Eye Health in Aboriginal and Torres Strait Islander Communities

Uwankuru palya ngalkalpai — Better vision for all
EYE HEALTH
IN
ABORIGINAL AND
TORRES STRAIT
ISLANDER
COMMUNITIES

Hugh R. Taylor

The Report of a review commissioned by the Commonwealth Minister for Health and Family Services, the Hon. Dr Michael Wooldridge, MP

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Better vision for all
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Cover: Photograph of diabetic retinopathy in an Aboriginal person taken with a non-mydriatic retinal camera by an Aboriginal Health Worker.

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The Hon. Dr Michael Wooldridge
Minister for Health and Family Services
Parliament House
CANBERRA ACT 2600

13 June 1997

Dear Minister,

It has been a privilege to undertake this Review and a pleasure to present this Report to you.

Despite the hard work and commitment of a number of individuals and organizations over the last ten to twenty years, the standards of Aboriginal eye health in some areas of our country remain appalling, and this seems inexcusable. However, having said that, I believe there is good reason for optimism as there are a number of examples of the effective delivery of quality eye care.

I have tried to identify the key elements from these examples and to use them to develop a regional model for eye care. This model combines both public and private resources and has three components: the provision of infrastructure by State and Territory governments; the support of specialist eye services by Medicare; and the organization of these specialist services by the health services in the region with linkage provided by Aboriginal Health Workers.

The components and resources needed for the successful delivery of eye health to indigenous Australians are generally available, what is required is the political will and commitment to implement this and to ensure ongoing accountability and performance.

I wish to gratefully acknowledge the input and support of the many people across the country who made this Review possible.

Yours sincerely,

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TABLE OF CONTENTS

LIST OF TABLES AND FIGURES ................................................................. x

ACKNOWLEDGMENTS .............................................................................. xi

ABBREVIATIONS ....................................................................................... xii

EXECUTIVE SUMMARY ............................................................................ 1

Introduction ............................................................................................ 1

Service Delivery .................................................................................... 1

Primary Eye Care Services ................................................................. 1

Specialist Eye Services ........................................................................ 2

Specific Eye Conditions ...................................................................... 4

Refractive Error .................................................................................... 4

Cataract ................................................................................................. 5

Diabetic Retinopathy .......................................................................... 6

Trachoma ............................................................................................. 7

The Cost of the Status Quo ................................................................. 8

The Environment ................................................................................. 8

A National Information Network ....................................................... 8

CHAPTER ONE – INTRODUCTION ......................................................... 11

Background to the Review .................................................................. 11

Introduction ........................................................................................ 11

The 1982 Mayers Report .................................................................... 12

The 1984 Report by the Task Force on the Future of the NTEHP ........ 13

The 1985 Trachoma and Eye Health Report .................................... 13

The National Aboriginal Health Strategy ........................................... 14

The Office for Aboriginal and Torres Strait Islander Health Services (OATSIHS) ................................................................. 15

The Current Review ............................................................................ 15

Terms of Reference ............................................................................ 16

The Review Process ........................................................................... 17
CHAPTER TWO — PRIMARY EYE HEALTH CARE ........................................ 19
  Findings from the Current Review ............................................. 19
  Recommended Practices ......................................................... 20
  Clinical Practice Guidelines .................................................... 20
  Training .................................................................................. 21
  Aboriginal Health Workers ....................................................... 21
  Equipment ............................................................................... 22
  Links to Specialists .................................................................. 22
  Chronic Disease Registers ....................................................... 23
  Reporting .................................................................................. 24

CHAPTER THREE — SPECIALIST EYE HEALTH CARE .................... 27
  Introduction ............................................................................. 27
  Commonwealth-funded Trachoma and Eye Health Committees .... 28
    Northern Territory .............................................................. 28
    Queensland ........................................................................ 31
    South Australia ................................................................... 32
  Eye Services in other States .................................................... 34
    New South Wales ............................................................... 34
    Tasmania .......................................................................... 34
    Victoria ............................................................................. 35
    Western Australia ............................................................. 36
  Army Field Hospitals .............................................................. 36
  The Far North Queensland Model ............................................. 37
  Findings from the Current Review ............................................ 41
    Ophthalmic work force ....................................................... 42
    The Public-"Voluntary" Model ............................................... 44
    The Regional Public-Private Model ....................................... 45
  Recommended Practices ......................................................... 46
    Funding Issues ..................................................................... 47
    Linkages ............................................................................. 48
    Implementation Issues ........................................................ 49
  Anomalies in Current Arrangements ........................................ 51
    Regional Centres ................................................................ 51
    Cross-Border Issues ............................................................ 52
    Other Issues ........................................................................ 52
    Clinical Practice Guidelines ................................................. 53
    Ophthalmic Registrars ........................................................ 54

CHAPTER FOUR — REFRACTIVE ERROR AND THE PROVISION
OF GLASSES ................................................................. 57
  Introduction ............................................................................. 57
  Current Status and Findings ................................................... 58
  Recommended Practices ......................................................... 59
    Low-cost and Subsidised Glasses ......................................... 59
    Ready-Made Reading Glasses .............................................. 60

CHAPTER FIVE — CATARACT .................................................. 63
  Introduction ............................................................................. 63
  Current Status ........................................................................ 63
  Findings from the Current Review .......................................... 65
  Recommended Practices ......................................................... 66

CHAPTER SIX — DIABETIC RETINOPATHY ................................. 69
  Introduction ............................................................................. 69
  Current Status ........................................................................ 70
    Prevalence of Diabetes ......................................................... 70
    Incidence of Diabetes ........................................................... 71
    Obesity .............................................................................. 72
    Treatment and Prevention of Diabetes .................................. 72
    Prevalence of Diabetic Retinopathy ...................................... 73
  Findings from the Current Review .......................................... 74
  Recommended Practices ......................................................... 77

CHAPTER SEVEN — TRACHOMA .............................................. 81
  Introduction ............................................................................. 81
  Current Status ....................................................................... 82
    Prevalence of Active Trachoma ............................................ 82
    Prevalence of Trachoma and Trichiasis .................................. 86
  Findings from the Current Review .......................................... 87
    Azithromycin .................................................................... 88
  Recommended Practices ......................................................... 89
## LIST OF TABLES AND FIGURES

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1</td>
<td>Services provided by the Far North Queensland Project in 1996</td>
</tr>
<tr>
<td>3.2</td>
<td>Types of spectacles dispensed in the Torres Strait (1995 to 1996)</td>
</tr>
<tr>
<td>3.3</td>
<td>Types of lenses dispensed in the Torres Strait (1995 to 1996)</td>
</tr>
<tr>
<td>5.2</td>
<td>Predicted rate of cataract surgery by theoretical level of visual impairment</td>
</tr>
<tr>
<td>6.1</td>
<td>Prevalence of diabetic retinopathy</td>
</tr>
<tr>
<td>6.2</td>
<td>Estimated prevalence of diabetes in communities visited during this Review</td>
</tr>
<tr>
<td>7.1</td>
<td>Overall prevalence of trachoma in Aboriginal people found by NTEHP 1976-1979</td>
</tr>
<tr>
<td>7.2</td>
<td>Current prevalence of follicular trachoma in children by region</td>
</tr>
<tr>
<td>7.3</td>
<td>Prevalence of follicular trachoma for children in the Pilbara</td>
</tr>
<tr>
<td>7.4</td>
<td>Prevalence of follicular trachoma for children aged 0-9 years in the Murchison Region</td>
</tr>
<tr>
<td>7.5</td>
<td>Prevalence of follicular trachoma among schoolchildren in the Kimberleys</td>
</tr>
<tr>
<td>7.6</td>
<td>Twenty year prevalence of follicular trachoma</td>
</tr>
<tr>
<td>7.7</td>
<td>Prevalence of follicular trachoma for children in Anangu Pitjantjatjara communities 1976-1990</td>
</tr>
<tr>
<td>8.1</td>
<td>Prevalence of blindness by age</td>
</tr>
<tr>
<td>8.2</td>
<td>Age-standardised public and private hospital admission rates for eye conditions, Northern Territory, 1979-1988</td>
</tr>
<tr>
<td>8.3</td>
<td>Age-standardised public and private hospital admission rates for eye conditions, South Australia, 1991-1994</td>
</tr>
<tr>
<td>8.4</td>
<td>Age-specific rate ratios for eye conditions leading to hospitalisation</td>
</tr>
<tr>
<td>1</td>
<td>Ophthalmic and Optometric services in Australia</td>
</tr>
<tr>
<td>2</td>
<td>Diabetes prevalence in relation to age in Australians of European origin and Aboriginal people from ten communities in northern and central Australia 1983-1995</td>
</tr>
<tr>
<td>3</td>
<td>Comparison of the prevalence of follicular trachoma among Aboriginal children</td>
</tr>
</tbody>
</table>

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ABBREVIATIONS

ABS  Australian Bureau of Statistics
AEHW  Aboriginal Eye Health Worker(s)
AHC (SA)  Aboriginal Health Council of South Australia
AHRC  Aboriginal Health Resources Committee Pty Ltd
AHW  Aboriginal Health Worker(s)
AIHW  Australian Institute of Health and Welfare
AMS  Aboriginal Medical Service(s)
AMSANT  Aboriginal Medical Services Alliance of the Northern Territory
AMWAC  Australian Medical Workforce Advisory Committee
ATEHP (SA)  Aboriginal Trachoma and Eye Health Program (SA)
ATSIC  Aboriginal and Torres Strait Islander Commission
FHF  Fred Hollows Foundation
FNQ  Far North Queensland
NACCHO  National Aboriginal Community Controlled Health Organisations
NAIHO  National Aboriginal and Islander Health Organisations
NAHS  National Aboriginal Health Strategy
NPDR  Non-proliferative diabetic retinopathy
NTAEHC  Northern Territory Aboriginal Eye Health Committee
NTEHP  National Trachoma and Eye Health Program
PDR  Proliferative diabetic retinopathy
QAIAHF  Queensland Aboriginal and Islander Health Forum
QTEHP  Queensland Trachoma and Eye Health Program
RACO  Royal Australian College of Ophthalmologists
TAC  Tasmanian Aboriginal Centre
TF  Trachomatous inflammation — Follicular
THS  Territory Health Services
TI  Trachomatous inflammation — Intense
TS  Trachomatous scarring
TT  Trachomatous trichiasis
VACCHO  Victorian Aboriginal Community Controlled Health Organisations
WAACCHO  Western Australian Aboriginal Community Controlled Health Organisations
WHO  World Health Organisation

EXECUTIVE SUMMARY

Introduction
The current review was instructed to report on:
- the status of eye health amongst Aboriginal and Torres Strait Islander peoples;
- the effectiveness of eye health programs and their capacity to meet eye health needs; and
- how quality eye health services could be delivered in the future.

The review consulted broadly with communities, health organisations, health services, health staff and health policy units in the development of this report and its recommendations.

Service Delivery
Primary Eye Care Services

Overall, the provision of primary eye care was found to be reasonable with some exceptions. Screening for diseases such as diabetic retinopathy, or trachoma in endemic areas, is not well integrated into a comprehensive primary health care program. The provision of training is variable with most nurses and Aboriginal Health Workers developing their eye care skills on the job. Medical Officers report the need for additional training particularly for conditions that are rarely seen in urban Australia such as trachoma and trichiasis. There is a need to develop clinical practice guidelines for primary eye care and for them to be disseminated and updated regularly. Regular in-service training would assist in the implementation of these guidelines.

Recommendation 1
The Commonwealth Government should commission an appropriate group to develop evidence-based, clinical practice guidelines for primary eye care for Aboriginal and Torres Strait Islander peoples. These guidelines should be developed in consultation with the relevant health professions especially those working in Aboriginal Medical Services. Appropriate in-service training modules should be developed around these guidelines for all those working in the primary health care setting. These should be provided to the National Information Network for wide distribution.
Disease registers are essential for the proper management of chronic diseases especially for diabetes. Most health services lack adequate registers or information systems.

Commercially available, computer-based systems now exist and health services should be actively encouraged to use these for patient recall and management. Governments should provide incentives for services to acquire and use computer-based, patient management and recall systems.

**Recommendation 2**

The Commonwealth and State and Territory Governments should provide financial incentives for health services to purchase and use computer-based, patient management and recall systems. Training must be provided to these organisations to assist in integrating these systems into the work of the service. The Commonwealth and State/Territory Governments should develop performance information and minimum data reporting requirements for eye health that can then be generated by the patient management and recall systems.

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**Specialist Eye Services**

The provision of specialist eye services varies greatly across Australia and in some areas is grossly inadequate.

Some services use public funding to provide sessional or volunteer ophthalmology services. The State Trachoma and Eye Health Committees in the Northern Territory, Queensland, and South Australia follow this model, as do some other services.

However, the best eye health care was provided through a regional public-private model. This combines public funding for infrastructure and hospital services, together with Medicare bulk billing for specialist eye services. The specialist eye service is organised regionally. This model is used in the Pilbara and Eastern Goldfields regions and in Far North Queensland. This model ensures ongoing commitment from both the private ophthalmologist and the health services within the region. The regional public-private model also provides services to outlying communities that are visited at least annually. Cataract and laser surgery and more frequent patient review can be carried out at the regional centre.

The successful implementation of this model requires the following:

- the organisation of eye services regionally;
- all health services in the region should be involved in its organisation;
- AHW with a liaison responsibility should link the eye service with the primary health care service and the hospital;

---

State/Territory funding is required for an overhead-free environment including liaison, infrastructure, administrative support, travel and accommodation; and

Commonwealth funding through Medicare bulk billing is required for clinical services.

A lack of commitment and funding from either the Commonwealth or the State/Territory Governments will prevent the model from working and prevent the delivery of eye care.

**Recommendation 3**

3a. Eye services should be delivered through a regional public-private model. The provision of these services is the joint responsibility of the Commonwealth and State and Territory Governments. Where possible outpatient services should be delivered through Aboriginal Medical Services.

3b. The proposed funding method for the regional model is for the Commonwealth Government to:

- continue to allow Medicare bulk billing for specialist eye services; and
- make available Commonwealth funding, through Medicare or another mechanism to cover the surgeon’s involvement in cataract and other eye surgery performed in public facilities in remote regions.

State and Territory Governments are to provide funds for the overhead-free environment required for the provision of the above services. This would include, among other things, equipment, infrastructure, travel and support.

3c. Regional and local health care services must identify a person, preferably an Aboriginal person, to be responsible for the administration and community liaison for the specialist eye services. Hospitals should be resourced to provide Aboriginal Health Workers with liaison responsibilities to assist Aboriginal patients undergoing surgery.

3d. Links should be established between primary health care services in urban areas and optometrists, ophthalmologists and hospitals that provide eye services so that primary health care services can readily refer their patients for appropriate eye care.

3e. The Commonwealth and State and Territory Governments must ensure that cross-border funding issues are addressed at a local level so that the quality of care is not jeopardised for patients who may be referred from centres in other States.
**Diabetic Retinopathy**

Diabetes has become a major health problem for Aboriginal and Torres Strait Islander peoples. In many communities, 8% to 13% of people have diabetes. All people with diabetes are at risk of developing diabetic eye disease (retinopathy) that can lead to blindness. Most of this blindness can be prevented by regular screening to detect early stages of retinopathy followed by timely retinal laser treatment.

Aboriginal people with diabetes should have their eyes examined once a year, but this does not happen. Computer-based patient management systems readily facilitate regular examination and new retinal cameras allow health workers to perform eye screening. Laser treatment should be readily available either in local communities or in regional centres (see also Recommendations 1, 2, 3b and 4).

**Recommendation 10**

The State and Territory Governments should provide regionally-based equipment such as non-mydriatic fundus cameras and portable laser equipment necessary for the management of diabetic retinopathy. Appropriate training should be made available to primary health care workers who will use the photographic equipment.

**Recommendation 11**

Clinical practice guidelines for diabetic retinopathy should include at a minimum, the use of patient management and recall software, the importance of annual eye examinations and advice on the use of laser treatment in Aboriginal and Torres Strait Islander communities.

**Recommendation 12**

12a. A Medicare item number should be provided for annual retinal photographic screening for retinopathy in people with diabetes by practitioners other than ophthalmologists and optometrists.

12b. Aboriginal Health Workers or nurses should be able to provide annual retinal photographic screening for retinopathy in people with diabetes under the supervision of a medical practitioner, in keeping with the ‘On behalf’ provisions, and thereby attract a Medicare rebate under the supervising medical practitioner’s name.

**Trachoma**

Trachoma is a slowly blinding eye infection. Although the prevalence and intensity of trachoma may have decreased in some areas, other areas show little or no improvement over the last 20 years. Many seem to have disregarded trachoma and current data on active trachoma underestimate the problem as they often come from incomplete cohorts of older children. Information on trichiasis is grossly inadequate and in most areas, cases are not actively sought (see Recommendations 1 and 4).

An integrated primary health approach is required to manage trachoma. This should combine screening, azithromycin antibiotic treatment, personal hygiene and environmental improvement. This approach has been codified by the World Health Organisation in the “SAFE strategy”. It is unconscionable that trachoma remains a blinding disease in Australia.

**Recommendation 13**

Clinical practice guidelines for trachoma should be developed for Aboriginal and Torres Strait Islander peoples based on the WHO guidelines and in consultation with the relevant health professionals including those working in Aboriginal Medical Services. They should include at a minimum, the screening for trachoma, the WHO simplified grading, the surgical treatment of trichiasis, the family-based treatment with azithromycin, the promotion of facial cleanliness and environmental improvement.

**Recommendation 14**

14a. As a matter of urgency, the Therapeutic Goods Administration should put to the Pharmaceutical Benefits Advisory Committee the issue of scheduling azithromycin under the Pharmaceutical Benefits Scheme for the treatment of trachoma, including the use of a paediatric suspension for infants.

14b. The Commonwealth Minister for Health and Family Services should authorise funding under Section 100 of the National Health Act or through some other mechanism, the distribution of azithromycin through alternative arrangements that substitute for doctors and community pharmacists.
The Cost of the Status Quo

Blindness occurs up to 10 times more frequently in Aboriginal and Torres Strait Islander peoples than in other Australians. Most of this blindness is due to corneal scarring from trachoma or unoperated cataract. Diabetes is likely to figure more prominently as a cause of blindness in the near future. However, few current data are available for blindness or for hospital utilisation for eye services.

Blindness has significant and definable costs to Governments as well as significant but less quantifiable costs to the individual and to the community. Interventions that relieve or prevent blindness from cataract, diabetic retinopathy or trachoma have been shown to be highly cost-effective. There can be no grounds, either economic or moral, not to address the problems of eye disease in Aboriginal and Torres Strait Islander peoples.

The Environment

The environment plays a key role in the maintenance of health and in eye health it is particularly relevant for the persistence of trachoma. Good environmental health requires the provision of functioning resources that are necessary for healthy living — health hardware. Poor design, poor supervision and construction faults are responsible for many initial problems with health hardware. However, the key to healthy living is the long term provision of planned and funded maintenance to keep health hardware functioning. Sound maintenance programs are extraordinarily cost-effective and provide both an improved environment and a healthier community. These proven initiatives should be broadened to encompass all rural and remote Aboriginal and Torres Strait Islander communities (see also Recommendation 13).

Recommendation 15

The three tiers of government must make concerted and sustained improvements in housing, water supply, waste disposal and other important aspects of the environment in Aboriginal and Torres Strait Islander communities that ensure the provision of functional health hardware. Resources should also be allocated and provided for planned maintenance. Attention must focus on the regional delivery of housing and the responsibility of local government to provide infrastructure.

A National Information Network

The proposed delivery of eye services on a regional basis requires access to information about the nature and delivery of eye services and feedback about progress made in the region and service targets that have been reached.

This resource service and co-ordination is best delivered by a National Information Network that provides current information about best clinical practice for the delivery of eye care, answers specific questions as they arise, and collects and collates data to be used for the documentation of program achievements and to assist in the planning of eye care services.

Recommendation 16

The Commonwealth Government should fund the establishment of a National Information Network to undertake the tasks that have been identified in this report. The Network would be a low-cost, small-scale organisation, possibly with a secretariat working on contract.

It is important that the information to be gathered is based on performance indicators and these must be built into core accountability mechanisms for Commonwealth and State/Territory Governments, the professions and Aboriginal and mainstream health service providers. Health service funding should be linked to performance indicators.

Recommendation 17

The National Information Network should report on a regular basis to Health Ministers on the performance of health providers of eye health care. This report should be based on information gathered by the Network and include, at a minimum, the following performance indicators:

- the number of pairs of glasses provided;
- the number of cataract operations performed;
- the number of people on the waiting list for cataract surgery, and the time that they have been on the waiting list;
- the percentage of people with diabetes who have an annual eye examination;
- the number of people with diabetes for whom treatment was recommended and the number who were actually treated;
- the status of trachoma on a community basis including the prevalence of trachoma in children aged five to nine years;
- the number of people treated for trachoma with azithromycin; and
- the prevalence of trichiasis in women over 40 years.

These performance indicators should be built into the framework of performance indicators being developed through Australian Health Ministers’ Advisory Committee to report on Australia’s national and jurisdictional performance in Aboriginal health.
CHAPTER ONE

INTRODUCTION

Summary
Concern about the poor status of Aboriginal eye health led the Commonwealth to fund the National Trachoma and Eye Health Program which ran from 1976 to 1978 under the directorship of Professor Fred Hollows. Since that time, several reviews have considered the need for national and state-based structures to provide eye services to Aboriginal and Torres Strait Islander peoples. Three State-based Trachoma and Eye Health Committees still operate. The Commonwealth Department of Health and Family Services now administers Aboriginal health and regional planning is being instituted with States and Territories.

The current review was instructed to report on the status of eye health amongst Aboriginal and Torres Strait Islander peoples, the effectiveness of eye health programs, their capacity to meet eye health needs, and how quality eye health services could be delivered in the future. The review has consulted broadly with communities, health organisations, health services, health staff and health policy units in the development of this report and its recommendations.

Background to the Review

Introduction
The poor state of eye health of Aboriginal and Torres Strait Islander peoples has been recognised since reports of Father Frank Flynn in 1944, and Professor Ida Mann in the early 1950's. Work by Professor Fred Hollows in the early 1970s, led to the National Trachoma and Eye Health Program (NTEHP) for which some $1.4m was provided by the Commonwealth to the Royal Australian College of Ophthalmologists (RACO). The NTEHP, which ran from 1976 to 1978 under the direction of Professor Fred Hollows, aimed to eliminate trachoma in Aboriginal people and screen, diagnose and treat eye diseases in rural Australia. It screened over 102,000 people (60% of whom were Aboriginal and Torres Strait Islander peoples), in rural and remote areas throughout Australia.
The NTEHP was a major undertaking that had profound and far-reaching effects on the communities visited, Aboriginal health, especially the work of Aboriginal Health Workers, the emergence of Aboriginal Medical Services and the people, Aboriginal and others, who worked on the project. Its aims were:
1. the elimination of trachomatous blindness in Australia; and
2. presentation of the ocular health status of persons in rural Australia to interested agencies;
3. provision of immediate eye care to persons in rural Australia; and
   based on the experience gained:
4. establish an ongoing eye care program for rural Australia; and
5. train medical, paramedical and interested lay persons in the skills necessary to provide appropriate eye care in rural Australia.

The findings of the NTEHP were detailed in the 1980 report entitled "The National Trachoma and Eye Health Program of the Royal Australian College of Ophthalmologists". Its recommendations were broad-ranging including the need for better environmental health conditions namely, improved housing, water supplies, sewage systems and rubbish disposal, and better access to a full range of food including fresh fruit and vegetables, for all persons in rural Australia. More specifically, the report also recommended the appropriate continuation of a national program which included regular scheduled visits of ophthalmologists, and visits from a range of other specialists to rural and remote Australia, to monitor, treat, direct and advise on the prevention of a range of skin, ear, and respiratory diseases.

The 1982 Mayers Report

The RACO did not intend to continue to administer the ongoing national program and in November 1981, the RACO commissioned Ms Naomi Mayers to prepare a report based on consultations in each mainland State and the Northern Territory to advise the College on future administrative and management arrangements.

The report recommended new State and Territory-based Committees be established and be co-ordinated by a national body. It also recommended that a national coordinator be appointed to liaise directly with the Commonwealth and State Governments, and to provide direct access to the RACO for Aboriginal people who wished to complain, criticise, offer suggestions or compliments.

In 1982, the RACO established State and Territory committees and secretariats, together with decentralised treatment programs, but it did not appoint a national coordinator. The committees had a majority of Aboriginal members with other members drawn from RACO State Branches and State health authorities. Ophthalmologists for field treatment programs were to be recruited from the State RACO branches, and surgery was to be supported by programs such as the Isolated Persons Travel and Accommodation Scheme or other ambulatory support systems.

The 1984 Report by the Task Force on the Future of the NTEHP

The RACO withdrew from total management responsibility in December 1983, at which time the Minister for Health appointed a task force that included representatives from the Department of Health and NAIHO, and Professor Hollows, to advise on the future of the NTEHP. Shortly afterwards, NAIHO withdrew from this review. The 1984 Task Force report recommended a national secretariat in preference to state-based secretariats, to oversee the development of a revitalised National Trachoma and Eye Health Program consisting of a national field program and a national data collection and an epidemiological surveillance unit. The report expressed concerns about the current program's lack of direction, the amount of funding directed to State-based secretariats and the lack of any statistical information and data.

The 1985 Trachoma and Eye Health Report

Aboriginal health programs were transferred from the Commonwealth Department of Health to the then Commonwealth Department of Aboriginal Affairs in January 1985. In light of ongoing difficulties experienced by the program, the Minister for Aboriginal Affairs requested another review of the National Trachoma and Eye Health Program.

The review committee was chaired by Mr Sol Belller, with representation from the NAIHO, the Departments of Aboriginal Affairs and of Health, and Professor Fred Hollows or his nominee. Its terms of reference were to report on the current state of ocular health, assess the effectiveness of existing eye health programs and provide plans to effectively deal with poor eye health.

Its major recommendations were to:
- retain an ongoing National Aboriginal and Islander Health Organisation Eye Health, Blindness Prevention and Trachoma Eradication Program;
- establish a Program secretariat to be based initially in Sydney;
- wind down funding for the existing State/Territory trachoma and eye health committees;
- increase the resources for Aboriginal community-controlled health services and expand the number of those facilities; and
- provide resources to develop a public and family health strategy with particular emphasis on homelands' needs.

There was little support for the recommendations. Concerns were expressed that the
national secretariat would direct funds away from service delivery. Some AMS also considered that they were better placed to deliver co-ordinated eye health programs.

The Minister established the National Trachoma and Eye Health Conference that was to meet twice annually, to co-ordinate existing trachoma and eye health services and to advise on programmatic changes. The National Conference endorsed goals and objectives of progressive improvement in Aboriginal health status, the provision of adequate eye health services, the maintenance of trachoma education programs and improvements in environmental health services. The Conference also formulated a version of the WHO Trachoma grading system and arranged the training of AHW to use this system. The Conference was also advised that future funding for programs would be linked to demonstrated effectiveness and were advised to develop performance indicators against which progress could be measured.

The National Aboriginal Health Strategy

The National Aboriginal Health Strategy (NAHS) was released in March 1989, and outlined a broad agenda for Aboriginal health. For ocular health it set the following goals:

- reduce the incidence of trachoma amongst Aboriginal communities and develop public health measures aimed at preventing trachoma amongst Aboriginal people; and
- reduce the incidence of diabetes amongst Aboriginal peoples in recognition that diabetes was likely to be the major cause of blindness amongst Aboriginal people as trachoma recedes as a cause of blindness.

It also recommended the following strategies:

- eye health screening and treatment programs be developed in those states not currently served by State Trachoma and Eye Health Committees;
- eye health programs be introduced at the primary level of care through Aboriginal health services;
- cataract surgery (using intraocular lens) be made freely available to Aboriginal people;
- better public health measures, health awareness and education programs be developed; and
- primary health care services are better integrated with specialist trachoma and ocular health programs.

NAHS still guides policy direction in Aboriginal health. It sought a more “holistic” treatment of health recognising that health was land-centred and encompassed all aspects of well being. It identified community control and community participation as key to improved health for Aboriginal and Torres Strait Islander peoples.

As a matter of policy, the Commonwealth supported the establishment of community controlled health services. By 1994 there were 68 community controlled Aboriginal Health Services and 44 clinics funded through the Aboriginal and Torres Strait Islander Commission (ATSIC)\(^4\). With the establishment of ATSIC on 5 March 1990, responsibility for Aboriginal health funding programs including the Trachoma and Eye Health Program moved to that body\(^5\). ATSIC developed regional-based and State-based decision making and the capacity for national funding decisions diminished. The National Trachoma and Eye Health Conference ceased to meet after ATSIC decentralised its decision making\(^6\).

The Office for Aboriginal and Torres Strait Islander Health Services (OATSIHS)

The evaluation of the NAHS implementation\(^7\) set the agenda for the transfer of Aboriginal health programs to the then Commonwealth Department of Human Services and Health, in July 1995. In 1996, Commonwealth/State Agreements on Aboriginal and Torres Strait Islander Health were signed with most States/Territories. Regional-based, co-operative planning between the Commonwealth, State, ATSIC and NACCHO was a major plank of these Agreements and has been instituted in all States and Territories. These plans provide the basis for Commonwealth funding decisions for the Aboriginal health program announced as part of the 1996/97 Budget. These funds are to be used for health services to 35 rural and remote communities that had previously not had access to these services.

With the exception of Trachoma and Eye Health Committees funded by the Commonwealth in the Northern Territory, Queensland and South Australia many of the current arrangements for specialist eye health care delivery in rural and remote Australia, have developed in the absence of any nationally-based or even State-based plan. These ad hoc arrangements involve a mix of public health services and private practitioners. Some Aboriginal organisations, such as AMSANT, welcomed the review of the priorities of eye health services that they regarded as being long overdue.

The Current Review

In November 1996, the Commonwealth Minister for Health and Family Services, Dr Wooldridge, commissioned Professor Hugh Taylor, Chair and Head of the Department of Ophthalmology at the University of Melbourne and Director of the
Centre for Eye Research, Australia, to review eye health in Aboriginal and Torres Strait Islander communities. A steering committee (Appendix VI) was established consisting of:

- Mr Brian Dixon (Australian Health Ministers’ Advisory Committee);
- Dr J.E.K. Galbraith (Royal Australian College of Ophthalmologists);
- Mr Robert Griew (Office for Aboriginal and Torres Strait Islander Health Services);
- Mr Arnold Hunter (National Aboriginal Community Controlled Health Organisations);
- Mr Michael Mullins (Commonwealth-funded Trachoma and Eye Health Committees);
- Professor Hugh Taylor (Reviewer); and
- Ms Vicki Taylor (Consultant).

**Terms of Reference**

The terms of reference for the review reflect the generally held belief that eye health priorities are changing and require a different emphasis to that of the National Trachoma and Eye Health Program. In addition, there have been marked changes in the way primary health care services are delivered, both in terms of the number of Aboriginal community controlled health services and the availability generally of health services to rural and remote Australia. The review was therefore directed to:

A. Describe the changing epidemiology of eye disease in Aboriginal and Torres Strait Islander peoples;

B. Describe and assess the appropriateness and efficiency of:
   - current Commonwealth funded trachoma and eye health programs in South Australia, Northern Territory and Queensland including the Northern Territory mobile team model;
   - programs organised on an ad hoc basis using individual ophthalmologists and some mainstream arrangements with regional hospitals;
   - an approach to delivering specialist ophthalmology and optometrist services to remote communities in the Cape York region, because of unique funding arrangements; and
   - any other approaches to the treatment of trachoma and other eye health issues in Aboriginal and Torres Strait Islander communities identified by the Centre.

C. Make recommendations to the Minister on how best to ensure that Aboriginal and Torres Strait Islander communities have good quality, appropriate primary and specialist eye health care, with particular reference to:
   - the most appropriate role and funding model for various parts of the health care sector;
   - how to ensure appropriate linkages between primary and secondary care; and
   - the future role of Commonwealth funded trachoma and eye health programs.

**The Review Process**

*Formal invitation for submissions*

Details about the review and a request for written submissions were sent to:

- all State and Territory Health Ministers;
- chief medical officers in each State and Territory Health Department;
- all community controlled health organisations and health services including the three Commonwealth-funded Trachoma and Eye Health Committees in Northern Territory, Queensland and South Australia;
- the Royal Australian College of Ophthalmologists and members of that College with a special interest in Aboriginal eye health;
- the Australian Optometrical Association;
- the Royal Australian College of General Practitioners;
- the National Rural Health Alliance;
- the Fred Hollows Foundation;
- the Royal Flying Doctors’ Service; and
- the Defence Forces.

Some 51 written submissions were received during the first phase of the review. Appendix I contains the list of those individuals and organisations who provided written submissions. Additional organisations were contacted and requested to send existing data on the status of eye health in their patient population (Appendix II).
Consultation and Information Gathering

Field trips and meetings were organised across the country to obtain more detailed information to supplement written submissions. Detailed information was sought on the types of, and funding arrangements for primary eye health care and specialist eye health care that was provided to communities, links between the two services, the adequacy of current eye health care, perceptions about what an optimal service might include and how the current system should or could be changed. Information was also sought on the status of diabetes and diabetic retinopathy, trachoma, ocular trauma and the provision of glasses.

The review met with community members, staff from local health services (both state-funded and state-run, and Commonwealth-funded), hospitals, public health units, ophthalmologists, eye institutions, the RFDS and health policy units (Appendix III). Reports of each meeting were sent back to the organisation and each organisation was invited to make further comments or changes where the report did not accurately reflect the views expressed at the meeting.

The following reports were specifically commissioned:

- The status of eye health in Aboriginal and Torres Strait Islander communities — Dr Neil Thomson;
- Environmental health issues and eye health — Dr Paul Torzillo;
- Diabetes in Aboriginal and Torres Strait Islander peoples — Professor Kerin O’Dea; and
- The Far North Queensland Project — Dr Garry Brian.

These reports have been used extensively in the preparation of this review. The report on the status of ocular health relied on existing data rather than the collection of new data through specific new field surveys.

Final Report

Three half-day workshops of key stakeholders were held to discuss the issues raised in the Review (Appendix VII). Each workshop was jointly chaired by Mr Sol Belleair and Dr Peter Brennan. The final report takes into consideration the discussions at these meetings and the comments provided by others (Appendix I).

CHAPTER TWO

PRIMARY EYE HEALTH CARE

Summary

Overall, the provision of primary eye care was found to be reasonable with some exceptions. Screening for diseases such as diabetic retinopathy, or trachoma in endemic areas, is not well integrated into a comprehensive primary health care program. The provision of training is variable with most nurses and Aboriginal Health Workers developing their eye care skills on the job. Medical Officers report the need for additional training particularly for conditions that are rarely seen in urban Australia such as trachoma and trichiasis. There is a need to develop clinical practice guidelines for primary eye care and for them to be disseminated and updated regularly. Regular in-service training would assist in the implementation of these guidelines.

Disease registers are essential for the proper management of chronic diseases especially for diabetes. Most health services lack adequate registers or information systems. Commercially available, computer-based systems now exist and health services should be actively encouraged to use these for patient recall and management. Governments should provide incentives for services to acquire and use computer-based, patient management and recall systems.

Findings from the Current Review

Primary health care in Australia is delivered by a range of health services that are government-funded or government-run and may have community control processes in place. A medical practitioner is usually part of the primary health care team, although in smaller communities a registered nurse or Aboriginal Health Worker (AHW) may have primary clinical responsibility. In general, primary eye care is provided as an integral part of primary health care, whether it is provided by a medical officer, a nurse, or an AHW.

The capacity of different primary health care professionals to deal with eye problems depends on their level of training. This was found to vary considerably and was exacerbated by high levels of staff turnover in many rural and remote
locations. Most AHW and registered nurses stated that they received little or no formal training about primary eye care and developed their eye care skills on the job. This can cause problems in those clinics where nurses or AHW are responsible for clinical eye care in the absence of medical officers. Those people who present with an eye problem more severe than simple conjunctivitis are usually referred to the next person in the referral chain. Some nurses expressed confidence in their management of superficial corneal foreign bodies and referred to printed clinical practice guidelines for the management of other common ocular problems.

Overall, the standard of primary eye care seems reasonable and most submissions and reports received from Health Services during the consultation, indicated that they were reasonably confident about the management of simple eye problems or they felt that an appropriate referral chain existed.

Rehabilitation services are not widely available in most areas. In some rural areas such as in Victoria, the Royal Victorian Institute for the Blind and The Association for the Blind have initiated specific pilot projects to supply services to Aboriginal people. The Guide Dogs Association of South Australia and the Northern Territory and The Association for the Blind in WA also provide some visiting services to blind people living in remote communities. These efforts are to be applauded and the particular problems of visually-impaired or blind Aboriginal and Torres Strait Islander peoples need emphasis and attention.

Recommended Practices

Clinical Practice Guidelines

Some form of clinical practice guidelines for primary health care was available to most clinics. The most common and comprehensive of these manuals seems to be the CARPA Manual prepared by the Central Australian Rural Practitioners Association. In one case it was referred to as the "bible for bush nurses". The CARPA Manual was initially developed for use in central Australia, and it undergoes periodic revision. Its next revision is to include sections relating to tropical health to extend its use in northern Australia. With regard to eye disease, the CARPA Manual is comprehensive, although it would benefit from some further ophthalmic input in its next revision. The section on trachoma needs some revision to include reference to azithromycin and to emphasise the importance of the ongoing detection and treatment of trachiasis in areas where trachoma existed.

The development and use of clinical practice guidelines for primary eye care is seen to be important and should be encouraged. Although these guidelines should be developed nationally, they need to be periodically reviewed and updated as necessary at the local level.

Training

The extent of eye care training for all health professionals in primary health care services varied and almost all those consulted expressed the need for regular in-service training. Many health professionals lacked the most basic knowledge about best practice for many common eye diseases. Most medical officers seemed to be comfortable with providing basic eye care in the primary health care setting, but few have received formal training about trachoma and few were willing to dilate pupils for fundus examinations even in patients with diabetes. In the Alice Springs Hospital, training medical officers in ophthalmic care had been identified as a priority area.

Health service staff recognized the need for in-service training linked with up-to-date guidelines for the management and prevention of eye conditions. During the consultations, health service staff asked repeated questions about best practice for eye health including information on trachoma grading, treatment and prevention. In-service training would better equip health staff to deal with the common eye problems in their communities, particularly in areas with high staff turnover.

Aboriginal Health Workers

The importance and appropriateness of AHW have been tenets of the provision of health services to Aboriginal and Torres Strait Islander peoples for decades. Although this premise is widely accepted, there is surprising variation in its actual application. During this review much confusing and conflicting information was gathered about the role of the AHW.

The training and career structures for AHW vary widely across the country. In some States, such as Victoria, there are no AHW training programs and no career structures. Most States/Territories have some training programs that offer at least a one-year certificate. However, in Western Australia the one-year course has been extended to three years and a clearly defined career path has been established. These changes have paradoxically led to at least one region re-introducing a more basic Aboriginal health worker concept with informal training provided in the community.

The role and responsibilities of AHW in the field also vary widely. In some cases AHW are well integrated into the health care team and are invaluable. In other cases their role is less clear. They may have administrative and managerial responsibilities for which they have not received training; they may not use, and so lose, their clinical skills in situations where most or all patients are seen by a nurse or a doctor anyway. In other circumstances they may be expected to work way beyond their level of clinical competency and so be set up for failure and exposed to criticism. Others may
have developed special clinical skills but do not receive recognition for them or are transferred to areas where these skills cannot be used. In some extreme cases AHW are even employed under the CDEP program.

With this diversity, broad generalisations are difficult. However, it is clear that AHW play an important role, although this role may be different in different circumstances. Whatever their job description or responsibilities it is essential that AHW receive adequate training for the tasks they are expected to perform. This requires both adequate basic training and ongoing in-service training.

At a minimum the basic training for AHW should include information about common eye conditions and the simple ocular examination. This should cover the measurement of visual acuity, external eye examination, conjunctivitis, trachoma, minor ocular trauma, cataract, diabetic retinopathy and presbyopia. It is important for AHW to know something about what the patient can expect to happen during and after cataract surgery and laser treatment for diabetic retinopathy, so that the AHW can counsel and reassure prospective patients.

Information about eye disease contained in clinical practice guidelines and manuals can readily provide the source material for this training. The content of in-service training will obviously depend on the responsibilities of the AHW at the time and should also be based on best clinical practice.

**Equipment**

A number of communities had slitlamps available in either a hospital or a medical centre. This was greatly appreciated by the medical officers who used them for the removal of corneal foreign bodies and to assess ocular trauma. The lack of even basic equipment such as magnifying loupes compromised the ability of some nurses and AHW to deliver basic eye care. The RACGP indicated their concern that general practitioners often did not have access to basic ophthalmic equipment negating any training in the use of that equipment.

At least the minimum basic equipment needed for an ophthalmic examination should be available in the primary care setting (see Appendix V).

**Links to Specialists**

A number of medical officers referred to their need to talk to hospital-based ophthalmologists or ophthalmic registrars to seek advice about various eye conditions. Most reported good support. In some cases there was concern that the advice provided did not recognise the difficulties of providing services to remote areas, or to Aboriginal people in general. Several of the medical officers reported that they would have appreciated at least some time with the visiting ophthalmologist to talk about specific cases and receive some in-service training.

Telemedicine is one developing option available for medical officers to link with their specialist colleagues. Telemedicine is not yet widely used for ophthalmic management in rural and remote Australia. Several small exploratory projects in Mt Isa, Shepparton and Bourke have had some success, but little information is available about them.

Although telemedicine offers a number of obvious advantages, its use in ophthalmology is constrained by the need to have ophthalmic instruments such as a slitlamp or a fundus camera to obtain the images. These instruments are quite costly, require skill to use and the images of the eye need to be of high quality and high resolution. Anterior segment images using a slitlamp and currently available CCD cameras may be used satisfactorily, but currently live retinal images do not have sufficient resolution.

Further studies developing telemedicine links with CCD slitlamp biomicroscopy seem worthwhile, although for the time being it seems likely that single image or polaroid non-mydriatic retinal photography will continue to have a major role for the remote assessment of retinal lesions.

**Chronic Disease Registers**

Good eye health management requires primary health care services to regularly screen for eye disease such as trachoma and diabetic retinopathy and to monitor conditions such as diabetic retinopathy. The screening processes and any subsequent treatment should be fully integrated into the comprehensive primary health care system. Where services have successful programs in place, they rely on up-to-date and workable patient registers that identify the target groups and assist with the appropriate recall and monitoring processes. Functioning registers also can provide data on service delivery and service targets.

Most services performed little opportunistic screening for decreased visual acuity, for trachoma or for diabetic retinopathy, although many recognised the importance of an annual screen for retinopathy in those with diabetes. Many of the health services used paper-based, chronic disease registers, although most of the registers were neither up to date nor did they include all people known to have diabetes. A few services either have developed or were developing their own local computer database, usually in “Access”. Some services had a commercial computer-based record system such as FERRET or PACSS. These computer-based registers seemed to be easy to use and to contain relevant information for diabetes management. If registers are to be used successfully, they must be seen as part of the ongoing work
of the health professionals in the health service and not a tedious data entry process that is of little relevance.

Some services indicated that a state-wide system was under development. Where a state-wide system was in place, it had little support from the local clinic staff. It was not perceived as being relevant to their work and any modifications were slow to be included, taking 6 months or more.

Overall the concept of computer-based systems has general support from the local health service and when available, they were quickly integrated into the work of the health service.

**Reporting**

There are significant advantages for governments to provide incentives for health services to install computer-based patient register and recall systems. These systems are able to generate minimum datasets and output standard reports that would form part of the accountability arrangements with funding agencies. Primary health care services also have an important role in monitoring eye health in their communities and contributing to state and national surveillance systems. Minimum datasets on eye health could be incorporated into the reporting process to include the following:

- the number of glasses provided;
- the number of cataract operations performed;
- the number of people on the waiting list for cataract surgery, and the time they have been on the waiting list;
- the percentage of people with diabetes who have had an annual eye examination;
- the number of people with diabetes for whom treatment was recommended, and the number who were actually treated;
- the status of trachoma on a community basis including the prevalence of trachoma in children aged five to nine years;
- the number of people treated for trachoma with azithromycin; and
- the prevalence of trichiasis in women over 40 years.

Computer-based, patient management systems would facilitate information collection and reporting.

**RECOMMENDATION 1**

The Commonwealth Government should commission an appropriate group to develop evidence-based, clinical practice guidelines for primary eye care for Aboriginal and Torres Strait Islander peoples. These guidelines should be developed in consultation with the relevant health professions especially those working in Aboriginal Medical Services. Appropriate in-service training modules should be developed around these guidelines for all those working in the primary health care setting. These should be provided to the National Information Network for wide distribution.

**RECOMMENDATION 2**

The Commonwealth and State and Territory Governments should provide financial incentives for health services to purchase and use computer-based patient management and recall systems. Training must be provided to these organisations to assist in integrating these systems into the work of the service. The Commonwealth and State/Territory Governments should develop performance information and minimum data reporting requirements for eye health that can then be generated by the patient management and recall systems.
CHAPTER THREE

SPECIALIST EYE HEALTH CARE

Summary
The provision of specialist eye services varies greatly across Australia and in some areas is grossly inadequate.

Some services use public funding to provide sessional or volunteer ophthalmology services. The State Trachoma and Eye Health Committees in the Northern Territory, Queensland, and South Australia follow this model, as do some other services.

However, the best eye health care was provided through a regional public-private model, that combines public funding for infrastructure and hospital services, together with Medicare bulkbilling for specialist eye services. The specialist eye service is organised regionally. This model is used in the Pilbara and Eastern Goldfield regions and in Far North Queensland. This model ensures ongoing commitment from both the private ophthalmologist and the health services within the region. The regional public-private model also provides services to outlying communities that are visited at least annually. Cataract and laser surgery and more frequent patient review can be carried out at the regional centre.

The successful implementation of this model requires specialist eye services to be delivered regionally and all health services in the region to be involved in the organisation of specialist eye services, the States and Territories to fund an overhead free environment including the liaison, infrastructure, administrative support, travel and accommodation and the Commonwealth to provide funds through Medicare bulkbilling for clinical services. Aboriginal Health Workers with a liaison responsibility are essential to link the eye service with the primary health care service and the hospital.

Introduction
The provision of specialist eye services has developed variably in each State and Territory. The reason for these variations seems to be historical. In the Northern Territory, Queensland and South Australia, the Commonwealth continues to fund
Aboriginal controlled Trachoma and Eye Health Committees. Very little specialist eye service delivery exists for Aboriginal and Torres Strait Islander peoples in these two States and Territory outside that provided by these committees. An exception is a project by the Fred Hollows Foundation in Far North Queensland. In the remaining States, specialist services have arisen on an ad hoc basis with little state-based co-ordination or assessment of need against service delivery.

A description of the specialist services in each State and the Northern Territory is provided below, along with comments on gaps in service provision and recommendations for future service provision.

Commonwealth-funded Trachoma and Eye Health Committees

The Commonwealth-funded Trachoma and Eye Health Committees in the Northern Territory, Queensland and South Australia are part of the infrastructure established under the RACO in 1983. Since then each committee has evolved separately.

The Committees generally organise visits to communities by ophthalmologists (although for the Northern Territory the lack of ophthalmologists has limited this function), provide linkages between the community and specialist services, and inform communities about the specialists’ visits. They are all Aboriginal controlled, and they provide free glasses and have the ophthalmic equipment and supplies needed for field trips.

A brief description of the work of each of the Committees follows.

Northern Territory

The Northern Territory Aboriginal Eye Health Committee (NTAEHC) consists of a representative from each of 6 regions in the Northern Territory. On the retirement of a member, an appropriate replacement is endorsed by the Committee. In 1995/96, it received $315,271 and $303,782 in 1996/97.

Its objectives are to control trachoma by:

• control and treatment of established disease;
• prevention through school-based programs;
• monitoring of communities for early detection of disease;
• provision of education to AHW, doctors, and nurses to assist in detection and treatment; and
• provision of education to communities to promote improvement in standards of personal and environmental hygiene.

However, their activities have been broadened to include other eye health issues in addition to trachoma. The NTAEHC initiated the army eye surgery operations in Katherine, Alice Springs, Tiwi Islands and Maningrida. Since 1989 the NTAEHC has engaged several optometrists from OPSM and Laubman and Pank to provide a territory-wide optometric service. The cost of this service was $43,000 in 1995/96 and an additional $37,000 was allocated in 1995/96 for glasses dispensed through this service. For some parts of the Territory, a visit from the NTAEHC optometrist has been the only regular eye service available.

Prior to 1992, the Committee jointly supported four specialist Aboriginal eye health workers (AEHW) with Territory Health Services (THS). These workers were viewed by the Committee as being their front-line practitioners for eye health. The importance of dedicated AEHW was explained in the biennial report (1990/91-1991/92) as being a service provided at the grass roots level, and as an option to specialist eye care provided by ophthalmologists in other states. A review of health services in the Northern Territory resulted in the abolition of these positions on the assumption that their functions would be taken up at a service level by other AHW. The loss of these positions has consequently led to the loss of the regional expertise and resources in eye health in THS.

Other activities of the NTAEHC include sponsoring an Eye Health Week in 1994 that was held in Alice Springs, Tennant Creek, Katherine and Darwin. In 1995 and 1996 the NTAEHC conducted three eye health and diabetes workshops in Alice Springs, Tennant Creek and Darwin for AHW and other interested Aboriginal people. The purpose of these workshops was to increase awareness of eye health and diabetes in Aboriginal communities and create local community resources.

In 1995, NTAEHC advocacy led to a review of Aboriginal eye health services in the Northern Territory by THS. Implementation of the recommendations from this review has not occurred, although they may be considered as part of the next budget process.

From 1989 to 1996, the NTAEHC saw 6832 patients and referred 1227 to an ophthalmologist. From July to December 1996, 51 communities were visited, 1009 people screened, 703 surgeries performed, 703 glasses dispensed, and 64 pairs of sunglasses issued. The services provided by the NTAEHC with the exception of optometrical services are now mostly located in the Top End.

The Committee has produced a number of reports, the last for the period 1993 to 1995.

Mobile Eye Unit

An initiative supported by the NTAEHC was the piloting of a mobile eye unit. This unit took several forms. The original mobile eye unit was reported as an AHW, an optometrist, a volunteer nursing sister and an ophthalmologist, Dr Nandor Jaross.
They received assistance from the Australian Defence Forces. The Unit acquired portable ophthalmic equipment that later included a laser and a portable mydriatic fundus camera.

In 1992/93, the unit travelled to communities and covered 20,412 kms of road travel, 60 hours of air travel, identified 241 surgical cases and screened 280 of the 328 known diabetics in 14.5 weeks\(^7\). In 1994, a new proposal was developed for a large mobile vehicle containing an operating room and a surgery. The purpose of a mobile vehicle was so that it could be driven to any location within the NT to provide eye services.

In 1996 Dr Jaross continued his community visits in the Katherine region with support from the NTAEHIC, although he has now left the Northern Territory. He developed a regional eye service that had close links with both the AMS and the hospital in Katherine and provided an annual visit to each surrounding community. Regular, second monthly visits were made to Katherine where day cataract surgery was performed. Patients were housed post-operatively at the Aboriginal hostel and AHW assisted with the post-operative care. A regular examination was provided for those with diabetes and in some cases, laser treatment was given in the community. Although the funding arrangements for this service were insecure, the way in which eye services were delivered to the communities and to the region was highly successful. This success was reflected in the high level of satisfaction expressed by the health service providers, the good management of diabetic eye disease and the reduction in the waiting list for eye surgery.

Delivery of services at the community level resulted in savings in the Patient Assisted Travel Scheme administered by THS and ensured a culturally appropriate service.

**Other specialist eye services provided in the Northern Territory**

The Northern Territory has a population of 170,000, but only two private ophthalmologists and a public ophthalmologist are available to provide ophthalmic services. The recent Australian Medical Workforce Advisory Committee report on ophthalmic services combined the Northern Territory with South Australia and unfortunately the real shortage of ophthalmic workforce in the Northern Territory was obscured\(^7\).

In Alice Springs, an ophthalmologist works in the hospital for three half days per week. This is supplemented by a visiting ophthalmic service from Flinders University where an ophthalmologist visits Alice Springs 4 days per month. The visiting ophthalmologist also supervises an unaccredited registrar position based at Alice Springs Hospital. This registrar has started to do unsupervised one day visits to communities.

In Darwin, a private ophthalmologist provides two half day sessions per week to the hospital, and another ophthalmologist is based at Royal Darwin Hospital. A second year and a fourth year registrar from the Sydney Eye Hospital rotate for three months to the Royal Darwin Hospital. The fourth year registrar works full time in the hospital, but the second year registrar spends two weeks per month working without supervision in communities in three regions.

**Queensland**

The Queensland Trachoma and Eye Health Program (QTEHP) is overseen by an annually elected committee. The program operates in two regions: the north and the south, with approximately 70% of its budget allocated to the north. In 1995/96 it received \$477,835 and \$471,844 in 1996/97\(^7\).

It aims to alleviate the suffering from trachoma and other diseases of the eye that were endemic in Aboriginal communities by:

1. eliminating trachoma and improving the eye health of Aboriginal communities and the disadvantaged population of Queensland;
2. arranging, co-ordinating and participating in initiatives for the treatment of the eye health of Aboriginals, Aboriginal communities and the disadvantaged population of Queensland;
3. preparing and disseminating information, publicising and undertaking educational programs in relation to the eye health of Aboriginals, Aboriginal communities and the disadvantaged population of Queensland with a view to obtaining financial and community support;
4. arranging, co-ordinating and participating in initiatives to train persons and in particular Aboriginals, in the methods of treating and improving the eye health of Aboriginals and Aboriginal communities and the disadvantaged population of Queensland;
5. initiating, encouraging and participating in research into eye and related diseases of Aboriginals and the disadvantaged population of Queensland;
6. co-ordinating and fostering communication between all initiatives and programs which are concerned with improving the eye health conditions of Aboriginals and Aboriginal communities and the disadvantaged population of Queensland; and
7. doing all other things that may in the opinion of the Management Committee be necessary to facilitate the attainment of the above objects\(^7\).

The Committee is elected annually by its 200 financial members and a committee member can only serve for three consecutive terms\(^7\). This has implications for the continuity of any long term planning and implementation. At the time of the review, there were complaints about the outcome of an election and an interim committee had formed to challenge the recently elected committee. Each committee met separately with the review team.
QTEHP pays the travel and accommodation costs for the visiting ophthalmologists who are also paid a daily rate. The two regional co-ordinators liaise with the communities to be visited and ensure that equipment is available for ophthalmologists on their visits. In the north, from 9 field trips in 1996, 26 communities were visited, 1247 patients seen, 814 glasses prescribed, 347 diabetics screened and 103 surgical procedures undertaken. In the south, from 10 field trips in 1996, 23 communities were visited, 1151 patients seen, 520 glasses prescribed, 94 diabetics screened and 16 surgical procedures undertaken.

The Committees specifically see their role as the provision of ophthalmic services to rural and remote communities. They organise visits by ophthalmologists every one or two years to those communities that they serve. The Committees considered that they were the major deliverer of eye health services to rural and remote Aboriginal and Torres Strait Islander communities in Queensland. The Queensland Department of Health provides few ophthalmic services in regional Queensland and health staff in the region reported waiting lists for patients for surgery of one year in Townsville, and two years in Mt Isa. It was also reported that public eye operations were not performed on indigenous people in Cairns. However, several communities reported that other visiting ophthalmologists also came to their community in addition to the QTEHP. Some other communities reported that the QTEHP had last visited them in 1989.

About two years ago, the QTEHP purchased a portable laser and a mydriatic fundus camera. This camera requires more expertise to use than the more recent non-mydriatic cameras now used in some other States.

Recommendations from the interim committee call for greater funding resources to conduct more screening and survey programs on eye health problems.

The Committee published an annual report of its work for 1996.

Other specialist eye services provided in Queensland

In Far North Queensland, the Fred Hollows Foundation has undertaken a project to provide specialist eye services to the Cape, the Torres Strait and to some communities around Cairns (see below). As well, some private ophthalmologists are located in the larger rural centres or visit some of the small towns in southern Queensland.

South Australia

The Aboriginal Trachoma and Eye Health Program, South Australia, (AEHP(SA)) has regional representation chosen from communities within each region, although the Committee also has the capacity to co-opt members as required. In 1995/96, it received $205,365 and $204,765 in 1996/97.

Its objectives are:
1. to eliminate trachoma and improve the eye and general health of Aboriginals, Aboriginal communities and those persons residing therein;
2. to arrange, co-ordinate and participate in initiatives for the treatment of the eye and general health of Aboriginals, Aboriginal communities and those persons residing therein;
3. to prepare and disseminate information, publicise and undertake educational programs in relation to the eye and general health of Aboriginals, Aboriginal communities and those persons residing therein;
4. to arrange, co-ordinate and participate in initiatives to train persons and in particular Aboriginals, in the methods of treating and improving the eye and general health condition of Aboriginals and Aboriginal communities;
5. to initiate, encourage and participate in research into eye and related diseases of Aboriginals;
6. to co-ordinate and foster communication between all initiatives and programs which are concerned with improving the eye and general health conditions of Aboriginals and Aboriginal communities; and
7. to do all other things that may be necessary to facilitate the attainment of the above objects.

The service focuses on the eye health needs of rural and remote communities and it plans visits by ophthalmologists either yearly or second yearly. Ophthalmologists are paid a sessional fee as well as for their transport and accommodation. The program co-ordinator ensures equipment is available for ophthalmologists on their visits.

Services provided during these visits include visual acuity testing for all patients seen and refraction and the dispensing of glasses. People with diabetes have a dilated fundus examination and any follow-up treatment is arranged. Any other eye problems that present are treated or referred.

In addition, ready-made reading glasses and antibiotic eye drops and ointment are provided free to rural and remote Aboriginal health services on demand. Ophthalmologists are discouraged from taking additional staff to assist with refraction or from taking registrars on community visits.

The program owns a mydriatic fundus camera similar to that owned by the QTEHP. For 1996, 15 field trips were undertaken and 916 patients were seen in 16 communities. Eighty-nine pairs of glasses were dispensed, 123 diabetics screened and 59 cases of trachoma were recorded and treated.
Annual reports were not available.

Other specialist eye services provided in South Australia

In South Australia, most ophthalmologists are located in and around Adelaide. Visiting public and private services are provided in some larger towns such as Port Augusta and to a few smaller centres such as Ceduna. These services are not co-ordinated with the services provided by the AEHP(SA).

Eye Services in other States

New South Wales

Specialist ophthalmic services are organised on a local basis, in an ad hoc fashion and vary considerably across the State. There seems to be no monitoring of eye services against eye health needs at the State level. Most of the larger rural cities have ophthalmology services available to them. The smaller more remote towns have various levels of service. Some specialist services are provided to remote areas through the RFDS, who stated that their service was predominantly crisis management and was largely provided to the non-indigenous community. Information on the use of the service by Aboriginal people was not available.

There are regional variations in the way services are funded. For example, in Brewarrina, the visiting ophthalmologist was paid a “fee-for-service” for visits, whilst other visiting specialists bulkbilled Medicare. In Bourke, the visiting ophthalmologist bulkbilled Medicare and also paid a nominal rent for rooms in the local hospital. In Broken Hill, ophthalmic services are provided by visiting ophthalmologists from Melbourne who are paid a sessional rate from a trust fund that is maintained in part by Medicare bulkbilling.

The Department of Health is pilot testing different models of integrated diabetes management delivery, to move the delivery from a hospital environment to the primary health care sector. Clinical practice guidelines are being developed as part of these trials. These trials will provide a process for care for people with diabetes and their outcomes are to be measured at a state level. Two projects are based in rural areas and they will provide additional information on current services available in those regions and how they are organised and delivered. Longer-term plans will include the introduction of successful components of these models to all regions in the State.

Tasmania

Little information is available on the number of Aboriginal people using eye services in Tasmania or the eye conditions being treated. This is mainly a result of health information systems that do not yet include identifying information. The Department of Community and Health Services reported recent initiatives to collect these data from general services.

There is a low provision of public specialist eye services in Tasmania. In Hobart, most eye care is provided in private and a private group performs public eye surgery on contract. It is unclear what use is made by Aboriginal people of the limited public specialist eye clinics in Hobart and in Launceston and what use is made of private services. The AMS in Hobart refers patients with eye problems to Accident and Emergency at the Royal Hobart Hospital. The Department reported difficulties attracting ophthalmologists to the north of Tasmania.

Public hospitals are located in Hobart, Launceston and Burnie and most communities are close to these facilities. One exception is Cape Barren Island. Health services there recently have been reduced and the Island does not have an airstrip capable of emergency evacuations at night.

Victoria

No State-wide plan for eye care services for Aboriginal people is in place or is planned. There have been two specific programs associated with Aboriginal eye health: a survey by the Royal Victorian Institute for the Blind in Swan Hill and a project in Rumbalara with the University of Melbourne screening for retinopathy in Aboriginal people with diabetes and testing vision of the whole Aboriginal population of Rumbalara. The International Diabetes Institute provides education and training in the general management of diabetes through an Aboriginal Diabetes Unit.

Public ophthalmic services to rural and remote areas of Victoria have contracted recently. It was reported that there were essentially no public specialist eye services outside Melbourne and the major regional cities.

The Department of Human Services is currently considering new funding models to move from funding vertical programs to a smaller number of programs related to “streams of care”. Overall, it was considered that Aboriginal eye health was not a major issue, although the management of diabetes was a high priority. The future focus for Aboriginal health in Victoria is through “the health outcomes agreement” with the VACCHO. This agreement provides a framework for better planning for health service delivery through a more co-ordinated health service delivery involving the community controlled sector, the Commonwealth sector and the State sector.
Western Australia

A number of different models were found in Western Australia with regional variations both in the regularity of service and funding mechanisms. In at least two regions, visiting ophthalmologists use a regional public-private model and visit on a regular basis. In an adjacent region, ophthalmologists were paid daily rates for services and the region was visited less frequently. The latter region reported a backlog of surgical procedures, lower attendance at appointments and limited community visits.

Western Australia seems to have a willing pool of ophthalmologists prepared to visit rural and remote locations. It has a well co-ordinated scheme for this purpose and encourages eye registrars to visit rural and remote areas. Many of the ophthalmologists are accompanied by an optician and in one case, the visiting ophthalmologist also brings a theatre nurse and an anaesthetist.

Regional Public Health Units organise annual screening for trachoma that is now linked with azithromycin treatment. AHW trained through Marr Mooditj receive specific training on trachoma and also on the use of non-myriatic fundus cameras. In Western Australia, there are three non-myriatic cameras and one myriatic camera in use. Overall with some exceptions, Western Australia is relatively well placed in eye health care.

In the Kimberleys, the Department of Agriculture is studying the use of dung beetles to reduce fly populations and thereby the transmission of trachoma.

Western Australia also has taken a proactive approach to training and employing Aboriginal Environmental Health Workers who will have a significant impact on trachoma levels in the longer term.

Army Field Hospitals

As part of the NTEHP in the 1970s the Army was called upon to help deal with the surgical load generated by the Program and to provide surgery locally, near where people lived. Two army exercises were held, one in 1976 in Amata, SA and the other in 1977 in Utopia, NT.

Army surgery exercises were again undertaken in the 1990s — in 1994 in Alice Springs, in 1995 in Katherine and in 1996, on the Tiwi Islands and in Maningrida. On this occasion, these exercises were initiated to reduce the backlog of eye surgery that had developed because of the lack of a sustained and regular operating service.

Overall, comments about continuing these army exercises were cautious and advised that they should only be instituted if further backlogs in surgery occurred. They were not seen as a way of providing ongoing or routine care. In at least two regions in the Northern Territory where these exercises have been held, an effort is being made now to systematically identify eye problems requiring surgery and to operate when they are found, to prevent the development of another surgical backlog.

The Far North Queensland Model

The Fred Hollows Foundation developed a model for specialist eye service delivery to rural and remote communities of Far North Queensland because of its potential application both in this region, and elsewhere in Australia.

The following were guiding principles:

- the quality of service to be no less than that expected by urban Australians and be sufficiently comprehensive to deal with the more prevalent problems occurring in the target population.
- service delivery to be in or near to communities and thereby improve patient access and increase uptake. It should be integrated with existing primary health care services where possible.
- local people should be trained and used as service managers where possible.
- avoid duplication with already successful service provision.
- achieve long term sustainability through coordinating the current resources of disparate authorities and organisations, and
- identify and clear the backlog of diagnostic and therapeutic interventions before settling to a sustainable ongoing service determined by population need and resource availability.

Although primarily aimed at the indigenous residents of Far North Queensland, the eye service examines and treats all patients who present.

Its development included negotiations with a range of key stakeholders in the region including:

- the Torres Strait Health Council, the Apunipima Cape York Health Council and Wuchopperen Medical Service;
- the responsible Regional Health Authority and the hospitals in the regions;
- community members and their Indigenous Health Workers;
- the Royal Flying Doctors' Service in Cairns;
— the Royal Australian College of Ophthalmologists;
— the Far North Queensland Division of General Practice;
— the Queensland Trachoma and Eye Health Program;
— private optometrists and ophthalmologists; and
— Medicare.

The program provided services to three regions, the Torres Strait, Cape York and communities around Cairns. Both the Torres Strait and the communities around Cairns have a regional service, but two regional services have developed in the Cape.

**Torres Strait**

The Torres Strait has a total population of 8,230 people, most of whom are Torres Strait Islanders. Dr Brian visits the Torres Strait every two months. Each ophthalmic visit includes a visit to Thursday Island and to some of the communities on the outer islands and the adjacent Cape. Every community in the region is visited once a year. Patients are examined, and spectacles organised in each community. Patients with any ocular condition necessitating earlier or more frequent assessment, including those with significant diabetic retinopathy or those who have had laser surgery, can be seen as frequently as once every two months during subsequent ophthalmic visits to Thursday Island.

For people with diabetes, an eye examination is included as part of their annual systemic review to assess such things as renal function, blood pressure, and the health of their feet. Those with diabetic retinopathy receive laser surgery as required either at Thursday Island or in their own community.

Cataract surgery is performed on Thursday Island (Table 3.1). Patients travel from their community to Thursday Island, where they either stay with relatives or in the hostel. Day surgery under local anaesthetic is used, and the patient returns home after a couple of days. Almost all cataract surgery is done with phacoemulsification. A portable YAG laser is available for posterior capsulotomy.

Equipment for the service was jointly provided by the ophthalmologist (through the Fred Hollows Foundation) and the District Health Service. Equipment such as an operating microscope, some surgical instruments, and outpatient equipment have been purchased by the Thursday Island Hospital. (See also Appendix V.)

### Table 3.1 Services provided by the Far North Queensland Project in 1996

<table>
<thead>
<tr>
<th>Service provided</th>
<th>Torres Strait</th>
<th>The Cape</th>
<th>Wuchopperen</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ophthalmic consultation to new clients</td>
<td>563</td>
<td>548</td>
<td>366</td>
<td>1477</td>
</tr>
<tr>
<td>Ophthalmic consultation to existing clients</td>
<td>245</td>
<td>156</td>
<td>111</td>
<td>512</td>
</tr>
<tr>
<td>Laser treatment sessions for retinal disease</td>
<td>61</td>
<td>16</td>
<td>13</td>
<td>90</td>
</tr>
<tr>
<td>Cataract surgery</td>
<td>37</td>
<td>60</td>
<td>55</td>
<td>152</td>
</tr>
<tr>
<td>YAG laser capsulotomy</td>
<td>14</td>
<td>4</td>
<td>4</td>
<td>22</td>
</tr>
<tr>
<td>Pterygium excision with conjunctival autograft</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Minor procedures</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

A Rockhampton-based optometrist from a group practice visits the Torres Strait in conjunction with this service and is responsible for refraction and the dispensing of glasses, predominantly though the low-cost glasses scheme administered through the local hospital (Tables 3.2 and 3.3).

### Table 3.2 Types of spectacles dispensed in the Torres Strait (1995 to 1996)

<table>
<thead>
<tr>
<th>Spectacle Finance</th>
<th>No. of Patients</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>State welfare spectacle scheme</td>
<td>275</td>
<td>49%</td>
</tr>
<tr>
<td>Private spectacle purchase</td>
<td>139</td>
<td>25%</td>
</tr>
<tr>
<td>Private spectacles ordered/not paid</td>
<td>128</td>
<td>23%</td>
</tr>
<tr>
<td>State welfare/private purchase</td>
<td>17</td>
<td>3%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>559</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

### Table 3.3 Types of lenses dispensed in the Torres Strait (1995 to 1996):

<table>
<thead>
<tr>
<th>Type</th>
<th>No. of spectacles</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single vision lens</td>
<td>495</td>
<td>72%</td>
</tr>
<tr>
<td>Bifocal lens</td>
<td>144</td>
<td>26%</td>
</tr>
<tr>
<td>Progressive lens</td>
<td>10</td>
<td>2%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>559</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

This model provides outpatient care, spectacles, management of diabetic retinopathy including laser surgery, and ophthalmic surgery including cataract, all in the Torres Strait. Few patients now require transfer south for more sophisticated care.
examination (for example: CT scan) or for treatment (for example: vitreoretinal surgery), or for severe ocular trauma. There is an increasing use of this service as confidence in the service builds and as people become familiar with the service and practitioners.

Cape York

The estimated population of Cape York is 11,400 people\(^2\). The model developed for the Cape has two regional centres for surgery located in Weipa and Cooktown. They are organised along similar lines to that described for the Torres Strait. Weipa is the regional centre for annual visits to Kowanyama, Pormpuraaw, Aurukun, Coen, and Lockhart. Cooktown is the regional centre for annual visits to Laura, Wujal Wujal, and Hopevale. An optometrist from Brisbane provides optometrical services in conjunction with the ophthalmic visits.

Wuchopperen

Wuchopperen’s patient record base in 1995 was 20,000 people and included people from Cairns, Mareeba, and Kuranda, as well as the Cape and the Torres Strait. In the absence of a public hospital outpatient ophthalmology service in Cairns, a private ophthalmologist had made some time available to see some patients referred from Wuchopperen (less than fourteen per month) on a fee-for-service basis. Those patients needing surgery were added to the Cairns Base Hospital waiting list, reportedly in excess of three years.

Cairns, Innisfail, Mareeba and Mossman have optometric practices with access to the state government spectacle scheme and AMS in these towns use local optometrists. For this reason, the new service does not include a visiting optometrist.

The Fred Hollows Foundation project started a regular clinic in Wuchopperen AMS mainly for laser surgery for diabetic retinopathy. The patients from the Mulungu Medical Service in Mareeba are seen at a clinic held at the Mareeba Hospital and clinics are also held in Manu Medical Service in Innisfail, and at the Mossman Hospital. Cataract patients from these clinics receive day surgery at the Mareeba Hospital.

**Essential Components of the Far North Queensland Model**

The essential components of the regional service developed by the Fred Hollows Foundation are:

- repeated visits by the team, prompt surgical intervention, and good surgical outcomes, to build up community trust and willingness to access the service.
- medical professionals who are financially committed to the service as a constituent of their regular practice. The same standards and commitment are expected for this service as for other parts of their practice.
- a regional hub at which surgery can be performed and from which community visits can be undertaken.
- a mix of funding arrangements to meet the substantial costs associated with providing such a service, including State Government funds and resources for transport, accommodation, facilities, equipment, ancillary staff costs of the service. For lost time due to travel, some costs of the specialist’s city-based practice may need to be covered. Commonwealth funds are provided through Medicare bulkbilling for outpatient services and for day surgery conducted in public hospitals.
- an optometrist who handles refraction and spectacle dispensing, and frees the ophthalmologist for the work if/when it’s more appropriately trained to deal with.
- the use of local indigenous health staff to facilitate service delivery to the communities.
- more flexible referrals procedures agreed by Medicare such as a patient’s name on a clinic list to see the ophthalmologist or an appointment made by a nurse or clerical worker at a hospital, or by a nurse or health worker resident in a community. In reality, patient management is shared more intimately by medical and nursing staff in these communities, so that a referral is from the management team, including the doctor, rather than an individual.
- protocols covering inventory, supply ordering, outpatient management, preoperative preparation and theatre preparation for hospitals involved in the eye surgery. It is important that local staff are familiar with these protocols and with eye surgery generally. A theatre nurse from Thursday Island was seconded to Cooktown and Mareeba when surgery was first started at these hospitals, to develop and implement these protocols.

**Findings from the Current Review**

In many areas of rural and remote Australia, the provision of specialist eye services is woefully inadequate to meet the needs of indigenous and non-indigenous people. The State and Territory governments have not provided public specialist services in many of these areas and usually citizens are expected to travel to a capital city for treatment. The provision of public specialist services is a State/Territory responsibility. These areas also lack private specialist eye services as the number of people in the area is not sufficient to support a full-time practice and there seems to be little incentive to develop a visiting practice.
Ophthalmic Work Force

Specialist eye services are provided by ophthalmologists who are trained and accredited by the RACO. The recent AMWAC report on Ophthalmology suggested that overall the number of ophthalmologists in Australia was sufficient to meet current needs\(^2\). The report also recommended some additional training positions be added progressively over the next few years to increase the number of ophthalmologists to meet the needs of an increasing and aging population. Funding for these training positions is provided by the States/Territories. The Commonwealth and the RACO are keen to have these training positions created but so far the States/Territories have not provided the funding to establish these positions.

Although the overall number of ophthalmologists in Australia is considered to be adequate, their geographic distribution is not (Figure 1). The AMWAC Report comments on the disparities between states, but it does not address the rural/urban distribution of specialist eye services. Some of their data presentation is misleading in that the data for the Northern Territory and South Australia are combined and the real lack of ophthalmic service in Northern Territory is not apparent. The Northern Territory has 3.2 full time equivalent ophthalmologists providing services to a population of 170,000 (1.53,125). This compares with the national ratio of 1.26,702\(^2\). At a regional level, many rural and remote regions receive an inadequate specialist ophthalmic service.

In those rural areas that do not provide the opportunity for “full-time” specialist private practice it is usually impossible to get a consultant who can provide part-time public sessions. Full-time specialist positions are rarely taken up by Australian-trained and registered specialists (who can practise anywhere in Australia) but rather by foreign-trained physicians who obtained a limited medical license and registration for that particular area.

During the review, both Tasmania and the Northern Territory commented on the difficulties in attracting ophthalmologists to rural practices, and an ophthalmologist position in Alice Springs has remained unfilled for two or three years.

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Figure 1. Ophthalmic and Optometric services in Australia

A. Ophthalmologists — Number of Patient Services per 1,000 Population

B. Optometrists — Number of Patient Services per 1,000 Population

Currently, ophthalmologists who are potentially available to visit rural and remote locations are not well matched to the needs of those regions. In those rural and remote areas in which specialist eye services are provided they are usually irregular, of short duration and inadequately linked to local services. Long waiting lists for eye services act as a deterrent to any further referrals from the primary health care sector.

Generally, the ophthalmic services can be characterised into two distinct groups by the way they are organised: a publicly funded service; or a regional service using a mix of private and public funding. The organisation of the service seems to be significantly related to the efficiency of the service, to its output and the level of satisfaction of both consumers and those involved in service delivery.

**The Public-“Voluntary” Model**

Services provided under this model can be characterised as being funded by the public health system and using ophthalmologists who may be volunteers, salaried, paid a sessional fee, or paid fee-for-service to conduct eye clinics and to perform surgery. This model is in general use by the State Trachoma and Eye Health Committees, and in most regions of Western Australia, the Northern Territory and in rural NSW.

Features of this model are:

- the ophthalmologist’s visits to a given rural or remote area are usually infrequent, of short duration, and subject to change of date or personnel.
- the model builds little direct commitment on behalf of either the ophthalmologist or the local community.
- it is not clear how many of those who require assessment by the ophthalmologist actually receive attention. Generally during the brief, infrequent visits, about half the patients are seen for a diabetic eye check, the other half require either glasses or may have more serious eye disease such as cataract or possibly trichiasis.
- feedback from the ophthalmologist about the patients who have been seen, their treatment and their follow-up requirements is usually seen as inadequate.
- there is very little time for preventive activities, promotion, or in-service education.
- the ophthalmologist’s visits are usually appreciated by local health staff because, in most cases, they are the only ophthalmic service available to the community.
- they are appreciated by the ophthalmologists as a change from the routine of capital city practice, and as a philanthropic activity.
- the visits are relatively low cost because of their low frequency and short duration.
- overall the service is inadequate and does not meet the existing need and, therefore, generates a low demand.

**The Regional Public-Private Model**

This model is organised on a regional basis and uses a mixture of public funding and Medicare rebates where the ophthalmologist bulkbills Medicare for services and the State or regional health service pays the costs of travel and accommodation, and provides appropriate facilities and liaison. It is essentially run as a subsidised branch of a private practice.

In some cases, an additional monetary incentive is provided by the region to the ophthalmologist to ensure that the visits are comparably remunerative as their city-based practice.

This model of service delivery is in use in the Pilbara region and Eastern Goldfields regions of WA, and in Far North Queensland. It is basically similar to the way in which ophthalmology services are delivered to mainstream rural communities in all States.

Features of this model include:

- the service is organised regionally.
- regular regional visits every two to three months. Each visit includes the regional centre where surgery is performed and trips to the surrounding communities in the region.
- this model allows sufficient time for all patients to be seen within a reasonable time.
- it benefits from having the flexibility to change at short notice the sequence of visits if a community is closed for example, for a funeral.
- there is a sense of local ownership of the service within the community.
- there is also a sense of ownership by the ophthalmologist.
- the frequent visits lead to a close understanding and a strong relationship between the community and the visiting ophthalmologist.
- the provision of primary eye care is reinforced by the frequent specialist visits.
- the ophthalmologist has a personal commitment due to their financial involvement with this service and the health services also have a financial commitment.
- the service is perceived as being outstandingly successful by all who are involved or served.
Recommended Practices

The service provided by the regional model was far superior to any other service observed during this review and this model should be implemented in other regions across Australia. This regional model has the capacity to meet the largely unmet eye care need in many parts of Australia. Its implementation will lead to a better quality service, an increased level of service and also an increased cost as the unmet need is addressed. It will mean that services in rural and remote Australia are more similar to those provided in urban areas.

The organisation of ophthalmic services at a regional level is consistent with the planning of health services through Commonwealth/State Agreements on Aboriginal and Torres Strait Islander Health. At present regional plans are being developed throughout Australia as part of these Agreements, and the infrastructure established to develop these plans could be readily used to organise specialist ophthalmic services.

In many areas close, practical collaboration occurs between AMS and State/Territory services despite the varying degrees of disharmony that may exist at higher management levels. The lack of co-operation at higher levels is quite destructive and clearly has the potential to prevent the development of any new service, including the proposed regional model. Success of the regional model will require close co-operation and co-ordination between all health services in the region and between them and the visiting specialist. This success can only be built on good communication.

The successful operation of the regional public-private model in rural and remote regions also requires what has been termed as an "infrastructure-free environment". As well as paying for the travel and accommodation for the visiting ophthalmologist, the host service or region must also provide the day-to-day administrative and secretarial support, AHW, local transport, ancillary support staff, including anaesthetic staff, and the basic ophthalmic equipment. A list of basic ophthalmic equipment is provided in Appendix V.

Aboriginal and Torres Strait Islander peoples in urban areas have similar problems in obtaining adequate specialist eye care to those located in rural and remote areas. Although specialists and public eye services are generally available in urban areas, they are usually neither readily accessible nor seen to be appropriate. In addition, health services usually lack good referral links to specialists who are willing to bulkbill Medicare. Cost and culturally-inappropriate services deter most Aboriginal and Torres Strait Islander peoples from using these services in urban locations.

Urban AMS should actively seek links with local optometrists who can provide regular optometric services on site. There is a role for the RACO and the recruitment agencies run by state-based NACCHO organisations to work together to link city-based AMS with ophthalmologists who have indicated a willingness to provide services to Aboriginal and Torres Strait Islander peoples and to bulkbill them. The NACCHO recruitment agencies are still being developed and the provision of specialists is a low priority for them. The development of linkages between urban AMS and ophthalmologists must not be postponed if these agencies are not yet ready to take on this role.

Funding Issues

Some potential difficulties that were foreseen with this model include the possibility of over-servicing by "unscrupulous" ophthalmologists who might bulkbill for screening, or for services not actually provided. This issue could be raised for any practitioner who bulkbills and it is unlikely that visits to rural and remote locations will provide an extra incentive for fraud. Having the local health services provide the administrative back-up for the specialist service is an additional safeguard against this.

Other difficulties might arise if there were too few patients for a particular visit to be financially viable. This could be a problem in small communities. Also there may be problems when the ophthalmologist undertakes significant screening, teaching, or extended travel to isolated communities. Some additional supplement or sessional payment will need to be negotiated with the regional health services to cover these instances especially while the regional eye service is being developed. In this case, this process will need to be clearly stated and transparent.

Problems can arise when a patient does not have a current Medicare number. Almost all health services visited, regardless of their funding and their management structure (either community-controlled or state-run) had documented in their medical records the Medicare numbers for almost all permanent community members. Many AMS now routinely bulkbill and more have started to do this even in the last few months. However, streamlined procedures within the Health Insurance Commission are needed to expedite the issuing of new Medicare numbers and to assist with Medicare forms that may not be complete. With the widespread use of Medicare cards in AMS this will become a decreasing problem. In the interim, at least, the Health Insurance Commission will need to set up mechanisms to handle difficulties that arise.
Some arrangements will need to be made to have some flexibility in the referral to the ophthalmologist. Patients are likely to be referred by health service staff including AHW and nurses in addition to the local medical officers. Suitable arrangements were negotiated as part of the Far North Queensland project.

Throughout much of rural Australia, specialist services, whether for eye care or for other specialty areas are usually provided by visiting specialists who essentially operate a “branch” private practice. This practice may combine bulkbilling some patients, and charging a scheduled fee for others. Usually an arrangement will be made with the local public hospital to perform surgery there on a fee-for-service basis. The regional public-private model should be seen as a variation of this with more regional support needed for infrastructure because of the greater time and costs involved in travel and the need to attract ophthalmologists to provide services in more remote areas.

Some AMS already have a number of visiting specialists who bulkbill for their services. The ophthalmologists supported by Trachoma and Eye Health Committees were seen to be an exception to this. Several AMS visited by a Committee-sponsored ophthalmologist reported that this visiting ophthalmologist was the only visiting specialist who now did not bulkbill Medicare. There seems to be little reason for the Commonwealth-funded Trachoma and Eye Health Committees to continue to provide services through arrangements that are so different to those for other mainstream services. Some justification for these different arrangements might have come from the provision of a better service. However, this was not observed to be the case.

One medical service in Western Australia reported that their visiting ophthalmologist also provides services to the non-Aboriginal community. This has meant that non-Aboriginal patients have access to specialist services. They visit the AMS to see the ophthalmologist and this helps to break down barriers. Overall it has become a successful PR exercise for the AMS in that community.

### Linkages

Key to any successful health care model is the effective linkage of the primary care services with the visiting specialist. A local individual, preferably an AHW with responsibility or “ownership”, needs to be identified to provide this linkage.

At the primary health care service level, the linkage tasks include reconfirming scheduled appointments; explaining the procedures and organising transport for patients to their appointment.

A team approach can be used successfully to plan the ophthalmologist’s visit to a hospital. This planning would include reminder notices to patients and communities about appointments, the organisation of transport for patients, co-ordination with AHW with a liaison responsibility to assist Aboriginal people when they come to the hospital and to arrange accommodation or even special meals if needed for diabetic patients. Port Hedland Hospital and Katherine Hospital have used this approach successfully and reported high attendance rates for scheduled eye surgery.

Many AMS have in place mechanisms that ensure high attendance to clinics and appointments. AMS regularly reported attendance rates of 80% to 100% and transport officers and administrative staff play an important role in this. This was contrary to comments received from some hospitals that provide little support for Aboriginal people attending eye appointments and have high non-attendance rates. Although some hospitals have appointed Aboriginal Liaison Officers, they have not always been successfully utilised. The appointment of these staff must be in consultation with the local AMS. They should be supported from within the hospital and should establish links with the AMS. The successful use of AHW with a liaison responsibility builds trust between the Aboriginal community and the hospital and ensures that Aboriginal people who use the hospital have someone with whom they can talk to about any problems that they may have.

This Review strongly recommends that eye services be developed and delivered on a regional level. Once these regional services have been established, there would seem to be no ongoing role for the State-based Trachoma and Eye Health Committees. The expertise of staff employed by these committees could best be utilised in the liaison role at the regional level.

### Implementation Issues

The implementation of the proposed regional model will require the commitment of funds to provide services that are currently not provided and to meet the presently unmet needs. Its successful implementation will need to bring together all three sectors concerned with eye care delivery; the Commonwealth, the States/Territories, and the private sector, especially practicing ophthalmologists.

In rural or remote regions some specialist eye services are already provided by the State, whether through fee-for-service or sessional payments. In these cases, the current funding can be redirected to provide the resources needed for the overhead-free environment of the regional model. Additional funds for the ophthalmic and optometric services can be provided by the Commonwealth through Medicare bulkbilling. However, for other regions where the State/Territory currently provides
little or no specialist eye service, for example in much of Queensland, the Northern Territory, South Australia and New South Wales, new resources will have to be found. Here the implementation will require State/Territory governments to commit and provide additional resources.

In urban areas, the implementation of this model will require the proper utilisation of existing mainstream services, both public and private. The marginal costs for the increased utilisation by Aboriginal people of public ophthalmic services are likely to be minimal, although the State governments must provide funds for the AHW with a liaison responsibility. The increased utilisation of private ophthalmic or optometric services will depend on the development of appropriate linkages and arrangements between the AMS and private ophthalmologists and optometrists.

Particular attention and support will need to be given to those who have local or regional control of resources such as operating theatre time, vehicles, clinic space and staff. The availability of these resources is essential for the successful implementation of this model.

RECOMMENDATION 3

3a. Eye services should be delivered through a regional public-private model. The provision of these services is the joint responsibility of the Commonwealth and State and Territory Governments. Where possible outpatient services should be delivered through Aboriginal Medical Services.

3b. The proposed funding method for the regional model is for the Commonwealth Government to:
- continue to allow Medicare bulkbilling for specialist eye services; and
- make available Commonwealth funding, through Medicare or another mechanism to cover the surgeon’s involvement in cataract and other eye surgery performed in public facilities in remote regions.

State and Territory Governments to provide funds for the overhead-free environment required for the provision of the above services. This would include, among other things, equipment, infrastructure and support.

3c. Regional and local health care services must identify a person, preferably an Aboriginal person, to be responsible for the administration and community liaison for the specialist eye services. Hospitals should be resourced to provide Aboriginal Health Workers with liaison responsibilities to assist Aboriginal patients undergoing surgery.

3d. Links should be established between primary health care services in urban areas and optometrists, ophthalmologists and hospitals that provide eye services so that primary health care services can readily refer their patients for appropriate eye care.

3e. The Commonwealth and State and Territory Governments must ensure that cross-border funding issues are addressed at a local level so that the quality of care is not jeopardised for patients who may be referred from centres in other States.

Anomalies in Current Arrangements

Regional Centres

For most rural and remote areas there is an obvious regional centre that services surrounding communities. Communities serviced by the Nganampa Health Council in the Pitjantjatjara Lands are an obvious exception. Predominantly located in South Australia, the nearest regional centre is Alice Springs, 5 hours away by road and 94% of the referrals from Nganampa are sent to Alice Springs. Ophthalmic services are organised through the ATEHC(SA) who refer their patients to Adelaide
for surgery. Nganampa Health Council has set up support services in Alice Springs to assist its people when they are referred there, but no similar support system exists in Adelaide.

The establishment of a day surgery unit in the Lands would significantly reduce the need for referrals for eye and other specialist services to either Alice Springs or Adelaide. It would require the provision of specialised equipment and additional staff who would need appropriate support and housing. Other specialists who could use such a facility could include general surgeons, gynaecologists, ENT surgeons and orthopaedic surgeons. Such arrangements seem to work well in a number of other communities and have greatly enhanced local or regional service delivery.

Another alternative would be to provide visiting rights to the Alice Springs Hospital for the ophthalmologists who visit the Lands. The services could then be organised along similar lines as other regional services with the ophthalmologist visiting several communities at a time as well as providing surgery at the Alice Springs Hospital to patients from the Lands. Arrangements would have to be made to fund the costs of surgery.

Cross-Border Issues

Problems associated with hospital services for patients in communities near State borders were raised on several occasions. Often patients may require treatment in the adjacent State or Territory. This can result in large hospital and transport bills to the referring health service, and be seen as an annoyance to the hospital and the health service. For example Kununurra is less than one hour by plane from Darwin, but patients are routinely sent 2000 km to Perth for treatment. Health services have said that patients would prefer to go to Darwin. As mentioned above, this is also a problem in central Australia.

Although State and Territory Health Ministers had agreed to meet the costs of patients from other states, at the hospital level, problems have arisen with the changed funding arrangements that use DRG casemix formulae. This has meant that departments within hospitals are reluctant or unable to meet the costs of interstate patients and the referring health services are billed directly for these costs. This issue must be resolved and the resolution transmitted to those directly involved at the service delivery level.

Other Issues

Other examples of funding anomalies arose during the review. For example, in Port Hedland, the costs of transporting patients from their community to regional centres for eye surgery is covered by the Patient Assistance Travel Scheme. For short stays this scheme does not cover food and accommodation, so day patients are reminded to bring funds to cover these costs. Food and accommodation are provided for inpatients. Under casemix, the hospital receives a lower funding rate for cataract procedures if they are done as day surgery and the costs for post-operative care for day surgery patients are not taken into account in the funding formulae. Overall there are significant financial incentives for the hospital to admit the patient as an in-patient even though day surgery is less traumatic for the patient and, where possible, is a more preferred option for surgery for Aboriginal people. However, current funding arrangements are discouraging the better option.

State and Territory Governments are responsible for funding hospital surgery. An exception is in the Fred Hollows Foundation project in Far North Queensland where it was agreed that surgery could be performed on public patients in a public hospital and could be bulk billed through Medicare. The rationale for this decision may apply to other regions and therefore decisions on the funding source should be made on a region by region basis and the issue raised during future Medicare negotiations.

In Cooktown, the cataract surgery service is in jeopardy because of the failure of the State Government to provide the ongoing incidental costs for this surgery.

At present there are two initiatives that will potentially change the way that health services are funded and delivered to the general community. One initiative in Western Australia allows primary health care services to directly purchase hospital services such as cataract and laser surgery. The other initiative is testing the use of care co-ordinators to manage funds and to directly purchase a mix of health and community services for their patients. If introduced Australia-wide, these initiatives would result in fundamental structural changes in the funding and delivery of health services. It is beyond the scope of this review on Aboriginal eye health to pre-empt the outcomes of these initiatives.

Clinical Practice Guidelines

As with the variations seen with models for service delivery, there was an equally great variation in the actual service that was delivered. Appropriate and current clinical practice guidelines need to be developed, or adapted, for the delivery of eye care for Aboriginal people in rural and remote areas. These guidelines are best developed by the Aboriginal and Rural Eye Health Committee of the Royal Australian College of Ophthalmologists. They will need to be broadly disseminated. Training in the implementation of the guidelines could also be incorporated into Continuing Medical Education training for general practitioners in rural and remote locations.
These guidelines need to address cross-cultural issues and therefore should be developed in collaboration with individuals and organisations with experience in this area. One issue, for example, would be to help visiting specialists learn how to ask the right questions about people and their circumstances.

The RACGP, in its submission to the Review supports the notion of additional training in the management of common eye problems that present to general practitioners in Aboriginal and Torres Strait Islander communities in rural and remote locations. It also made the statement that appropriate facilities must be available to trained general practitioners so that their training can be put to practical use. (See Appendix V).

RECOMMENDATION 4

Evidence-based, clinical practice guidelines for the provision of specialist eye care to Aboriginal and Torres Strait Islander patients should be developed in consultation with the Royal Australian College of Ophthalmologists and other relevant bodies. The guidelines should include cataract surgery, trachoma and diabetic retinopathy. These should be provided to the National Information Network for wide distribution.

Ophthalmic Registrars

In some States, ophthalmologists take registrars with them on their rural and remote visits. This is an important training activity. This exposure leads many young ophthalmologists to recognise the need for specialist eye care in rural and remote areas and their social responsibility to provide it. It is an important strategy to induce specialists to provide services to rural and remote areas. It should be actively encouraged.

There are some training positions for registrars in rural and remote areas. This is also to be strongly supported, but it is essential that adequate supervision be provided. The level of supervision required will vary with the responsibilities and the level of training of the registrar. Unsupervised or under-supervised placements may have a very negative impact. With inadequate supervision and support during field visits to remote communities, the registrar may be overwhelmed when confronted with difficult clinical problems and demanding situations. There is a risk of this occurring especially during fieldwork undertaken by registrars in the Northern Territory.

Adequate supervision is also mandatory for surgery undertaken by registrars in rural and remote areas, as it is in the rest of the country.

RECOMMENDATION 5

State/Territory Governments and the Royal Australian College of Ophthalmologists should develop registrar training positions with appropriate supervision in rural and remote areas. The Royal Australian College of Ophthalmologists should encourage registrars to accompany ophthalmologists during visits to rural and remote regions and facilitate this.
CHAPTER FOUR

REFRACTIVE ERROR AND THE PROVISION OF GLASSES

Summary

Traditional Aboriginal people are known to have excellent distance vision and little refractive error. Presbyopia is the major refractive error they experience. In addition to regular optometric visits ready-made reading glasses need to be made easily available. Ready-made reading glasses are both convenient and cheap. Little infrastructure is required to provide them and they overcome the continuing difficulties with replacement of lost or broken glasses.

Urban Aboriginal and Torres Strait Islander populations have vision and refractive problems more similar to the general population. Although many are eligible for low-cost glasses through the State or Territory schemes, access and utilisation seems poor because of in-built barriers in these schemes. These schemes need to be re-evaluated.

Introduction

Overall, Aboriginal people had much better visual acuity than non-Aboriginal people\(^3\). In some Aboriginal people, acuity is much better than that documented for any other racial group.

Part of the superiority of acuity could be explained by lower rates of refractive error among Aboriginal people who were found to have much less myopia\(^4\). Astigmatism was also less common in Aboriginal people. The same cannot be said for urban Aboriginal people where diet, environmental and genetic influences all may have changed their refractive status. A recent survey by the Rumbalara Health Service found that 20% of schoolchildren, of young and of older adults required referral for poor vision due to uncorrected refractive error. Increasingly people in these communities will have refractive status similar to the general community rather than those Aboriginal people in more remote communities.
Presbyopia or difficulty with near vision is a universal problem as people age and most people over the age of 40 will need to use reading glasses for near work. This is particularly a problem for people who do not have myopia and so presbyopia is a major problem for older Aboriginal people. Those who do not read will still need good near vision for many essential activities such as sewing, repairing a gun or a carburettor, or for handicrafts such as painting or carving.

Current Status and Findings

There is evidence of significant unmet need in the Aboriginal community for refractive services. A recent study examining the eye care needs of Aboriginal and Torres Strait Islander peoples concluded that current services were not meeting the perceived refractive needs of most communities, particularly in rural communities. The study identified the three main reasons for the low utilisation rate of currently available services as: limited physical accessibility of optometrical services; cultural barriers; and lack of education.

A related survey of the provision of optometric services to Aboriginal and Torres Strait Islander peoples, indicated that only a small proportion of those optometrists surveyed provided services to rural communities. The study found that many optometrists had indicated their willingness to provide a service if there were an identified need.

The unmet need was also apparent from many comments received about long waiting lists for appointments with visiting eye specialists. Communities look forward to the “eye doctor's visits” and most health services indicated that communities sought out refraction services and appreciated the visits and service. Visiting ophthalmologists also commented on the high demand for refraction services in the communities that they visit.

In some states the model for the provision of glasses is to have a visiting ophthalmologist perform the refraction and measurements for spectacle frames. This information is then sent to an optical company and the glasses are ultimately sent back to the community. Delays of up to six months were commonly reported. In some instances, the ophthalmologists involved do not routinely reframe in their own normal practice. This seems to be a grossly inefficient way to provide glasses.

Other visiting ophthalmologists may be accompanied by an orthoptist or optometrist who works as a member of the visiting eye team. This is a much more efficient model, although larger teams have the potential to swamp the resources available in some smaller communities.

The most satisfactory model was to have an optometrist who worked regularly in a given community. These visits may be co-ordinated with a visiting ophthalmologist or held independently. The frequency of the visits might vary widely. In some towns visits were on a regular fortnightly basis, whilst in other smaller communities they were on an annual basis. Usually the optometrist bulkbills for the examination and in some instances received a subsidy from the local health service or State/Territory Trachoma and Eye Health Committee to cover travel, accommodation or lost revenue.

The Commonwealth also offers special assistance for optometrists to provide optometrical services to patients in remote areas. The rates are based on the number of patients seen, travelling costs and half of the remaining expenses. It is uncertain to what extent optometrists use this scheme. One optometrist commented that the scheme was so paper intensive and so tightly administered that it was debatable whether it was worth the trouble to apply for funding under this scheme.

Recommended Practices

Low-cost and Subsidised Glasses

In all states and the Northern Territory, low-cost spectacles or subsidised spectacles are available for eligible residents. The most basic of these schemes are those in Western Australia and South Australia where a rebate of about $50 is available once every two years to eligible participants for low-cost glasses.

In Tasmania, glasses in standard frames are provided free to eligible residents. Although it seems to be a generous scheme, eligibility criteria are strictly applied and the uptake of the scheme seemed to be low compared to the rates in other States and the Territories. In the previous year possibly 70 pairs of glasses were provided to Aboriginal people.

In Queensland, glasses are provided to eligible participants through public hospitals. This scheme has not worked well and is currently under review.

In New South Wales and Victoria, eligible participants are prescribed glasses by participating optometrists or clinics and offered a choice of standard frames. Residents holding Health Care cards are eligible under this scheme, but in New South Wales an additional means test is included. The costs are fixed for single focal glasses and bifocal glasses. In Victoria, extra features to glasses can be provided only if the patient agrees to pay the full cost of the glasses. It is believed that the scheme in Victoria offers the best quality for the funding provided, although it was not possible to assess its accessibility or utilisation by Aboriginal people.
These systems or schemes are not well advertised, and are not well understood. Barriers are built into the schemes to even up demand and could be seen by Aboriginal people to be insurmountable. We heard frequent complaints of people having to pay $300 or more for glasses. Although this may have been for replacement glasses or for frames that were not covered by the low-cost spectacle scheme, the stories have wide currency and lead to mistrust about the subsidised optometric services. These state-based schemes should reconsider their processes to improve access to and utilisation by Aboriginal and Torres Strait Islander peoples.

At the moment, the three State-based Trachoma and Eye Health Committees provide free glasses to Aboriginal people in those rural and remote communities that the Committees serve. Free glasses are not available to those who live in other communities or in urban areas. These people must meet the eligibility criteria for the low-cost glasses schemes run by the State to obtain subsidised glasses. QAHEF drew attention to the flaws in the policy that denies access to urban Aboriginal people. There is little justification for free glasses being selectively provided to Aboriginal people in only some rural and remote areas when this policy is not implemented for all Aboriginal and Torres Strait Islander peoples.

Governments could broadly implement a free glasses policy for all Aboriginal and Torres Strait Islander peoples. Alternatively, they could evaluate the State-run, low-cost glasses schemes to assess their ease of use by eligible Aboriginal and Torres Strait Islander peoples.

The broad implementation of a free glasses policy would have little support in the current climate and there are few reasons for its continuation. Therefore, it is recommended that the low-cost glasses schemes in States and Territories be reviewed for their acceptability and utilisation by Aboriginal and Torres Strait Islander peoples and restructured if found to be deficient.

**Ready-Made Reading Glasses**

As previously mentioned, traditional Aboriginal people usually have outstandingly good vision. These people have little or no distance refractive error and certainly have never worn distance correction. The NTAEHC reported 70% of glasses dispensed in such communities were for presbyopia and this seems to be similar in the Torres Strait.

Ready-made, half-frame reading glasses should be widely available in these Aboriginal communities at a minimal cost. They are ideal for use in these situations. At present they can be purchased in any city for $10 to $20 from chemists and a wide range of other shops. They should be readily available in Aboriginal and Torres Strait Islander communities and clinics so that those who need them can obtain them and lost or broken glasses can be rapidly replaced. People in these communities do not always have the conveniences to keep glasses safe and glasses are often lost or broken. The AEHC(SA) has used full-frame ready-made reading glasses with some success. However, half-frame glasses should be used rather than full-frame. Patients have great difficulty with full-frame reading glasses. They are unable to walk around in them and if the glasses are taken off they are likely to be lost, scratched or broken.

**RECOMMENDATION 6**

Health services should ensure the availability of ready-made reading glasses through local outlets or through the health service.

**RECOMMENDATION 7**

The Commonwealth Government should review the effectiveness of the visiting optometrist scheme in meeting the needs of Aboriginal and Torres Strait Islander communities particularly in remote areas.

**RECOMMENDATION 8**

State and Territory Governments should review their low-cost spectacle schemes to improve their accessibility and utilisation by eligible Aboriginal and Torres Strait Islander peoples.
CHAPTER FIVE

CATARACT

Summary
Cataract surgery is the major eye surgery required by Aboriginal and Torres Strait Islander peoples. Although the absolute numbers are small, left untreated, significant surgical backlogs can develop quickly. This results in considerable personal suffering and community loss. The regular provision of cataract surgery overcomes this problem.

Aboriginal people are usually accepted for cataract surgery at a more advanced stage than those in the general community in part because of late presentation and concerns about moving away from the community for surgery. The surgical procedures for cataract removal vary considerably. The development of clinical practice guidelines for cataract surgery in Aboriginal and Torres Strait Islander peoples is important to improve the quality of surgical outcomes. Cataract surgery should be provided at a regional level and requires appropriate facilities and equipment.

Introduction
A cataract is an opacity of the crystalline lens of the eye and prevents light from reaching the retina at the back of the eye. Cataract is increasingly frequent as people grow older and its occurrence doubles with each decade after the age of 40\(^a\).

Cataract develops progressively. At an early stage, cataract may only reduce vision a little, but with time a mature cataract can cause marked blindness. Because a cataract forms in the lens of the eye, the eye will not focus properly after cataract surgery without a replacement lens. An intraocular lens is now implanted at the time of surgery for this purpose. The quality of vision after modern cataract/intraocular lens surgery is usually excellent, although normal bifocal glasses are usually needed.

Current Status
There has been no systematic assessment of the prevalence of cataract among Aboriginal people since the NTEHP. It reported an overall prevalence of lens abnormalities of 3.6\% among Aboriginal people compared to 0.8\% among non-
Aboriginal people (Table 5.1). After adjustment for differences in the age structures of the Aboriginal and non-Aboriginal populations, lens abnormalities were reported to be twice as common for Aboriginal people as for non-Aboriginal people.

Although the age-specific prevalence of cataract is relatively high, the absolute numbers of Aboriginal people with cataract are relatively small and the annual incidence of people needing surgery each year is small if there is no surgical backlog.

Table 5.1 Prevalence of cataract in Aboriginal people and non-Aboriginal people

<table>
<thead>
<tr>
<th>Age</th>
<th>Aboriginal People</th>
<th>Non-Aboriginal People</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number seen</td>
<td>Number with cataract</td>
</tr>
<tr>
<td>0-29</td>
<td>44,802</td>
<td>145</td>
</tr>
<tr>
<td>30-39</td>
<td>4,568</td>
<td>67</td>
</tr>
<tr>
<td>40-49</td>
<td>3,897</td>
<td>125</td>
</tr>
<tr>
<td>50-59</td>
<td>2,698</td>
<td>284</td>
</tr>
<tr>
<td>60+</td>
<td>3,923</td>
<td>1451</td>
</tr>
<tr>
<td>TOTAL</td>
<td>59,888</td>
<td>2072</td>
</tr>
</tbody>
</table>

The only recent information relating to cataract amongst Aboriginal and Torres Strait Islander peoples comes from service data. These data are particularly vulnerable to selection bias for surgery.

Out of 405 patients seen in the Katherine region of the Northern Territory in 1993, 31 (8 per cent) required surgery for cataract. In 1994 the Army eye surgical operation in Katherine performed 39 cataract extractions. In 1994, a waiting list of 2 years or more for cataract operations among Aboriginal people in central Australia, resulted in 90 procedures on 75 patients by the Australian Defence Forces using a mobile hospital in Alice Springs. A similar operation in 1996 on Bathurst Island resulted in 7 cataract operations. From June 1996 to March 1997, the Alice Springs Hospital Eye Clinic performed 18 cataract operations on Aboriginal people. It has a one year waiting list of about 30 people, this contrasts with Tennant Creek where 3 or 4 people have waited two years for surgery. The cataract operations at Alice Springs were performed on relatively young Aboriginal people (2 were from the age group 20-39 and 3 from the age group 40-59). During visits to Hermannsburg and Kintore in February 1997, 6 people with cataract were noted amongst the 47 patients seen, again cataract affected a younger age group (1 was aged 20-39, 3 were in the age group 40-59 and 2 were in the age group 60+).

Similar levels of unoperated cataract were seen among new consultations in the Far North Queensland project. In 1995, 65 cases (6% of consultations) required surgery increasing to 152 (10%) in 1996. The QTEHP organised 52 cataract operations in 1995 and 55 cataract operations in 1996.

Findings from the Current Review

Cataract is the most common major eye surgery that is performed. However, during this review a large variation in surgical practice was seen and this has a major impact on the efficiency of different programs.

The pre-operative assessment varies greatly. Typically, patients from rural and remote communities who require cataract surgery are first assessed by the visiting ophthalmologist. Then they are referred to a hospital for further pre-operative assessment often by a different ophthalmologist before being sent to the hospital for the surgery. For the patient, this may result in up to three trips out of the community, often to the capital city, as in South Australia, or to a larger regional centre. This requires significant organisation by the health service and causes additional and unnecessary cost to the health system. For example, staff in Domadgee reported that visits by patients from Domadgee who are to have cataract surgery in Townsville cost the local community $500 to $5,000 each.

In contrast, cataract surgery in the Pilbara Region and in Far North Queensland is performed shortly after the diagnosis has been made and performed by the ophthalmologist who made the diagnosis. Only one or two trips are required by the patient and a regular service to the region has removed the surgical backlog and waiting lists.

Although most cases are performed as extracapsular cataract extractions (ECCS) with intraocular lens implantation, phacoemulsification is performed almost exclusively by some surgeons. ECCE is preferred by some ophthalmologists because of the dense nuclear opacities that are commonly found and the difficulty of operating in eyes with corneal scarring. Those surgeons who prefer phacoemulsification advocate the good post-operative results that they achieve, the lack of post-operative refractive error, and the minimum post-operative care that is required. The technique to be used will obviously depend on both the surgeon and the eye.

In some areas all cases are routinely performed under local anaesthetic, while in other areas all cases are routinely performed under general anaesthetic, and in others neurolept anaesthetic is used. Again, in some areas all patients are routinely admitted to hospital for up to one week, while in others day surgery is the rule with the use of either hostel or low-dependency accommodation. In some areas, patients are admitted several days pre-operatively for routine antibiotic treatment. Some post-operative care is provided by AHV when hostel accommodation is used. Several raised concerns about the harmful effects that can follow unsuccessful or
complicated surgery and the need to have operations performed by well-trained or well-supervised surgeons.

In most programs the post-operative follow-up of patients is incomplete at best and a distance or near refraction is rarely, if ever given. It would seem that every patient should at least be given a pair of reading glasses at the time of initial post-operative discharge. In some instances, sunglasses are provided to all patients post-operatively. In Far North Queensland, Townsville and Katherine, YAG laser capsulotomy can be done locally. Elsewhere, patients may have to travel to the state capital city.

**Recommended Practices**

The RACO has prepared clinical practice guidelines entitled, “Preferred Practice Patterns for Cataract and Intraocular Lens Surgery in the Otherwise Healthy Adult Eye”\(^a\). These guidelines represent quality eye care commensurate with present knowledge and resources. They are evidence-based where possible and in other cases draw on the collective judgment and evaluation of available evidence by ophthalmologists.

These guidelines recommend cataract surgery when visual disability results in impaired ability to carry out needed or desired activities, when visual acuity in the affected eye is 6/18 or worse and when the patient determines that the benefits of cataract surgery and expected visual improvement outweigh the cost, risks and inconvenience of surgery. The guidelines also provide advice on pre-operative assessment and post-operative care including routine follow-up. Possible complications are also detailed, in particular the guidelines advise that those patients with diabetes mellitus may require special pre- and post-operative management by both the involved anaesthetist and an endocrinologist.

Clinical practice guidelines for cataract surgery in Aboriginal people in rural and remote areas need to be developed to reduce the great variation in the pre-operative work-up that occurs. These inefficient practices add enormously to the cost and complexity of cataract surgery.

Clinical practice guidelines should discuss both the possibility of ECCE or phacoemulsification. They should emphasise the need to identify and train a key nurse who would have responsibility for organising the eye surgery and especially the ophthalmic surgical equipment. The guidelines should aim to encourage the use of day surgery with local anaesthesia, and the utilisation of local Aboriginal hostels with some post-operative care provided by AHW. It is also important to have Aboriginal liaison staff working with the hospital or surgical centre, and a team planning approach to the surgery. A portable YAG laser for capsulotomy should also be available at the regional level.

Clinical practice guidelines should also include the details for a surgical audit. All surgical patients should be followed-up some months post-operatively and at the least their visual acuity should be recorded. Results must be regularly reviewed to ensure that surgical standards are maintained. This is no more than already happens in major hospitals, and Aboriginal people are entitled to the same standards as urban Australians. Audit is now a fact of professional life, and must form a part of any Aboriginal program.

For most Australians the practical indications for cataract surgery will be when their vision is reduced by a cataract so that they can no longer drive a car or perform everyday activities. For most remote services older criteria are still used so that cataract surgery is often not performed until the person is bilaterally legally blind. In some instances patients having cataract surgery are required to have count finger vision.

Data collected from the general population in Melbourne show how the rate of cataract surgery increases greatly as the criterion for visual impairment is reduced (Table 5.2).

**Table 5.2 Predicted rate of cataract surgery by theoretical level of visual impairment\(^b\)**

<table>
<thead>
<tr>
<th>Visual Impairment Criterion</th>
<th>Predicted Rate of Cataract Surgery (Cataract operations per 1,000 per year)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;6/60</td>
<td>0.6</td>
</tr>
<tr>
<td>&lt;6/36</td>
<td>1.2</td>
</tr>
<tr>
<td>&lt;6/24</td>
<td>3.1</td>
</tr>
<tr>
<td>&lt;6/15</td>
<td>10</td>
</tr>
<tr>
<td>&lt;6/9</td>
<td>23</td>
</tr>
</tbody>
</table>

As modern cataract surgery is made more available to Aboriginal and Torres Strait Islander communities, the demand for surgery will increase. Clearly, this phenomenon has already occurred in the general population where the number of cataract operations had increased nearly three-fold in an eight-year period. The rate of cataract surgery in Australia is now approximately 4.7/1000 per year\(^b\). We cannot determine the current rate of cataract surgery in Aboriginal people, but it is likely to be much less than one tenth of this. Therefore, with the provision of adequate services to Aboriginal people, the demand for cataract surgery may well increase up to ten-fold. This is the increase that would occur if the rate were to be comparable to that of the rest of Australia.

**RECOMMENDATION 9**

Cataract surgery should be routinely provided at a regional level and requires appropriate facilities and equipment.
CHAPTER SIX

DIABETIC RETINOPATHY

Summary

Diabetes has become a major health problem for Aboriginal and Torres Strait Islander peoples. In many communities, 8% to 13% of people have diabetes. All people with diabetes are at-risk of developing diabetic eye disease (retinopathy) that can lead to blindness. Most of this blindness can be prevented by regular screening to detect early stages of retinopathy followed by timely retinal laser treatment.

Aboriginal people with diabetes should have their eyes examined once a year, but this does not happen. Computer-based patient management systems readily facilitate regular examination and new retinal cameras allow health workers to perform eye screening. Laser treatment should be readily available either in local communities or in regional centres.

Introduction

Diabetes is a serious and increasing health problem in populations world-wide. Although diabetes has been recognised for hundreds and in some cases thousands of years, it is only in the last 20-30 years that it has affected such large numbers of people. It is very much a disease of western lifestyle, referred to as a “disease of affluence”, occurring primarily in affluent western societies. However, its distribution has now changed, and the worst affected populations are those that have undergone a rapid “westernisation” of diet and lifestyle.

Diabetes occurs in epidemic proportions (20%-50% of adults) in many indigenous populations that no longer follow a traditional lifestyle. Examples include urbanised Melanesians in Papua New Guinea, Nauruans and other Pacific Islanders, many American Indian populations, and Australian Aboriginal and Torres Strait Islander peoples.

Most Aboriginal people in Australia today follow a westernised lifestyle, eat western foods and lead a sedentary life. Obesity, non-insulin dependent diabetes (NIDDM) and coronary heart disease occur in epidemic proportions amongst these people. Insulin dependent diabetes appears to be rare or unknown in Aboriginal
people unless they have European genetic admixture. Relative to the rest of the
Australian population, Aboriginal people have a 20 year shorter-life expectancy, up
to four times higher prevalence of coronary heart disease and, in the 20-50 year
age-group, more than 10 times the prevalence of diabetes.

Diabetic retinopathy is one of the most serious complications of diabetes and results
from damage to small blood vessels, including those in the retina. Diabetic
retinopathy shows a progression of changes termed non-proliferative retinopathy.
These include microaneurysms, retinal haemorrhages, lipid exudates, areas of
microinfarction or cotton wool spots, intraretinal microvascular abnormalities and
venous beading. Proliferative retinopathy is characterised by growth of new vessels
and fibrous scar tissue and may lead to pre-retinal and vitreous haemorrhage. Leaks
from macular capillaries result in macular oedema. Vision can be reduced or lost
from haemorrhage, macular oedema or retinal detachment. Once vision is lost from
diabetic retinopathy, it usually cannot be restored. Cataract may also develop more
quickly in people with diabetes.

At the time of diagnosis, 13% of Europeans with NIDDM will have some signs of
non-proliferative diabetic retinopathy. This rises to almost 100% after 20 years of
diabetes. Overall 8% of people diagnosed with diabetes who do not have signs of
retinopathy, will develop retinopathy each year, and 7% of those with background
retinopathy will progress to vision threatening retinopathy each year. Diabetic
retinopathy especially macular oedema seems to occur earlier and to be more severe
in Aboriginal people.

The duration of diabetes is the most important factor determining the presence of
diabetic retinopathy, although good diabetic control can reduce the development and
progression of retinopathy. Visual loss from diabetic retinopathy, can be prevented
by the early detection and monitoring of retinopathy with regular and appropriately
timed fundus examinations and laser treatment.

Acknowledgment is given to Professor Kerin O’Dea and Dr Neil Thomson who
provided much of the material for this chapter.

Current Status
Prevalence of Diabetes

Surveys conducted in Aboriginal communities from across Australia indicate that
Aboriginal people have much higher prevalence rates of diabetes, and a much
younger average age of onset (Figure 2). NIDDM has been reported in
Aboriginal teenagers and the peak prevalence is about 40 years, 30 years earlier
than in Europeans.

The prevalence of diabetes in Aboriginal communities closely follows the extent of
westernisation. The lowest rates occur in communities with the least exposure to
western lifestyle and the highest rates in those with the greatest exposure.

A survey of Torres Strait Islanders in 1981 reported a prevalence of diabetes of
13%-19%. A smaller survey in 1994-95 found 40% of Torres Strait Islanders over
35 years had diabetes.

Figure 2. Diabetes prevalence in relation to age in Aboriginals of European origin
and Aboriginal people from ten communities in northern and central Australia
1983-1995

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>15-24</td>
<td>European</td>
</tr>
<tr>
<td>25-34</td>
<td>Aboriginal</td>
</tr>
<tr>
<td>35-44</td>
<td></td>
</tr>
<tr>
<td>45-54</td>
<td></td>
</tr>
<tr>
<td>55-64</td>
<td></td>
</tr>
<tr>
<td>65-74</td>
<td></td>
</tr>
<tr>
<td>75+</td>
<td></td>
</tr>
</tbody>
</table>

Note: There were insufficient numbers in the Aboriginal cohort to include data for subjects aged
>65 years.

Available data indicate that the expected pattern of micro- and macro-vascular
complications seen in Europeans with NIDDM is also seen in Aboriginal people
with diabetes. Renal and eye disease are particularly serious areas of concern.

Incidence of Diabetes

There are no published data on the incidence of diabetes in Aboriginal people or
Torres Strait Islanders.

Unpublished data come from two Aboriginal communities in central Australia that
were surveyed in 1987, 1988 and 1995. These two communities have had quite
different experiences of western culture. In those over 35 years of age the prevalence
of diabetes was 17% in the community that had maintained its traditional way of life.
and 30% in the community that had been established as a mission 100 years ago. In 1995, the incidence of diabetes was twice as high in the community that had been a mission — 19 versus 9 cases per 1000 person years.

These two communities probably represent the upper and lower incidence rates for Aboriginal populations. The incidence of 19 cases per 1000 person years is similar to some of the worst affected populations in the world such as the Nauruan, although it is less than the Pima Indians. The lower rate of 9 cases per 1000 person years is still much higher than the rate of 2-4 cases per 1000 person years for northern European populations. Incidence data are not available for the Australian population.

The strongest predictor of diabetes in both Aboriginal communities studied above was baseline body mass index, with leanness (BMI<22kg/m2) being protective at all ages. Being either overweight or obese strongly increased the risk of diabetes.

**Obesity**

Obesity is very common in less traditional Aboriginal communities. Average BMI increases steadily over the 15-45 year age range in both men and women, and more than 60% of those over 35 years of age are overweight or obese (BMI> 25 kg/m2).

When Aboriginal people lived traditionally as hunter-gatherers they were very lean (BMI usually <20 kg/m2) and their weight did not increase with age. They were active and physically fit, free of any indicators of risk for NIDDM and coronary heart disease and with no biochemical evidence of malnutrition.

Aboriginal people living a western diet and sedentary lifestyle have a cluster of metabolic and pathophysiological characteristics associated with increased risk of NIDDM and also coronary heart disease, obesity, hypertriglyceridemia, low HDL cholesterol levels, hypertension and proteinuria. Smoking is also highly prevalent in many Aboriginal communities.

**Treatment and Prevention of Diabetes**

Oral hypoglycaemic drugs are the mainstay of treatment of NIDDM. However, in Aboriginal and Torres Strait Islander peoples control is often poor, possibly complicated by poor compliance. Given the high proportion of the adult Aboriginal population with diabetes, the focus should be on both primary and secondary prevention, and directed at families and communities.

There is a compelling argument for primary prevention programs aimed at lifestyle modification especially to reduce the risk of obesity and thereby the risk of NIDDM. Such programs should be targeted at adolescents and those in their early twenties as risk factors are already clearly evident in young adults. They should emphasise increased physical activity in daily routines and the development of sustainable modifications to the diet that minimise the potential for overconsumption. However, for long term success they must be developed by the Aboriginal communities themselves to ensure that they are culturally appropriate and acceptable, and therefore able to be “owned” by the community rather than imposed in a well-meaning, but inappropriate, fashion from the outside.

Secondary prevention or the delay of onset of complications should be a high priority in Aboriginal people with diabetes. A health care team approach is essential. It should include access to podiatry and advice on nutrition, early detection and treatment of infections, and the regular monitoring of renal function, eye disease and peripheral and cardiovascular disease.

**Prevalence of Diabetic Retinopathy**

The prevalence of diabetic retinopathy in people with diabetes who present to diabetic clinics is between 35% and 49%, and between 22% and 36% in people with diabetes in the community. This gives an overall prevalence of diabetic retinopathy of 1.1% to 2.2% among older Australians. The prevalence of vision threatening retinopathy is between 6% and 13% among people with diabetes in the community.

Very limited data are available on the prevalence of diabetic retinopathy among Aboriginal and Torres Strait Islander peoples. The NTIEHP did not systematically identify all Aboriginal people with diabetes nor did it specifically perform dilated retinal examinations on all known diabetics. Only 59 (0.1%) of the 62,116 Aboriginal people screened by the NTIEHP were identified as having diabetes, and only 32 (0.05%) had diabetic retinopathy.

The crude prevalence of diabetic retinopathy among Aboriginal people who have diabetes appears similar to the general Australian diabetic population that is between 8% and 35% (Table 6.1). About half of those with diabetes have vision-threatening retinopathy. However, one study in rural Western Australia in the early 1980s found 31% of Aboriginal people with diabetes had retinopathy compared with 20% of non-Aboriginal people. ‘Obstructive retinopathy’ was more common among Aboriginal people (12%) than among non-Aboriginal people (8%).

These crude prevalences are likely to under-estimate the relative magnitudes of background and proliferative retinopathy among both Aboriginal and non-Aboriginal people, as they do not take account of the ages of affected people or more importantly the duration of diabetes. The higher prevalence of diabetic
Findings from the Current Review

There can be no question that diabetes is a major health problem in Aboriginal communities and it is rapidly increasing in frequency. Diabetic retinopathy is also a major problem and its increased prevalence and increased severity in Aboriginal people is associated with poor diabetes control, late presentation and irregular monitoring. Diabetes in Aboriginal people is frequently associated with hypertension and hyperlipidaemia, both of which exacerbate diabetic retinopathy.

As mentioned previously, almost all the diabetes that occurs in Aboriginal people is "adult onset" or NIDDM and so the majority of retinal changes are due to macular oedema. Macular oedema in Aboriginal people seems to be particularly florid and this may well be due to co-existing hyperlipidaemia and hypertension.

Information collected during the consultations for this review found that prevalence of diabetes ranged from 2% to 13% of the whole community (Table 6.2). In most cases less than one third of those with diabetes had had a recent eye examination, although in two communities 75% had been examined. Overall, most health services reported irregular eye examinations and usually retinopathy was not detected until it was well advanced.

Table 6.2 Estimated prevalence of diabetes in communities visited during this Review

<table>
<thead>
<tr>
<th>Location</th>
<th>Organisation</th>
<th>Estimated population or patient load</th>
<th>Estimated number with diabetes</th>
<th>% of diabetics had eye examination</th>
</tr>
</thead>
<tbody>
<tr>
<td>Melbourne, Vic</td>
<td>Victorian Aboriginal Health Service</td>
<td>5,000</td>
<td>250</td>
<td>5%</td>
</tr>
<tr>
<td>Katherine, NT</td>
<td>Wurli Wurlungu AMS</td>
<td>5,000</td>
<td>120 — 130</td>
<td>3%</td>
</tr>
<tr>
<td>Barunga, NT</td>
<td>Barunga Community Health Service</td>
<td>300</td>
<td>35</td>
<td>12%</td>
</tr>
<tr>
<td>Beswick, NT</td>
<td>Beswick Health Service</td>
<td>500</td>
<td>9 (on medication)</td>
<td>5%</td>
</tr>
<tr>
<td>Lajamanu, NT</td>
<td>Barunga Community Health Service</td>
<td>800</td>
<td>80</td>
<td>10%</td>
</tr>
<tr>
<td>Tennant Creek, NT</td>
<td>Anyinginyi AMS</td>
<td>1,500</td>
<td>50</td>
<td>3%</td>
</tr>
<tr>
<td>Newman, WA</td>
<td>Newman Community Health Service</td>
<td>n/a</td>
<td>30</td>
<td>n/a</td>
</tr>
<tr>
<td>Jigalong, WA</td>
<td>Puutakura AMS</td>
<td>900</td>
<td>43</td>
<td>5%</td>
</tr>
<tr>
<td>Roebourne, WA</td>
<td>Mawankara AMS</td>
<td>1,700</td>
<td>87</td>
<td>5%</td>
</tr>
<tr>
<td>Kununurra, WA</td>
<td>East Kimberley AMS</td>
<td>2,000</td>
<td>91</td>
<td>5%</td>
</tr>
<tr>
<td>Wilcannia, NSW</td>
<td>Wilcannia Hospital</td>
<td>1,600</td>
<td>50</td>
<td>3%</td>
</tr>
<tr>
<td>Bourke, NSW</td>
<td>Bourke AMS</td>
<td>1,575</td>
<td>96</td>
<td>6%</td>
</tr>
<tr>
<td>Emuanga, NSW</td>
<td>Bourke AMS</td>
<td>100</td>
<td>40</td>
<td>40%</td>
</tr>
<tr>
<td>Cape York communities, QLD</td>
<td>Apunijima Cape York Health Council</td>
<td>11,400</td>
<td>1,000</td>
<td>9%</td>
</tr>
</tbody>
</table>
Table 6.2 Estimated prevalence of diabetes in communities visited during this Review — continued

<table>
<thead>
<tr>
<th>Location</th>
<th>Organisation</th>
<th>Estimated population or patient load</th>
<th>Estimated number of diabetes</th>
<th>% of diabetes had eye examination</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hopevale, QLD</td>
<td>Hopevale Community Health Service</td>
<td>1,200</td>
<td>150</td>
<td>13%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>25% examined (HbA1c&gt;10)</td>
</tr>
<tr>
<td>Donaldee, QLD</td>
<td>Donaldee Hospital</td>
<td>1,200</td>
<td>50</td>
<td>4%</td>
</tr>
<tr>
<td>Ceduna, SA</td>
<td>Ceduna AMS</td>
<td>4,000</td>
<td>69</td>
<td>2%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>25% examined</td>
</tr>
<tr>
<td>Yalata, NT</td>
<td>Yalata/Maralinga AMS</td>
<td>500</td>
<td>20</td>
<td>4%</td>
</tr>
<tr>
<td>Apunala, NT</td>
<td>Apunala Health Service</td>
<td>278</td>
<td>12</td>
<td>4%</td>
</tr>
<tr>
<td>Pijarrajara</td>
<td>Fregon Clinic</td>
<td>1,100</td>
<td>113</td>
<td>10%</td>
</tr>
<tr>
<td>Lands, SA</td>
<td></td>
<td></td>
<td></td>
<td>75% examined (8% lasered)</td>
</tr>
<tr>
<td>Alice Springs, NT</td>
<td>Central Australia</td>
<td>12,000</td>
<td>1,240</td>
<td>10%</td>
</tr>
<tr>
<td></td>
<td>Aboriginal Congress Inc</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shepparton, VIC</td>
<td>Rambala AMS</td>
<td>1,700</td>
<td>50</td>
<td>3%</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>70% (12% needed treatment)</td>
</tr>
</tbody>
</table>

Health service staff often did not understand the management of diabetic retinopathy once it has been detected. Complaints were heard about trips to the ophthalmologist for patients with retinopathy who were not treated but rebooked for a second costly trip shortly after. The current practice calls for repeated examinations every 6 to 12 months once mild non-proliferative retinopathy has been detected and more frequently if threatened maculopathy is present. Better communication between specialists and medical officers about management regimes is needed.

Compliance with recommendations for laser treatment was poor, in large part because of the lack of specialist services and laser equipment. Health services reported that patients were usually required to travel to the State capital for laser treatment, which in Western Australia could be more than 2000 km away. Transport is expensive and inconvenient, arrangements to assist patients on arrival are informal and ad hoc, and patients are often unfamiliar with the city and intimidated by it. A few services, notably in Far North Queensland and in Katherine, had used a portable laser and this had allowed them to provide adequate treatment for diabetic retinopathy in the community.

Often there is little follow-up of patients after initial laser treatment, and also little possibility of this in most communities. This contributes significantly to the poor management of diabetic retinopathy.

Registers or databases of patients with diabetes are irregularly kept, although most clinics had some form of listing. Often this was a card-file or register book, although simple, locally developed computer databases were used by several services. A few services were found to use commercially-available, patient management systems. See Chapter Two for further discussion on this issue.

Recommended Practices

The current best practice for diabetic retinopathy is guided by three principles:

1. All people with diabetes are at risk of developing diabetic retinopathy;
2. Nearly all blindness from diabetes can be prevented by early detection and appropriate laser treatment; and
3. Regular (annual) eye examinations are needed to detect retinopathy early.

Like other people with diabetes, all Aboriginal people with diabetes are at risk of developing diabetic eye disease, and current best practice dictates that they must have regular annual ocular examination, prompt referral if diabetic retinopathy is detected, appropriate laser treatment that ideally should be provided locally and appropriate follow up.

The National Health and Medical Research Council is finalising “Clinical Practice Guidelines for the Management of Diabetic Retinopathy”. These guidelines are to assist professionals to make management decisions about diabetic retinopathy and improve the quality of care.

The Guidelines contain a specific chapter for Aboriginal and Torres Strait Islander peoples. This chapter advises that from the time of diagnosis, Aboriginal and Torres Strait Islander peoples with diabetes should have annual eye examinations. The annual ocular examination should include a measurement of visual acuity and a retinal examination. A clinical retinal examination can be performed by an ophthalmologist, optometrist, or local medical officer, but should follow the NHMRC guidelines and must include pupillary dilation. Retinal photography also can be used as a screening examination. Screeners who are not ophthalmologists should refer patients to an ophthalmologist whenever visual acuity loss, non-proliferative diabetic retinopathy, proliferative diabetic retinopathy or macular oedema is detected.

Ophthalmologists are advised to repeat eye examinations every 6 to 12 months in the case of mild non-proliferative diabetic retinopathy, every three months to six months in the case of moderate or severe mild non-proliferative diabetic
retinopathy, and more frequently if macular oedema is present. Retinal laser therapy is indicated for the treatment of proliferative retinopathy and macular oedema. Fluorescein angiography may be needed to guide laser treatment of macular oedema.

The management of patients with diabetes needs to be built around an adequate database to ensure that all people with diabetes receive an annual eye examination in addition to the other routine components of diabetic care. It is recommended that commercially available computer databases such as FERRET or PACSS be made widely available for tracking routine examinations of patients with diabetes.

An effective alternative to dilated ophthalmoscopy, is the use of retinal cameras. Mydriatic retinal cameras are used in several areas. They usually provide excellent retinal photographs but are relatively difficult to use and require considerable training and skill to use.

More recent non-mydriatic cameras provide good retinal photographs more easily and without the need for dilating drops*. These cameras can be operated by AHW or nursing staff after minimal training. They are simple to operate and with polaroid film, can provide instant feedback. The photographs can be taken as part of a preliminary screen at the local level and those photographs with any abnormalities should be referred for further ophthalmic assessment and a decision about the management of that particular patient. These cameras may also be used with mydriasis to perform fluorescein angiopathy in regional centres.

A camera can be shared by a number of communities on a regional basis, and can be regularly moved from community to community so that all patients with diabetes can be examined. This currently happens with the AMS in the Kimberleys and in Rumbalara in Victoria*. The polaroid photograph provides a visual means of explaining to people with diabetes what is happening to their eyes and why laser treatment may be necessary. The photographs also provide a pictorial record of the development of retinopathy.

People with diabetes who have retinal changes need an ophthalmic examination in a timely fashion, and should have laser treatment performed locally, preferably in their community or, at least, in their regional centre. This is achievable under the proposed regional public-private model of service delivery.

A surgical audit to monitor the outcome of laser treatment needs to be an integral part of the clinical practice.

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**RECOMMENDATION 10**

The State and Territory Governments should provide regionally-based equipment such as non-mydriatic fundus cameras and portable laser equipment necessary for the management of diabetic retinopathy. Appropriate training should be made available to primary health care workers who will use the photographic equipment.

**RECOMMENDATION 11**

Clinical practice guidelines for diabetic retinopathy should include at a minimum, the use of patient management and recall software, the importance of annual eye examinations and advice on the use of laser treatment in Aboriginal and Torres Strait Islander communities.

**RECOMMENDATION 12**

12a. A Medicare item number should be provided for annual retinal photographic screening for retinopathy in people with diabetes by practitioners other than ophthalmologists and optometrists.

12b. Aboriginal Health Workers or nurses should be able to provide annual retinal photographic screening for retinopathy in people with diabetes under the supervision of a medical practitioner, in keeping with the ‘On behalf’ provisions, and thereby attract a Medicare rebate under the supervising medical practitioner’s name.
CHAPTER SEVEN

TRACHOMA

Summary

Trachoma is a slowly blinding eye infection. Although the prevalence and intensity of trachoma may have decreased in some areas, other areas show little or no improvement over the last 20 years. Many seem to have disregarded trachoma and current data on active trachoma underestimate the problem as they often come from incomplete cohorts of older children. Information on trichiasis is grossly inadequate and in most areas, cases are not actively sought.

An integrated primary health approach is required to manage trachoma. This should combine screening, azithromycin antibiotic treatment, personal hygiene and environmental improvement. This approach has been codified by the World Health Organisation in the “SAFE strategy”. It is unconscionable that trachoma remains a blinding disease in Australia.

Introduction

Trachoma is chronic conjunctivitis caused by repeated episodes of infections with the obligatory intracellular bacterium, Chlamydia trachomatis. The early stages of active infection, “follicular trachoma” are largely seen in young children and if long-standing and moderately severe this leads to “cicatricial trachoma” in later life. Severe scarring of the eyelids causes in-turning of the eyelashes (trichiasis), opacification of the cornea and blindness.

Whether trachoma was a pre-existing problem in Aboriginal communities is unclear and seems unsolvable\(^5\). Certainly high levels of trachoma were recorded in the 1940s by Flynn\(^1\) and in the 1950s by Mann\(^5\). The NTEHP undertook an exhaustive study in the 1970s and found that trachoma was widespread, severe in many places and the leading cause of blindness in Aboriginal people\(^1\). Since then several studies have suggested that the prevalence and severity of trachoma has decreased somewhat. However, Australia is noted by WHO as one of the 54 countries that still has hyperendemic blinding trachoma.
Acknowledgment is given to Dr Neil Thomson who provided much of the material for this chapter.

Current Status

Prevalence of Active Trachoma

Nearly all the recent data on trachoma simply reports the presence of “follicular” or “inflammatory” trachoma. This is consistent with the WHO sign of Trachomatous inflammation-follicular — TF. The more severe form, TI — Trachomatous inflammation — intense, is rarely reported separately. As a result, the information presented in this section has to be restricted to follicular trachoma. Most examinations have been of incomplete cohorts of older children whereas the most susceptible group are younger preschool children (Table 7.1).

Table 7.1 Overall Prevalence of Trachoma in Aboriginal People found by NTEHP, 1976-1996

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Numbers Seen</th>
<th>Numbers Affected</th>
<th>Prevalence (%)</th>
<th>Age Group</th>
<th>Numbers Seen</th>
<th>Numbers Affected</th>
<th>Prevalence (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-1</td>
<td>2240</td>
<td>388</td>
<td>17%</td>
<td>0-2</td>
<td>3605</td>
<td>76</td>
<td>2%</td>
</tr>
<tr>
<td>2-3</td>
<td>3182</td>
<td>1096</td>
<td>34%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4-5</td>
<td>4877</td>
<td>1503</td>
<td>31%</td>
<td>3-5</td>
<td>6690</td>
<td>624</td>
<td>9%</td>
</tr>
<tr>
<td>6-7</td>
<td>6453</td>
<td>1540</td>
<td>24%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8-9</td>
<td>5785</td>
<td>1109</td>
<td>19%</td>
<td>6-9</td>
<td>12241</td>
<td>2539</td>
<td>21%</td>
</tr>
<tr>
<td>10-13</td>
<td>9980</td>
<td>1350</td>
<td>14%</td>
<td>10-14</td>
<td>11897</td>
<td>3187</td>
<td>27%</td>
</tr>
<tr>
<td>14-19</td>
<td>7525</td>
<td>466</td>
<td>6%</td>
<td>15-19</td>
<td>5608</td>
<td>1855</td>
<td>33%</td>
</tr>
<tr>
<td>20-29</td>
<td>6573</td>
<td>156</td>
<td>2%</td>
<td>20-29</td>
<td>6573</td>
<td>2521</td>
<td>38%</td>
</tr>
<tr>
<td>30-39</td>
<td>4568</td>
<td>59</td>
<td>1%</td>
<td>30-39</td>
<td>4568</td>
<td>2100</td>
<td>46%</td>
</tr>
<tr>
<td>40-49</td>
<td>3898</td>
<td>53</td>
<td>1%</td>
<td>40-49</td>
<td>3897</td>
<td>1873</td>
<td>48%</td>
</tr>
<tr>
<td>50-59</td>
<td>2698</td>
<td>18</td>
<td>1%</td>
<td>50-59</td>
<td>2698</td>
<td>1347</td>
<td>50%</td>
</tr>
<tr>
<td>60+</td>
<td>3016</td>
<td>24</td>
<td>1%</td>
<td>60+</td>
<td>3923</td>
<td>2700</td>
<td>69%</td>
</tr>
<tr>
<td>All ages</td>
<td>61695</td>
<td>7762</td>
<td>13%</td>
<td>All ages</td>
<td>61700</td>
<td>18822</td>
<td>31%</td>
</tr>
</tbody>
</table>

Most available data come from periodic surveys undertaken in areas known to have trachoma. They must be interpreted carefully because most of the surveys were undertaken to guide service provision rather than to collect epidemiological data. The lack of standardisation of diagnostic criteria; observer variation; variation of age groups surveyed; selection criteria for survey participants; seasonal factors and the time relationship between surveys and treatment activities, must be borne in mind.

Table 7.2 Current prevalence of follicular trachoma in children by region

<table>
<thead>
<tr>
<th>Region</th>
<th>Year</th>
<th>Age-group</th>
<th>Numbers</th>
<th>Prevalence (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pilbara</td>
<td>1996</td>
<td>Children</td>
<td>261/473</td>
<td>55% (51-60%)</td>
</tr>
<tr>
<td>Alice Springs</td>
<td>1989/90</td>
<td>1-9 years</td>
<td>315/724</td>
<td>44% (40-47%)</td>
</tr>
<tr>
<td>Central Desert</td>
<td>1994</td>
<td>Schoolchildren</td>
<td>67/189</td>
<td>36% (29-42%)</td>
</tr>
<tr>
<td>Anangu Pitjantjara</td>
<td>1990</td>
<td>0-9 years</td>
<td>67/246</td>
<td>27% (22-33%)</td>
</tr>
<tr>
<td>Eastern Goldfields</td>
<td>1990</td>
<td>0-9 years</td>
<td>86/396</td>
<td>22% (18-26%)</td>
</tr>
<tr>
<td>Katherine</td>
<td>1996</td>
<td>Schoolchildren</td>
<td>55/289</td>
<td>19% (15-24%)</td>
</tr>
<tr>
<td>Murchison</td>
<td>1996</td>
<td>0-9 years</td>
<td>34/189</td>
<td>18% (13-23%)</td>
</tr>
<tr>
<td>Kimberley</td>
<td>1996</td>
<td>Schildren</td>
<td>366/2522</td>
<td>15% (13-16%)</td>
</tr>
<tr>
<td>East Arnhem</td>
<td>1988/89</td>
<td>1-9 years</td>
<td>63/411</td>
<td>15% (12-19%)</td>
</tr>
</tbody>
</table>

For those areas where recent data are available, substantial numbers of children are affected by follicular trachoma and the prevalence in many areas appears to be still at hyperendemic levels, that is more than 20% in children under 10 years of age have follicular trachoma. (Table 7.2 and Figure 3).

Figure 3. Comparison of the prevalence of follicular trachoma among Aboriginal children


Notes: NTEHP data for 0-9 year olds.

Data collected by the ATEHP (SA) suggest an overall prevalence of active trachoma in 1996 of 10% (95% confidence interval: 6-14%) among 187 children aged 0-9 years\(^\text{20,87}\). This estimate uses aggregated data from diverse communities, some of which have no trachoma or trachoma at very low levels.

Some longitudinal data are available for several communities in Western Australia. In the Pilbara, trachoma is still hyperendemic in eight of the communities examined and at mild to moderate levels in the other four (Table 7.3). The ages of children examined vary with the different examinations.

In the Murchison region, the levels of follicular trachoma among 0-9 year old children have remained fairly steady over the last 10 years (Table 7.4) but if anything, may have increased.

The Kimberleys shows a small decline in follicular trachoma in school children over the last 4 years, although trachoma remains a significant problem in both Balgo and Hall’s Creek (Table 7.5).

### Table 7.3 Prevalence of follicular trachoma for children in the Pilbara\(^\text{20,87}\)

<table>
<thead>
<tr>
<th>Community</th>
<th>1987 (0-18 yr)</th>
<th>1996 (0-9yr)</th>
<th>1991 (children)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Punmu</td>
<td>35%</td>
<td>92%</td>
<td>n/a</td>
</tr>
<tr>
<td>Yandeyarra</td>
<td>20%</td>
<td>65%</td>
<td>79%</td>
</tr>
<tr>
<td>Roebourne</td>
<td>6%</td>
<td>44%</td>
<td>76%</td>
</tr>
<tr>
<td>Parngurr</td>
<td>n/a</td>
<td>70%</td>
<td>n/a</td>
</tr>
<tr>
<td>Jigalong</td>
<td>28%</td>
<td>80%</td>
<td>66%</td>
</tr>
<tr>
<td>Nullagine</td>
<td>17%</td>
<td>74%</td>
<td>62%</td>
</tr>
<tr>
<td>Parnawina</td>
<td>n/a</td>
<td>67%</td>
<td>26%</td>
</tr>
<tr>
<td>Port Hedland, 12 mile camp</td>
<td>n/a</td>
<td>21%</td>
<td>n/a</td>
</tr>
<tr>
<td>Ooloo</td>
<td>5%</td>
<td>18%</td>
<td>n/a</td>
</tr>
<tr>
<td>Marble Bar</td>
<td>5%</td>
<td>44%</td>
<td>13%</td>
</tr>
<tr>
<td>Port Hedland</td>
<td>12%</td>
<td>13%</td>
<td>n/a</td>
</tr>
</tbody>
</table>

### Table 7.4 Prevalence of follicular trachoma for children aged 0-9 years in the Murchison Region\(^\text{88}\)

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Wiluna</td>
<td>15%</td>
<td>24%</td>
<td>43%</td>
<td>74%</td>
<td>44%</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Karalundi</td>
<td>n/a</td>
<td>43%</td>
<td>n/a</td>
<td>n/a</td>
<td>100%</td>
<td>n/a</td>
<td>32%</td>
</tr>
<tr>
<td>Yalgoo</td>
<td>8%</td>
<td>4%</td>
<td>0%</td>
<td>0%</td>
<td>n/a</td>
<td>n/a</td>
<td>20%</td>
</tr>
<tr>
<td>Burrinbah</td>
<td>n/a</td>
<td>20%</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Meekatharra</td>
<td>7%</td>
<td>29%</td>
<td>25%</td>
<td>90%</td>
<td>17%</td>
<td>32%</td>
<td>19%</td>
</tr>
<tr>
<td>Mt Magnet</td>
<td>5%</td>
<td>6%</td>
<td>3%</td>
<td>100%</td>
<td>13%</td>
<td>4%</td>
<td>10%</td>
</tr>
<tr>
<td>Coo</td>
<td>6%</td>
<td>26%</td>
<td>6%</td>
<td>78%</td>
<td>50%</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

### Table 7.5 Prevalence of follicular trachoma among schoolchildren in the Kimberleys\(^\text{20,88}\)

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Balgo</td>
<td>46%</td>
<td>34%</td>
<td>18%</td>
<td>19%</td>
<td>37%</td>
</tr>
<tr>
<td>Halls Creek</td>
<td>45%</td>
<td>33%</td>
<td>12%</td>
<td>28%</td>
<td>33%</td>
</tr>
<tr>
<td>Fitzroy Crossing</td>
<td>77%</td>
<td>52%</td>
<td>37%</td>
<td>33%</td>
<td>19%</td>
</tr>
<tr>
<td>Kununurra</td>
<td>7%</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>14%</td>
</tr>
<tr>
<td>Derby</td>
<td>18%</td>
<td>11%</td>
<td>14%</td>
<td>7%</td>
<td>13%</td>
</tr>
<tr>
<td>Broome</td>
<td>3%</td>
<td>8%</td>
<td>3%</td>
<td>10%</td>
<td>9%</td>
</tr>
<tr>
<td>Wyndham</td>
<td>18%</td>
<td>10%</td>
<td>30%</td>
<td>14%</td>
<td>5%</td>
</tr>
<tr>
<td>All areas/ communities</td>
<td>20%</td>
<td>22%</td>
<td>19%</td>
<td>16%</td>
<td>15%</td>
</tr>
</tbody>
</table>

Detailed longitudinal data are available for the last 20 years in five communities that were surveyed in 1976-1979, in 1985 and again in the 1990s. Although the prevalence of follicular trachoma may have declined in some communities, all four that were hyperendemic for trachoma in 1976-79 were still hyperendemic when re-examined in 1996 (Table 7.6).

### Table 7.6 Twenty year prevalence of follicular trachoma (Note the selection of children and their ages vary over time)\(^\text{14,38,40,60}\)

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Jigalong</td>
<td>83%</td>
<td>73%</td>
<td>80%</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Yiyili (Louisa Downs)</td>
<td>58%</td>
<td>71%</td>
<td>82%</td>
<td>66%</td>
<td>69%</td>
</tr>
<tr>
<td>Halls Creek</td>
<td>45%</td>
<td>42%</td>
<td>76%</td>
<td>73%</td>
<td>88%</td>
</tr>
<tr>
<td>Billiluna</td>
<td>100%</td>
<td>78%</td>
<td>84%</td>
<td>36%</td>
<td>27%</td>
</tr>
<tr>
<td>Katherine</td>
<td>20%</td>
<td>22%</td>
<td>n/a</td>
<td>26%</td>
<td>n/a</td>
</tr>
</tbody>
</table>

* Collected after treatment

### Table 7.7 Prevalence of follicular trachoma for children in Anangu Pitjantjatjara communities\(^\text{41}\)

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Numbers LF/Total examined</th>
<th>Prevalence (95%CI)</th>
<th>Numbers LF/Total examined</th>
<th>Prevalence (95%CI)</th>
<th>Numbers LF/Total examined</th>
<th>Prevalence (95%CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>50/94</td>
<td>53% (43-64%)</td>
<td>23/28</td>
<td>82% (63-94%)</td>
<td>33/110</td>
<td>30% (22-40%)</td>
</tr>
<tr>
<td>5-9</td>
<td>84/151</td>
<td>56% (47-64%)</td>
<td>27/99</td>
<td>46% (33-59%)</td>
<td>34/136</td>
<td>25% (18-32%)</td>
</tr>
<tr>
<td>0-9</td>
<td>134/245</td>
<td>55% (48-61%)</td>
<td>50/87</td>
<td>57% (47-68%)</td>
<td>60/246</td>
<td>27% (22-33%)</td>
</tr>
</tbody>
</table>
Age-specific longitudinal data come from the Anangu Pitjantjatjara Lands. Some decline in follicular trachoma rates was seen here between 1976 and 1990\textsuperscript{17,18} (Table 7.7). However, trachoma is still hyperendemic (>20%) in every age group.

**Prevalence of Cicatricial Trachoma and Trichiasis**

Nearly all the recent data on trachoma simply focuses on the presence of active trachoma and rarely, if ever is Trachomatosus scarring (TS) or Trachomatous trichiasis (TT) looked for or recorded. Most of the recent trachoma screening is of schoolchildren. Trichiasis is predominantly found in older people (Table 7.1), especially women\textsuperscript{a}, and if not specifically looked for, it will almost certainly be missed.

Cross-sectional, natural history and longitudinal studies show that trichiasis will continue to be a significant public health problem for years or decades after follicular trachoma ceases to exist\textsuperscript{15}. This is because of the cohort effect of those people who have severe inflammation as children and who will go on to develop trichiasis in middle age. This is especially true for women who may have four times the rate of trichiasis compared to men.\textsuperscript{a}

The development of trichiasis is strongly age-related. The NTEHP found trichiasis in only 0.2% of those under 30 years, 1.1% in those 30 to 39, 1.9% in those 40 to 49, 3.4% in those 50 to 59 and 11.8% for those over age 60.\textsuperscript{e} These rates were for all Aboriginal people examined. The rates were much higher in some regions, although in the NTEHP report the regional data on trichiasis were combined with other data in a variable called CT-A. Overall, 41% of all eyes with trichiasis found by the NTEHP were blind\textsuperscript{c}. There is no reason to suspect the fundamental biology of trichiasis has changed in the last 20 years.

In 1990, a survey in the Anangu Pitjantjatjara Lands found 39 (2.6%) of 1,514 people had trichiasis. Twenty-six of those with trichiasis were aged 60 years or older. The rate of trichiasis in those over 60 years was 19%.\textsuperscript{a}

In 1993, a survey by trainee Aboriginal Health Workers under ophthalmic supervision examined 308 people in six communities in the Fitzroy Crossing region. They found scarring in 154 (50%) people, and trichiasis in four (1%)\textsuperscript{a}. Age-specific rates are not available.

**Findings from the Current Review**

In some of the services and regions visited, primary care physicians considered that "trachoma was no longer a problem". In most instances, there were either no data or very incomplete data on the status of trachoma in preschool children, the most susceptible group, or in the elderly, especially women, who have the highest rates of trichiasis. Most examinations are done "naked eye" without magnification and this will lead to an underestimation of disease prevalence. Often the grader had had little or no specific training about trachoma grading.

The prevalence of trachoma varied quite widely. For example, 53% children at the La Grange Mission outside Broome had active trachoma, but trachoma was not a problem in Broome itself where only 1% of schoolchildren were affected. The highest prevalences of active trachoma reported to us were 70% in Jigalong and 64% in Ringers Soak.

Health professionals’ assessments of the prevalence of trachoma was often at wide variance with reality. In one community in central Australia, the schoolchildren had been examined for trachoma recently. The nurse who had done the grading reported that "trachoma was not much of a problem — just a little bit in the schoolchildren". An examination of the records showed that 9 of 51 schoolchildren examined had TF (18%) but an additional 13 (25%) had severe inflammation (TI). This gave a total of 43% with active trachoma. Another doctor in central Australia had also recently screened schoolchildren for trachoma and remembered an estimate of about 10-20% with trachoma. However, a review of the records showed the true rate to be 30%.

In some areas the prevalence and severity of active trachoma has decreased, and in some instances active trachoma may have disappeared. However, in other communities, the prevalence and intensity of trachoma remains unchanged over the last 20 years. In these unfortunate communities many children still have active trachoma (TF) with a significant number of them having intense or severe trachoma (TI). Without intervention, these children are set to go blind from trachoma as adults.

Trichiasis does not receive the attention or treatment it deserves. Many elderly people still have trichiasis, although the data are grossly deficient. Trichiasis is still very widely reported and not infrequent. Anecdotal examples included "10 cases per year in Katherine; 3 out of 3 people who were reviewed for unusual eye problems at Tennant Creek; occasionally seen and treated with ointment in Mt. Newman; 5 to 10 cases operated per year in Broome (10% of surgical cases); one quarter of eye surgical cases in Kununurra; still a major problem in Balgo; still around in NSW; only occasional cases in Coober Pedy, 3 or 4 people treated regularly with epilation in Ceduna; plenty of cases in Oak Valley outside Yalata; 6 cases seen in 3 one-day community visits around Alice Springs; 5 women out of 11 over the age of 40 years and 1 man out of 6 over the age of 40 years at a clinic in central Australia; 10 cases operated at Alice Hospital". Trichiasis "was not seen" in Hopevale nor at Rumbalara and "was not known" in Jigalong.
The lack of concern for trachoma in some ways is a consequence of the prominence that trachoma received during the 1970s and 1980s. Many of those now working in Aboriginal health have other priorities and are actively working on other health issues. There has been a general trend away from vertical programs, the so-called “body-part” approach. In some areas trachoma has been regarded as a disease that is handled by the school nurse as part of their regular screening of schoolchildren so that there is no need for other health professionals to be concerned about it. The link between trichiasis and active trachoma has been mentally broken and as trachoma is regarded as “no longer a problem”, trichiasis and trachomatous blindness are woefully neglected.

**Azithromycin**

Azithromycin is a new erythromycin-like macolide antibiotic that is effective therapy for trachoma when used as a single dose\(^\text{a}\). It replaces previous treatment that relied on prolonged courses of tetracycline ointment or drops that had poor compliance and were relatively ineffective. Over the last two years, trachoma activities in a number of regions have been reinvigorated with the incorporation of azithromycin treatment. One region has developed new public health education material.

An azithromycin treatment program was started in the Katherine region in 1995\(^\text{a}\). The treatment protocol was based on the WHO guidelines and used a single dose of 20 mg/kg of azithromycin for all affected children. The rate of active trachoma fell from 49% in 1995 to 19% in 1996. Regional azithromycin treatment programs have followed in the Pilbara and the Kimberleys and in other communities. In the Pilbara 220 (77%) of 286 children with active trachoma were re-examined 6 to 8 weeks after azithromycin treatment\(^\text{a}\). Trachoma had resolved in 95% of them.

However, the introduction of azithromycin has been slow in some other areas, in part because of concern about the development of bacterial resistance following the widespread use of azithromycin.

Chlamydia do not develop antibiotic resistance even with the prolonged exposure to the relatively inefficient antimicrobials such as sulfonamides or tetracycline.

Erythromycin-resistant gram positive organisms show cross resistance to azithromycin\(^\text{a}\). Despite extensive use of erythromycin over many years there have been only limited sporadic outbreaks of resistance to it. Comparative *in vitro* studies indicate that *H. influenzae*, *S. pyogenes*, and *S. aureus* develop resistance to azithromycin less easily than resistance to erythromycin. β-lactamase production does not influence azithromycin sensitivity.

Resistance is less likely to develop to azithromycin following *in vivo* use than to conventional antibiotics because of the unusual pharmacokinetics of azithromycin\(^\text{a}\). The high concentrations of azithromycin reached at sites of inflammation far exceed the mean inhibitory concentration, so that therapeutic levels are assured at these sites. Because a single dose is all that is required to maintain adequate tissue levels for a period of days, the possibility of an incomplete course essentially does not exist.

**Recommended Practices**

It is quite clear that trachoma remains a significant problem in some areas of Australia. Some areas show imperceptible changes over the last 20 years, although the rates may have fallen in other areas. A concerted organised approach to the reduction of trachoma is considered essential. Health professionals in areas where trachoma is still known to be prevalent, should continue to screen and treat trachoma.

There are three important messages about trachoma that need to be widely known:

1. Trachoma is the disease of the crèche.
2. The simplified WHO grading scheme (FISTO) should be used and its implications understood\(^\text{a}\).
3. The SAFE strategy of WHO should be implemented\(^\text{a}\).

The first point emphasises that most of the transmission of trachoma occurs within the family living unit\(^\text{a}\). Transmission of infection is between young children and between them and their mothers or female caretakers, including sisters, aunts or grandmothers – “the crèche”\(^\text{a}\). Screening should identify children, especially young children with active trachoma and treatment should be given to all members of the living unit or “crèche”\(^\text{a}\).

The simplified assessment of trachoma and its complications developed by WHO\(^\text{a}\) focuses on five key signs of inflammatory and cicatricial disease: Trachomatous inflammation, follicular (TF), that identifies significant active disease; Trachomatous inflammation, intense (TI), that indicates the future group “at risk” for trachomatous blindness; Trachomatous scarring (TS), that indicates present and previous inflammatory disease and risk of future trichiasis; Trachomatous trichiasis (TT), the potentially blinding lesion – that requires corrective trichiasis surgery; and Corneal Opacity (CO), that shows the amount of corneal blindness due to trachoma.

People who are to perform trachoma grading or screening must receive appropriate instruction or teaching material\(^\text{a}\). They must use the appropriate magnification glasses or loupes (x2) and record and report their findings.
The WHO Grading scheme needs to be uniformly adopted and the relevance of age-specific rates of the various signs made widely known. Rapid assessment techniques can be used to ascertain the distribution of trachoma and identify those communities and families where trachoma is a significant problem and requires treatment.

The SAFE strategy developed by WHO needs to be widely distributed amongst those working in trachoma areas. It lists the four essential components for a successful intervention against trachoma:

Surgery for trichiasis
Antibiotics (azithromycin) to treat families with active trachoma (TF and TI)
Facial cleanliness in children by promoting face washing
Environmental activities to improve the water supply and household sanitation.

WHO has noted the successful results of azithromycin treatment for active trachoma and recommend the use of a single dose of azithromycin on an annual basis.

Rather than community-based distribution, the current Review recommends that azithromycin be given to all members of the family or living unit in which active trachoma has been diagnosed. This is consistent with the known epidemiology of the disease, that is, it is the disease of the crèche. It also minimises the total number of people treated and so reduces cost and the risk of bacterial resistance.

WHO has developed a manual for training eye workers how to do tarsal rotation surgery for the community-based treatment of trichiasis. Although most trichiasis surgery in Australia is likely to be performed by ophthalmologists, they should be informed of the procedure recommended by WHO. It is the only trichiasis procedure to be fully evaluated in randomised clinical trials.

It should be emphasised that the SAFE strategy requires ongoing dialogue, partnership and the full participation of the communities. It is an archetypal example of a holistic and integrated approach to disease control and is not a vertical program.

It is unconscionable that in this day and age, and with the resources available in Australia, that trachoma remains a blinding disease.

RECOMMENDATION 13
Clinical practice guidelines for trachoma should be developed for Aboriginal and Torres Strait Islander peoples based on the WHO guidelines and in consultation with the relevant health professionals including those working in Aboriginal Medical Services. They should include at a minimum, the screening for trachoma, the WHO simplified grading, the surgical treatment of trichiasis, the family-based treatment with azithromycin, the promotion of facial cleanliness and environmental improvement.

RECOMMENDATION 14
14a. As a matter of urgency, the Therapeutic Goods Administration should put to the Pharmaceutical Benefits Advisory Committee the issue of scheduling azithromycin under the Pharmaceutical Benefits Scheme for the treatment of trachoma, including the use of a paediatric suspension for infants.

14b. The Commonwealth Minister for Health and Family Services should authorise funding under Section 100 of the National Health Act or through some other mechanism, the distribution of azithromycin through alternative arrangements that substitute for doctors and community pharmacists.
Chapter Eight

Other Eye Conditions

Summary

Blindness occurs up to 10 times more frequently in Aboriginal and Torres Strait Islander peoples than in other Australians. Most of this blindness is due to corneal scarring from trachoma or unoperated cataract. Diabetes is likely to figure more prominently as a cause of blindness in the near future. However, few current data are available for blindness or for hospital utilisation for eye services.

Blindness

The NTEHP found that overall Aboriginal people in rural Australia had nearly ten times more blindness that non-Aboriginal people. The rates of blindness were 1.49% in Aboriginal people compared to only 0.16% of non-Aboriginal people (Table 8.1).

Table 8.1 Prevalence of blindness by age

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Aboriginal people</th>
<th>Non-Aboriginal people</th>
<th>Aboriginal people</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(95% CI)</td>
<td>(95% CI)</td>
<td>(95% CI)</td>
</tr>
<tr>
<td>0-49</td>
<td>0.18%</td>
<td>0.02%</td>
<td>0.28%</td>
</tr>
<tr>
<td></td>
<td>(0.15-0.22%)</td>
<td>(0.01-0.05%)</td>
<td>(0.067%-0.38%)</td>
</tr>
<tr>
<td>50-59</td>
<td>2.76%</td>
<td>0.69%</td>
<td>1.67%</td>
</tr>
<tr>
<td></td>
<td>(2.15-3.38%)</td>
<td>(0.14-1.24%)</td>
<td>(0.491%-0.764%)</td>
</tr>
<tr>
<td>60+</td>
<td>18.88%</td>
<td>4.65%</td>
<td>10.92%</td>
</tr>
<tr>
<td></td>
<td>(17.67-20.09%)</td>
<td>(3.27-6.02%)</td>
<td>(10.00-17.84%)</td>
</tr>
<tr>
<td>All ages</td>
<td>1.49%</td>
<td>0.16%</td>
<td>0.59%</td>
</tr>
<tr>
<td></td>
<td>(1.38-1.58%)</td>
<td>(0.12-0.19%)</td>
<td>(0.10-1.41%)</td>
</tr>
</tbody>
</table>

*RBlindness ≥6/60. **Blindness <6/60.
The causes of blindness were substantially different for Aboriginal people and non-Aboriginal people. Corneal disease was responsible for 50% of the blindness seen among Aboriginal people, including 41% due to trachoma. Only 7% of the blindness among the non-Aboriginal people examined was due to corneal disease. Cataract caused 39% of the blindness among Aboriginal people, and 23% among the non-Aboriginal people. Retinal disease caused 52% of blindness among the non-Aboriginal people, but only 6% among Aboriginal people1.

In 1989-90, the prevalence of blindness was 1.45% among Anangu Pitjantjatjara using the definition for legal blindness (<6/60) in Australia (Table 8.1)24. The NTEHP found a prevalence of blindness (≤6/60) for the Red Centre zone of 2.3%3. If this overall prevalence of blindness for the Red Centre zone were representative of the situation in the Anangu Pitjantjatjara communities, the 1989-1990 survey results suggest that prevalence of blindness for these communities has not changed significantly over the ten to fifteen year period. The causes of blindness in 1989-90 also were similar to those found by the NTEHP, with trachoma and cataract each responsible for around 40% of blindness.

The prevalence of visual impairment (vision of 6/18 or less) was similar for Aboriginal people (9.5%) and non-Aboriginal people (8.5%) in Bourke3. The rates of monocular blindness were also similar for Aboriginal people (4.8%) and non-Aboriginal people (4.1%). The rate of binocular blindness was 0.4% and was not separated for Aboriginal people and non-Aboriginal people.

Glaucosa

Glaucosa, especially primary glaucoma, is rare among Aboriginal people1. Although the NTEHP found 57 Aboriginal cases of glaucoma out of over 60,000 Aboriginal people, only 11 (19%) of these were listed as primary open angle glaucoma. However, not one certain case of either primary open angle glaucoma or primary closed angle glaucoma among Aboriginal people was seen by Professor Hollows, an acknowledged glaucoma expert. With genetic admixture, glaucoma will become more common in Aboriginal people as at least some glaucoma has a clear genetic basis199.

Pterygium

The NTEHP found that pterygium was more common among Aboriginal people (2,194 cases — prevalence 3.4%) than among non-Aboriginal people (442 cases — 1.1%)3.

Service data provide the only recent information about pterygium, but they did not permit any useful prevalences or trends to be derived. However, pterygium is still a common problem in the Kimberleys for example, pterygium surgery accounts for about one third of all eye surgery performed.

Ocular Trauma

Ocular trauma is one eye condition that requires immediate attention by primary health care services. This seemed to be a variable problem in Aboriginal communities. In some communities eye injury is relatively infrequent and limited to occasional corned foreign bodies, although in other areas more serious eye injuries may occur quite commonly. Severe eye injuries are frequently associated with alcohol abuse. NACCHO in its submission to the review, commented that Aboriginal people were exposed to higher levels of physical injury and trauma than non-Aboriginal people.

The management of minor eye trauma seems to be straightforward, but there is often little option but to evacuate those with severe ocular trauma to major ophthalmic centres. The outcome is facilitated by having already established close linkages with the receiving ophthalmologists and this ensures good feedback.

Hospitalisation for Eye Conditions

Hospital admissions (or more strictly separations) generally are for more serious types of eye disease and do not necessarily accurately reflect the extent or pattern of treatable eye conditions in the community. However, they do provide some measure of the use of eye services by Aboriginal and Torres Strait Islander peoples.

Some information was available about hospitalisation from several States for conditions classified to the International Classification of Diseases (ICD) group 'Disorders of the eye and adnexa' (ICD codes 360-379). These rates can be influenced by many factors including variation in admission policies, geographic accessibility of hospitals and the inclusion of private hospital data.

Northern Territory

In the Northern Territory, admission rates for eye conditions for Aboriginal people were much higher than for non-Aboriginal people (Table 8.2. Rates for Aboriginal people tended to increase with time, whereas rates for non-Aboriginal people have not. Admission rates are consistently higher for Aboriginal males than Aboriginal females.
Table 8.2 Age-standardised public and private hospital admission rates for eye conditions, Northern Territory, 1979-1988

| Year | Males per 100,000 | | Females per 100,000 | | |
|------|------------------|------|-------------------|------|
|      | Aboriginal       | Non-Aboriginal | Aboriginal | Non-Aboriginal |
| 1979 | 462              | 352            | 199        | 300            |
| 1980 | 424              | 318            | 240        | 184            |
| 1982 | 363              | 214            | 285        | 209            |
| 1983 | 406              | 200            | 367        | 171            |
| 1984 | 642              | 287            | 445        | 250            |
| 1985 | 494              | 278            | 449        | 313            |
| 1986 | 482              | 208            | 430        | 179            |
| 1987 | 724              | 312            | 548        | 366            |
| 1988 | 618              | 271            | 569        | 204            |

Queensland

The overall hospital admission rate for disorders of the eye (ICD codes 360-379) was examined. The rate for Queensland Aboriginal and Torres Strait Islander peoples of 530 admissions per 100,000 population was slightly higher than the rate of 400 per 100,000 for the total Queensland population. Marked regional variation was seen. The rate was 30 per 100,000 in Mackay region and 700 per 100,000 in the North region.

South Australia

In South Australia, admission rates for eye conditions for those living in Adelaide, were lower for Aboriginal people than non-Aboriginal people. The rates for those living in country areas were similar (Table 8.3).

Table 8.3 Age-standardised public and private hospital admission rates for eye conditions, South Australia, 1991-1994

<table>
<thead>
<tr>
<th>Population / Region</th>
<th>Admission rate per 100,000</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adelaide</td>
</tr>
<tr>
<td>Aboriginal people</td>
<td>319</td>
</tr>
<tr>
<td>Other South Australians</td>
<td>417</td>
</tr>
</tbody>
</table>

Western Australia

In 1993, Western Australian Aboriginal people were admitted to hospital for conditions of the eye and adnexa at a rate of 805 per 100,000, compared to 509 per 100,000 for Western Australian non-Aboriginal people. A total of 83 cataract operations in Aboriginal people were recorded in Western Australia in 1993. The crude rate of cataract surgery was 160 and 196 per 100,000 for Aboriginal males and females respectively compared to 284 and 430 per 100,000 for non-Aboriginal males and females. In 1996 a total of 7241 cataract operations were performed on non-Aboriginal people compared with 90 on Aboriginal people; 10 of these were performed in Perth, 17 in the Pilbara and 40 in the Kimberleys (the Western Australia Department of Health).

Victoria

In 1995/96, only 25 Aboriginal males and 41 Aboriginal females were listed as being admitted to any Victorian hospital (public or private) for cataract surgery. This number is too small to permit any meaningful analyses, although this rate was not significantly different from that for all Victorians after aged-standardisation (the Victorian Department of Human Services).

Age-pattern of Admissions

Information from Western Australia and South Australia show that the difference between Aboriginal and non-Aboriginal admission rates is greatest among young and middle-aged adults (Table 8.4). The age-specific rate ratios are highest in the 30-39 years and 40-49 years age groups. The age-specific rate ratio is the Aboriginal admission rate divided by the non-Aboriginal rate for the specific age group.

Table 8.4 Age-specific rate ratios for eye conditions leading to hospitalisation

<table>
<thead>
<tr>
<th>Age group</th>
<th>Western Australia (1993)</th>
<th>South Australia (1991-94)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adelaide</td>
<td>Country</td>
</tr>
<tr>
<td>0-4</td>
<td>0.4</td>
<td></td>
</tr>
<tr>
<td>5-9</td>
<td>0.5</td>
<td></td>
</tr>
<tr>
<td>10-14</td>
<td>0.4</td>
<td></td>
</tr>
<tr>
<td>15-19</td>
<td>2.7</td>
<td></td>
</tr>
<tr>
<td>20-29</td>
<td>2.2</td>
<td></td>
</tr>
<tr>
<td>30-39</td>
<td>2.0</td>
<td></td>
</tr>
<tr>
<td>40-49</td>
<td>3.1</td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>3.4</td>
<td></td>
</tr>
<tr>
<td>60-69</td>
<td>2.0</td>
<td></td>
</tr>
<tr>
<td>70-79</td>
<td>0.9</td>
<td></td>
</tr>
<tr>
<td>80+</td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>All ages</td>
<td>1.6</td>
<td></td>
</tr>
</tbody>
</table>
It is not possible to discern from the available data the reasons for the much higher admission rates for Aboriginal than non-Aboriginal people in these age groups, although admissions in the younger age groups could be due to admissions for traumatic eye conditions and/or retinal laser photocoagulation and the relatively early onset of cataract.

CHAPTER NINE

ECONOMIC COST OF EYE DISEASE

Summary

Blindness has significant and definable costs to Governments as well as significant but less quantifiable costs to the individual and to the community. Interventions that relieve or prevent blindness from cataract, diabetic retinopathy or trachoma have been shown to be highly cost-effective. There can be no grounds, either economic or moral, not to address the problems of eye disease in Aboriginal and Torres Strait Islander peoples.

Blindness

Blindness has significant cost in both financial terms and social terms, to the individual, the community and the government.

A recent paper on the direct costs associated with blindness estimated an annual cost of $20,000 for a married Australian with diabetic retinopathy who had one child. For an older Australian, blind with cataract, the annual cost was $13,000. These estimates included costs associated with the Disability Support Pension or Age Blind Pension and additional benefits and subsidies that are entitlements to the holders of these pensions. However, they did not include the annual concession card benefits. Nor did they include any allowance for the loss of wages or productivity or the personal or societal costs of blindness.

Moreover, people who are visually impaired regardless of cause, have an increased risk of death. The increased overall risk of death among the blind was 1.45% in the USA and 2.5 times higher for blind males and 3.8 times higher for blind females with onchocerciasis in West Africa.

A prospective, population-based study in Tanzania found mortality rates for blind people aged between 40 and 79 years were 3.3 times higher than for age- and village-matched controls. These data are quite relevant to Australia as the conditions in these central Tanzanian villages are strikingly similar to many...
Australian outback communities and trachoma and cataract were the two leading causes of blindness in Tanzania as they are in Australia.

**Cataract**

The World Bank Report on Investing in Health (1993) found cataract removal and the management of the complications of diabetes to be highly cost-effective health interventions\(^\text{a}\). It referred to reports that cataract surgery cost US$20-US$40 per disability adjusted life year (DALY) saved\(^\text{a}\). This compares to US$2,000 for the oral treatment of hypertension, and US$30,000 for the management of unstable angina or acute myocardial infarction.

A recent cost effectiveness study for cataract surgery in Nepal, found that cataract surgery was one of the most cost-effective of public health interventions even under the most pessimistic set of assumptions\(^\text{a}\). The estimated mortality rates of those who received surgery and of those who did not, were among the variables that most influenced the cost.

**Diabetes**

A number of studies have examined and confirmed the cost-effectiveness of early intervention and treatment of diabetic retinopathy. These studies have been reviewed recently in the NHMRC Clinical Practice Guidelines for the Management of Diabetic Retinopathy\(^\text{b}\). Included in this document are estimates of the significant potential savings to the government that can be achieved by regularly screening all Australians with diabetes.

An epidemiology-based model network simulation program was used. It showed progressive cost savings with increasing compliance to the recommended screening. The maximum savings were achieved when 80% compliance had been reached. This saved some $14 million per year. This analysis used information for the general community and was not specific to the Aboriginal and Torres Strait Islander community.

**Trachoma**

The cost-effectiveness and cost utility of preventing visual impairment from trachoma were recently assessed for the Trachoma Control Program in Burma that ran from 1964 to 1993\(^\text{c}\). The impact of the program on the prevalence of trachoma blindness was used to calculate years of life saved by averting premature mortality and visual handicap. Both measures contribute to the calculation of a single measure of utility referred to as Handicap Adjusted Life Years (HALY).

The study showed dramatic improvements in the cost-utility as the program evolved from implementation to maintenance. The implementation phase involved concentrated attacks and vertical control efforts to combat the high prevalence of trachoma and trachomatous blindness. As the prevalence of trachoma and its complications decreased there was a shift to consolidation and maintenance activities that were more community based.

The overall cost-utility of the Trachoma Control Program was $4 per HALY averted. The cost-utility was $3 per HALY for non-surgical interventions such as antibiotic treatment and community education, compared to $10 for the surgical treatment of trichiasis. Although both types of intervention have a very good cost-utility, these findings confirm that prevention (non-surgical intervention) was far more effective than cure (surgical intervention).
CHAPTER TEN

ENVIRONMENTAL HEALTH ISSUES IN REMOTE AND RURAL ABORIGINAL COMMUNITIES

Summary

The environment plays a key role in the maintenance of health and in eye health it is particularly relevant for the persistence of trachoma. Good environmental health requires the provision of functioning resources that are necessary for healthy living — health hardware. Poor design, poor supervision and construction faults are responsible for many initial problems with health hardware. However, the key to healthy living is the long term provision of planned and funded maintenance to keep health hardware functioning. Sound maintenance programs are extraordinarily cost-effective and provide both an improved environment and a healthier community. These proven initiatives should be broadened to encompass all rural and remote Aboriginal and Torres Strait Islander communities.

Introduction

Some may say that a people cannot remain healthy without access to knowledge, and others say that one cannot have a healthy body in an unhealthy environment. It is clear that the environment plays a major role in the maintenance of health. Nowhere is this more obvious than in Aboriginal health. One of the most striking associations between a poor environment and poor health is trachoma.

Over the years, many have drawn attention to the poor environmental health, particularly the poor housing in many, if not most, Aboriginal communities. The NIEHP made four specific recommendations about environmental health concerning housing, water supply, waste disposal and food storage. Although much has been tried and written about environmental health issues, no one has followed the systematic and detailed approach used by those associated with Health Habitat in their work with the Nganampa Health Council. The following material was
supplied by Dr. Paul Torzillo who outlines this work on health infrastructure, its
design, construction and maintenance.

Assessment of Health Hardware

In 1986 Nganampa Health Council in conjunction with the South Australian Health
Commission initiated a review of environmental health issues on the Anangu
Pitjantjatjara Land. This project was called Uwankara Palyanyku Kanyintjaku
(UPK).

This survey had four key components:

1. A list of nine healthy living practices was developed and prioritised in order of
the likely impact on health status of Aboriginal people in the region. The
practices were:
   - washing people
   - washing clothes/bedding
   - waste removal
   - reduction in crowding
   - nutrition
   - separation of dogs and children
   - dust control
   - temperature control
   - reduction in trauma

The most important items in this list were those which involved the washing of
people and the immediate living environment. “Water in” and “waste out”, were
the major priorities. The project then outlined the evidence that related
improvements in these areas to improvements in health status. The major benefit
of this work was to be the reduction of infectious disease in Aboriginal children.

2. The study team then undertook a detailed study of the living environment of
Aboriginal family groups. This included a detailed study of the living
environment in camps and houses in addition to surveying major community
infrastructure such as power and water supply. In particular the focus was on
functioning “health hardware”, that is, those resources necessary to carry out
healthy living practices.

3. During the survey process minor items were repaired, more major failures were
documented and passed on to local staff. Immediately after each survey the
status of the community was discussed at a full community meeting.

4. A series of recommendations about design, construction, supervision and
maintenance of infrastructure and health hardware were made.

A number of issues emerged from this work:

(a) The focus of interest was on the availability of functioning health hardware.
The survey did not focus on how things looked, but rather on how they
worked. Community tidiness or the existence of hard waste such as car
bodies strewn around communities was not seen as a priority in terms of
health impact. Assessment focused on testing health hardware rather than on
looking at whether houses appeared neat and tidy.

(b) Housing and infrastructure programs were assessed on their ability to
deliver functioning health hardware. For example, new housing, prior to
occupation, had drainpipes blocked with concrete so that the housing was
unable to ever function as a healthy environment or as health hardware.

(c) Maintenance was established as a key issue. Previously maintenance had not
been planned, funded, or conducted. For health hardware to continue to
function, maintenance was essential. When maintenance was lacking,
housing and infrastructure became a health hazard rather than a health
resource. Houses without maintenance became areas of high risk for
infection because of their failure to deliver water for washing or failure to
remove waste.

This project then assessed whether it was possible to deliver affordable and
sustainable maintenance.

Provision of Maintenance

The Housing for Health Project at Pippytyjara started in 1992 and included an
initial detailed assessment of all health hardware and maintenance requirements.
This assessment was repeated regularly over a 12 month period. Total community
maintenance requirements were documented and all necessary maintenance
performed.

New shower, laundry and toilet areas for houses had been built in Pippytyjara.
These new “wet areas” were designed to reduce the most common failures
previously observed. Improved levels of supervision in the construction process
also had a major impact on the final performance of the wet areas.

The Pippytyjara study clearly documented a major improvement in the level of
functioning health hardware. In 1986, the level of function of housing and
infrastructure to deliver cold water, hot water, waste disposal, safe power and other
core components of health hardware was less than 50%. In 1992 the level of
function was up to 90%. This documented that improvement in design and
supervision could improve the level of functioning health hardware in the
community.
Water use in general, and the amount of water used by individual items of health hardware was assessed in detail. Water meters were used on the main community water supply, on branch lines within the community, on house supply pipes and on individual items such as showers, toilets, washing machines and hot water systems. This work showed that if health hardware were functioning it was constantly used. This clearly contradicted a major myth in Aboriginal environmental health that Aboriginal people in remote communities will not use health hardware facilities if they are available.

The second major myth to be refuted was the notion that vandalism is the major cause of house failure. In fact in the one year study period only one minor incident of vandalism occurred. Vandalism played no significant role at all in house or health hardware failure. Subsequent experience has confirmed that vandalism occurs after health hardware has failed and houses have stopped being used as living places.

The maintenance program proved both achievable and affordable. Most maintenance requirements were met by local community staff using simple equipment. The average cost of essential health hardware maintenance per house for the year was approximately $500, far cheaper than most had predicted.

The major maintenance cost was the repair of poor initial construction, particularly the underground drainage works. These problems were not caused by overuse or misuse by occupants. They could have been overcome with more rigorous supervision of the building process and in particular the installation of drainage works.

Since 1992, the process utilised at Pipalyatjara has been modified and used to improve maintenance for approximately 250 houses in a number of other communities. The amount of functioning health hardware in these communities has been approximately doubled. Increasing benefits are shown by sustained projects. In Pipalyatjara, once the poor initial construction faults were fixed, plumbing maintenance costs fell dramatically in the second and third year of a sustained maintenance program.

In 1996 a similar project at Pormpuraaw was started in conjunction with Apunipima Health Council, the Centre for Appropriate Technology (Cairns) and the Pormpuraaw Community Council. This provided an opportunity to see how many of the lessons from central Australia were generic and could be applied in a community that was very different in location, geography, climate, size and access to alcohol.

The initial survey in this community of 530 people, involved approximately 100 houses. The key problems were again found to be of poor construction of in-ground work and the lack of a planned, funded and sustained maintenance program.

This project has also highlighted the major difficulties in effecting change in remote communities. The problem is not because of unanswered medical research questions, but predominantly because of the failure of service agencies to deliver what should be considered standard professional service and performance.

**Recommended Practices**

It is important to ask the question, “why has there been so little improvement in the living environment in many remote Aboriginal communities?” It has not been because of the failure to acknowledge the principle importance of Aboriginal environmental health. Government statements acknowledging this go back for 25 years. The problem has been in moving from rhetoric to the detailed action necessary for change to occur.

The following are the key issues:

1. The prime objective of housing and infrastructure programs should focus on the delivery of functioning health hardware. For any mother to wash her child, there is a critical chain that links the community bore, windmill, community supply pipe, house pipe, wet area connection, tap, tub, plug, drain pipe and the surrounding area being free of waste. If any of these fail than it is likely that the mother will not be able to wash that child.

   Focusing on delivering only part of this chain will not result in improvement in healthy living practices.

2. In general, remote communities have suffered because the usual standards of service delivery, trade work and professional advice either has not been required or not delivered. This has led to gross inadequacies in planning, design specifications, construction supervision and ongoing maintenance.

3. Product development and the assessment of key hardware components such as washing machines, hot water systems and stoves are research priorities.

4. Supervision is essential during the planning, tendering and construction of all infrastructure and building projects. The difficulty of building in remote areas needs to be acknowledged.

5. Infrastructure and building program funding must include a planned and funded mechanism for ongoing maintenance of essential health hardware.

6. Training of Aboriginal environmental health workers and initiating housing management programs will not overcome poor housing conditions. Unless a baseline of reasonable functioning housing stock can be achieved, environmental health workers are unlikely to be able to change the health status.
7. There must be an acceptance that change in communities is incremental even in the best setting. Massive changes to practice and performance will not occur overnight. This will require the sustained and diligent provision and management of housing and infrastructure.

8. However, there is a critical mass in environmental improvement. The majority of health hardware must function, for almost all the time, for the majority of the population to achieve a substantial health benefit.

RECOMMENDATION 15
The three tiers of government must make concerted and sustained improvements in housing, water supply, waste disposal and other important aspects of the environment in Aboriginal and Torres Strait Islander communities that ensure the provision of functional health hardware. Resources should also be allocated and provided for planned maintenance. Attention must focus on the regional delivery of housing and the responsibility of local government to provide infrastructure.

CHAPTER ELEVEN

A NATIONAL INFORMATION NETWORK

Summary
The proposed delivery of eye services on a regional basis requires access to information about the nature and delivery of eye services and feedback about progress made in the region and service targets that have been reached.

This resource service and co-ordination is best delivered by a National Information Network that provides current information about best clinical practice for the delivery of eye care, answers specific questions as they arise, and collects and collates data to be used for the documentation of program achievements and to assist in the planning of eye care services.

It is important that the information to be gathered is based on performance indicators and these must be built into core accountability mechanisms for Commonwealth and State/Territory Governments, the professions and Aboriginal and mainstream health service providers. Health service funding should be linked to performance indicators.

Introduction
This report recommends that eye care should be delivered as a regional service. In rural and remote areas, ophthalmic services should be provided by a visiting ophthalmologist who will bulkbill Medicare for services and who will use the overhead-free infrastructure provided by the health services in the region.

The regional centre will be visited on every trip. Some surrounding communities also will be visited on each trip so that each community is visited at least once per year. Cataract surgery and laser treatment will be provided during regular visits to the regional centre, although laser treatment might also be performed in the local communities. Optometry services will be provided by similar means and the optometry visits will be co-ordinated with and complement the ophthalmic visits.
In urban areas links need to be made and strengthened between primary health services and the existing specialist and hospital services.

In both rural and remote areas and in urban areas, the regional model depends on strong links between the visiting specialist on the one hand and the primary health services and the regional hospital on the other. This linkage is best provided by designated AHW with a liaison responsibility.

The provision of primary eye care will be strengthened by the close liaison with the visiting ophthalmologist and by the development and dissemination of clinical practice guidelines and in-service training.

Specialist ophthalmic services also will be strengthened and streamlined by the use of clinical practice guidelines that will lead to improvements in cost-effectiveness and service outcomes.

Co-ordinated and well-planned screening programs and appropriate follow-up for conditions such as diabetes, and trachoma in endemic areas, are important components of primary health care. Such screening would be fully integrated into a comprehensive primary health care program. The screening for diabetic eye disease should use computer-based patient management system and non-mydriatic retinal cameras operated by an AHW or a nurse.

These regional programs will lead to substantive improvements in the delivery of eye care to Aboriginal and Torres Strait Islander peoples and to real improvements in their eye health. However, the achievement of this vision will need a significant input of technical information on current best practice and a distribution network for information about new developments.

The proposed model of regional delivery of eye services, is in line with the overall devolution of health service delivery from the state to the regional level. However, this devolution has led to the loss of accountability at both the state and national levels. The implementation of the recommendations of this report must include monitoring arrangements to ensure accountability.

At a service level, data from different centres should be collected and collated to document the achievement of service goals and to provide feedback on progress and future needs.

**A National Information Network**

An appropriately structured National Information Network is recommended to meet many of these requirements. The National Information Network should be targeted at all health professionals who deliver eye care to Aboriginal and Torres Strait Islander peoples. It should be seen as a resource centre to answer questions and provide helpful information about the delivery of eye care to Aboriginal and Torres Strait Islander peoples. It should act as a link or clearinghouse between health services in various regions and specialist bodies.

The host organisation should be one standing in health and education and should have established expertise in the following areas: ophthalmology, Aboriginal and Torres Strait Islander health, teaching and training, data analysis and dissemination of information. It could be located within the RACO, in a University Department or elsewhere.

The National Information Network will have three roles: the distribution and dissemination of technical information on eye health; the collection and collation of service data on eye care; and the monitoring and reporting on eye health care delivery.

**Distribution of Information**

Information about current best practice will be needed by those medical officers, nurses and AHW who provide primary eye care, by those developing training programs and by those ophthalmologists and optometrists who provide specialist care. Similar information will be needed by health service planners at local, regional, state and national levels.

The responsibilities of the National Information Network for the distribution of information will include the following:

- the development and distribution of clinical practice guidelines for use in the primary health care sector in consultation with the appropriate specialists and organisations;
- the provision of material for the regional development of in-service modules for the training of registered nurses and AHW;
- the holding of workshops, for example: on the management of cataract, trachoma or diabetes; on the establishment of regional ophthalmic or optometric services; or for training of AHW in primary eye care;
- in conjunction with the RACO, the development and distribution of clinical practice guidelines for ophthalmologists for the provision of eye care services to Aboriginal and Torres Strait Islander communities including cross-cultural issues;
- the monitoring of the implementation of the various clinical practice guidelines;
- the preparation and release of reports based on data and information about eye health collected at a service, state or national level;
- the provision of technical advice;
- the strengthening of links with established organisations such as the WHO or the RACO and the dissemination of information from these bodies to services in Aboriginal and Torres Strait Islander communities; and
• the distribution of information on changes in therapy and new advances in eye care to rural and remote practitioners.

Data Collection

The ongoing planning, prioritisation and provision of eye care services makes it essential that a minimum national database exists. It is quite extraordinary that in 1997 there are so few existing data on Aboriginal eye health and that they are of such poor quality and so poorly collated. This is even more so given the explicit recommendation by the NTEHP in 1980 and the repeated calls from the meetings of the National Trachoma and Eye Health Conference.

In every State and Territory, state and community-controlled health organisation representatives expressed their need for more and better quality data for their health service planning. Some state trachoma committees reported that they had a 10 to 15 years accumulation of field information that had not been analysed or collated. Other people stressed the need for surgical audits.

Surprisingly, a number of groups, including community controlled organisations, requested further vertical surveys specifically looking at eye disease. The findings of the current review suggest that this is neither warranted nor desirable. However, the request is a further manifestation of the need for accurate information and data.

The information may also contribute to the surveillance being provided by the ABHW/ABS Unit in Aboriginal and Torres Strait Islander Health and to Aboriginal Health Performance Information and Targets under the Australian Health Ministers’ Council.

Monitoring and Reporting

Information collected by the National Information Network should be processed and disseminated to reinforce regional successes. It can highlight regions where programs are working effectively so that they can be used as benchmarks and others can learn from their successful methods.

However, during the consultations associated with the review, health professionals at a number of levels repeatedly stressed the need for real accountability. This is to ensure that eye health is not overlooked and that health service providers meet key performance targets. The linkage of performance information to funding will lead to accountability.

The National Information Network can assist in this process. The Network should assist in the development of relevant and realistic performance indicators and information to be collected at local and regional levels. Most importantly, the Network can monitor performance, report regularly on achievements, and recommend areas where further improvement or remedial action is required. In such cases, the Network should assist and provide expertise and advice to the service and, where necessary, assist with the training of staff. The Network may also be able to negotiate assistance from other professional bodies.

The public reporting of agreed performance information is a vital accountability mechanism to ensure problem areas are identified quickly and concerted action taken. It is important for the successful ongoing delivery of eye services that accountability mechanisms are in place and that health ministers are informed about the performance of services in their jurisdictions on an annual basis.

RECOMMENDATION 16

The Commonwealth Government funds the establishment of a National Information Network to undertake the tasks that have been identified in this report. The Network would be a low-cost, small-scale organisation, possibly with a secretariat working on contract.

RECOMMENDATION 17

The National Information Network should report on a regular basis to Health Ministers on the performance of health providers of eye health care. This report should be based on information that is gathered by the Network and include, at a minimum, the following performance indicators:
• the number of pairs of glasses provided;
• the number of cataract operations performed;
• the number of people on the waiting list for cataract surgery, and the time that they have been on the waiting list;
• the percentage of people with diabetes who have an annual eye examination;
• the number of people with diabetes for whom treatment was recommended and the number who were actually treated;
• the status of trachoma on a community basis including the prevalence of trachoma in children aged five to nine years;
• the number of people treated with azithromycin; and
• the prevalence of trichiasis in women over 40 years.

These performance indicators should be built into the framework of performance indicators being developed through Australian Health Ministers’ Advisory Committee to report on Australia’s national and jurisdictional performance in Aboriginal health.
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APPENDIX I:

WRITTEN SUBMISSIONS TO THE REVIEW

Written Submissions to the Review
1. Dr Wilfred Win Law, Senior Specialist Ophthalmologist, Alice Springs Hospital
2. Biripi Aboriginal Corporation Medical Centre,
3. Walgett Aboriginal Medical Service Co-operative Ltd
4. Royal Australian College of General Practitioners
5. Royal Australian College of Ophthalmologists
6. Danila Dilba Aboriginal Medical Services, Darwin
7. Dr Paul Beaumont
8. Queensland University of Technology, Faculty of Health
9. Pika Wiya Health Service, Port Augusta
10. Fred Hollows Foundation
11. Dr Peter Hall
12. Dr J.E.K. Galbraith
13. Dr Jamie La Nauze
14. Central Australia Rural Health Training Unit, c/- Institute of Aboriginal Development, Alice Springs, NT
15. Dr Gary R. Lillicrap
16. Lions Eye Institute, Perth, WA
17. Dr David Moran
18. Armidale and District Services Incorporated Aboriginal Medical Service, NSW
19. Northern Regional Health Authority, Mt Isa, Qld Health
20. Kimberley Aboriginal Medical Services' Council, Broome, WA
21. Professor Douglas J Coster, Flinders Medical Service, South Australia
22. Australian Defence Force
23. NT Eye Health Committee Inc Darwin, NT
24. Woolgoolga and Northern Beaches Medical Centre, NSW
25. Torres District, Queensland Department of Health
26. Council of Remote Area Nurses of Australia, Alice Springs, NT
27. Department of Community and Health Services, Tasmania
APPENDIX II:

ORGANISATIONS AND INDIVIDUALS CONTACTED BY THE REVIEW

State Health Authorities
Department of Community and Health Services Tasmania
Department of Health and Community Care, ACT
Health Department of Western Australia
Northern Territory Department of Health and Community Services
Queensland Department of Health
The Department of Human Services, Victoria
The New South Wales Health Department
The South Australian Health Commission

State and Territory-based Eye Health and Trachoma Programs
NT Aboriginal Eye Health Committee
Queensland Trachoma and Eye Health Program
South Australia Trachoma and Eye Health Program

Other Organisations
Albany Public Health Unit, WA
Alice Springs Hospital
Kalgoorlie Public Health Unit, WA
Kimberley Public Health Unit, WA
Lions Eye Institute, WA
Midwest Public Health Unit, WA
Pilbara Public Health Unit, WA
Ophthalmologists and Individual Researchers

Dr Anderson
Dr Beaumont
Dr Brian
Dr Cameron
Dr Cooper
Professor Coroneo
Professor Coster
Dr Dowse
Dr English
Dr Galbraith
Dr Glasson
Dr Graham
Dr Guest
Dr Hall
Dr Hazell
Dr Heine
Dr House
Dr Isaacs
Dr Jaross
Dr Karunarathne
Dr Kearney
Dr Keefe
Dr La Nauze
Dr Laming
Dr Lenton
Dr Lillicrap
Dr Loane
Dr Mahmood
Dr Maloof
Dr McAllister
Dr Minogue
Dr Moran
Dr Newland
Dr Rawson
Dr Stanton
Dr Torzillo
Dr Van Buynder
Dr Wallace
Dr Welborn
Dr Win Law

Aboriginal Controlled Health Services

Aboriginal & Islander Community Health Service (AICHS) Ipswich QLD
Aboriginal & Islander Community Health Service (AICHS) Wooloongabba QLD
Aboriginal Corporation Barkly Highway Mount Isa QLD
Aboriginal Health Council of SA Adelaide SA
Aboriginal Medical Service Co-Operative Limited Reidfern NSW
Aboriginal Medical Service of WA Inc East Perth WA
Aherrenge Association Inc Alice Springs NT
Alpururulam Community Alice Springs NT
Ampilatwatja Health Centre Alice Springs NT
Angrurru Community Government Council Inc Aluungula NT
Anjinginyi Congress Aboriginal Health Service Tennant Creek NT
Apunipima Health Council Cairns QLD
Armidale & Districts Services Inc Armidale NSW
ATSI Health Worker Education Program Aboriginal Corporation Cairns QLD
Awabakal Newcastle Aboriginal Co-operative Ltd Islington NSW
Ballarat Aboriginal Health Service Ballarat VIC
Bay of Isles Aboriginal Community Inc Esperance WA
Bega Gamibirri Nggu Health Service Kalgoorlie WA
Benelongs Haven Ltd Kinchela Creek NSW
Biripi Aboriginal Corporation Medical Centre Taree NSW
Bloodwood Tree Aboriginal Inc. South Hedland WA
Bourke Aboriginal Health Service Bourke NSW
Brewarrina Aboriginal Health Service Brewarrina NSW
Broome Regional Aboriginal Medical Service (BRAMS) Broome WA
Bulgarr Nguru Health Service Co-Operative Ltd Grafton NSW
Bundjalung Tribal Society Limited Lismore NSW
Bundybunna Aboriginal Corporation Mullawa WA
Carnarvon Aboriginal Medical Services (CAMS) Carnarvon WA
Ceduna Koonibba Aboriginal Health Service Ceduna SA
Central Australian Aboriginal Congress Inc. (CAAC) Alice Springs NT
Central Gippsland Aboriginal Health & Housing Co-Op. Ltd Morwell VIC
Charleville & West Areas Aboriginal & Torres Strait Islander Co-operative for Health Charleville QLD
Coomealla Health Aboriginal Corporation Dareton NSW
Coranderrk Koori Co-op Healesville VIC
Corporation of the City of Port Augusta Port Augusta SA
Daguragu Community Government Council Katherine NT
Dandarung & District Aboriginal Co-operative Society Ltd. Dandenong VIC
Daruk Aboriginal Medical Service Co-Operative Ltd Mt Druitt NSW
Doomooc Self-healing Aboriginal Corporation Nowra NSW
Durkibha Community Council Incorporated Goolbudalla SA
Durri Aboriginal Corporation Medical Service Kempsey NSW
East Kimberley Aboriginal Medical Service (EKAMS) Kununurra WA
Eastern Zone House Aboriginal Corporation Matraville NSW
Emnareelk Association Inc Broadmeadows VIC
Flinders Island Aboriginal Assoc Inc Flinders Island TAS
Gallang Place Aboriginal & Torres Strait Islander Corporation Wooloongabba QLD
Gagupiyak Community Inc Gagupiyak NT
Gehgre Aboriginal & Torres Strait Islanders Corporation Gladstone QLD
Geraldton Regional Aboriginal Medical Service (GRAMS) Geraldton WA
Gippsland & East Gippsland Aboriginal Co-op Bairnsdale VIC
Gooburu Health Advancement Aboriginal Corporation Mobile Dental Service Toowoomba QLD
Goolum Goolum Aboriginal Co-operative Ltd Horsham VIC
Goondir Aboriginal and Torres Strait Islanders Corporation for Health Services Dalby QLD
Gumariji Association Nhulunbuy NT
Gumbi Gumbi Aboriginal & Torres Strait Islanders Corporation Rockhampton QLD
Gunditjimara Aboriginal Co-operative Wyndham VIC
### APPENDIX III:

**SCHEDULE OF VISITS**

<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
<th>Contact Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>24th January</td>
<td>Melbourne, Victoria</td>
<td>Mr Brian Corcoran (Chair, H&amp;FS), Mr David Murray Smith (DHS), Mr Ian Hamm (DHS), Mr Troy Austin (ATSC), Mr Alan Brown (VACCHO), Ms Lois Atkinson (H&amp;FS),</td>
</tr>
<tr>
<td>24 January</td>
<td>Melbourne, Victoria</td>
<td>VAHS: Dr Steve Whiteside, Dr Cathy Adami, Ms Edna Brown</td>
</tr>
<tr>
<td>31 January</td>
<td>Melbourne, Victoria</td>
<td>Victorian's Department of Human Services, Mr Ron Jones, Mr Ian Hamm, Johanna Cook</td>
</tr>
<tr>
<td>31 January</td>
<td>Melbourne, Victoria</td>
<td>VACCHO meeting</td>
</tr>
<tr>
<td>6 February</td>
<td>Thursday Island, Queensland</td>
<td>Dr Peter Holt, Dr Garry Brian, Mr Phillip Mills Mrs Grace Fisher, Dr Elehana Fa'afou</td>
</tr>
<tr>
<td>7 February</td>
<td>Thursday Island, Queensland</td>
<td>Ms Freda Filewood, Mr Ross Naylor</td>
</tr>
<tr>
<td>10th February</td>
<td>Katherine, Northern Territory</td>
<td>Mr Wes Miller, Administrator, Wurlu Wurlingan Aboriginal Medical Services</td>
</tr>
<tr>
<td>10th February</td>
<td>Katherine, Northern Territory</td>
<td>Sr Marie Hughes (Director of Nursing), Sr Kelly Humphries (Enrolled Nurse), Dr Watson (Medical Director), Katherine Hospital</td>
</tr>
<tr>
<td>10th February</td>
<td>Katherine, Northern Territory</td>
<td>Mr George Kruger, Senior Aboriginal Health Worker, Health Promotion Unit, Katherine Region, Territory Health Services</td>
</tr>
<tr>
<td>11th February</td>
<td>Jilkminggan, Northern Territory</td>
<td>Sr Mike Mizen and Sr Beth Morgan Jilkminggan Health Service</td>
</tr>
<tr>
<td>12th February</td>
<td>Barunga, Northern Territory</td>
<td>Sr Jim Collins, Barunga Health Service Dr Andrew Bell, DMO, Katherine Region Territory Health Services</td>
</tr>
<tr>
<td>12th February</td>
<td>Beswick, Northern Territory</td>
<td>Sr Charmain Taylor and Ms Nancy Weston (Senior Aboriginal Health Worker) Beswick Health Service</td>
</tr>
</tbody>
</table>
13th February
Tennant Creek, Northern Territory
Dr Justin and Dr Robyn Hughes Anyinginyi Health Service

13th February
Tennant Creek, Northern Territory
Dr Tim Baker (DMO) and the Remote Area Health Team Tennant Creek Hospital

14th February
Darwin, Northern Territory
NT Eye Health Committee

14th February
Darwin, Northern Territory
AMSANT representatives

14th February
Darwin, Northern Territory
Dr John Mathews, Dr Barbara Paterson, Dr Bart Currie, Dr Andrew Laming, Dr Tania Wallace, Menzies School of Health and Medical Research

14th February
Darwin, Northern Territory
Mr Brian Lynch, District Manager of Darwin Remote, THS, Mr Graham Symons, Deputy Secretary, THS

19th February
Port Augusta, South Australia
SA Aboriginal Health Council

23rd February
Perth, Western Australia
Dr Peter Graham, Dr Ian McAllister

24th February
Newman, Western Australia
Ms Maple Merrit (Senior Aboriginal Health Worker) and Mr Kevin Dorizzi (Aboriginal Health Worker), Newman Community Health Service

24th February
Newman, Western Australia
Dr Green, GP, Newman

24th February
Jigalang, Western Australia
Mr John Siedlowski (Administrator), Dr Toby McLear (Medical Director), Sr Jo Brody, Puntukurra Aboriginal Medical Service

25th February
Port Hedland, Western Australia
Sr Iacqui Gerard, Ms Kater Papertalk (Aboriginal Liaison Officer) and Ms Mae Eckermann (Senior Aboriginal Health Worker), Port Hedland Hospital

25th February
Port Hedland, Western Australia
Dr Moira McKinnon (Director), Dr Mandy Sear (Head, Communicable Diseases Unit), Sr Lyn Hamilton (diabetes educator), Sr Sally Connolly (Senior Public Health Nurse) Pilbara Public Health Unit

25th February
Roebourne, Western Australia
Sr Dan Lodge (Education Officer), Sr Carole Lodge (Family Support Worker), Sharon Dorschov (Co-ordinator, domestic violence) Mawankara Aboriginal Medical Service, Dr Warren Young, GP

26th February
Broome, Western Australia
Mr Henry Councillor, Director, Broome Aboriginal Medical Service, Dr Richard Murray Medical Director, Kimberley Aboriginal Medical Service Council

26th February
Broome, Western Australia
Mr Eni Halbert, AIG General Manager, Kimberley Health Service, Dr Mark Dawson, Medical Director, Broome Hospital, Dr Sarah Giles (Director), Sr Eleanor Platt, Sr Lauren Hogan, Kimberley Public Health Unit, Mr Kevin Cox, Office for Aboriginal Health, WA Health, Sr Helen McArthur

27th February
Kununurra, Western Australia
Mr David Miller (Operations Manager), Ms Amy Trust (Senior Aboriginal Health Worker), Ms Mylce Ward (Senior Aboriginal Health Worker) Dr Anne Ward (DMO), Dr Wally McEvilly (DMO), Kununurra Hospital

27th February
Kununurra, Western Australia
Dr Mary Price, Dr Sue Matalca, Ms Stephanie Lockyer (Senior AHW), Dr Stephen Leffmann, Sr Pepita Papal, East Kimberley Aboriginal Medical Service

28 February
Darwin, Northern Territory
Mr Graham Symons, Dr Vino, Peter Plummer, Dr Devensons, THS

28 February
Darwin, Northern Territory
Dr Mahmood, Dr Andrew Laming

5th March
Wilcannia, New South Wales
Dr Hugh Bourke, Public Health Unit, Far West Ward Health Service, Mr William Bates, Chair, Far West Ward Aboriginal Health Service, Dr Bruce Sanderson, Medical Director, Royal Flying Doctors’ Service, Dr Peta Robertson, Director, Wilcannia Hospital
<table>
<thead>
<tr>
<th>Date</th>
<th>Location</th>
<th>Speaker/Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>5th March</td>
<td>Bourke, New South Wales</td>
<td>Dr Heather Dalgety (GP), Dr Lawrence Berold (GP), Dr Martin Weatherhead (GP)</td>
</tr>
<tr>
<td>5th March</td>
<td>Bourke, New South Wales</td>
<td>Ms Judy Johnson (Director) Sr Wendy Fletcher, Bourke AMS, St Joanna Barton, NSW Community Health, Bourke.</td>
</tr>
<tr>
<td>6th March</td>
<td>Sydney, New South Wales</td>
<td>Aboriginal Health Resource Committee/NSW Department of Health Partnership meeting</td>
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<tr>
<td>6th March</td>
<td>Sydney, New South Wales</td>
<td>Dr Paul Torzillo, Medical Director Ngarampa Health Service</td>
</tr>
<tr>
<td>7th March</td>
<td>Sydney, New South Wales</td>
<td>NSW Aboriginal Health Forum with representatives from the NSW Department of Health, Commonwealth Department of Health and Family Services, ATSIC, and Aboriginal Health Resource Committee</td>
</tr>
<tr>
<td>7th March</td>
<td>Sydney, New South Wales</td>
<td>Dr George Ruben (Chief Medical Officer) Mr Tim Agius (Director, Aboriginal Health), Dr Glen Close, Ms Helen Townsend NSW Department of Health</td>
</tr>
<tr>
<td>7th March</td>
<td>Sydney, New South Wales</td>
<td>Fr Frank Flynn</td>
</tr>
<tr>
<td>10th March</td>
<td>Brisbane, Queensland</td>
<td>Qld Aboriginal Health Partnership meeting with Representatives from QAIHF, ATSIC, Qld Department of Health and Commonwealth Department of Health and Family Services</td>
</tr>
<tr>
<td>10th March</td>
<td>Brisbane, Queensland</td>
<td>Qld Trachoma and Eye Health Committee</td>
</tr>
<tr>
<td>10th March</td>
<td>Brisbane, Queensland</td>
<td>Interim Qld Trachoma and Eye Health Committee</td>
</tr>
<tr>
<td>10th March</td>
<td>Brisbane, Queensland</td>
<td>Mr Sol Bellear (Director) and Ms Claire Runciman, Aboriginal and Islander Health Unit, Dr Ian Ring (Director) Epidemiology Mr Michael Hill and Ms Helen Havens Health Outcomes Unit Queensland Department of Health</td>
</tr>
<tr>
<td>17th March</td>
<td>Kawana, QLD</td>
<td>QAIHF membership</td>
</tr>
<tr>
<td>18th March</td>
<td>Hopevale, Queensland</td>
<td>Dr Jenny Wilson (DMO) Cooktown Hospital Sr Judy Radburn (Director) and Ms Joanne Bambie (AHW) Hopevale Community Health Service</td>
</tr>
<tr>
<td>18th March</td>
<td>Cooktown, Queensland</td>
<td>Sr Paul Stephenson, Director of Nursing, Cooktown Hospital</td>
</tr>
<tr>
<td>18th March</td>
<td>Cairns, Queensland</td>
<td>Dr Robyn McDermott, Tropical Public Health Unit, Queensland Department of Health Ms Barbara Flick Apunipima Cape York Health Council</td>
</tr>
<tr>
<td>19th March</td>
<td>Domadgee, Queensland</td>
<td>Dr Sarah Lithgoe (Medical Director) and Sr Robin Atwood (Director of Nursing) Domadgee Hospital</td>
</tr>
<tr>
<td>19th March</td>
<td>Domadgee, Queensland</td>
<td>Anne O’Keefe (Senior AHW) and Chris Toby (AHW) Domadgee Community Health</td>
</tr>
<tr>
<td>20th March</td>
<td>Perth, Western Australia</td>
<td>WAACCHO</td>
</tr>
<tr>
<td>20th March</td>
<td>Perth, Western Australia</td>
<td>Mr Shane Houston Director Office for Aboriginal Health WA Health</td>
</tr>
<tr>
<td>20th March</td>
<td>Perth, Western Australia</td>
<td>Dr Phil House, Ophthalmologist Perth, WA</td>
</tr>
<tr>
<td>20th March</td>
<td>Perth, Western Australia</td>
<td>Dr Dermot Roden, Ophthalmologist Perth, WA</td>
</tr>
<tr>
<td>21st March</td>
<td>Adelaide, South Australia</td>
<td>SA Trachoma and Eye Health Committee</td>
</tr>
<tr>
<td>21st March</td>
<td>Adelaide, South Australia</td>
<td>Professor Doug Coster, Flinders University, Mr Brian Dixon, Mr Chris Sheedy, South Australian Health Commission</td>
</tr>
<tr>
<td>24th March</td>
<td>Ceduna, South Australia</td>
<td>Dr Neville Carlier (Medical Director), Harriet Coleman (STD Education Officer), Gwen Miller (Director, AHW), Sr Val Puckridge Ceduna Aboriginal Medical Service</td>
</tr>
<tr>
<td>24th March</td>
<td>Yalata, South Australia</td>
<td>Sr Margaret Glass Yalata/Maralinga Aboriginal Medical Service</td>
</tr>
<tr>
<td>24th March</td>
<td>Adelaide, South Australia</td>
<td>Dr Henry Newland Department of Ophthalmology University of Adelaide</td>
</tr>
<tr>
<td>25th March</td>
<td>Aputula, Northern Territory</td>
<td>Sr Don Blackman Aputula Health Service</td>
</tr>
</tbody>
</table>
APPENDIX IV:

DATA COLLECTION METHODOLOGY

Sources of Information

The assessment of the current status of Aboriginal eye health was performed by Dr Neil Thomson. It has used data from a variety of sources. These have included published reports and articles; research studies; information from State and Territory health authorities; information from Aboriginal controlled health services; service level information from ophthalmologists, doctors, and optometrists; theses; opportunistic local surveys; prevalence surveys conducted during treatment programs; and anecdotal evidence from practitioners in the field. (Appendix II)

Broadly, two types of information have been utilised — information already available in the public domain and information provided in response to requests for collected data. The requests for material produced a mixed response — from some areas a wealth of collected data was provided and from others little or no information was received.

Most State and Territory health authorities expressed support for the review, but reported that they did not maintain special collections in the area. Few of the Aboriginal-controlled health services that responded to the request were able to provide useful information. The three State-based trachoma programs provided a variety of information, much of it service-related.

Quality, Comparability and Availability of Data

The quality and comparability of data varied greatly. Wherever possible, the data selected for inclusion are of a reasonable epidemiological standard, with emphasis being given to published reports, articles and research studies. Where this information has not been available (or current), other data sources or anecdotal evidence have been used. Much of the information provided had been collected at a service level, and often reflects access to services rather than actual population served. There are thus doubts about the denominator (population to which the cases relate) as well as the numerator (numbers of cases involved). This often makes accurate estimation of the prevalence of particular eye disorders difficult, at best.

26th March
Pitjantjatjara
Lands,
South Australia
Mr John Wilson (Health Services Co-ordinator),
Dr Kerry Jill, (General Practitioner)
Dr Claire Stainsbury and
Sr Leah Tapsicott (Amata Clinic) Nganampa Health Service

27th March
Alice Springs,
Northern Territory
Dr Win Law, Dr Andrew Foster-Massie
Department of Ophthalmology Alice Springs Hospital

27th March
Alice Springs,
Northern Territory
Dr John Boffia (Medical Director) and
Ms Chrissie George (Program Manager)
Central Australia Aboriginal Congress Inc

27th March
Alice Springs,
Northern Territory
Dr David Scrymgour, Menzies School of Health and Medical Research

27th March
Alice Springs,
Northern Territory
Dr Jim Thurlow, (Paediatric Department)
Dr Winlaw, and Dr Andrew Foster-Massie,
(Ophthalmology Department)
Dr Tim Baker (DMO, Barkley Region),
Ms Pat Field (Project Management)
Alice Springs Hospital

27th March
Alice Springs,
Northern Territory
Mandy Pusmuscans (CEO) CRANA

4th April
Melbourne
Victoria
Professor Barry Cole, Mr Michael Anjou,
Ms Heather Johnson

4th April
Shepparton
Victoria
Service
Ms Joyce Doyle, Paul Briggs, Josie Briggs,
Kay Briggs, Rumbulara Aboriginal Medical Service

28th April
Hobart,
Tasmania
Ms Debra Reid, Dr Jack Sparrow,
Mr Mark Davies: Tasmanian Department of Community and Health Services

28th April
Hobart, Tasmania
Ms Cheryl Mundy, AMS, Tasmanian Aboriginal Centre,
With regard to trachoma, children have been the main focus of many trachoma programs in recent years and, as a result, much less information has been collected about scarring and trichiasis.

Much of the data that were provided had been summarised in non-standard ways. This made it difficult to incorporate these data into a broader picture. There has been no standard method or form for data collection at either a state or the national level. A recording form was provided with the request for information (see end of this Appendix), but data were difficult to interpret when the original material had not been collected with sufficient specificity.

**General Methodological Issues**

General methodological issues for data used in this review include: a lack of standardisation of diagnostic criteria; intra and inter observer variation; lack of consistency in age-groups surveyed; method of selection of survey participants; seasonal factors; time relationship between surveys and treatment activities; a lack of denominator population; identification of Aboriginality; transient populations; and differences in the combining of towns and/or communities in the presentation of the data. This has been a particular issue with the data in Trachoma but also affects data in other areas.
## APPENDIX V:

### OPHTHALMIC EQUIPMENT REQUIRED BY A REGIONAL SERVICE

<table>
<thead>
<tr>
<th>Item</th>
<th>Approximate Cost</th>
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</thead>
<tbody>
<tr>
<td>Trial lenses and trial frames</td>
<td>$1600</td>
</tr>
<tr>
<td>Retinoscope</td>
<td>$700</td>
</tr>
<tr>
<td>Visual Acuity charts*</td>
<td>$20</td>
</tr>
<tr>
<td>Slitlamp — portable</td>
<td>$6,000</td>
</tr>
<tr>
<td>Slitlamp — floor model*</td>
<td>$8,000</td>
</tr>
<tr>
<td>Ophthalmoscope — direct*</td>
<td>$40</td>
</tr>
<tr>
<td>Ophthalmoscope — indirect</td>
<td>$1,700</td>
</tr>
<tr>
<td>Lenses 20D, 78D*, or 90D*</td>
<td>$700</td>
</tr>
<tr>
<td>2 mirror gonio lens</td>
<td>$150</td>
</tr>
<tr>
<td>Portable YAG laser</td>
<td>$36,000</td>
</tr>
<tr>
<td>Diode laser — slitlamp and indirect delivery</td>
<td>$35,000</td>
</tr>
<tr>
<td>A-scan portable</td>
<td>$8,000</td>
</tr>
<tr>
<td>Keratometer</td>
<td>$5,000</td>
</tr>
<tr>
<td>Tonopen</td>
<td>$4,000</td>
</tr>
<tr>
<td>Loupes*</td>
<td>$200</td>
</tr>
<tr>
<td>Operating Microscope</td>
<td>$30,000</td>
</tr>
<tr>
<td>Phacoemulsification machine</td>
<td>$35,000</td>
</tr>
<tr>
<td>Three sets of surgical instruments and trays</td>
<td>$6,000 each</td>
</tr>
</tbody>
</table>

* items also required at the local level.

## APPENDIX VI:

### STEERING COMMITTEE MEMBERS AND MEETING TIMES

- **Mr Brian Dixon** (Australian Health Ministers' Advisory Committee)
- **Dr J.E.K. Galbraith** (Royal Australian College of Ophthalmologists)
- **Mr Robert Grew** (Office for Aboriginal and Torres Strait Islander Health Services)
- **Mr Arnold Hunter** (NACCHO)
- **Mr Michael Mullens** (Commonwealth-funded Trachoma and Eye Health Committees)
- **Professor Hugh Taylor** (Reviewer)
- **Ms Vicki Taylor** (Consultant)

**Ms Jill Guthrie** (OATSIBIS) Secretary

**Meeting Times**

- 6 December 1996
- 31 January 1997: apologies from Mr Dixon and Mr Hunter
- 18 April 1997: Mrs Val Power replaced Mr Mullins, and apologies from Mr Hunter
- 6 June 1997: Mr Sol Bellar and Dr Peter Brennan in attendance
- 13 June 1997: apologies from Mr Dixon and Mr Hunter
APPENDIX VII:

ATTENDEES AT THE STAKEHOLDERS WORKSHOPS

Workshop — 29th May, 1997

Mr Mitchell Anjou  College of Optometry, University of Melbourne
Dr Ben Bartlett  CARPA
Mr Ian Blumenthal  Adelaide-based optometrist
Dr Garry Brian  Cairns-based ophthalmologist
Dr Gordon Briscoe  Fred Hollows Foundation
Dr Scott Cameron  South Australian Health Commission
Dr Bob Cooter  RACGP
Mr Brian Dixon  South Australian Health Commission
Dr J.E.K. Galbraith  RACO
Ms Rebecca Ivers  University of NSW
Mr Cedric Jacobs  Marr Mooditj
Dr Janine Liddle  NSW Department of Health
Dr Mark Loane  Brisbane-based ophthalmologist
Dr Dermot Roden  Perth-based ophthalmologist
Dr Neil Thomson  Edith Cowan University
Ms Tanya Utkin  Commonwealth Department of Health and Family Services

Workshop — 30th May 1997

Ms Mary Butler  QTEHP (Townsville)
Mr Ken de la Cruz  NTEHP (Darwin)
Ms Diane Dudley  QTEHP (Brisbane)
Ms Janice Hearn  QTEHP (Townsville)
Mrs Bella Jackson  AEHP (SA)
Mr Charlie Jefferys  NTEHP (Darwin)
Mr Chippy Miller  NTEHP (Alice Springs)
Mr Michael Mullins  NTEHP (Darwin)
Ms Barbara O’Connor  QTEHP (Brisbane)
Ms Val Power  AEHP (SA)

Mr Bill Redfern  AEHP (SA)
Mrs Muriel Vanderbyl  AEHP (SA)

Workshop — 6th June 1997

Dr John Boffa  AMSANT — Congress, Alice Springs
Ms Harriet Coleman  Ceduna Aboriginal Medical Service
Mr Les Collins  QAIHF, Brisbane
Mr Steve Larkin  NACCHO Secretariat, Canberra
Ms Naomi Mayes  Vice-Chair, NACCHO
Ms Colleen Prideaux  SA Aboriginal Health Council, Ceduna
Ms Dea Thiele  Darkan Medical Service, Mt Druitt
Mr Ted Wilkes  Perth AMS

Each workshop was jointly chaired by Mr Sol Bellear and Dr Peter Brennan.