>.

#### 2.2.2 Health Workforce and Infrastructure

Infrastructure and services are concentrated in the key population centres of the region (Karratha, Port Hedland and Newman) with great distance to other smaller town centres and Aboriginal communities. High costs in regional centres and low population densities across the remainder of the region often make it unviable to support locally operated eye health services. Local healthcare is provided through a mix of government and private services including general practice, allied health, hospital, community and Aboriginal Medical Services (AMS).

The 'hub and spoke' model is the standard delivery model for public health service provision across Country WA. In the Pilbara, Hedland Health Campus in South Hedland and Nickol Bay Hospital in Karratha, act as the regional 'hub' and referral centres for diagnosis, secondary level acute and surgical health services. Similarly, a service and administrative 'hub' in an AMS network will span several remote outreach community clinics (Figure 3).

<sup>&</sup>lt;sup>3</sup> Place of Usual Residence (PURP), 2016

A number of private optometry practices provide local and visiting services to the larger Pilbara towns of Port Hedland, Karratha, Pannawonica, Tom Price, Paraburdoo, Newman and surrounding communities. This includes three commercial optometry providers based in Karratha (2) and Port Hedland (1) and other Perth based visiting providers. Services may be supported through the Visiting Optometry Scheme (VOS) in areas of need, or delivered under private corporate arrangements. There are no resident ophthalmology providers in the region.

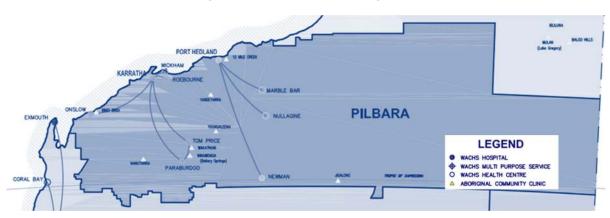


Figure 3. Pilbara health service configuration

While the 'hub and spoke' model helps to maintain service delivery levels in the face of challenges such as workforce shortages, high staff turnover and widely dispersed populations; limited transport options still mean extremely long travel distances and times for both providers of outreach services and patients seeking care (Figure 4).

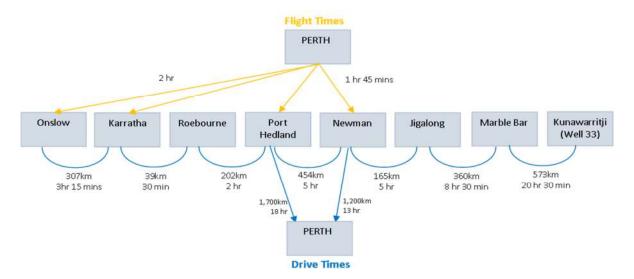


Figure 4. Pilbara drive and flight times

#### 2.3 Lions Outback Vision

Lions Outback Vision (LOV) was established in 2010 with the support of the Lions Eye Institute and the University of Western Australia. As the outreach arm of the Institute, LOV is firmly committed to preventing blindness and vision loss among regional, remote and Indigenous Western Australians.

A current provider of outreach eye health services throughout much of the state, LOV believes that all Australians should be able to access comprehensive and appropriate eye health care services irrespective of where they may live.

Together with partners and supporters, LOV aims to address the unique challenges of delivering equitable and quality eye health care to regional, remote and Aboriginal communities across our state with the development and implementation of innovative and sustainable models of service delivery.

#### 2.3.1 Model of Care

The LOV Program recognises the widely differing health needs of regional, remote and Aboriginal communities and the importance of integrated care to ensure people get the right care, at the right time in the right place.

The novel model of care developed by LOV supports collaborative care between optometry, ophthalmology and frontline health services (Figure 5). It is focused on building relationships between professions and health services - bringing the three streams of eye health together to improve patient outcomes: diabetic retinal screening, optometry and ophthalmology. Uniquely, LOV is a provider of each stream of care, but also collaborates with local and other visiting providers to deliver efficient and effective services.

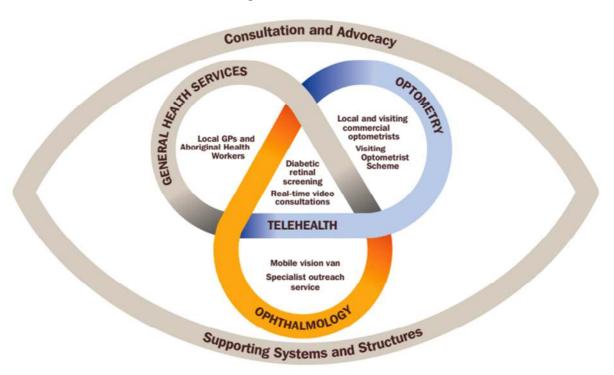


Figure 5. LOV model of care

It is a comprehensive and integrated approach to delivering care, extending across the patient journey through different care providers. A combination of innovative service delivery models such as telehealth and a mobile eye health facility augments traditional face-to-face optometry and ophthalmology services.

Importantly, the LOV Program model is underpinned by robust systems and structures including an integrated electronic medical record (EMR), and a commitment to wide consultation and evidence-informed advocacy.

The model has evolved over time, driven by research and changes in local community needs, policy and workforce composition, that has led to the development of new services and modalities (Box 1).

## **Box 1. LOV Program Timeline**

A series of key interventions, service developments and policy changes have shaped the evolution of the LOV Program within the Pilbara region.

- 2005 **Visiting Optometry Services Established**: Northwest Eye Program (NWEP) establishes visiting optometry services in Pilbara, under the Visiting Optometrists Scheme (VOS).
- 2010 Lions Outback Vision Established: Focused on outreach eye health service provision.
- New surgical services established in Karratha funded by IRIS program.

**GP Telehealth Rebates:** New MBS items and incentives introduced for GP to specialist videoconferencing consultations

**Diabetic Retinal Screening Commences:** Wirraka Maya Health Service is first Pilbara site to commence DR screening.

2013 **Integrated Optometry:** Lions Outback Vision takes over management of VOS from NWEP, strengthening eye health service coordination.

**Surgical Intensives:** Surgical service established for Aboriginal patients in Jigalong and surrounding communities to address cataract backlog.

2014 **DR Coordinator:** Regional coordinator role introduced to support diabetic retinopathy screening.

**Stimulated Uptake:** LOV introduces multifaceted intervention to increase VC uptake. Includes online booking portal, logistical support and optometrist remuneration.

FHF Fellowship Position Commences: An annually funded position for an ophthalmic Fellow.

Surgery Expanded: LOV takes over surgical services from Dr House in Hedland.

2015 Targeted Support: Indigenous Eye Health Coordinator (IEHC) position established.

**State Fund holders**: DoH introduces new program administration arrangements appointing Rural Health West as WA fund holder for optometry outreach.

2016 **New Optometry MBS:** LOV successfully advocates for new MBS optometry items, supporting optometrist reimbursement for telehealth services.

**Statewide Pilot:** LOV and WA Health project commences to increase access to specialist ophthalmology services via telehealth technologies.

**Lions Outback Vision Van Launched:** A state of the art mobile clinic delivering eye health services to 16 (later expanded to 20) regional communities.

2017 **Reducing Patient Cost**: Partnership established with Essilor Vision Foundation reducing the cost of custom-made glasses.

**Coordination Roles Cease:** Completion of Pilbara DR Screening and Statewide Telehealth projects, and associated coordination roles.

**New DR Screening MBS:** New MBS items support retinal screening in general practice.

**VOS Pilot with Vision Van:** A combined optometry and DR Screening service was piloted in Onslow on the Vision Van with great support from local community.

LOV Food program commences in Hedland and Karratha primary and high schools.

#### 2.3.2 LOV Service Profiles

LOV coordinates and provides eye health services covering the whole continuum of care - prevention, screening, diagnosis, and treatment. Services can be broadly classified into the three service delivery streams of diabetic retinal screening, optometry and ophthalmology. For each stream, a service profile presents an overview of the service characteristics, and touches on the interrelations between them for continuity of patient care.

#### **Diabetic Retinal Screening**

Diabetes is the fastest growing chronic condition in Australia affecting up to an estimated 1.7 million people. This includes an estimated 500,000 Australians who don't even know it, putting them at risk of devastating health consequences such as blindness and amputations<sup>14</sup>. Diabetic eye screening is a key part of diabetes care.

One in three people with diabetes are at risk of damage from diabetic retinopathy, a condition that can lead to irreversible sight loss if not treated<sup>15</sup>.

Multiple sites across WA equipped with permanent and roaming digital retinal cameras feed into the LOV diabetic retinal screening service. LOV provides training and upskilling to camera operators, generally AMS staff, including Aboriginal Health Workers (AHW) and nurses. Local operators identify diabetic patients, provide basic diabetic eye health education, take retinal photos and perform visual acuities. Electronic images are forwarded via store and forward telehealth technology to LOV for grading. Where available, Regional Eye Health Coordinators (REHC) provide on the ground support, arrange screening blitz's, and additional mobile screening in areas where no local camera is available or there is a lack of an operator. At LOV, centralised graders return electronic patient reports to originating sites with recommendations for care based on the graded disease severity and detection of other ocular pathologies. It is the originating site's responsibility to coordinate follow up patient care, by either placing the patient on screening recall, optometry review or referral for ophthalmology review.

Figure 6. Pilbara DR Screening Coordinator Alex Ramirez leading education and training in the Pilbara





#### Optometry

Refractive error is the leading cause of visual impairment among Australians<sup>7</sup>, yet it is also the most readily treatable<sup>16</sup>. For the most part, refractive error is easily correctable by spectacles, highlighting the importance of access to optometry services.

Uncorrected refractive error causes almost two thirds of vision impairment among both Indigenous and non-Indigenous Australians<sup>7</sup>.

Optometrists provide comprehensive eye and vision care, including refraction and vision correction, as well as preventative eye health examinations and treatment. As commonly the first point of contact in the eye healthcare system, optometry plays a pivotal role in detecting chronic eye and vision disease and ensuring appropriate referral for treatment and ongoing management.

LOV delivers outreach optometric services in the Pilbara under the Federal Government's Visiting Optometrists Scheme (VOS)<sup>4</sup>. VOS optometrists are independent contractors who receive a daily stipend and are reimbursed for a proportion of their expenses including: travel costs; equipment transport; facility fees; absence from practice allowance; administrative support; and cultural training. A VOS Coordinator manages the pool of contractor optometrists, coordinates trips with local health services, arranges logistics and orders and distributes glasses. Optometry clinics are hosted within the AMS facilities in larger communities and outreach nursing posts elsewhere. There is no appointment system; rather patients are seen in order of their arrival.

Services are delivered in a circuit format for greater efficiencies. Typically, a VOS week involves several one or two-day clinics, travelling time to and from each location, and a day of administration to finalise referrals and complete patient notes. Clinical visits are usually scheduled in the more weather favourable 'dry season', with a solo optometrist flying commercially to the region from Perth, then travelling by hire 4WD or local service plane into each community. Substantial travel time is required to cover the great distances (up to 4,300km) of each circuit.

To correct refractive error, accessible optometry services must be delivered alongside the accessible provision of glasses. A state WA Spectacle Subsidy Scheme subsidises the cost of glasses for eligible patients by cheque reimbursement but this process is an impediment to many LOV optometry patients who have no fixed postal address nor nearby banking facilities. Instead, LOV delivers its own in-house low cost glasses program to support VOS service provision, ensuring those in greatest need can access affordable and appropriate glasses.

Almost all diagnostic equipment, a selection of frames and a selection of ready-made hypermetropic and myopic prescription glasses are transported by the VOS optometrist. When available, the slit lamp biomicroscope and retinal camera stationed at the AMS is utilised by the optometrist.

Patients requiring glasses can purchase ready-made frames at the time of their eye exam (if sufficient to meet their prescription) or order custom-made glasses for later delivery. Prepaid prescriptions for custom-made glasses are sent to LOV's partnering lens laboratory, checked at LOV and posted to the patient at their community AMS. If a patient requires attention by ophthalmology, the optometrist will refer the patient onwards or request a telehealth consultation.

Following each optometry clinic, LOV sends electronic patient reports to each community allowing AMS staff to transfer this information into their own local patient record (e.g. MMex/Communicare).

<sup>&</sup>lt;sup>4</sup> Managed and funded by the Commonwealth Government, the Visiting Optometrists Scheme (VOS) was established in 1975 to support optometric service provision in geographically isolated locations across Australia. The scheme provides funding to address a range of financial disincentives incurred by optometrists providing outreach services and in 2009 was expanded to support targeted service provision in remote and very remote Indigenous communities

#### Ophthalmology

Australia as a whole has a large specialised workforce but its distribution is inequitable. In remote WA, specialist coverage is up to 19 times lower than in urban Australia<sup>17</sup> and rural residents are three times less likely to have seen an ophthalmologist.

Almost a third of the Australian population<sup>13</sup>, but only 16% of ophthalmologists, live in regional and remote areas<sup>18</sup>.

Ophthalmologists practice both medicine and surgery. They provide primary care as well as highly specialised treatment, accessed by referral from a health practitioner. LOV delivers a unique combination of ophthalmic service delivery models, including general outreach clinics, targeted surgery and treatment blitzes, a mobile Vision Van and tele-ophthalmology. All support a multidisciplinary team based approach to service delivery, though the composition of the team will vary depending on the nature of the service and the location it is being delivered in. Integration with local health facilities and existing staff is crucial for effective services and is a key component of ophthalmology service planning and delivery.

Each delivery modality below is an important link in the chain of services being continually developed by LOV to advantage patient access to quality clinical assessment, treatment review and follow up; and build local capacity in eye health.

#### 1. Outreach Clinics

Outreach clinics are coordinated visits by ophthalmologists to regional hospitals or medical centres to support specialist eye health procedures and surgeries. Usually several locations are combined into weeklong outreach visits for greater cost efficiencies.

#### 2. Intensive Surgical Blitz

Targeted surgery trips address the cataract surgery and diabetic eye waiting list and significant access barriers for Aboriginal patients in remote communities. A surgical ophthalmology team comprising of an ophthalmologist, registrar, ophthalmic nurse, ophthalmic assistant and care coordinator travel from Perth to deliver surgical services at regional hospital. Patients referred from visiting and regional optometrists, GPs, District Medical officers and specialists are triaged by the ophthalmology team for categorisation of clinical priority for surgery. Surgical patients, carers and community escorts are supported with chartered travel arrangements (by air or road) and accommodation and food expenses whilst in town.



Figure 7. LOV founder and ophthalmologist A/Prof Angus Turner with patient Mavis Arnott from Jigalong.

#### 3. Lions Outback Vision Van (LOVV)

A tertiary level mobile eye health facility launched in March 2016. It is fitted with state-of-the-art equipment and staffed by highly-skilled professionals. It travels all over the state allowing patients to access gold standard of care otherwise only available in Perth or major regional centres. It is normally staffed by an ophthalmologist, a resident doctor and nurse/driver. A typical community visit lasts between 1 and 5 days, depending on the size of the community.



Figure 8. Lions Outback Vision Van

#### 4. Tele-ophthalmology

Tele-ophthalmology involves a real-time video consultation between the patient and an ophthalmologist, on the referral of a health care provider. Consultations are typically carried out using videoconferencing equipment consisting of computers or tablet/handheld devices, with broadband connections and built in or attached audio-video devices. A telehealth appointment is usually made in advance by the referring provider, clerical staff or in the case of a referring hospital, by a designated telehealth coordinator. Consultations typically last from 10 to 20 minutes in duration and, much like face-to-face consultations, involve introductions and a discussion between the ophthalmologist and patient. These are augmented by images of the eye and the results of diagnostic tests sent by the referring provider to aid the ophthalmologist in making clinical decisions. A diagnosis and management plan is made and follow-up is jointly arranged for a suitable time.

Figure 9. Process for conducting a tele-ophthalmology consultation

# Mr Fintan is a 45 year old male truck driver in Karratha who visited the optometrist for a pair of reading glasses



- Due to family history of glaucoma, a routine eye pressure test was performed. The tests showed a raised visual measurement
- A visual field test also demonstrated optic nerve damage in keeping with glaucoma



 The next ophthalmologist outreach visit to the region was not scheduled for over two months



- A telehealth consultation was held on the same day and the ophthalmologists prescribed medication to lower the eye pressure.
  - Follow-up will include the next outreach visit and subsequent telehealth consultations

Figure 10. Telehealth in action (Jigalong and Halls Creek)





Photograph courtesy of Alan McDonald

# **Diabetic Intervention: LOV Food**

"we're really happy that we learned how to cook food from local culture, it was easy to make and tasted great"

In 2017 LOV introduced a diabetes awareness program called LOV Food which is aimed at teaching children the benefits of healthy food to maintain good eye health. Many children are aware that bad food and too much sugar can cause diabetes but they are not aware that diabetes can lead to blindness if not treated. The program is delivered by a trained Chef and qualified teacher who leads the lesson with some information awareness about diabetes and eye health before leading the children in preparing a healthy meal using locally available and culturally relevant ingredients.. Since May this 2017, 600 students have participated in classes in the North West, 255 of those in the Pilbara. The focus is on diabetes and how it leads to blindness, basic nutritional information, being creative with left overs and using basic chef safety skills in the kitchen. Sessions have extended to include teachers and parents recognising that knowledge and information learnt in school must also be demonstrated and embraced in the home to ensure sustainable behaviours.

Figure 11 LOV Food Classes at South Hedland High School and South Hedland Primary School





# 3 Summary of Analysis

## 3.1 Inputs

- Funding Sources
- Mean cost per patient

The responsibility for eye health programs and services in Australia is currently spread across governments, the private sector, health care professions and non-government organisations. Multiple funding sources contribute to the LOV Program, listed in Table 1.

Table 1. Sources of funding for LOV Program

Source	Component			
Federal	Medicare Rebates			
	<ul> <li>Visiting Optometrists Scheme (VOS)</li> </ul>			
	<ul> <li>Rural Health Outreach Fund (RHOF)</li> </ul>			
	<ul> <li>Eye and Ear Surgical Support Service (EESS)</li> </ul>			
State	WA Country Health Services			
	Rural Health West			
	<ul> <li>Clinic/Surgical infrastructure and consumables</li> </ul>			
	<ul> <li>Patient accommodation transport scheme (PATS)</li> </ul>			
Other	<ul> <li>Non-Government Organisations, e.g.</li> </ul>			
	<ul> <li>Lions Eye Institute(LEI)</li> </ul>			
	<ul> <li>The Fred Hollows Foundation (FHF)</li> </ul>			
	Eye Surgeons Foundation			
	• Lotterywest			
	Private Foundations, e.g.			
	<ul> <li>McCusker Charitable Foundation,</li> </ul>			
	Newman's Own Foundation Fund			
	<ul> <li>Indigenous and Remote Eye Service (IRIS)</li> </ul>			
	Corporate Sponsorship, e.g. Devil Creek Joint Venture			
	The University of Western Australia			
	<ul> <li>Industry, e.g.</li> </ul>			
	• Allergan,			
	<ul> <li>Device Technologies,</li> </ul>			
	• Telstra			
	Patient out-of-pocket income			

In many instances, funds from different sources cannot be apportioned to specific regions. As a result, costs per patient by service type are presented in Table 2 , complied from existing LOV literature.

Table 2. Mean cost per patient

Service	Mean cost per patient
Optometry (Pilbara region)	\$171
Ophthalmology – Outreach Clinic <sup>8</sup>	\$444
Ophthalmology – LOVV	\$320
Ophthalmology - Telehealth <sup>8</sup>	\$213
TRANSFER TO PERTH <sup>8</sup>	\$1589

## Case Study.

## Surgical staff member, Nickol Bay Hospital, Karratha

## "it's just been a really great service"

The participant is very familiar with the work of Dr Turner and LOV as she has been in her role at the hospital since Dr Turner first commenced provision of ophthalmology services at the hospital and has witnessed the expansion of the service over time. She believes there has been an enormous impact from having the LOV service at the local hospital, both for outpatient appointments and cataract surgery. This has meant residents have been given a localised service that has enabled many people to access services they may not otherwise have done so. The participant describes how there have been many patients who have been able to have cataracts in both eyes addressed because of the access to their local hospital. She acknowledges that it is "much easier for them to have it done in their country, where they are living."

The participant describes how the work of the LOVV and the presence of the ophthalmologists and optometrist attending the area means the hospital are getting far more referrals, so much so that the increase meant she was recently questioned by Hospital management about the eye surgery waitlist. She states "word is out there definitely, you hear it in the community, how fantastic it is that they do come up here and what a good service they get from it." She believes previously people may have avoided having their eyes checked because the result could mean having to travel to Perth, "but now people are attending appointments and seeking out the services to do something about their eyes".

In accounting for the increased number of patients attending their appointments and undergoing surgery, the participant identifies the approach of LOV staff to patients as very important. She describes how staff have "built those bonds with the people in the community... that trust always has to be built first before they start engaging in the service and I think that has definitely been achieved". She believes that most patients are generally nervous and anxious about anything to do with their eyes, however the contact made with patients prior to the hospital/surgical visit and in their own community means they feel a little more comfortable, especially seeing a familiar face. "You can see when they see the people from the eye bus 'they are like 'oh yeh' and they know its ok."

From the hospital's perspective, having the LOVV means they can see a larger volume of patients and access all the equipment required. Without the LOVV she acknowledges that the hospital would be always trying to get new equipment and "we just don't have all the equipment that they need". Prior to the LOVV service, the hospital was sharing equipment with Port Hedland Hospital which is very challenging logistically and impractical because of the sensitivity of much of the equipment. The fact that patients don't have to have a general anaesthetic also means some patients can be seen who otherwise may not have been be able to.

The engagement between LOV staff has also facilitated greater engagement between the hospital based Drs who can now phone Dr Turner for an immediate consult if they have a patient with something wrong with their eye. The plan for the new hospital is to install teleconference facilities so they can get Dr Turner to look at the images straight away and consult with the Drs and the patient while they are in the hospital.

The participant also believes that over time she has witnessed less Did Not Attend (DNA)'s which she attributes to both the trust and confidence in the LOV staff, as well as the hospital and LOV staff establishing and embedding better processes. This includes the staff at LOV engaging in open communication and being proactive about alerting the Hospital staff about patients so they can book all patients. For example, 18 patients booked for eye injections on the visit to Karratha that day which she regards as a lot of patients and evidence of the streamlined approach. The process also involves hospital staff liaising with MHS to ensure they coordinate patients including the provision of transport.

In terms of the impact of the surgery the participant has witnessed patients coming back for their second cataract operation and seen their excitement at the impact the first operation has had – "they are so excited they can see now... you can see that they can see, which does make a big difference." She knows that the service has enabled many patients to be able to keep working, especially by driving, because their eye issues are being properly managed or addressed and she acknowledges the range of benefits this means for the patients, their family and the towns.

The impact of the service is "extremely positive ... it would be a great loss to the community if it wasn't to continue."

#### 3.2 Activities

#### Service Provision

- Service type, location and frequency
- Number of optometry and ophthalmology service days

Since 2011, the LOV Program has substantially increased its breadth and reach of services in the Pilbara region. Figure and b compare the physical availability of optometry and ophthalmology services from 2011-12 to 2016-17. Distinguished by type, it shows both LOV delivered services (colour) and estimated service provision by other local and visiting providers (grey).

Figure 12a. Physical ophthalmology and optometry service locations, Pilbara 2011-12



Figure 12b. Physical ophthalmology and optometry service locations, Pilbara 2016-17



LOV's increased footprint is attributed to both the introduction of new services such as the LOVV, and the handover of optometry and ophthalmology services from retiring providers.

Building on the founding outreach work of optometrist Margie O'Neill in the late 1990's and early 2000's, visiting optometry services to remote Pilbara communities have been supported by VOS since 2005. Crucial to service sustainability, VOS collaboration allowed the self-funded grassroots initiative to grow rapidly into the successful Northwest Eye Program (NWEP) comprised of a team of 15 optometrists servicing 45 communities across the north of the state. When founding NWEP optometrist and coordinator Margie O'Neill retired in June 2013, LOV embraced the opportunity for greater service integration and took over the provision of WA's northwest visiting optometry services, commencing clinics in Jigalong in September 2013.

Similarly, Dr Phil House had provided visiting outpatient and surgical ophthalmology services to Port Hedland for over 20 years before handing over provision to LOV in 2014.

As a primary service, optometry services have the greatest reach, visiting nine communities across the region, (including the recommencement of Onslow services in the current financial year). Following the 2013-14 transition of VOS services from NWEP to LOV, visiting frequencies were increased in locations of high need, reducing the wait time between optometry clinics and ensuring patients could be seen sooner. The smaller inland desert communities of Parngurr, Punmu and Kunawarritji are now visited twice a year (previously once under NWEP), and the larger coastal communities of Roebourne (Marwarnkarra) and South Hedland (Wirraka Maya), every two-four months for two days at a time. Jigalong (Puntukurnu), Marble Bar and Nullagine continue to receive biannual 1-day optometry clinics.

The introduction of the LOVV in 2016 added twice yearly ophthalmology services to two new sites (Newman and Onslow) and supplemented existing quarterly clinical and surgical outreach in Roebourne, Karratha and Port Hedland. It offers advanced diagnostic and treatment services, beyond what can be provided on standard outreach trips. While this saves patients having to fly to Perth to access this care, service frequencies are insufficient to meet the eye care needs of many patients requiring monthly injections, who must still travel to Perth to maintain treatment regimes when visiting ophthalmology services are unavailable.

Figure 9 shows ophthalmology service provision has increased by 260% in the region. The ophthalmology fellow and LOVV has contributed greatly to this increase in workforce capacity, resulting in increased ophthalmology days, and concurrent service delivery.

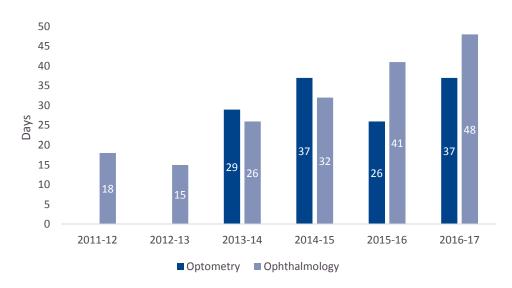


Figure 13. LOV visiting optometry and ophthalmology days, Pilbara

The University of Melbourne Indigenous Eye Health Unit (IEHU) Eye Services calculator estimates 177 optometry days and 61 ophthalmology days are required annually across the region to meet the eye care needs of Pilbara's Aboriginal population. Accounting for other VOS (but not resident optometry) providers, Table 3 suggests 79% of the projected ophthalmology workforce needs and just over half of optometry workforce needs are currently being met in the region.

	Projected annual workforce needs (service days)	Service days delivered by LOV	Service days delivered by other providers	Proportion delivered (all providers) %
Optometry	177	37	61	55%
Ophthalmology	61	48	NA	79%

Table 3. Estimated workforce requirements, Pilbara 2016-17

## Critical Success Factor

### **Coordinated Schedules**

Optometry and ophthalmology visiting schedules are coordinated to maximise service efficiencies and patient continuity of care. Where possible, visits are sequenced; with optometry preceding ophthalmology visits by 2-4 weeks to ensure patients are effectively triaged rather than being sent directly to ophthalmology. Alternatively, optometry clinics are scheduled after surgical outreach visits, to follow up on treated patients.

LOV's physical services are augmented by virtual outreach services including diabetic retinal screening and video-conferencing. Originating telehealth locations are dependent on the availability of telehealth equipment and the facility or practitioner requesting telehealth services, either of which may be mobile.

Service provision is greatly affected by local administration and clinic sustainability. Declining population and patient numbers can result in clinic closures or reconfigurations, and the loss of local support through the departure of community champions and administrative instability at host facilities is also likely to disrupt service provision.

#### Critical Success Factor

## Adopting a Partnership Approach

The fundamental foundations of effective primary health care, community involvement, governance and management<sup>19</sup> are demonstrated by the partnership of LOVV and the Aboriginal Health Council of Western Australia to pilot the Principles and Protocols for the Delivery of External Health Services in Rural and Remote Communities.

The Principles and Protocols require potential service providers to engage, consult and collaborate with communities to ensure evidence-based and integrated services that offer a demonstrably better approach to service delivery. The Principles and Protocols ensure that the design and delivery of outreach services are negotiated and implemented carefully and are based on durable and effective partnerships.

The provision of outreach through a bottom-up approach promotes accessible, safe and sustainable services.

## Case Study:

## Former MHS chronic disease coordinator, Roebourne resident, female

#### "Their work is tremendous."

The participant acknowledges that during her time in Roebourne both as a resident (10 years) and as a former staff member of MHS, she has observed an improvement in the attitude among community about looking after their eye health, and an improved understanding of the impact of diabetes on eye health. She attributes this to the ongoing presence of LOV staff and now the LOVV and its influence both on the community but also the clinic staff at MHS. "The more people talk about the issues, the greater acceptance and understanding."

She believes ongoing education and training for MHS staff, increased access to specialists, more staff involved in delivering eye health for diabetic patients, improved retinal machines and ongoing training from LOV staff, and the introduction of a comprehensive approach to diabetes management at MHS have contributed to a coordinated and integrated service.

She acknowledges that the access to services has made a big difference to patients' engagement with services because they know if there are any problems they won't have to travel to Perth. "Travelling to Perth or even Port Hedland is a big concern for them – alleviating that stress is really important".

The participant attributes incidences of DNAs to people simply "putting themselves last." She believes that across the community many people are dealing with a number of issues that detract from their health and looking after their health. Many also have family members and others they care for and this contributes to missing appointments. She doesn't believe DNAs would be linked to anxiety about procedures or people not wanting to do something about their eye health, and has witnessed talk among community members about the simplicity of the procedures.

She describes the way that the presence of LOV in the area has encouraged better coordination between the AMS and the local Optometrist in Karratha and led to a sense of a partnership approach between all providers and LOV. She believes LOV have "the right attitude" to local services and that good coordination is "so important".

The participant notes how much need there is the community for optometry and describes the long queues when the visiting Optometrists come to Roebourne and the importance of community being able to access inexpensive glasses.

In response to describing the impact of the LOV service on the community, the participant states "it has saved their eyesight".

## 3.3 Outputs

#### Service Utilisation

- Service Attendances
- Service characteristics and trends
  - Patient demographics
  - Consultation type

#### **Service Attendances**

Since July 2011, LOV has delivered over 7,200 outreach services to the Pilbara.

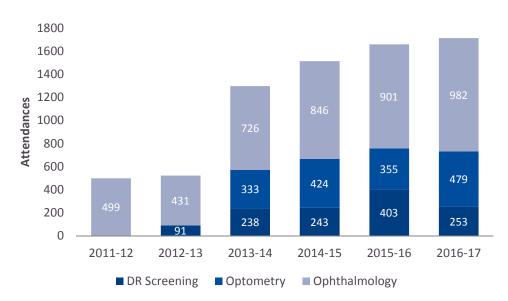


Figure 14. LOV Program attendances by service type

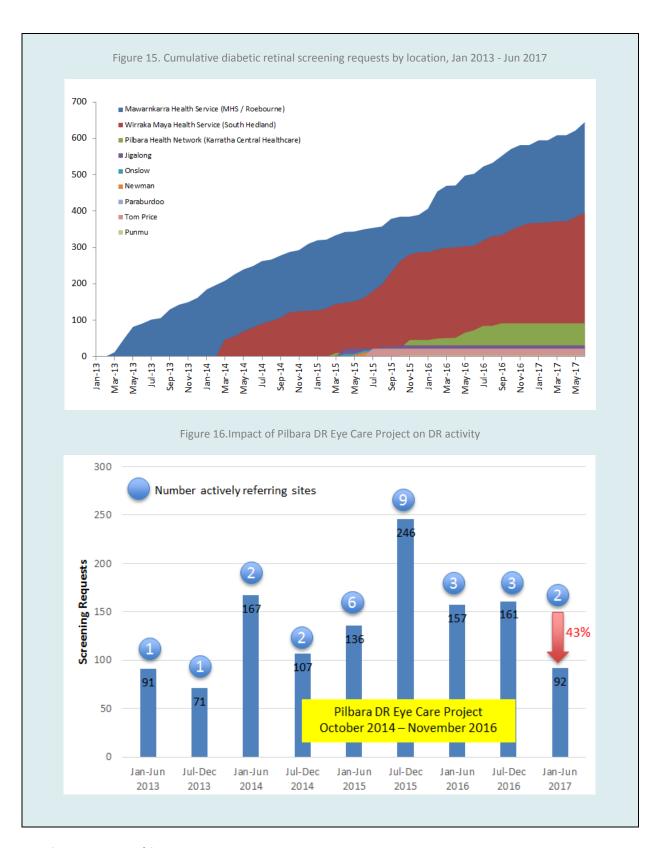
## Critical Success Factors

## **Sustained Coordination**

Regional coordination roles are shown to improve the quality, quantity and delivery of eye health services. They play an important role in building the capacity of local services. and improving the quality, quantity and delivery of eye health services. For example, the impact of the Pilbara Eye Health Coordinator can clearly be demonstrated by comparing the outputs of the Pilbara DR Eye Care Project to usual services. This project involved the employment of an on the ground Eye Health Coordinator between 2014 and 2016 to embed an integrated diabetic screening program for Aboriginal people into the Pilbara region of WA.

Prior to the project, only two locations were actively sending DR requests to LOV (Figure ). Over the course of the DR project, seven additional locations were equipped and trained in a short six-month period, however only one newly engaged location sustained services beyond these initial months. Activity at the remaining new location stopped once DR Coordinator role was discontinued in late 2016.

Furthermore, screening requests from the remaining two active (and first) locations dropped by 40% in the six months (Jan-Jun 2017) following role cessation compared to the two prior six month periods (161 and 157 respectively compared to 92) (Figure ). It illustrates that ongoing coordination and support is required for sustained service reach.



#### **Patient Demographics**

Demographic data including ethnicity and gender vary according to the type of service. Overall males are underrepresented across all services, comprising only 38-51% of the patient load, yet 61% of the general Pilbara population. Most (80%) of LOV's optometry patients are Aboriginal, reflective of the targeted service delivery in Aboriginal communities.

Table 4. Patient demographic summary, by service

Service	Ethnicity (% Aboriginal)	Gender (% Male)	Age	Available Data
Diabetic Retinal Screening	NR	45%	74% aged 40 and over	From 2014/15 FY
Optometry	80%	38%	Median age 54 (range 2-93)	From 2013/14 FY
Ophthalmology (Clinic)	42%	44%	NR	From 2016 CY
Ophthalmology (Surgery)	57%	52%	NR	From 2016 CY
NR not recorded, FY financial year, CY calendar year				

### Type of Consultation – Optometry services

The majority (41%) of LOV optometry consultations are billed as diabetic reviews.

Not
Billed/Unknown,
Brief 59, 4%
Consultation, 74,
5%
Subsequent
Consultation,
122, 8%

Comprehensive
Reassessment ,
196, 12%
Comprehensive

Figure 17. Optometry services - type of consultation

### Type of Consultation – Ophthalmology services

Three quarters of all ophthalmology services are clinical consultations.

Examination, 487, 30%

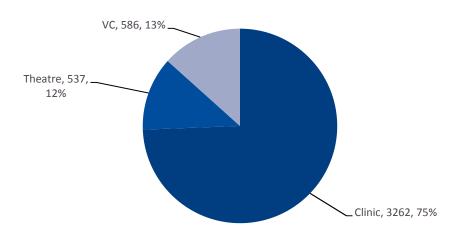


Figure 18. Ophthalmology services – type of consultation

## Case Study:

## Roebourne resident, Male, age 63

"If the van didn't exist then a lot of residents in Roebourne and other places like Roebourne would never get treatment."

The participant admits he initially wasn't that motivated or worried about the eye health care aspect of his diabetes because "it's not an immediate thing, you don't go blind overnight". He was alerted to the need to do something about his eyes after seeing the Optometrist in Karratha who encouraged him to see the Ophthalmologist. "When I came here (the hospital) I didn't know what to expect, the very first time they said to me 'you got to get an injection' so I rolled up my sleeve thinking I'm getting an injection in the arm and when they said 'no in your eyeball' I was like 'righto' (surprised face) 'I've never heard of this one..."

The participant admits initially he missed a few appointments because he did not know they were scheduled. He explained that the hospital will only send appointments as mail not emails, and he only clears his mail box once a month, or he receives a text on the day of the appointment and he would often be in another town, or was unable to attend due to travel with work.

He is now really committed to making the appointments and attends the appointments either in Perth, Karratha and Roebourne to ensure he makes the appointments on time. "I'm pretty well committed to doing the best I can with it... the alternative is not much chop"

He feels with the increased regular ophthalmology appointments he has experienced a slight improvement with his eyes and has been informed the scans are showing good results. The participant acknowledges that increased attendance to the ophthalmology appointments has improved his eye health literacy and understanding of the importance of managing his diabetes and receiving the injections for his eyes. "The more you come to these things the more you think about it... you think what can I do to improve it?" He is also motivated because he needs good eyesight to continue to work (trucks and construction).

He has also slowly improved at managing his diabetes, although admits that the travel he has to do for work makes it difficult to maintain a healthy diet. He says that managing his diabetes and his eye health is a "partnership" between himself and the health staff because "they can't perform miracles".

He believes that for some people the fear factor about the eye injections is a huge barrier. "It doesn't scare me but I imagine a lot of people getting these eye injections must absolutely be freaked out before they get them." He knows men who are avoiding doing anything about their eyes because of the fear factor about injections. The participant has accessed the LOVV at Roebourne and agrees it has brought important service to the communities in the area who would otherwise not access or seek out those services. He believes that poor sight is normalised amongst many in the community but that the presence of the LOVV and the regular access to Ophthalmologists is increasing people's awareness and opportunity to be more proactive about their eye health. He describes the long queues that can be seen in Roebourne on the day the LOVV and the VOS are in the town.

#### 3.4 Outcomes

### Clinical Management Outcomes

- Rate of referral from diagnosis and screening services
  - Diabetic retinal screening
  - Tele-ophthalmology
- Treatment services
  - o for refractive error
  - for cataract
  - o for diabetic eye disease

#### **Diabetic Retinal Screening**

Many eye diseases and conditions do not present obvious symptoms until irreparable damage has occurred. Comprehensive screening and examinations ensure timely detection and referral for treatment.

The presence of diabetic retinopathy was detected in nearly one third of all screening referrals originating from the Pilbara. A further 11% of images were unable to be graded. Overall, this resulted in one in three patients being referred to specialist eye clinicians for review (22% to ophthalmology, 11% to optometry).

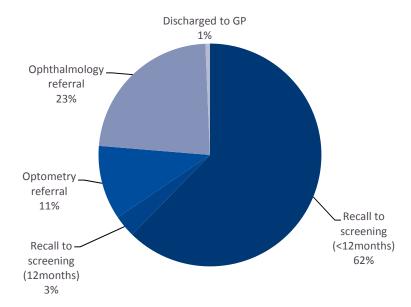


Figure 19. Rate of referral, diabetic retinal screening, Pilbara

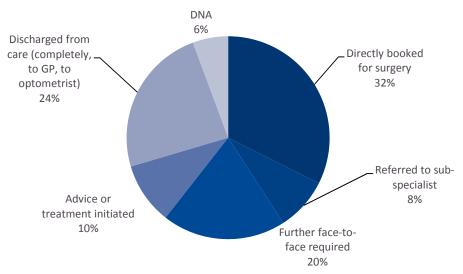
Had these patients not participated in diabetic screening, their general or diabetic ocular disease may have gone undetected.

#### Tele-ophthalmology (video-consultation)

Ophthalmology referrals are triaged to appropriate service delivery models. With only a quarterly physical presence in the Pilbara, tele-ophthalmology facilitates earlier consultation and more timely action, whether it be the initiation of treatment, or direct surgical bookings on next available outreach visits. Tele-ophthalmology does not comprise diagnostic accuracy<sup>20</sup> or patient satisfaction <sup>21</sup> and has the potential to optimise the surgical output of outreach visits by diverting appropriate patients to these virtual pathways. Tele-ophthalmology has the current estimated potential of managing 15% of urgent transfers and 24% of outreach consultations<sup>8</sup>.

Approximately one-third of Pilbara patients consulted through VC are directly listed for surgery (Figure 20).

Figure 20. Rate of referral, tele-ophthalmology, Pilbara



#### **Treatment services**

The leading causes of blindness and vision impairment are uncorrected refractive error, cataract and diabetic retinopathy.

#### Treatment services for refractive error

Refractive error can be simply diagnosed, measured and corrected, and the provision of spectacles is an extremely cost-effective intervention, providing immediate treatment.

Though the scope of practice for an optometrist continues to evolve, correcting refractive error remains their principal role. Approximately half of all VOS consultations resulted in spectacle prescription (new and repeat), and one in nine were referred to specialist eye services.

The outreach model enabled under VOS supports better access to optometry services; however it is the service providers' responsibility to facilitate improved accessibility to glasses. LOV has always provided spectacles at a nominal (\$10) rather than at no-cost, and visiting optometrists carry a selection of ready made frames. Consistently about 45% of optometry consults result in spectacle prescription. Annual dispense data revealed increasing treatment coverage rates. While readymade and custom-made spectacles are prescribed at the same rate, each accounting for half of all prescriptions, ready-made treatment rates are higher. Trends indicate increasing affordability and acceptability of spectacle provision.

This suggests a large unmet need, however it is likely coverage rates are underreported given the service focus in recent years is ensuring those in greatest need are most supported. As such, optometrists may compassionately dispense ready-made spectacles at no charge. On other occasions, a patient may take the prescription details and have the spectacles dispensed by another party. These numbers are not known or adequately accounted for in LOV optometry data sources.

Table 5. Spectacle prescription and dispensing rates

		2013-14	2014-15	2015-16	2016-17	All years
Specta	cles Prescribed	148	188	161	215	712
(as % total consults )		(44%)	(44%)	(45%)	(45%)	45%
<b>Treatment Coverage Rates</b>						
-	Overall	36%	59%	53%	55%	52%
-	Ready made	36%	70%	64%	63%	61%
-	<b>Custom made</b>	37%	43%	42%	48%	43%

## Case Study:

## Roebourne resident, female age 86

"I don't want to be in a world where I can't see, you may as well be dead."

The participant acknowledges that she has experienced "troubles with my eyes for quite a long time" and describes how even as a child she had trachoma growing up in the bush and desert. She is quite anxious now to ensure she can stop any further loss of vision associated with diabetes. She says she is motivated to keep attending her ophthalmology appointments: "I want to keep seeing as long as I can, I don't want to go blind...to go blind I would be completely lost...I would like to keep my eyes as long I can."

She received her glasses in Roebourne through the VOS scheme. She then subsequently visited the Optometrist in Karratha because of ongoing issues with her eyes and was referred to Dr Turner. She now attends both the Nickol Bay outpatient clinic in Karratha and the LOVV in Roebourne for her injections. She is happy to come to either although was originally concerned about communication between the LOVV and Dr Turner at the clinic but it has been explained to her how they communicate and she is reassured, "as long as he knows what's going on in between so we can keep track of ourselves."

She is currently still driving and recently passed her test. Her partner has dementia so she needs to be able to care for him and for both of their needs. "That's why I'm here to get my eyes fixed because I got to look after him and I depend on my eyes not just for driving but for everything."

#### Treatment services for cataract

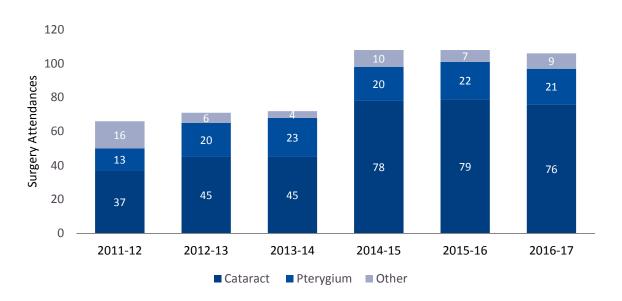
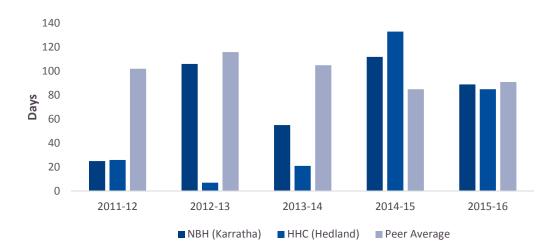


Figure21. LOV surgeries, Pilbara

LOV's surgical output increased in 2014-15, upon the expansion of surgical services to Port Hedland. Cataracts extraction account for two-thirds of surgical throughput, and LOV has performed 360 cataract operations since July 2011.

Patients' waitlisted for eye surgery are generally seen on the next quarterly surgical visit, illustrated by median waiting times of less than 90 days. Occasionally, patients may wait until the subsequent visit (>90days) before they receive treatment. Waiting times are determined by the interval between a patient being placed on the waiting list to surgery admission<sup>22</sup>.

Figure 22. Eye surgery median waiting times



The cataract surgery rates (CSR) have improved, but remain lower than the national average of 9,500. The higher Aboriginal CSR is a result of intensive surgical 'blitz' to address excessive cataract surgery waiting times.

Table 6. Cataract Surgical Rate, Pilbara

	CSR	CSR ATSI
2016-17	1246	5024

## Case study:

# Roebourne resident, female, age 68

## "They took that cataract out and I see far far away".

The participant attends both Nickol Bay outpatient clinic and the Lions Outback Vision Van (LOVV) at Marwarnkarra Health Service (MHS) in Roebourne for her ophthalmology appointments. She admits there are "lots of appointments... but got to do it... might get blind". She describes the injection as "bit scary... don't like needle" and "want to be careful with my eye... 'do it slowly now' I tell them." The participant says that most people who need injections go "round the back to the truck" and get the needle.

"Needle in the eye ...makes me look better. You know... medicine works in the eye"

She says that lots of old people are happy about the truck coming to Roebourne because they know "make your eye feel more good".

The participant has also had cataract surgery on one eye and will require surgery for the other eye. The participant said she was not too worried about getting cataract surgery when she was initially told. She explained that there were lots other older people in the community that have something done to their eyes and talk about it and she knows it's ok. She also tells others who may be worried that's it's all ok. She tells them "you don't feel it when they are pulling it out."

She admits her eye was bad for a long time before it "got seen to" and the surgery performed but she does learnt to live with it. She didn't realise that her second eye was bad and needed cataract removal surgery but now that she knows (she was informed by Dr Turner) she is keen to have the cataract removed so that she can have good vision and get her driver's licence back. She wants to be able to drive to help the other ladies in the community do their shopping in Karratha, to visit her brother in a nearby community, and to go fishing.

Since the cataract surgery she has noticed a big difference in her eye and describes how "makes it easier for me... looking at the TV and at country". "I look around really good now in this eye"

#### Treatment services for diabetic eye disease

Treatments for diabetic retinopathy include intravitreal injections and retinal laser can be performed in outreach clinics and on the LOVV. The LOVV has increased access to these diagnostic and therapeutic technologies, previously only available in tertiary hospitals. Importantly two-thirds of patients who received intravitreal injections were Aboriginal, which highlights the value of access for treatment since Aboriginal people have 14 times higher rates of vision loss due to diabetes.

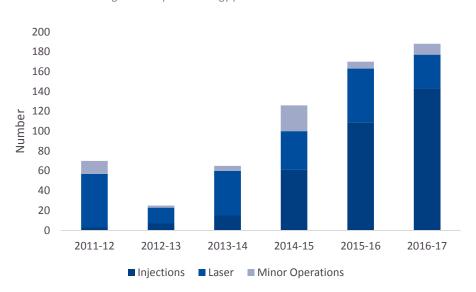


Figure 23. Ophthalmology procedures and treatments

Figure 24. Eye check on the Vision Van in Newman



## Case study.

## Karratha resident, female, age 40

## "It's a life saver for eyesight"

The participant attends the LOVV in Roebourne and has started coming to Nickol Bay Hospital for scheduled injections at the outpatient clinic. The participant acknowledges that it has been a long time since she last came to the outpatient clinic as she has missed a few appointments. One of the reasons for this was because she didn't realise the importance of regular attendance and adherence to the injections. This was explained by Dr Turner through a recent teleconference that enabled her to understand why she needed to come for the regular injections both at Nickol Bay and when the LOVV comes to Roebourne. She also missed a couple of appointments because she had to go to a funeral in Carnarvon.

Outside of the appointments she will also sometimes present to MHS and the optometrist in Karratha because her eyes are "hurting and blurry". She says that she doesn't worry about the injections, "I'm ok with the injections... they're to make me get well." She also notes the ongoing eye health information she is receiving both from LOV staff and staff at MHS. "Every time I come here (Nickol Bay Hospital) or I go to the AMS they speak to me about it and show me (impact of diabetes on her eyes, bleeding behind the eyes) ... that lava thing" (sugar diabetes at the back of the eye).

The participant regularly experiences dizziness, headaches and feels her eyes have been bad for some time. Her poor eye health is causing her some distress and making her feel unwell. "I do get worried about the vision. Sometimes it does make you want to cry actually. Walking around not seeing the people." She admits that she would like to be able to "see a bit better" because reading and seeing things close up is currently very difficult. The participant also doesn't own any glasses.

The participant was diagnosed with diabetes 13 years ago when she was pregnant with her daughter which came as a big shock to her. "From the outside I look well but on the inside my body's not good at all". She admits that she finds it challenging to manage her diabetes and feels sad about her condition and the challenges diabetes poses to her life. "Sometimes I wish I didn't have diabetes, I wish it would just go away... It's very hard to look after yourself when you are having a lot of issues." She admits she is not managing her diabetes and is not checking her levels or eating very well, although she did note with pride that she had ceased drinking seven years ago, "I feel good about that".

The participant had to have her toe amputated six years ago and was shocked to realise the impact of diabetes following a small cut on her toe. She described seeing posters around the clinics and in the newspaper about many of the risks but didn't pay much attention because she didn't really think these things could happen to her.

She acknowledges that the LOV team are doing a good job and says "it's looking after my eyes, I think it's done a little bit of amazing things, like stopping the blurry."

# 4 Impact

Without visiting and telehealth outreach services, patients would have limited access to eye health care. The LOV Program plays a vital role in meeting the needs of many people in a number of communities who would otherwise avoid or simply be unable to address their eye health issues. For some communities, the nearest permanent optometrist can be nearly 800km away, and take up to 22 driving hours on rough unsealed roads. Such logistical and financial barriers contribute to the normalisation or tolerance of poor vision, along with increased risks associated with untreated eye disease and related complications.

The provision of outreach eye health services in the Pilbara is having a number of important health and social impacts including:

- Improving patients quality of life, health and wellbeing,
- increasing eye health literacy of patients and local clinic staff,
- enhancing patients' engagement with eye health services,
- supporting enhanced diabetic management and diabetic patient health behaviors,
- supporting innovation within local health facilities and better coordination and collaboration across local services.

#### Visual benefits

Access to treatment services provides immediate visual benefits, giving patients new or improved abilities to drive, work, and participate in hobbies. Practitioners and patients also reflect on further health benefits realised by wearing glasses or cataract surgery including the ability to read medication labels and blood sugar level measurements when self-testing for improved management of their diabetes.

"Getting reading glasses allows me to read the bible and see my medicines, my computer and phone and playing the keyboard"

#### Patient health literacy

Any LOV Program eye screening, examination or treatment presents an opportunity for health professionals to provide education to help patients best understand and manage their health. This includes reinforcing the importance of holistic health, healthy eating and lifestyle choices.

Increased access to services through the LOVV and the attendance of the Ophthalmologists at the hospital is contributing to improved eye health literacy in diabetic patients and the wider community. Patients understand the importance of treatment, and are more able to appreciate the potential consequences of their disease, which they had previously ignored.

Their increased understanding results in better attendance and adherence to treatment regimens such as monthly injections, and subsequently better patient outcomes. Education also positively affects patient behaviour and engagement with preventative health services. Knowledge encourages asymptomatic diabetic patients to present to annual retinal screenings because they understand the 'silent' nature of diabetic eye disease.

LOV developed resources including the award winning 'Bad Sugar, Bad Eyes' patient education video greatly contributes to improved patient health literacy. Translated into Nyangumarta for use among an Aboriginal language group in the Pilbara, local health workers positively evaluated the video as very culturally appropriate, understandable and relatable. Patients who saw the video agreed that it increased their knowledge about diabetic retinopathy and corrected misconceptions about diabetic retinal screening<sup>23</sup>.

Patient health literacy motivates greater service attendance where the 'fix' for bad eyes is understood to be relatively simple and immediate, such as in the instance of wearing glasses or having cataract surgery to 'stop

the blurry'. Patient awareness and knowledge of a chronic conditions such as diabetes underpins their capacity to self-manage that condition and related complications.

While LOV drive improved health literacy through patient education, it is the local eye champions at the core of the LOV Program model who are the most valuable advocates within their own community, and help spread the word about caring for your eyes. A constant need for ongoing and improved education, awareness and capacity building is required to address health issues such as diabetic management, where early intervention, education and regular monitoring can reduce the prevalence of vision related impacts.

## Case study:

## Onslow resident, male, age 53

## ""keep them motivated"

The participant admits he is very passionate about telling other members of his community to go and have their eyes checked and to look after their eyes if they are diabetic. He has a video on his phone showing the injection process that he uses to show others "to keep them motivated" and to get their eyes seen. He also shows people to reassure them that there is nothing to be worried about in having your eyes checked or even with having the injections.

The participant is motivated to look after his health and his eyes as best he can and has given up drinking and smoking. "It's within yourself to be so strong about looking after your health... health is the most important thing in your life."

The participant requires regular injections but admits he has missed some appointments because his business keeps him busy and travelling around. As a traditional owner he also has many commitments and sits on the Boards of several corporations, which takes up time and requires travel. The LOVV service in Roebourne and the outpatient clinic in Karratha has assisted this participant to better manage his eye health. He acknowledges that his range of commitments would be seriously impacted by having to travel to Perth for his eye health care.

During the appointment at Nickol Bay Hospital the patient was informed that he will require cataract surgery at some point in 2018. Dr Turner discusses this with the patient who wasn't very clear about cataract surgery. Dr Turner explains the impact of this on the patient's eye in clear simple language and describes what the participant would be currently experiencing and how surgery can address this. Dr Turner also outlines the complications with sugar diabetes and cataract surgery. The participant appears to understand the issues and agrees he is experiencing the symptoms Dr Turner has outlined. The participant also understands the need for his next appointment to involve undergoing a more thorough check of the cataracts and the impact of this on his ability to self-transport – he drives more than 7 hours round trip for his appointment. The participant describes how he wants to do all he can to look after his vision and continue working and driving and will ensure he makes the appointment to assess his cataract. "It's about how your eyes are coping through your life's journey...you want to keep your vision going, it's very hard for us to keep on the right path through diabetes and everything else... we have to be more focused on looking after our eyes."

#### Enhanced service engagement

Providing services for Aboriginal patients within culturally appropriate facilities is known to improve access <sup>24</sup>. Outreach services hosted within an AMS 'on country' is more culturally acceptable than requiring Aboriginal people from remote communities to travel 'to town' for treatment. For many, leaving country can be daunting and fraught with obstacles. While the state government subsidises travel expenses for people accessing specialist care, the barriers created by travel time, distance, cultural differences, and unfamiliar hospital processes can be almost insurmountable.

In addition to the prohibitive costs and efforts seeking care away from home, patients are dislocated from family and usual supports. As such, there can be great anxiety attached to attending services off country, and patients may miss their appointment and forego essential eye care.

Delivering LOV services on country means patients have shorter travel distances and times to care, and subsequently less stress, reduced costs and fewer disruptions to family, community and working commitments.

Novel virtual service delivery models also contribute to improved attendance. Increasingly patients are happy to participate in videoconferences (VC), as there is no need for them to travel to receive specialist services. The establishment of a regular afternoon VC clinic and online booking portal in January 2014 allowed referrers (predominantly optometrists) to book scheduled appointments for consults. Prior to this, the referring practitioner could only contact the solo ophthalmologist directly to arrange an ad-hoc VC appointment. VC is a valuable medium for direct surgical bookings and coordinated after care. Later in 2015 the ophthalmology Fellow was engaged as an additional VC provider, increasing service access and offering improved booking flexibility for referrers and patients. As a result, more patients are able to receive ophthalmology care from the convenience of their local community.

#### Service continuity and commitment

Sustained regular attendance by the LOV staff and the LOVV has built established relationships based on rapport, trust and confidence among the community and local clinic staff. Familiarity with staff and recognition of services such as LOVV, enhances access by contributing to increased patient attendance.

LOV demonstrates a culture of engagement with community and local services (AMS, Hospital and the local Optometrist) and a commitment to improving local eye health capacity. Local health workers can often feel isolated, and formal and informal upskilling opportunities provided by LOV increases their confidence clinically and reduce feelings of professional isolation.

Ongoing attendance of LOV staff to the AMS for many years has enabled every clinic staff member in Roebourne to be trained in retinal photography and to instil awareness among staff of the importance of a rigorous approach to diabetic patients' eye health. This in turn results in a better understanding of the need to encourage and facilitate patient attendance at annual screening, so they can continue to drive, care for family, and see their country.

#### Service integration and coordination

It is through close community engagement, relationship and trust building that the LOV Program can be sustained effectively.

Communication with key AMS personnel at each location ensure the service days are compatible with the clinics and communities in which they are held (e.g. taking into account other visiting services, preceding ophthalmology services and the community's social calendar).

LOV staff employ culturally appropriate strategies to communicate effectively with patients including simple clear language, tailoring the words to the patient's level of understanding, using visual props, encouraging patients to ask questions, seeking feedback and being aware that patients may not ask questions because they do not know what to ask. All staff complete cultural awareness and diversity training.

Local and central coordination roles provide pivotal links between the local community and LOV services and an Aboriginal Eye Health Coordinator helps facilitate the patient journey by providing logistical and emotional support.

The ongoing presence of LOV in the area is contributing to better integration and coordination across services and practitioners including the VOS and local Optometrist, AMS, and Hospital. Clear referral processes prevents patients being lost in the 'leaky pipe', and ensures they receive timely care. Clear communication and tools such as integrated eye health records facilitate a streamlined journey of care, placing less stress on the patient.

The importance of eye health care and the increased access to services has contributed to responsive systems within LOV, the local AMS and regional hospitals. Services change because of regular internal process reviews involving direct communication with local health and administrative staff for each town, so they continue to meet the needs of the community and improve continuity of care.

## Case Study:

## AMS staff. Roebourne

2 x AHP (A), (E), Chronic Disease Nurse (M)

"Of all the specialists that come here, if they (patients) know the vision van is here they will come out of the woodwork... There are people who come to the vision van we never get to see, they will come from all directions to see the vison van." (M)

"Vision to them (the patients) is a really important thing. They really value their eyesight". (M)

Local staff recognise that the importance of vision to patients means it is easier to motivate patients to do something about their eye health and this can be seen in their attitude to the LOVV when it is in Roebourne. "They all know when that van is around" (A)

The attitude to the LOVV is also associated with many patients' reticence to travel to Perth for any health issue. "They hate going to Perth". (M)

"They don't feel scared by the vison van whereas mention the word Perth and they say 'I'm not going down there'" (M)

The participants identify significance in how LOV staff engage with patients. They describe how the LOV staff approach patients in a way that engenders trust and alleviates anxiety, especially associated with the injections. They also note that two of the Ophthalmologists of LOV have had a long-standing relationship with MHS and the Roebourne community and this is a really important aspect of LOV and patients engagement with the service.

Although vision is extremely important to the patients, the participants also admit that poor vision is normalised by many in the community with patients tolerating the situation for a long time. One participant describes how she often provides basic reading glasses to patients in the clinic to sign paperwork and witnesses the expression and exclamation on their face when they put the glasses on. She notes the way that patients always describe being surprised and amazed at how well they can suddenly see with a pair of basic reading glasses.

MHS services the town of Onslow (once a month) but patients needing cataract surgery have to provide their own transport for cataract surgery in Karratha. Last time the LOVV was in Onslow MHS aligned their outreach service and used their transport to find patients. This proved successful as the LOVV that normally sees around 10 patients saw more than 40.

MHS have created a system where they are notified of all patients' specialist appointments—in Perth or Karratha, to ensure they can enhance attendance through transport and dedicated liaison contacts. In some cases they have also started accompanying the patient into the consultation and this is proving beneficial to enhancing the communication to the patient and their understanding and reducing the incidence of DNAs. The participants acknowledge that while patients are increasingly motivated about their eye health, DNAs are still an ongoing problem. They note that provision of transport, even in a small town, is critical to increasing patient's attendance to any appointment. They also note that sometimes transport staff just cannot find people on the day to take them to their eye health appointment. They also know that if there are funerals, cultural or community based events then people will miss their appointments, as these are priorities for

Aboriginal people. For example, a forthcoming native title determination meeting on country the following week is cited as an example where very few residents will be in the town.

Poor communication is also identified by the participants as contributing to patients missing appointments. They believe that patients do not always understand the importance of the appointment and the procedure. LOV staff and MHS staff are working at ways to address this – especially through effective use of telehealth. MHS is doing an increased volume of telehealth. "patients love telehealth because it means they don't have to go to Perth" (M) Patients also like that staff sit with them during the telehealth consultation and have access to the file (which specialists don't if patients go to the hospital) and can talk to the specialist as well as interpret what is being said to the patient.

One of the AHPs has worked at MHS for 10 years, and believes she has witnessed in that time more people coming for their appointments for eye health. She attributes this to a combination of factors: patients are more familiar with the processes and procedures, they have more understanding about the importance of attending, and now have better access to services, and "they like the eye health staff".

The participants all agree that MHS is proactive about retinal photography. They describe how every diabetic patient is regularly screened and alerts checked in their files to ensure they are up to date with screening. Improved machinery at the health service and the provision of regular training by LOV staff has enhanced the willingness of MHS clinic staff to undertake retinopathy. The clinic staff have also become far more proactive at getting the patients involved and seeking to increase their understanding about the impact of diabetes on their eyes. Once they have the photograph they show the patient the image, explain to the patient what they are looking for and why they do it, describe it to the patient as "like having a heart attack in your eye" and that if they keep taking the images then they can pick things up early and stop people from going blind. The participants believe that utilising the image in this way is very effective for eye health literacy because Aboriginal patients tend to be very visual in their learning and respond to the use of the images. The staff believe they are having positive results taking this approach with patients. They also utilise iPads to show patients a movie (Bad Eyes) before they get the photos taken. They believe this movie is easy for patients to understand.

The participants cannot identify any negative consequences associated with the LOVV or attendance of LOV staff in Roebourne, Onslow or Karratha. Rather, as one participant commented: "if that van ever left it would have a huge impact".

#### 4.1 Conclusion

The LOV Program has demonstrated its value in creating positive individual and community impact, however more work is to be done. The scalability of the LOV Program model of care is limited by the capacity of hospitals and host facilities to accommodate services. As such, the current model is unable to address national recommendations of increased access to care, particularly with regard to treatment for diabetic eye disease. Until such time, equality of access for people in regional, remote and Aboriginal communities will remain unattainable.

Shifting the balance of care to preventative and early treatment is vital to stem the burden of eye disease. It is imperative the LOV Program continues to provide comprehensive and integrated holistic care to facilitate this.

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