

Epidemiology and Treatment of Eye Disease

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The Cape York Regional Eye Health Programme (1999-2004)

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Abstract

Background: The burden of poor eye health and visual impairment on Indigenous Australians from remote areas is exacerbated by poor access to eye health services. The Cape York Regional Eye Health Programme (CYREHP) was established in 1999 to deliver quality eye health care directly to Cape York's predominantly Indigenous communities.

Aim: To describe the epidemiological patterns of eye disease in Cape York communities and to quantify the services delivered by the CYREHP (October 1999-October 2004).

Methods: The retrospective audit of 5484 de-identified Microsoft Access records required extensive data cleaning and coding measures before prevalences for diabetic retinopathy (DR) and cataract and summary statistics for selected interventions could be calculated.

Results: The CYREHP completed 4421 consultations with 1894 individuals via 177 visits to 12 communities over 5 years. There were 132 patients with DR and 34 had laser treatment. The prevalence of DR was 25.0% (95% Confidence Interval (CI): 21.3-28.7%) among all Cape York diabetics and 27.0% (CI: 23.1-30.9%) among diabetics that presented to the CYREHP. Cataract accounted for 71.0% of all non-diabetic diagnoses. There were 152 patients diagnosed with cataracts, producing a prevalence of 2.3% (CI: 1.9-

2.7%). Seventy-four percent of cataract cases were referred for surgery at Weipa but over 98% of the data on these surgeries were missing. There were no data on the prevalence of refractive error. However, 680 pairs of spectacles (50% Readers; 32% Bifocals; 18% Distance vision) were dispensed to 569 individuals for low vision (63%), DR (30%) and cataract (6%).

Conclusions: The prevalences for DR and cataract in Cape York are similar to those detected in other Indigenous and non-Indigenous populations. The CYREHP's DR screening and consultation rates are better than those in other Indigenous eye health programmes. Improved data collection measures will enable the CYREHP to better document its future performance.

Keywords: **Cape York, Indigenous, eye disease, diabetic retinopathy, cataract**

Statement of Originality

This dissertation is my own original work. No part of it has been submitted for credit for any other degree/ award or part thereof.

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Dedicated to my Sai Rama

~

Yemi ledhu, yemi ledhu

Woka chinna pushpamu mātbrame

Mee pādhamulaku arpinchina

Woka chinna pushpamu mātbrame.

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LIST OF ACRONYMS

ACCHS	Aboriginal Community-controlled Health Service(s)
ATSIEHP	Aboriginal and Torres Strait Islander Eye Health Programme
CBH	Cairns Base Hospital
CEA	Cost-effectiveness Analysis
CI	Confidence Interval
CUA	Cost-utility Analysis
CYREHP	Cape York Regional Eye Health Programme
DALY	Disability-adjusted Life Years
DR	Diabetic Retinopathy
HALY	Health-adjusted Life Years
NATSIEHP	National Aboriginal and Torres Strait Islander Eye Health Programme
NHS	National Health Survey
NTEHP	National Trachoma and Eye Health Programme
OATSIH	Office of Aboriginal and Torres Strait Islander Health
OR	Odds Ratio
PC	Presenting Complaint(s)
PR	Prevalence
QALY	Quality-adjusted Life Years
RANZCO	Royal Australian and New Zealand College of Ophthalmologists
REHC	Regional Eye Health Coordinator
RR	Relative Risk
SAFE	Surgery Antibiotics Face-washing Environmental improvement
SPSS	Statistical Package for Social Sciences
VTR	Vision Threatening Retinopathy
WHO	World Health Organisation
YLL	Healthy Years of Life Lost
YLD	Healthy Years of Life Lost to Disability

Chapter 1 ~ Introduction

The twin burdens of eye disease and visual impairment among Indigenous Australians are significant and exacerbated by poor access to necessary eye care services. The Cape York Regional Eye Health Programme (CYREHP) was established in 1999 to address this issue and aims to deliver comprehensive, high-quality, regional-based eye health services to 13 predominantly Indigenous communities in Cape York.

The Wu Chopperen Medical Service, Cairns (an Aboriginal Community-controlled Health Service - ACCHS) coordinates the programme, which is funded by the Commonwealth Office of Aboriginal and Torres Strait Islander Health (OATSIH). It is the only ophthalmology service to regularly serve all residents (Indigenous and non-Indigenous) of 12 Cape York Indigenous communities: Aurukun, Coen, Cooktown, Hopevale, Kowanyama, Laura, Lockhart River, Mapoon, Napranum, Pormpuraaw, Weipa and Wujal Wujal. In addition, it covers Yarrabah with eye health professionals from Cairns Base Hospital. The geographic location of the communities is mapped in Appendix 1.

The current team comprises 7 Brisbane- and Cairns-based eye health professionals (4 ophthalmologists and 3 optometrists) and 1 Regional Eye Health Co-ordinator (REHC). The eye health professionals are allocated specific communities that they visit with the REHC at least once a year.

Trips span 2-3 weeks and take in a number of communities at a time. Outreach clinics are conducted at community health centres and operative cases are referred to the annual operating list at Weipa Hospital.

To date, the performance of the CYREHP has only been gauged empirically. Moreover, there is only anecdotal evidence of the patterns of eye disease in Cape York - the unchanging presence of cataracts and refractive error; emergence of DR and disappearing trachoma, for example [Dr. Mark Loane, personal communication, 19 October 2004]. Quantitative evidence is absent.

The documentation of disease epidemiology and service provision patterns has numerous public health benefits. Firstly and most importantly, it will inform effective and efficient resource allocation decisions at all levels to improve eye health services to Cape York. Secondly, in doing so, it will allow this Queensland programme to be benchmarked against others in Australia [Jaross *et al.*, 2003, 2005; Layland *et al.*, 2004; Mak *et al.*, 2003; Taylor *et al.*, 2003]. And finally, it will allow assessment of the ideals of service delivery underlying the Specialist Eye Health Guidelines [OATSIH, 2001].

Since 1999, the CYREHP has assembled an electronic database with the potential to fulfil these objectives. This study audited these data in order to describe the epidemiology of eye diseases in Cape York and to quantify the

services delivered by the CYREHP in response to them. This process is documented in the current dissertation, in which:

Chapter 2 ~ Literature Survey provides the background to the study. It begins by examining the context of Indigenous eye health. It describes eye diseases prevalent among the Indigenous population and summarises their epidemiology. The economic and societal burdens they impose and cost-effective interventions to relieve them are considered. The history and distribution of Indigenous eye health programmes - the vehicles for these interventions - are summarised. A challenge common to these programmes – the collection of good quality data – is discussed. The chapter concludes by articulating the research question underpinning this study.

Chapter 3 ~ Methodology describes the methods used to address this research question. It begins by defining the populations of interest. The study variables and confounding factors are then described. The measures taken to clean and code the raw data are detailed. The chapter concludes by outlining the analytical strategies employed.

Chapter 4 ~ Results presents the outcomes of applying this methodology. The overall features of the CYREHP are summarised first. The factors contributing to missing data on presenting complaints and diagnoses are assessed. The overall and community prevalences of the three key eye diseases encountered by the CYREHP - diabetes, cataract and refractive

error – and the frequency of interventions used to address them are calculated.

Chapter 5 ~ Discussion analyzes the implications of salient results, in turn, before commenting briefly on less dominant eye diseases. Comparisons are made with data from regional Indigenous eye programmes elsewhere in Australia. The overall performance of the CYREHP and prevalence of the key eye conditions are considered.

Chapter 6 ~ Data Collection discusses how the CYREHP may collect better quality data. The existing process of data collection is examined to locate vulnerabilities. The chapter and dissertation concludes with a summary of key findings and recommendations.

Chapter 2~ Literature Review

2.1 INTRODUCTION

The sense of vision is critical to interacting with one's physical environment. Visual impairment can increase the risk of injury (through falls and other accidents), thereby increasing dependence on others [Burns and Thomson, 2003]. In addition, the ability to participate in society through employment, education and social interaction becomes limited with diminishing eyesight [Burns and Thomson, 2003].

The health of Indigenous Australians follows developing world trends and diverges from the world-leading health status enjoyed by the rest of the country [AIHW, 2004; OECD, 2004; WHO, 2001]. For example, Australia is one of the top-six healthiest countries in the world in terms of quality of life and life expectancy but Indigenous people live for 17-20 years less than non-Indigenous people [AIHW, 2002, 2004]. In fact, any disease burden impinging on mainstream Australia is magnified several-fold among the Indigenous, leaving them with the poorest health status of any Australian ethnic sub-group for whom there is data [McClelland *et al.*, 1992; Palmer and Short, 2000]. On the other hand, the complex interplay of disadvantages in every determinant of health – socio-economic; geographic; social exclusion; employment; access to transport, for example [Wilkinson and Marmot,

1998] - leaves many Indigenous Australians with relatively poor access to health care services [Dwyer *et al.*, 2004].

Given that eye health is subject to the same determinants as general health and often mirrors it [Burns and Thomson, 2003], begs the question of whether the burden of eye disease differs between Indigenous and non-Indigenous people. Furthermore, the research question underpinning the current work is how well the Cape York Regional Eye Health Programme (CYREHP) has addressed the evolving patterns of eye disease facing it. This chapter draws from current literature to construct a platform of knowledge that will provide meaning and background to these questions.

The chapter begins by considering the epidemiology of eye diseases common among Indigenous people. The economic and societal burden imposed by these conditions is evaluated but not before introducing the attendant terminology. Cost-effective treatments of the eye conditions most prevalent among Indigenous people are compared next. The history of the current National Aboriginal and Torres Strait Islander Eye Health Programme (NATSIEHP), which aims to deliver these treatments, is then charted. Regional Indigenous eye health programmes are surveyed and a common thread identified – the need for adequate data collection. The chapter concludes by articulating the research question and the objectives of the study.

2.2 EYE CONDITIONS COMMON AMONG INDIGENOUS AUSTRALIANS

It is highly likely that Indigenous eye health – particularly in terms of colour vision, strabismus (non-alignment of both eyes on the object of attention), astigmatism (focusing error causing asymmetric blur) and visual acuity - was excellent prior to European colonisation [Burns and Thomson, 2003]. In fact it probably exceeded that of the colonisers [Thomson and Paterson, 1998]. These conclusions are drawn from the ground-breaking survey work of Father Frank Flynn and Dame Ida Mann in the 1940s and 1950s and confirmed by Professor Hugh Taylor a quarter of a century later [Taylor, 1997; Thomson and Paterson, 1998].

There is little recent information about many of the common causes of visual impairment among Indigenous people or of their overall eye health [Burns and Thomson, 2003; Thomson and Paterson, 1998]. However, available data suggest that the state of Indigenous eye health is currently very poor. For example, blindness is 10 times more prevalent among some Indigenous communities than in mainstream Australia [Taylor, 1997]. Trachoma, which is potentially blinding, is restricted to the Indigenous community and the incidence and prevalence of other conditions is comparatively higher among Indigenous people [Burns and Thomson, 2003; Taylor, 1997; Taylor *et al.*, 2003]. Diabetic retinopathy, cataracts, refractive error and trachoma are accepted as the most significant threats to eye health

and vision among Indigenous people [Burns and Thomson, 2003; DHA, 2004; Macnamara, 2001; OATSIH, 2001; Taylor, 1997; Taylor *et al.*, 2003; Thomson and Paterson, 1998; Veale, 2002; Wildsoet and Wood, 1997; Yohendran and Yohendran, 2004].

2.2.1 Diabetic Retinopathy

Diabetic retinopathy (DR) is a group of progressive and serious retinal or fundal lesions found in chronic diabetics due to vascular insufficiency [Klein and Klein, 1998; Taylor, 1997]. The main risk factors for DR are duration of diabetes and inadequate glycaemic control [Batterbury and Bowling, 1999; Khaw *et al.*, 2004; McCarty, 2003].

Diabetic retinopathy is responsible for 2% of overall visual impairment and 4% of the impairment not correctable by refraction in mainstream Australia [AE, 2004]. Refractive error and cataracts are the other significant causes (discussed below). After age-related macular degeneration, glaucoma and cataracts, DR accounts for the fourth highest burden of blindness [AE, 2004]. The prevalence of retinopathy (of any severity) among adult Australian diabetics has been estimated at 15-35% [McCarty *et al.*, 2003; McKay *et al.*, 2000; Mitchell *et al.*, 1998; Tapp *et al.*, 2003].

There is little comprehensive evidence on the prevalence of DR among Indigenous people. Crude estimates from the early to mid 1990s placed the prevalence at 8-35% [Taylor, 1997]. A study evaluating the use of a non-

mydriatic fundus camera found that 23% of Aboriginal diabetics' eyes in a rural WA community had DR [Diamond *et al.*, 1998], while cross-sectional data from Katherine NT found that the prevalence had increased from 18% in 1993 to 21% in 1996, though not statistically significantly [Jaross *et al.*, 2003, 2005].

The current prevalence of DR is probably similar in Indigenous and non-Indigenous populations [McCarty, 2003]. However, the large burden of diabetes among Indigenous people, underlined by earlier onset, higher prevalence [Irvine *et al.*, 2003], and poorer glycaemic control [McCarty, 2003] is likely to increase DR rates in the future [Burns and Thomson, 2003; OATSIH, 2001].

2.2.2 Cataract

A cataract is a severe opacification of the eye's lens and can be congenital, caused by trauma or be a consequence of age or other diseases [Evans, 1998; Khaw *et al.*, 2004]. The risk factors for cataract include: age (strongest), female gender (10-15% higher risk), low education or social level (probably mediating other risk factors), rural residence, cigarette smoking, alcohol, exposure to ultraviolet and ionising radiation and diabetes [Batterbury and Bowling, 1999; Evans, 1998; Khaw *et al.*, 2004]. The relative roles of genetic and environmental factors have not been investigated among Indigenous Australians [Taylor *et al.*, 2003] but smoking cessation and ocular sun

protection are the only effective universal primary prevention strategies [OATSIH, 2001; Taylor *et al.*, 2003].

Cataracts are the major cause of blindness worldwide [Evans, 1998; Holden *et al.*, 1997]. They are Australia's third most significant cause of blindness and our second most significant cause of visual impairment in over-40 year olds [AE, 2004]. In terms of visual impairment not correctable by refraction, cataracts are the dominant cause, accounting for 37% of visual impairment [AE, 2004].

Cataract prevalence in Indigenous Australia has not been systematically or objectively documented since the National Trachoma and Eye Health Programme (NTEHP) found that the crude overall prevalence was 3.5% among Indigenous people compared to 0.8% among non-Indigenous people, with an age-adjusted relative risk of 2 [RACO, 1980; Taylor, 1997]. The National Health Survey (NHS) reported that age-adjusted prevalence for cataract was similar for Indigenous and non-Indigenous people (2-3%) but more Indigenous males reported having cataracts (5% *vs.* 1% for non-Indigenous males) and there was a (statistically) significantly higher prevalence of cataract among Indigenous people in the over-55yo age group (11% *vs.* 8%) [ABS, 2002b].

2.2.3 Refractive Error

Visual impairment from refractive error covers the spectrum from long-sightedness (hypermetropia) to short-sightedness (myopia) with or without astigmatism [Khaw *et al.*, 2004]. Refractive error is the most significant cause of impaired vision in the world [Holden *et al.*, 1997] and in Australia, where it accounts for 62% of visual impairment [AE, 2004]. The overall prevalence of refractive error in Australia is 22% [Kempen *et al.*, 2004].

Compared to mainstream Australians, Indigenous people reported less myopia (Age-adjusted, 17% *vs.* 21%), but similar levels of hypermetropia (22-23%) in the 2001 NHS [ABS, 2002b]. It is believed that urban Indigenous and non-Indigenous people have similar rates of refractive error [Taylor, 1997].

2.2.4 Trachoma

Trachoma is a form of conjunctivitis caused by the *Chlamydia trachomatis* bacterium. The primary infection, usually in children, is known as follicular or inflammatory trachoma. Recurrent or chronic infection can lead to cicatricial trachoma (eyelid scarring) in later life, possibly complicated by trichiasis (involved eyelashes) and subsequent corneal opacification and blindness [Batterbury and Bowling, 1999].

The independent risk factors for primary infection are: age (the peak is at 2-6yo); general personal hygiene, particularly face washing; crowded

housing; and low socio-economic status [Ewald *et al.*, 2003; Frick *et al.*, 2003b; Frick and Mecaskey, 2002; OATSIH, 2001; Taylor, 2001]. Female care-givers of infected children are also at increased risk [Frick and Mecaskey, 2002]. Trachoma is easily spread by contact, especially between children and flies are vectors [Miller *et al.*, 2004].

The prevalence of trachoma is categorised as hyperendemic ($>20\%$ prevalence), mild-moderate ($5-20\%$) and non-endemic ($<5\%$) [Burns and Thomson, 2003]. Australia is the only developed country to have areas of hyper-endemic trachoma [Frick *et al.*, 2003b; OATSIH, 2001]. While trachoma has disappeared from urban, mainstream Australia, it still affects many remote Indigenous communities [Ewald *et al.*, 2003; Taylor, 1997, 2001].

Data on the prevalence of trachoma is drawn from periodic surveys (generally used to guide service delivery) and is therefore subject to biases and inaccuracies [Burns and Thomson, 2003; Ewald *et al.*, 2003; Lansingh *et al.*, 2001; Thomson and Paterson, 1998]. For example, the higher prevalence in the wet season is probably due to increased fly populations [daCruz *et al.*, 2002].

There has been no data on the prevalence of trachoma in Cape York [Taylor, 1997]. Recent evidence from elsewhere is limited to follicular trachoma. In endemic regions it ranged from 14% in the Kimberley to 55-

60% in Central Australia and the Pilbara [Burns and Thomson, 2003; Lansingh *et al.*, 2001; OATSIH, 2001; Taylor *et al.*, 2003]. Prevalence in the Kimberley may be falling [Taylor *et al.*, 2003] but remains high in Central Australia [Veale, 2002]. The decline is most dramatic in wealthier settings [Burns and Thomson, 2003; Taylor, 2001]. The prevalence in the arid inland NT communities remains high despite decreases along the urbanised coast [Burns and Thomson, 2003], for example. The prevalence has declined in children with some exceptions [Thomson and Paterson, 1998]. Data on the severity of follicular trachoma is unavailable but appears to be unchanged in some areas and better in many communities compared to 20 years ago [OATSIH, 2001; Stocks *et al.*, 1994; Taylor, 1997, 2001].

Prevalence data on scarring trachoma or trichiasis is scant and variable depending on the population studied and the definition of scarring used. The prevalence of trichiasis was estimated at 2.8% among over-50 year-olds in the Kimberley [Mak and Plant, 2001]. Prevalence of scarring and trichiasis was 50% and 1% respectively in a small sample of 308 people of unspecified ages from 6 Fitzroy Crossing communities [Thomson and Paterson, 1998]. A 1990 study of the Anangu Pitjanjatjara people found that 25% had scarring and trichiasis; less than 6% of those aged below 19 years had any scarring compared to 90% of over-60 year-olds [Stocks *et al.*, 1996].

2.2.5 Other eye conditions

Foreign bodies, violence or burns (thermal or chemical) may cause eye trauma [Batterbury and Bowling, 1999; Khaw *et al.*, 2004]. The incidence and prevalence of eye trauma varies between Indigenous communities [Burns and Thomson, 2003; Taylor, 1997]. Pterygium is a growth of fibrovascular tissue that extends from the conjunctiva and may encroach onto the cornea, but rarely causes visual symptoms [Batterbury and Bowling, 1999; Khaw *et al.*, 2004]. Pterygia were found to be more common among Indigenous people than non-Indigenous people in the NTEHP in the 1970s (3.4% versus 1.1%) but there are no recent data [Burns and Thomson, 2003; RACO, 1980; Taylor, 1997]. The highly infectious and vision-threatening gonococcal conjunctivitis is more common in neonates [Batterbury and Bowling, 1999; Khaw *et al.*, 2004]. There have been several outbreaks among Indigenous people in Central Australia but none have been reported since 1997 [Burns and Thomson, 2003].

2.3 THE BURDEN OF EYE DISEASE

Approximately 80% of blindness throughout the world is avoidable and concerted efforts by non-government and governmental organisations, the private sector and international bodies (*eg.* World Health Organisation (WHO), World Bank Development Agency) are underway to address this [Holden *et al.*, 1997]. Visual problems are Australia's most common disability [ABS, 2002c; AIHW, 2004]. Visual impairment and blindness lead

to substantial morbidity and premature mortality, whether by exacerbating pre-existing pathology or by contributing to deaths due to falls, motor vehicle accidents and depression [AE, 2004]. Consequently, they impose significant social and economic burdens [AE, 2004].

While data on the economic burden of eye disease worldwide are limited [Frick *et al.*, 2003a; Frick *et al.*, 2003b], for Australia, they are scant [AE, 2004] and for Indigenous Australia, non-existent [Taylor *et al.*, 2003]. Hence, inferences and extrapolations must be made from existing data sourced from around the world.

Measures such as quality-adjusted life year (QALY) and disability-adjusted life year (DALY) are used to quantify the impact of disease on society and to assess the effectiveness of health spending in purchasing years of healthy life [Mathers *et al.*, 1999; WHO, 2002]. The WHO Burden of Disease (BoD) methodology sums the burdens of mortality (years of life lost (YLL) due to premature death) and morbidity (years of healthy life lost due to disability, YLD) to calculate DALYs [Mathers *et al.*, 1999; WHO, 2002].

The Australian BoD study assessed the burden of a limited range of eye diseases (DR, cataracts, glaucoma and age-related macular degeneration – the latter two are not prevalent among the Indigenous [Taylor, 1997]) [Mathers *et al.*, 1999]. It calculated that Australia lost 1064 YLDs to trachoma and 5779 YLDs to cataracts in 1996. Extension of this work by

Access Economics calculated that Australians lose approximately 2000 YLDs due to DR [AE, 2004]. Most (50-70%) of the cataract burden occurred in the over-75yo age group [Mathers *et al.*, 1999]. It is reasonable to expect an earlier peak among Indigenous people due to their younger age distribution [AIHW, 2004].

Almost 75% of Australia's eye disease burden occurred in females [AE, 2004; Mathers *et al.*, 1999]. Females with trachoma bore the burden evenly through their lifespan, compared to males who incurred more than 50% of their burden in childhood [Mathers *et al.*, 1999]. Data from Tanzania show that non-vision impaired women with trichiasis may be as functionally limited as those with visual impairment from other causes [Frick *et al.*, 2001]. Extrapolating to Australia's Indigenous people, this would suggest significant social burdens in cultures where matriarchs play important roles [Thomas and Selfe, 1992].

2.4 COST-EFFECTIVE INTERVENTIONS

The burden of eye disease appears significantly worse for Indigenous Australians. Efforts to relieve this burden must be necessarily funded by Governments due to the minimal participation of Indigenous people in the private health care sector [AIHW, 2004; Deeble, 2003]. Naturally, any claim on scarce public resources will raise questions of efficiency. Economic evaluation techniques such as cost-effectiveness analysis (CEA) and cost-

utility analysis (CUA) aim to define criteria for efficient resource allocation by considering all costs and benefits of interventions - the intervention that maximises the benefit per cost is the most efficient [Hall *et al.*, 1996; Mooney, 2003]. In CEA, benefits are measured in common natural units and in CUA, lifespan is overlaid with a subjective measure of quality of life. Both techniques value costs in monetary units [Hall *et al.*, 1996; Mooney, 2003].

Economic evaluations of Indigenous-specific eye health interventions are limited. For example, no studies have examined Indigenous people's perception about lost utility associated with loss of vision; hence, studies among non-Indigenous people are used to impute QALY values to Indigenous people [Taylor *et al.*, 2003]. On the other hand, the greater costs of delivering health care to Indigenous people, especially in non-urban settings [Deeble, 2003], should be considered. For example, travel costs associated with providing eye surgery are often greater than the cost of the surgery itself [Taylor *et al.*, 2003].

2.4.1 Diabetic retinopathy

The effectiveness of early diagnosis and treatment of DR is well-established [Khaw *et al.*, 2004]. The NATSIEHP does not cover primary prevention of diabetes [OATSIH, 2001; Taylor *et al.*, 2003]. Proven prevention strategies for DR include laser photocoagulation, improved

glycaemic control, and hypertension control [Batterbury and Bowling, 1999; Khaw *et al.*, 2004].

The CEA and CUA of DR screening need to be extrapolated with care [Taylor *et al.*, 2003]. Further, the cost analyses of DR screening do not include the likely benefits of detecting other eye conditions (*eg.* cataracts) when methods other than camera screening are used [Taylor *et al.*, 2003].

Diabetic retinopathy screening and treatment programmes are efficient at various resource allocation levels [Taylor *et al.*, 2003]. Epidemiology-based economic modelling reveals that 80% compliance with regular screening of all diabetics confers savings to the government of \$14m a year [Taylor, 1997]. An American study concluded that screening is more cost-effective than other health interventions - the estimated cost for screening was US\$3190 per QALY saved (compared to US\$1996 and US\$3530 per QALY for Type 1 and 2 diabetes patients, respectively) [Javitt and Aiello, 1996].

In a study with more applicability to Australia's Indigenous population, the cost of screening First Nations people in British Columbia, Canada, for DR with a camera-based programme was cheaper than ophthalmologist examinations (C\$61,000 *vs.* C\$164,000) [Taylor *et al.*, 2003]. A recent 10-year study in Northern Ontario First Nations' people found that retinal photography and a travelling ophthalmologist, respectively saved 67 and 56 sight years at a cost of C\$15,000 and C\$37,000 per QALY [Maberley *et al.*,

2003]. The Australian Government considers assessing the cost-effectiveness of retinal photography in the detection of DR in remote locations “a matter of priority” [DHA, 2004].

2.4.2 Cataract

Although the risk factors for cataract are well known, there is no proven primary prevention or medical treatment. Surgical removal of cataract remains the therapy of choice [Congdon, 2001].

Even under the most pessimistic set of assumptions, cataract surgery is cost effective in reducing mortality and morbidity when compared to other medical treatments such as oral hypertension treatment and management of ischaemic heart disease [Taylor, 1997]. It costs US\$20-40 per DALY saved [Taylor, 1997]. The cost per QALY gained by cataract surgery has been estimated to be US\$4500 [Kobelt *et al.*, 2002] and US\$2020 [Busbee *et al.*, 2002]. Consequently, the World Bank has endorsed cataract surgery as a highly cost-effective intervention [Taylor, 1997] and it is accepted as such by eye health professionals [Taylor *et al.*, 2003].

There is very little literature on the outcomes of cataract surgery for Indigenous Australians [Taylor *et al.*, 2003], although it is acknowledged that cataract surgery is the main type of ophthalmic surgery needed by Indigenous Australians [OATSIH, 2001]. Indigenous people tend to present for surgery with more advanced cataracts, causing greater visual impairment

and worse quality of life compared to non-Indigenous people [OATSIH, 2001; Taylor *et al.*, 2003]. Hence, the benefits of cataract surgery are diminished. Further, the clinical and surgical procedures used for screening and removal of cataracts vary considerably, leading to much variation in the quality of surgical outcomes for Indigenous people [OATSIH, 2001]. These findings have led to the development of appropriate clinical practice guidelines for cataract surgery [OATSIH, 2001; Taylor *et al.*, 2003].

2.4.3 Refractive error

Discussions of cost-effective interventions to correct refractive error are considered redundant. It is generally agreed that visual acuity assessment and corrective lenses are required. Debate now centres on how best to deliver them to Indigenous people [Taylor *et al.*, 2003].

There are some reports of various models of optometric service delivery to Indigenous people, including low-cost spectacle programmes [Macnamara, 2001]. There are anecdotal reports that the assessment of refractive error and spectacle dispensing services are very popular in Indigenous communities [Taylor *et al.*, 2003]. For example, many people use self-selected ready-made spectacles bought through urban discount stores [Taylor *et al.*, 2003]. In addition, some community health services such as Nganampa, provide a range of low-cost magnifier spectacles on a “try before you buy” basis for about \$10, considered affordable and acceptable

by its clients [Taylor *et al.*, 2003]. The Royal Australian and New College of Ophthalmologists (RANZCO) states that such spectacles are no more damaging to the eye than custom-fabricated ones [RANZCO, 2004].

2.4.4 Trachoma

Reductions in the prevalence of trachoma have likely to have resulted from improvements in sanitation and socio-economic status [Taylor, 1997; Taylor *et al.*, 2003]. However, the persistent hyper-endemicity in some Indigenous communities points to region-specific interactions between the various determinants of health, feeding the argument that it is unacceptable to wait in hope for prevalence to eventually fall [Taylor *et al.*, 2003].

The WHO's SAFE programme (Surgery for trichiasis, Antibiotic (azithromycin), Facial hygiene and Environmental improvement (*eg.* good running water)), underpinned by a well-recognised grading system, provides a comprehensive management strategy for trachoma [Ewald *et al.*, 2003; Taylor, 2001; Veale, 2002]. The cost-effectiveness of the WHO SAFE strategy as a whole is unclear [Frick *et al.*, 2003b]. However, there is data supporting the effectiveness of the strategy's individual elements. Single-dose azithromycin is expensive but easy to administer and considered superior to other regimens [Frick and Mecaskey, 2002; Schachter *et al.*, 1999]. It has been shown to be effective in reducing the prevalence of trachoma infection in children in the Katherine region at 5-7 months follow-

up [Taylor *et al.*, 2003] In another NT community, a treatment effect was seen at 12 months follow-up but not at 24 months following a second round of treatment [Laming *et al.*, 2000]. The lack of effectiveness of a programme in Central Australia to improve housing infrastructure and provide antibiotic treatment was attributed to high population mobility, uncertain antibiotic compliance and persistently inadequate housing [Ewald *et al.*, 2003]. The authors' recommendation for regional-based programmes to accommodate high population mobility has been endorsed by others [Lansingh *et al.*, 2001].

People aged 40 years or more in current or ex-endemic areas should routinely have an eye examination for trichiasis [OATSIH, 2001]. Lid surgery can correct potentially blinding trichiasis and is considered highly cost-effective [Frick *et al.*, 2003b]. The bilamellar tarsal rotation technique has been proven to be more effective than any other to correct upper lid trichiasis [Reacher *et al.*, 1990; Reacher *et al.*, 1992]. It is the only procedure whose efficacy has been fully evaluated in randomised controlled trials [Cook, 1999; OATSIH, 2001; Reacher *et al.*, 1992]. The technique is simple, quick and can be performed successfully under local anaesthetic with minimal equipment at community level by trained para-medical staff [Bog *et al.*, 1993].

Seminal work in assessing the cost-effectiveness and cost-utility of a multi-faceted trachoma prevention and treatment programme preceded the

WHO SAFE programme. The Burma Trachoma Control Programme ran for 30 years from 1964 and combined community education with topical antibiotic and surgical treatment [Evans *et al.*, 1996]. The number of cases of visual impairment prevented indicated effectiveness. The utility measure, handicap adjusted life years (HALYs), combined the life-years lost from visual impairment and premature mortality with a subjective measure [Evans *et al.*, 1996]. The programme cost US\$193 and US\$47 per case of visual impairment prevented and US\$10 and US\$4 for each HALY averted by the surgical and non-surgical interventions, respectively [Evans *et al.*, 1996]. This programme is well regarded [Frick *et al.*, 2003b; Taylor, 1997].

2.5 INDIGENOUS EYE PROGRAMMES

2.5.1 History

National Trachoma and Eye Health Programme (1976-9)

The National Trachoma and Eye Health Programme (NTEHP, 1976-9) was initiated with an A\$1.4m Commonwealth grant to the Royal Australian College of Ophthalmologists and led by the late Professor Fred Hollows [RACO, 1980]. It examined approximately 100 000 people across remote locations, 60% of whom were Indigenous, and confirmed the high level of preventable eye disease, especially blindness, among the Indigenous [RACO, 1980]. The programme offered broad-ranging recommendations including the continuation of a national eye health programme with regular visits from

eye health professionals to rural and remote areas; improvements in environmental health; and access to good nutrition [RACO, 1980].

Review of eye health (1997)

Concerted efforts in Indigenous health policy development and health care delivery have only been under way for the last decade [Dwyer *et al.*, 2004] and the landmark review of Indigenous eye health undertaken by Professor Hugh Taylor in 1997 emerged from this milieu [Taylor, 1997]. It aimed to describe the changing epidemiology of eye disease and to assess the efficacy and efficiency of existing eye health service delivery [Taylor, 1997]. The review noted that most blindness was due to untreated cataracts and trachomatous scarring and warned of the emerging burden of DR [Taylor, 1997]. It made 17 key recommendations including: the establishment of regional eye health services with joint Commonwealth and State/ Territory responsibility; the development and implementation of evidence-based clinical practice guidelines for primary eye health care (particularly trachoma, cataracts and DR); and a national network to assess the implementation of the review's recommendations based on the quantification of specific performance indicators (*eg.* number of spectacles dispensed, cataract surgeries performed, percentage of diabetics screened annually for retinopathy and treated accordingly) [Taylor, 1997].

National Aboriginal and Torres Strait Islander Eye Health Programme

The 1997 review led to the advent of two important measures to relieve the burden of Indigenous eye disease. Firstly, the National Aboriginal and Torres Strait Islander Eye Health Programme (NATSIEHP) was established. It draws together three strands to improve health care access - coordination of regional eye health services or Aboriginal and Torres Strait Islander Eye Health Programmes (ATSIEHP); access to specialised equipment; and assistance for training [OATSIH, 2001; Taylor *et al.*, 2003]. The NATSIEHP is funded by the Office of Aboriginal and Torres Strait Islander Health (OATSIH, a division of the Commonwealth Department of Health and Ageing) [Taylor *et al.*, 2003]. Secondly, the “Specialist eye health guidelines (for cataract, DR, trachoma) for use in Aboriginal and Torres Strait Islander populations” were formulated. The guidelines are underpinned by the ideal that standards of care in rural or remote settings should be no less than those applied in urban ones [OATSIH, 2001].

2.5.2 Regional eye programmes

Regional eye health programmes (or ATSIEHP) have been established in Central Australia, South Australia (SA), Western Australia (WA), New South Wales (NSW), Victoria, Northern Territory (NT) and Queensland. None besides NSW has published its overall performance in peer-reviewed literature [Layland *et al.*, 2004] and only Victoria, Central and South Australia were described in the 2003 review of the NATSIEHP [Taylor *et al.*, 2003].

- The SA ATSIIEHP covers the entire state, involving a network of six Aboriginal Community-Controlled Health Services (ACCHS) that serve 4300 Indigenous people [Taylor *et al.*, 2003]. Hence, the programme delivers services over a large geographic area to small, scattered Indigenous populations. Programmes to train Indigenous health workers is an important feature of the programme [Amos *et al.*, 2002; King and Baxter, 2003].
- The relatively small size of Victoria and its Indigenous population enables the State programme to be centralised [Taylor *et al.*, 2003]. For example, it feeds DR data into a state-wide Indigenous diabetes register of over 2000 patients [Taylor *et al.*, 2003].
- The opposite is true for the Central Australia programme, which straddles SA and the NT, taking in the Pitjantjatjara people and the Tennant Creek region. A two-person (ophthalmologist-optometrist) team based at Alice Springs Hospital runs outreach clinics at community health centres [Taylor *et al.*, 2003].
- The NSW Aboriginal Eye and Visioncare Programme is aimed at Indigenous people across the state and is delivered through 65 ACCHS [Layland *et al.*, 2004]. The optometry-driven NSW South Coast Indigenous Eye Health Programme overlaps with the NSW Aboriginal

and Eye and Visioncare Programme. It involves three ACCHS at Bega, Nowra and Wollongong [Taylor *et al.*, 2003].

- The eye health of Indigenous people in North-West Australia falls under the broad scope of the Kimberley Public Health Unit which has had some success in implementing trachoma control and DR screening programmes [Johnson and Mak, 2003; Mak *et al.*, 2003]. The NT Eye Health Programme has documented epidemiological patterns of DR [Jaross *et al.*, 2003, 2005].
- The Cape York programme is the only regional programme in Queensland and targets the entire population of Cape York – Indigenous and non-Indigenous.

2.5.3 Data collection

Published research on Indigenous eye health has not kept pace with Australia's strong general ophthalmology research output [Davis and Wilson, 2003; Yohendran and Yohendran, 2004]. Moreover, Indigenous eye health research is often published in non-peer reviewed, low-impact journals [Yohendran and Yohendran, 2004]. Part of the reason may be the paucity of good quality data [Taylor, 1997] and the localisation of data to individual communities [Taylor *et al.*, 2003]. Moreover, there is no national data set specifically for Indigenous eye health and the Federal Government does not intend to establish one [DHA, 2004]. Computerised data collection systems

have been under-utilised for a variety of reasons, mostly to do with ease of use [Taylor *et al.*, 2003]. Moreover, variability in the implementation of the NATSIEHP and the roles of the regional eye health coordinators (REHC) is mirrored in the quality and type of data collected [DHA, 2004; Taylor *et al.*, 2003].

Data exist for certain conditions, based primarily on discrete studies *eg.* DR [Diamond *et al.*, 1998; Jaross *et al.*, 2005; Mak *et al.*, 2003; McCarty, 2003] and trachoma [daCruz *et al.*, 2002; Ewald *et al.*, 2003; Lansingh *et al.*, 2001; Mak and Plant, 2001; Stocks *et al.*, 1994; Stocks *et al.*, 1996]. However, comprehensive data collection from regional Indigenous eye health programmes has been historically poor [Taylor, 1997], even from programmes that are considered “successful” in terms of service delivery [Layland *et al.*, 2004]. Recent efforts to evaluate service delivery have concentrated on Medicare item number information; hospital separation data; and service activity reports from OATSIH but all these sources have major limitations [Taylor *et al.*, 2003]. There exists a need for an efficient and effective data system that can be incorporated into regional Indigenous eye health programmes and customised to suit local needs.

2.6 SUMMARY

The eye health of Indigenous Australians, like other indicators of health, is significantly worse than that of non-Indigenous Australians. For example,

trachoma, a disease of the developing world, is endemic in some Indigenous communities and the burgeoning burden of diabetes points to future increases in the rate of DR.

Eye diseases and visual impairment impose significant economic and societal burdens on mainstream Australia. These burdens are compounded by demographic and cultural traits unique to Indigenous Australians and made more acute by the socio-economic and geographic disadvantages they bear. Cost-effective interventions to relieve these burdens exist. The NATSIEHP, which evolved out of a succession of programmes and reviews, aims to deliver these interventions through regional-based programmes such as the CYREHP. However, the paucity of good quality data makes assessment of the performance of regional programmes problematic. The current study aims to address this challenge on behalf of the CYREHP.

2.7 RESEARCH QUESTION AND OBJECTIVES

2.7.1 Research question

What are the epidemiological patterns of eye disease among Indigenous people in Cape York during the 5 years that the CYREHP has been operating (October 1999-October 2004) and what services has the programme delivered in response to these patterns?

2.7.2 Objectives

1. To describe the prevalence and incidence of the three main causes of vision impairment and eye disease among Cape York communities: DR, cataract and refractive error.
2. To quantify the delivery of specific eye health services by the CYREHP:
 - Implantation of intra-ocular lenses for cataract
 - All forms of laser treatment for DR
 - Corrective lenses dispensed
 - Ophthalmologic and optometry consultations

The study factors (or independent/ explanatory variables) required to address the above research question are the demographic features of the patients presenting to the CYREHP: Indigenous status; gender; age; and community of residence. Other inputs to the CYREHP, namely eye health professionals (ophthalmologists and optometrists. For simplicity, the REHC and other health workers are not included.); the location where the service was delivered; and the reasons for presenting to the CYREHP, are also study factors. The outcome variables are the number of cases of the various eye conditions and the nature of therapeutic services delivered, whether as on-site interventions (medical, surgical or otherwise *eg.* advice) or by referral.

Chapter 3 ~ Methodology

The author's interest in Indigenous health and eye disease culminated in a September 2004 meeting with Dr. Mark Loane, a Brisbane-based private ophthalmologist, who had been steering the Cape York Regional Eye Health Programme (CYREHP) since 1999. The project was conceived and the research question and study objectives developed during this and subsequent discussions that also included Associate Professor Peter O'Rourke from the University of Queensland. Dr. Mark Loane facilitated discussions between the author and the Regional Eye Health Co-ordinator, Mr. Ross Jackamoss, who represented the Wu Chopperen Medical Service. It is hoped that the author will present the findings and recommendations of this study to the CYREHP and the Cape York communities via a separate report in early-2006.

This study used a retrospective audit of electronic database records spanning 5 years (October 1999-October 2004) to quantify epidemiological and service delivery patterns of the CYREHP. Following verbal approval by the Wu Chopperen Medical Service Management Board of the proposal presented in Appendix 2, this study was provided with three key documents: a raw data set containing 5484 de-identified records; a summary of diagnosed diabetics in Cape York; and the itinerary of visits made by the CYREHP.

This chapter aims to describe the methodology used to address the research question with these resources. It begins by characterising the populations of interest *viz.* the reference and study populations and study sample. It then describes the study variables and identifies confounding factors. The data management processes comprising data cleaning and coding are detailed. The chapter concludes with a summary of the analytical strategy.

3.1 POPULATIONS OF INTEREST

3.1.1 Reference population

Although the CYREHP provides services to Indigenous and non-Indigenous people, this study aimed to focus on the former. It is hoped that the results of this study will provide some guidance to those accessing and administering regional eye health programmes, including the CYREHP itself. Hence, the reference population to which the results of the study may be generalised is Indigenous people living in remote or very remote locations across Australia who potentially or currently require eye health care. This equates to 27% of Australia's estimated Indigenous population of 458 520, or 123 800 people [AIHW, 2004; Trewin and Madden, 2003].

3.1.2 Study population

The study population, that which is theoretically available to be studied, is the entire Indigenous population of the Cape York communities. The

Torres Strait Islands are excluded, as they are not covered by the CYREHP. The age distribution (“pre-adult” - <18yo, “young adult” – 18-44yo, “middle age” – 45-64yo, “elderly” - >65yo) and Indigenous proportion of the 13 Cape York communities serviced by the CYREHP is detailed in Tables 3.1 and 3.2. All data are from the 2001 Census [ABS, 2002a]. From Table 3.2, the theoretical study population comprises 7160 Indigenous people.

Table 3.1: Age distribution of Cape York communities.

	<18yo		18-44yrs		45-64yrs		>65yo		
Community	%Tot.		%Tot.		%Tot.		%Tot.		Total
Aurukun	367	35.1	459	43.9	183	17.5	36	3.4	1045
Coen	112	36.8	132	43.4	26	8.6	34	11.2	304
Cooktown	334	21.2	509	32.3	498	31.6	235	14.9	1576
Hopevale	273	36.5	338	45.2	109	14.6	27	3.6	747
Kowanyama	333	37.0	384	42.6	142	15.8	42	4.7	901
Laura*									
Lockhart River	124	27.1	232	50.8	86	18.8	15	3.3	457
Mapoon	164	49.2	138	41.4	24	7.2	7	2.1	333
Napranum	292	39.9	299	40.8	111	15.2	30	4.1	732
Pormpuraaw	200	30.1	315	47.4	117	17.6	32	4.8	664
Weipa	718	28.7	1128	45.1	574	23.0	81	3.2	2501
Wujal Wujal	38	13.8	170	61.6	59	21.4	9	3.3	276
Yarrabah	941	44.5	901	42.6	215	10.2	56	2.7	2113
	3896	33.4	5005	43.0	2144	18.4	604	5.2	11649

*Missing data

Table 3.2: Age distribution of Indigenous populations in Cape York communities.

	<18yo		18-44yrs		45-64yrs		>65yo			
Community	%Indig		%Indig		%Indig		%Indig		Total	%Indig
Aurukun	352	95.9	392	85.4	148	80.9	27	75.0	919	87.9
Coen	88	78.6	102	77.3	20	76.9	26	76.5	236	77.6
Cooktown	96	28.7	99	19.4	18	3.6	7	3.0	220	14.0
Hopevale	252	92.3	308	91.1	88	80.7	27	100.0	675	90.4
Kowanyama	288	86.5	318	82.8	110	77.5	38	90.5	754	83.7
Laura*										
Lockhart River	97	78.2	148	63.8	35	40.7	8	53.3	288	63.0
Mapoon	158	96.3	119	86.2	21	87.5	7	100.0	305	91.6
Napranum	283	96.9	278	93.0	93	83.8	23	76.7	677	92.5
Pormpuraaw	176	88.0	272	86.3	90	76.9	28	87.5	566	85.2
Weipa	139	19.4	126	11.2	34	5.9	3	3.7	302	12.1
Wujal Wujal	17	44.7	155	91.2	50	84.7	9	100.0	231	83.7
Yarrabah	881	93.6	854	94.8	199	92.6	53	94.6	1987	94.0
	2827	72.6	3171	63.4	906	42.3	256	42.4	7160	61.5

*Missing data

The Indigenous population is 50.2% female, with only Hopevale (47.8%), Mapoon (53.4%) and Kowanyama (54.7%) outside one standard deviation of this mean. The total population is 47.5% female, with only Weipa (43.5%), Mapoon (52.5%) and Kowanyama (52.7%) outside one standard deviation of this mean. The low proportion on females in Weipa is a feature of its mining industry, which is predominantly staffed by young, non-Indigenous men. After Weipa, Cooktown is the biggest township in Cape York with a tourism and agriculture-based economy supported

predominantly by non-Indigenous people, so its age distribution reflects that of mainstream Australia.

The proportions of pre- and young-adults in Wujal Wujal is incongruent with the Indigenous basis of the community; higher proportions are expected. This is an artefact of census counting that is currently being addressed by the ABS [Desmond Tayley, Chairperson - Wujal Wujal Community Council, personal communication, 8 June 2005]. Precise data on Laura was not available from the ABS or the community but the estimated total population is 100. Notwithstanding these inconsistencies, this study used the current data as published by the ABS and presented in Tables 3.1 and 3.2.

3.1.3 Study sample

The study sample, that subset of the study population actually studied, is the cohort of Indigenous patients seen by the CYREHP from 1999-2004. However, Indigenous status was not available from the raw data set (see Section 3.2.1). Hence, the study sample was the 2317 patients of unknown ethnicity seen by the CYREHP. Excluding Yarrabah (see Section 3.2.3), there were 1894 patients. Notwithstanding the lack of Indigenous status data, it can be assumed that at least 90 percent of the patients seen by the CYREHP are Indigenous [Dr. Mark Loane, personal communication, 22 November 2005].

3.1.4 External validity

The absence of Indigenous status meant that the actual study population required consideration of the entire population, regardless of ethnicity, of the 13 Cape York communities - 11649. Note that this is 4489 higher than the theoretical study population (see Section 3.1.2). The 12 communities excluding Yarrabah had a total of 9536 people.

The inherent selection bias in focussing only on Cape York community residents (see Section 3.2.1) is expected and acceptable. The re-definition of the study population limits the generalisability of the results of this study to the reference population. However, the high proportion of Indigenous people seen by the CYREHP and living in Cape York communities, with the exception of Cooktown and Weipa noted above, supports cautious generalisation. Data for these two communities is included for completeness.

3.2 STUDY VARIABLES AND CONFOUNDING

3.2.1 Explanatory variables

Of the seven explanatory variables required to address the research question listed in Section 2.7.2 – Indigenous status, age, gender, community of residence, community of consultation, eye health professional seen and presenting complaint - the first four were not included in the raw data set. Time and resource constraints prohibited the procurement of these demographic data from the original patient records. However, it is

reasonable to assume that all those seen by the CYREHP were residents of a Cape York community, most probably the one in which they were seen [Dr. Mark Loane, personal communication, 22 November 2005].

The communities are predominantly Indigenous (61.5% compared to the Australian average of 2.4% [AIHW, 2004]). However, Table 3.2 demonstrates the variability in the Indigenous proportion of Cape York communities from Weipa (12.1% Indigenous) to Napranum (92.5% Indigenous). Indigenous status is critical to the research question as originally framed.

The major presenting complaint was recorded for 549 of 1446 ophthalmic consultations (38%) and 1741 of 3796 optometric consultations (45.9%). Despite missing the majority of data, presenting complaints were included as explanatory variables due to their significant role in defining pathology cases, especially given the loss of other explanatory variables. The optometrist or ophthalmologist was named in almost all consultations. Hence, the actual study factors were: community of consultation; presenting complaint; and eye health professional seen.

3.2.2 Outcome variables

The outcome variables are the rates of the various eye diseases and the nature of eye health services delivered.

Disease rates require diagnoses. All diagnoses in the CYREHP were made clinically by an ophthalmologist and/ or optometrist and recorded in words in the electronic database *eg.* “Cataract”. The ophthalmologist and optometrist diagnosed DR jointly where possible and the sub-type was recorded *eg.* “Minimal Non-Proliferative Diabetic Retinopathy”; “Clinically Significant Macular Oedema”. The separate recording of diabetes data provided a logical sub-division of the analysis of diagnoses into diabetes and non-diabetes.

The outcomes of consultations and ophthalmic and/ or optometric services delivered were recorded. Ophthalmic procedures performed were named *eg.* “public cataract surgery”, “removal of foreign body”. The type of spectacles dispensed by optometrists was recorded *eg.* “readers”, “bifocals”. Non-physical treatment offered by optometrists was also recorded *eg.* “sun protection”, “eye exercises”. The need and time of follow-up and referral destination (*eg.* Cairns, Weipa surgical list) and team (*eg.* CYREHP, local general practitioner (GP)) were recorded.

Given these limitations of the raw data set, the research question was re-defined as: “What are the epidemiological patterns of eye disease encountered by the CYREHP (October 1999-October 2004) and what services has the programme delivered in response to these patterns?”

3.2.3 Confounding factors

The only ophthalmology service that co-services Cape York is based at Cairns Base Hospital (CBH). Acute ophthalmic cases and non-acute cases arising outside the window of the CYREHP's visits are treated at CBH. However, the CYREHP is the only out-reach programme that visits individual communities. It is beyond the scope of this study to precisely account for the 'leakage' of cases to Cairns between CYREHP visits. Consultations and procedures undertaken at CBH were excluded. Indigenous ophthalmology and optometry cases seen in the private sector at Cairns were also excluded.

Both the CYREHP and eye health professionals from CBH service the Yarrabah community. This study chose to focus on the CYREHP only. Hence, data from Yarrabah was excluded to minimise confounding.

Data on no other potentially confounding demographic features (*eg.* socio-economic and employment status, marital status) were recorded electronically. They are available from individual patient records that are housed in the various community health centres. These data were considered not essential to the research question and were not sought.

3.2.4 Measurement issues

No data was recorded *de novo* by the author; the CYREHP and the Regional Eye Health Co-ordinator (REHC) recorded all data. Hence, the

challenges of measuring all variables were faced in Cape York and any measurement errors flowed to the current study. The formatting of variables and the problem of missing data are discussed below.

3.3 DATA MANAGEMENT

The raw data has been gathered since 1999 on a Microsoft Access database. It is housed at Wu Chopperen Medical Service, Cairns, under the stewardship of the REHC. The raw data was transferred into a Microsoft Excel file to enable file compression before being emailed to Brisbane. Upon receipt, the database was copied *in toto* to a SPSS 12.0.1 for Windows file where all data management and analysis were conducted. The process of data management comprised data cleaning and coding.

3.3.1 Data cleaning

Gross features

The process of data cleaning began with a visual perusal of the data to identify gross trends and features. Each patient consultation generated a row of data. There were 5484 rows of data. Empty data rows were deleted at the outset. Two rows no other data but implausible dates (01-03-37 and 27-7-95) and were also deleted.

Formatting

There was considerable variability in data formatting in the capitalisation and spelling of word-based variables. Proper names and presenting

complaints provided good examples. The locations of some consultations were recorded as “Weipa”/ “weipa”; “CBH – Referral”/ “CBH – Refferal”/ “CBH – Refferal?”; “PVT Surgery Cairns”/ “Private Surgery Cairns”. The names of some optometrists and ophthalmologists were misspelt (*eg.* “Bill Bloggs”/ “Bill Blogs”/ “Bil Bloggs”), variably capitalised (*eg.* “Bill bloggs”), recorded as a familiar variation of the name (*ie.* “William Bloggs”), or as variation in their title/ designation (*ie.* “dr. Bill Bloggs”/ “Dr. Bill Bloggs”/ “Dr. Bill Bloggs – Locum GP”). Examples of variably formatted presenting complaints are “visual fields test”/ “visual Fields test”/ “Visual fields test” and “Pterygium”/ “Pterygiums”. All such errors and variations in formatting were corrected.

The binary variables “Optometrist” and “Ophthalmologist” denoted whether the corresponding professional had been seen (1=Yes, 0=No). Fifty-two and 60 records indicated that an optometrist or ophthalmologist, respectively, had not been seen yet had the name of the practitioner recorded. It was concluded that the error lay in not recording a ‘1’ in the Optometrist or Ophthalmologist column. Each of these records was traced and the correction made. Conversely, 42 and 23 records indicated that an optometrist or ophthalmologist, respectively, had been seen yet the name of the practitioner was not shown. These missing values were ascribed the

name of the practitioner of the day, as indicated by the CYREHP itineraries and contemporaneous records.

Schedule of visits

The itineraries were also used to smooth aberrant consultation dates. The database had imputed the first day of the month to records that had the month and year but not the day of consultation recorded. This led to clumping of records on the first day of certain months. The itineraries provided the correct dates, which were included in the revised data set. Where a clinic ran for multiple days, the first day of the clinic was recorded in the interests of streamlining the data without losing important information.

The itinerary covered the majority of visits by the CYREHP during the study period and proved to be a useful resource in corroborating the data. However, the itinerary did not cover the early-October 2000 visit to Weipa and all visits from January-June 2004. The raw data set indicated that the visits were optometric only. They were to Napranum (3rd March), Coen (6th March), Wujal Wujal (23rd March), Hopevale (26th March) and Laura (28th March). On the other hand, data for some completed visits (confirmed by the audits accompanying the itineraries) was not recorded in the database. These were optometry clinics at Weipa and combined clinics at Mapoon, Weipa (6th July and 12-13 August 2000) and Napranum (4-8 July 2004).

Manipulating variables

The raw data set contained 109 variables. Variables were culled on the basis of their value to subsequent analysis and on the extent of missing data. The latter was a two-step process.

Fourteen variables had no data whatsoever and were culled at the outset. The second step involved an assessment of the extent of missing data. An arbitrary threshold of a minimum of 50 completed records per variable was set. This threshold was not exceeded by 43 variables and they were culled. Each of these variables had no less than 98% of data missing. This included all variables for ophthalmic treatment (*eg.* cataract surgery) except laser treatment for DR.

Variables with only intrinsic value to the consultation were also culled. These were invariably to do with practitioner's comments (*eg.* "Take his wife as escort"; "John at Coen to follow-up and let us know"; "all good"; "no probs") or future consultation dates and times. The four binary variables to do with whether the REHC/ Health Worker had seen the patient and whether the ophthalmologist/ optometrist considered follow-up a priority were also deemed to have intrinsic value only.

The final phase of manipulating variables involved the merging of certain variables. A total of eight variables – four for each eye - represented diagnosis data (ophthalmic and optometric, diabetic and non-diabetic).

However, clinical intervention is governed by the predominating pathology, so a single diagnosis for each patient was sought. For diabetes, the diagnosis for the more severely affected eye was retained in the case of bilateral disease. For non-diabetes diagnoses, only cataract was separated into bilateral or unilateral, including cases of cataract and another disease in different eyes of the same patient. This process resulted in four variables, one each for diabetes and non-diabetes diagnoses made by ophthalmologists and optometrists respectively.

Original variables were renamed for clarity where necessary. Ultimately, 27 variables remained. They are described in Appendix 3. Broadly, they represent the explanatory and outcome variables listed in Table 3.3.

Table 3.3: Study variables remaining after data cleaning process.

Explanatory variables	Outcome variables
Place of consultation	Diagnosis: Diabetic/ Non-diabetic
Optometrist/ Ophthalmologist seen	Optometric treatment Spectacles dispensed
Presenting complaint: Major/ Minor	Diabetic laser treatment Referral: Destination venue/ Destination team/Reason

Format of variables

The “DateofConsultation” variable was in date format; the remainder had an integer value. Three variables (“ConsultationID”, “ClientNumber” and “ConsultationNumber”) carried the numeric value as recorded in the raw data set. Six were binary variables indicating whether: a patient had been

seen by the corresponding CYREHP team member (optometrist/ophthalmologist); and whether laser treatment had been delivered. The remaining 17 variables were coded.

3.3.2 Data coding

The community in which the consultation occurred was allocated a number in ascending alphabetical order: 1=Aurukun; 2=Coen; 3=Cooktown; 4=Hopevale; 5=Kowanyama; 6=Laura; 7=Lockhart River; 8=Mapoon; 9=Napranum; 10=Pormpuraaw; 11=Weipa; 12=Wujal Wujal; 13=Yarrabah; 14=Cairns – Other (*eg.* Calvary Hospital, Eye and Laser Centre, The Eye Specialists); 15=CBH; 16=Other (*eg.* Royal Brisbane Hospital).

The names of the eye health professionals were ranked according to alphabetic order of surname. Twenty different ophthalmologists and 4 optometrists have contributed to the CYREHP since its advent. The arbitrary minimum threshold of 50 consultations pruned this list to 8 ophthalmologists and 3 optometrists; the remainder were given the code ‘9’ and ‘4’, respectively.

Variables associated with pathology (presenting complaints and diagnoses) were gathered in logical groups. Presenting complaints were grouped as ‘Cataract’, ‘Retinal pathology’, ‘Diabetes’, ‘Glaucoma’, ‘Trauma’, ‘Private cataract surgery’, ‘Pterygium’ and ‘Other’. Presenting complaints to

optometrists carried additional codes for 'Diabetic review', 'General eye review' and 'Low vision'. Diagnoses other than diabetes were grouped as 'Cataract', 'Infection', 'Pterygium', 'Retinal pathology', 'Trauma', 'Other'. Optometric diagnosis carried an extra code for 'Inflammation'.

The diagnosis of diabetic retinopathy (DR) was coded according to a grading system suggested by national guidelines [OATSIH, 2001] and an acceptable ophthalmic text [Batterbury and Bowling, 1999]. "Mild" and "Minimal" non-proliferative DR were combined under one code. In increasing order of severity, DR was coded as 1=No DR, 2=Mild Non-proliferative DR, 3=Moderate Non-proliferative DR, 4=Severe Non-proliferative DR, 5=Proliferative DR, 6=Maculopathy and 7=Other.

Ophthalmic referrals were collected under the intended team (1=CYREHP optometrist; 2=Public surgery list, 3=Private surgery list; 4=CYREHP; 5=Local GP ± Others; 6=CYREHP Dr; 7=Other Dr; 8=Flecker House; 9=Other) and venue (1=Coen; 2=Hopevale; 3=Napranum; 4=Pormpuraaw; 5=Weipa; 6=Cairns-Other; 7=Cairns; 8=Other). The reasons for referral were coded similarly to those for diagnoses.

Optometric treatments were coded according to the nature of the intervention; 1=Exercises; 2=Lubricants; 3=Spectacles; 4=Sun protection; 5=Other. The type of spectacles prescribed were coded as 1=Bifocal,

2=Distance, 3=Readers, 4=Lens (in previous frames), 5=Constants. The point of dispensing was recorded as 'Hospital' or 'Private' under separate variables. A second variable to indicate the point of dispensing for a second pair of spectacles was carried over from the raw database.

3.4 DATA ANALYSIS

Following the data management step, data for Yarrabah and Cairns were excised from the master file. The remaining data set comprised 4421 rows of data representing 4990 consultations with 1894 patients. Missing data were characterised by comparing to recorded data with respect to visit number and community of consultation. The data were translated from a per-consultation basis to per-patient basis to enable disease prevalences to be calculated. Finally, descriptive statistics and cross-tabulations of explanatory and outcome variables were obtained to address the research question.

3.4.1 Missing data

To examine the nature of missing data for presenting complaints and diagnoses, the parent data set was split into two separate files, one each for optometric and ophthalmic consultations. Each file was further divided into whether or not consultations had the index of interest recorded (*ie.* presenting complaint or diagnosis - diabetic and non-diabetic diagnoses were combined). The frequencies for consultation number and community

for each sub-group were obtained. Odds ratios (OR) for each association suggested by the comparative frequencies were calculated.

3.4.2 Translation to per-patient basis

To calculate disease frequencies and prevalence, data had to be translated to a per-patient basis from the per-consultation basis recorded in the raw data set. The diagnostic categories – diabetes status and non-diabetic – and presenting complaints were analysed separately but identically for optometric and ophthalmic consultations. The process involved four key steps:

1. The diagnosis category was cross-tabulated with patient number to isolate patients with multiple diagnoses.
2. The variables for diagnosis code and patient number were sorted in order and listed adjacent to each other.
3. Each patient number with multiple diagnoses was identified and only their most severe and recent diagnosis was retained. (The coded order of severity was used for diabetes status. For non-diabetic diagnoses, bilateral cataract outranked unilateral cataract.)
4. Patients diagnosed for the same disease by both an optometrist and ophthalmologist were identified:

- i. Optometric and ophthalmic diagnoses for each category – diabetes status and non-diabetic - and presenting complaints were cross-tabulated to identify patients diagnosed by both professionals at the same consultation.
 - ii. A manual scan of apposed sorted patient numbers and diagnoses revealed duplicate diagnoses at separate consultations: The more severe diagnosis was retained; in the event of identically severe diagnoses made by both professionals, the ophthalmic one was retained (This decision was arbitrary. The resulting bias should be borne in mind when considering the results of this study.).
5. As a final check, Step 1 was repeated to confirm that each patient had been diagnosed once only.

3.4.3 Summary statistics

Frequencies of various indices were obtained for optometric and ophthalmic patients separately. Specifically, the frequencies of presenting complaints (primary and secondary), diagnoses and interventions were obtained. Proportions of the various sub-diagnoses were calculated. This enabled overall disease prevalences to be calculated.

The prevalence for DR was defined as the proportion of diabetics diagnosed with DR [Burns and Thomson, 2003; Jaross *et al.*, 2003, 2005;

Taylor, 1997; Taylor *et al.*, 2003; Thomson and Paterson, 1998]. The prevalence for cataract was defined as the proportion of the total population diagnosed with cataract [Fletcher *et al.*, 1996]. Note that these were period prevalences over the 5 years of the CYREHP [Fletcher *et al.*, 1996]. The surveillance of new cases arising from a population initially free of disease was considered not sensitive enough to allow incidence rates to be calculated in this setting.

Cross-tabulations were performed between: presenting complaints and diagnoses; community of consultation and diagnoses; diagnoses and referral venue, team and reason; diabetes diagnosis and laser treatment; optometric presenting complaints and community; optometric presenting complaints and type of spectacles dispensed. Disease frequencies in the various communities were used in conjunction with population data (Table 3.1) to calculate community prevalences.

3.5 SUMMARY

Numerous methodological obstacles punctuated the path between the raw data set provided and the research question governing this study. Key explanatory and outcome variables were absent or had substantially incomplete data. Data from some CYREHP trips were absent. Formatting errors were corrected; variables of little extrinsic value were culled; and data for all variables were grouped and coded. The characteristics of missing data

were compared to existing data to elicit reasons for their absence. Data based on consultations were translated to a patient-basis to enable calculation of disease prevalences. Consequently, it was possible to obtain descriptive statistics and cross-tabulations of certain explanatory and outcome variables, to address aspects of a modified research question. These results are presented in the next chapter.

Chapter 4 ~ Results

This chapter begins by describing the general characteristics of the CYREHP – the frequency and destination of visits; the eye health professionals seen; and the range of reasons for seeing them. It then approaches the research question through the three main eye conditions encountered by the CYREHP – DR, cataract and refractive error. It considers their severity; geographic distribution; and the interventions delivered.

4.1 OVERALL CHARACTERISTICS

4.1.1 Frequency and destination of visits

The CYREHP made 177 separate community visits during the study period. The annual spread of visits and number of consultations is given in Figure 4.1. Note that the visits in 1999 were primarily to assess feasibility and to plan the programme. The graph is limited to visits recorded in the raw data set. The low number of visits in 2004 is a consequence of the data being truncated at October and of excluding the March and July trips (see Section 3.3.1). The four missing trips in 2000 bring the tally for that year to 37. Thus, there is an even spread of annual visits in the middle four years of the programme. The trend in increasing consultations with the number of visits remaining steady indicates growing referrals to the programme from within and from GPs.

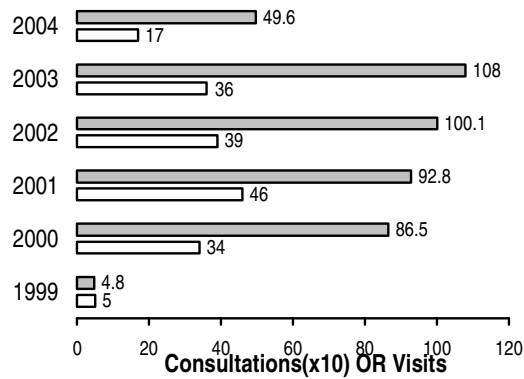


Figure 4.1: Number of community visits (unshaded) and consultations (shaded) per year.

The number of consultations at the 12 Indigenous communities over 5 years are summarised in Figure 4.2. (The Yarrabah, Cairns and ‘Other’ numbers are included for completeness.) Forty-six consultations did not have the place of consultation recorded. Each community had an average of 368.4 consultations. Kowanyama and Hopevale had the most consultations and Laura and Mapoon had the least.

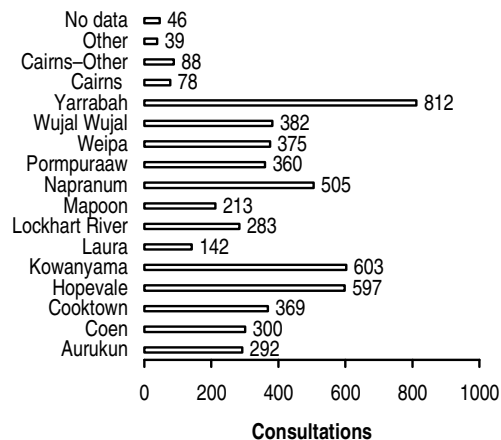


Figure 4.2: Number of consultations per community.

4.1.2 Eye health professionals seen

The majority of consultations were for optometrists - 2929 consultations were optometric only, 579 were ophthalmic only and 867 saw both eye health professionals. Consultant data was not recorded for 46 consultations. Hence there were a total of 3796 and 1446 optometric and ophthalmic consultations, respectively.

4.1.3 Presenting complaints

Ophthalmic

As indicated in Section 3.2.1, 62% of ophthalmic consultations did not have a presenting complaint (PC) recorded. Comparisons between the two groups (who did and did not have the PC recorded) with respect to other explanatory variables suggested differences that may have contributed to the differential rates of recording presenting complaints. The salient differences are summarised in Table 4.1 (Comparisons with odd ratio (OR) between 0.5 and 2.0 were deemed non-significant and omitted.). Calculation of odds ratio is based on the methods described in epidemiology texts [Bland, 2003; Fletcher *et al.*, 1996]

The reference category for comparisons of frequency of visits was 6 or more visits for all the comparisons in Sections 4.1.3 and 4.1.4. Those who had one consultation only were most likely to have the ophthalmic PC unrecorded compared to those who had 6 or more visits.

Napranum, the community with the largest proportion of Indigenous people, was chosen as the reference community for all the comparisons in Sections 4.1.3 and 4.1.4 (Weipa, the largest community, when used as a point of reference, produced spurious results due to there being only one consultation with ophthalmic diagnosis recorded.). Those seen at Laura were twice as likely to have the ophthalmic PC unrecorded than those seen at Napranum but the CI indicates the considerable variability of this estimate. Those seen at Cooktown were least likely to have the ophthalmic PC unrecorded.

Table 4.1: Relationship between odds ratio for selected exposures and unrecorded ophthalmic presenting complaints.

Exposure		OR	95% CI
Frequency of visits	1	7.26	4.93-10.70
	2	3.85	2.60-5.69
	3	2.19	1.44-3.33
Community	Laura	2.00	0.24-16.54
	Cooktown	0.11	0.06-0.19
	Hopevale	0.16	0.09-0.27
	Weipa	0.24	0.14-0.40
	Pormpuraaw	0.32	0.18-0.56
	Wujal Wujal	0.43	0.23-0.80

Of the 549 consultations that had a presenting complaint recorded, over 80% were for cataract or diabetes reasons (Table 4.2). Consultations for cataract were for assessment of un-operated cataract or for post-operative

follow-up. Consultations for diabetes were primarily for detecting or monitoring DR. Consultations for trauma were to assess recent injuries or to monitor old ones. Consultations for pterygia were to monitor progress of existing lesions or for post-operative follow-up. The presentations for glaucoma were to test visual fields and intraocular pressures. Generic presenting complaints such as “red eye”, “floppy eyelid” are gathered under “Other”.

Table 4.2: Ophthalmic presenting complaints.

Presenting complaint	Consultations	%Total
Cataract	243	44.3
Diabetes	214	39.0
Trauma	31	5.6
Pterygium	23	4.2
Glaucoma	5	0.9
Retina	3	0.5
Other	30	5.5
Total	549	100.0

Twenty-five of the 549 ophthalmic consultations also had a secondary presenting complaint recorded and these were also dominated by cataract (15) and diabetes (5). Pterygium (2), trauma, glaucoma and ‘other’ (1 each) made up the balance. Eighteen of the 25 presented for diabetes and cataract. Hence, there were a total of 258 and 239 presenting complaints for cataract and diabetes, respectively.

Optometric

Of the 3796 optometric consultations, 54.1% did not have a presenting complaint recorded. Comparisons between the two groups (who did and did not have the PC recorded) suggested differences that may have contributed to the differential rates of recording presenting complaints. The salient differences are summarised in Table 4.3.

Table 4.3: Relationship between odds ratio for selected exposures and unrecorded optometric presenting complaints.

		OR	95% CI
Frequency of visits	1	7.21	5.38-9.66
	2	3.76	2.77-5.11
	3	2.17	1.56-3.02
Community	Cooktown	0.26	0.19-0.36
	Wujal Wujal	0.47	0.35-0.61

Those who had one consultation only were most likely to have the optometric PC unrecorded compared to those who had 6 or more visits. Those seen at Cooktown were least likely to have the optometric PC unrecorded compared to those seen at Napranum. The OR was comparable to the corresponding comparison for ophthalmic PC.

Of the 1741 that had at least one PC recorded, over half were for low vision problems (Table 4.4). Diabetes was also a significant PC, more so than cataract, primarily for diabetic reviews. Presentations for cataract, trauma, pterygium, glaucoma and 'other' were for similar reasons to those

described above. Besides low vision, infection (*eg.* conjunctivitis, trachoma) and general eye review were categories of presenting complaint seen by optometrists but not ophthalmologists. The latter were presumably referrals from primary health care professionals with unspecified concerns.

Table 4.4: Optometric presenting complaints.

Presenting Complaint	Consultations	%Total
Low vision	961	55.2
Diabetes	535	30.7
Cataract	97	5.6
General eye review	71	4.1
Trauma	27	1.6
Pterygium	12	0.7
Glaucoma	6	0.3
Infection	5	0.3
Other	27	1.6
Total	1741	100.0

There were 131 optometric consultations which had a secondary PC recorded and they followed a similar pattern to primary presenting complaints, namely, predominantly low vision (63 or 48.1%), diabetes (29 or 22.1%) and cataract (15 or 11.4%). General eye review (5), trauma (4), glaucoma (3) pterygium (2), infection (1) and ‘other’ (9) made up the balance. Low vision with diabetes (63), cataract (23), general eye review (10) or trauma (7) and cataract with diabetes (7) comprised 84% of dual presenting complaints. Hence, of the total 1872 optometric primary and

secondary presenting complaints, low vision (1024 or 54.7%), diabetes (564 or 30.1%), cataract (112 or 6.0%), comprised 90.8%. General eye review, trauma, pterygium and ‘other’ made up the balance.

4.1.4 Diagnoses

Ophthalmic

Of the 1446 ophthalmic consultations, 332 emerged with a recorded diagnosis - 180 of diabetes status only, 128 with other diagnoses only and 24 had both. Thus, 1114 (77%) ophthalmic consultations had no recorded diagnosis.

Comparisons between the two groups (who did and did not have a diagnosis recorded) with respect to other explanatory variables suggested differences that may have contributed to the differential rates of recording diagnoses. The salient differences are summarised in Table 4.5.

Table 4.5: Relationship between odds ratio of selected exposures and unrecorded ophthalmic diagnoses.

		OR	95% CI
Frequency of visits	1	5.55	3.64-8.46
	2	2.83	1.87-4.28
Community	Weipa	8.48	2.83-25.45
	Hopevale	0.23	0.13-0.40
	Cooktown	0.24	0.14-0.42
	Wujal Wujal	0.40	0.21-0.77
	Pormpuraaw	0.46	0.25-0.84

Those who had one consultation only were most likely to have the ophthalmic diagnosis unrecorded compared to those who had 6 or more visits. Those seen at Weipa were more likely to have the diagnosis unrecorded but this is a spurious result as discussed in Section 4.1.3. Consultations at Hopevale and Cooktown were least likely to have the ophthalmic diagnosis unrecorded compared to those seen at Napranum.

Optometric

Of the 3796 optometric consultations, 608 emerged with a recorded diagnosis – 482 of diabetes status only, 98 with other diagnoses only and 28 had both. Thus, 3188 (84%) optometric consultations had no recorded diagnosis.

Comparisons between the two groups (who did and did not have a diagnosis recorded) with respect to other explanatory variables suggested differences that may have contributed to the differential rates of recording diagnoses. The salient differences are summarised in Table 4.6.

Table 4.6: Relationship between odds ratio of selected exposures and unrecorded optometric diagnoses.

Exposure		OR	95% CI
Frequency of visits	1	4.56	3.35-6.20
	2	2.14	1.57-2.94
Community	Coen	3.07	1.76-5.39
	Weipa	2.14	1.25-3.67
	Kowanyama	2.07	1.41-3.04

Those who had one consultation only were most likely to have the optometric diagnosis unrecorded compared to those who had 6 or more visits. Those seen at Coen were three times more likely to have the diagnosis unrecorded compared to those seen at Napranum.

The most common presenting complaints seen by the CYREHP were diabetes, cataracts and visual impairment. The pathologies that these presenting complaints point to – DR, cataract and refractive error – are now used to examine disease rates and service delivery patterns. The discussion is based on patients not consultations.

4.2 DIABETES

Of the 487 patients with diabetes-related primary and secondary presenting complaints (100 to ophthalmologists, 329 to optometrists and 58 to both), 450 patients had their DR status recorded. In addition, DR was diagnosed in 2 patients that presented for low vision.

4.2.1 Severity and prevalence

The outcome of all DR assessments is detailed in Table 4.7. The “Oph” and “Opt” columns indicate diagnoses made exclusively by an ophthalmologist or optometrist only, respectively. The “Oph+Opt” column indicates joint diagnoses. Thus each case is counted once only. Severity of disease increases down the table. More than 70% of those screened for DR were cleared.

Table 4.7: Outcomes of diabetic retinopathy assessments.

DR Status	Oph	Oph+Opt	Opt	Total	%
No DR	81	16	220	317	70.4
Mild non-proliferative	16	6	61	83	18.4
Moderate non-proliferative	10	0	15	25	5.6
Severe non-proliferative	3	2	8	13	2.9
Maculopathy	3	1	7	11	2.4
Other	0	0	1	1	0.2
Total	113	25	312	450	100.0

The distribution of severity of cases of diabetic retinopathy is detailed in Table 4.8. A total of 132 diagnoses of DR were made. Ophthalmologists contributed 32 cases, optometrists contributed 91 and 9 were jointly diagnosed. There is a concentration of mild cases, with progressively fewer cases of greater severity.

Table 4.8: Diabetic retinopathy severity.

DR Diagnosis	Cases	% Total
Mild non-proliferative	83	62.9
Moderate non-proliferative	25	18.9
Severe non-proliferative	13	9.8
Maculopathy	11	8.3
Total	132	100.0

The bias towards the more severe diagnosis in patients with successive diagnoses (described in Section 3.4.2) resulted in 3 diagnoses of mild non-proliferative DR being effaced by earlier diagnoses of moderate non-

proliferative DR (2) and maculopathy (1). The loss signifies a minimal loss of information on disease progression and the impact of treatment. This is outweighed by the detection of mild non-proliferative DR in 9 patients that were cleared on earlier screens. Notwithstanding these considerations, important conclusions can still be drawn about the severity of DR observed in the CYREHP (see Section 5.2.3).

The most commonly used definition of the prevalence of DR divides the number of cases by the number of diabetics [Burns and Thomson, 2003; Jaross *et al.*, 2003, 2005; Taylor, 1997; Taylor *et al.*, 2003; Thomson and Paterson, 1998]. There are 528 diabetics in the 12 Cape York communities according to the Excel file provided to this study. Hence, the prevalence of DR among Cape York diabetics is 25.0% (132 of 528) with a 95% confidence interval (CI) of 21.3-28.7%. The calculation of CI is based on the Confidence Interval for Single Large Sample described in [Bland, 2003].

The number of diabetics that presented to the CYREHP can be calculated from the number of patients that presented with diabetes as presenting complaint *ie.* 487. In addition, the 2 patients that presented for low vision but were diagnosed with DR were necessarily diabetic. Hence, 489 diabetics or 92.6% of the diabetics in Cape York (489 of 528) presented to the CYREHP. The PR of DR among them is 27.0% (132 of 489) (CI: 23.1-30.9%).

4.2.2 Geographic distribution

The geographic distribution of the PR of DR is given in Table 4.9. These data represent the sum of ophthalmic and optometric data. Ophthalmic data from Laura was missing. Prevalence ratios were calculated with respect to the prevalence at Coen (shaded), which had the lowest prevalence, and expressed as Relative Risk (RR). Calculation of the CI of the RR is based on the Difference Between Two Proportions of Small Samples method described in [Bland, 2003].

Wujal Wujal, Cooktown and Hopevale had the highest prevalence. Hopevale reported the most cases of DR. The wide confidence intervals of RR indicate the substantial variability in the prevalence of DR across the 12 communities. This is a result of the small number of DR cases in most communities. For example, half of the communities bore 20% of the disease burden of DR cases and the top third bore almost two-thirds of the burden.

4.2.3 Interventions

A total of 34 laser treatments for DR were recorded. Fourteen patients had bilateral treatment. Seven and 2 of these treatments were for moderate and severe non-proliferative retinopathy, respectively, and 3 were for maculopathy. Data on the severity of the remaining cases was not available but it can be concluded that 20 patients had severe enough retinopathy to require treatment ('vision threatening retinopathy').

The numbers to explore the relationships between DR diagnoses and referral destination, team and reason did not exceed 15 for optometric and ophthalmic diagnoses. This was considered too small to enable meaningful conclusions to be drawn.

Table 4.9: Prevalence of diabetic retinopathy in Cape York communities (Reference community shaded).

Community	DR Cases	Diabetics	PR (%)	RR	95%CI of RR
Aurukun	9	47	19.1	4.0	0.5-31.7
Coen	1	21	4.8	1.0	
Cooktown	16	44	36.4	7.6	1.0-57.6
Hopevale	34	95	35.8	7.5	1.0-54.9
Kowanyama	8	61	13.1	2.8	0.3-22.0
Laura*	3	12	25.0	5.3	0.6-50.5
Lockhart River	10	33	30.3	6.4	0.8-49.7
Mapoon	2	32	6.3	1.3	0.1-14.5
Napranum	18	87	20.7	4.3	0.6-32.6
Pormpuraaw	12	45	26.7	5.6	0.7-43.1
Weipa	2	11	18.2	3.8	0.4-42.1
Wujal Wujal	17	40	42.5	8.9	1.2-67.1
Total	132	528	25.0		

* Incomplete data

4.3 CATARACT

Ophthalmologists and optometrists made non-diabetic diagnoses in 110 and 99 patients, respectively. Five patients saw both eye health professionals. The dominance of cataract among non-diabetic diagnoses was evident (Table 4.10). The total number of non-diabetic cases is calculated by summing optometric (“Opt”), ophthalmic (“Oph”) and jointly diagnosed

cases (“Oph+Opt”). Cataract comprised 84.5% of all ophthalmic non-diabetic cases (93 of 110) and 55.6% of all optometric ones (55 of 99). In total, cataract accounted for 71.0% of diagnoses.

Table 4.10: Non-diabetic diagnoses.

Diagnosis	Oph	Oph+Opt	Opt		%Total
Cataract:	93	4	55	152	71.0
Unilateral	77	2	19	98	45.8
Bilateral	16	2	36	54	25.2
Pterygium	8	0	13	21	9.8
Infection	3	0	-	3	1.4
Trauma	2	0	1	3	1.4
Retinal pathology	1	0	4	5	2.3
Glaucoma	-	0	9	9	4.2
Inflammation	-	0	3	3	1.4
Other	3	1	14	18	8.4
Total	110	5	99	214	100.0

Pterygium accounted for 9.8% and the proportion of pterygium was higher for optometric diagnoses. The range of ‘Other’ diagnoses included “Brainstem CVA”, “age-related macular degeneration” and “corneal scarring”. Given the dominance of cataract among non-diabetic diagnoses, it is the focus of further analyses.

Of the 119 ophthalmic cases that had the diagnosis and presenting complaint both recorded, 82 (68.9%) and 20 (16.8%) cataract cases arose from presentations for cataract and diabetes, respectively. Cataract cases

diagnosed by optometrists originated from a wider range of presenting complaints. Of the 116 non-diabetic cases that had both the diagnosis and presenting complaint recorded for optometric consultations, 71 cataracts were diagnosed, of which only 11 (15.5%) arose from presentations for cataract: 36 (50.7%) emanated from presentations for low vision and 16 (22.5%) for diabetes. Excluding presentations specifically for cataract, those that presented with diabetes or low vision were 12.75 (CI: 4.56-35.68) and 6.34 (CI: 2.58-15.76) times more likely to be diagnosed with cataract than those presenting with other complaints (comprising general eye review, pterygium, infection/ inflammation and trauma).

4.3.1 Severity and prevalence

Bilateral cataract is considered more severe than unilateral. Optometrists diagnosed comparatively more bilateral cataracts than ophthalmologists (from Table 4.10, 17.2% of all cataracts diagnosed by ophthalmologists were bilateral compared to 65.0% for optometrists). Overall, 35.5% of cataracts diagnosed were bilateral.

The bias towards the more severe diagnosis in patients with multiple, successive diagnoses (described in Section 3.4.2) resulted in 11 ophthalmic diagnoses of unilateral cataract being effaced by earlier optometric diagnoses of bilateral disease. The loss signifies a loss of information on the impact of

treatment. However, the net effect on prevalence is nil as only the total number of patients with cataracts was considered.

The total number of cataract cases in the 12 Cape York communities is 152. The adult population of the 12 Cape York communities is 6581 (Table 3.1. The adult population is the difference between the total and <18yo populations.). Hence, the prevalence of cataract is 2.3% or 231 cases per 10000 people (CI: 1.9-2.7%, based on the Confidence Interval for Single Large Sample described in [Bland, 2003]).

4.3.2 Geographic distribution

The geographic distribution of the prevalence of cataract is given in Table 4.11. These data represent the sum of ophthalmic and optometric data. Ophthalmic data from Laura and optometric data from Mapoon were missing. Prevalence ratios were calculated with respect to the prevalence at Weipa (shaded), which had the lowest prevalence, and expressed as Relative Risk (RR). The 95% CI of RR is based on the Difference Between Two Proportions of Small Samples method described in [Bland, 2003].

Hopevale had the highest prevalence. As with DR, there is substantial variability in the number of cases reported and the prevalence of cataract across the 12 communities, as indicated by the broad CI of the RR in all cases. And as with DR, the small number of cases diagnosed is the cause of the variability.

Table 4.11: Prevalence of cataract in Cape York communities (Reference community shaded).

Community	Cataract cases	Pop.	PR (per 10000)	RR	95%CI of RR
Aurukun	10	678	147	8.8	2.4-31.9
Coen	9	192	469	27.9	7.5-102.9
Cooktown	28	1242	225	13.4	4.1-44.1
Hopevale	34	474	717	42.2	13.0-137.4
Kowanyama	19	568	335	19.9	5.9-67.2
Laura*	1	-	-	-	-
Lockhart River	6	333	180	10.7	2.7-42.8
Mapoon*	2	169	118	7.0	1.2-42.1
Napranum	12	440	273	16.2	4.6-57.4
Pormpuraaw	19	464	409	24.3	7.2-82.2
Weipa	3	1783	17	1.0	
Wujal Wujal	9	238	378	22.5	6.1-83.0
Total	152	6581	231		

* Incomplete data

4.3.3 Interventions

Recall from Section 3.3.1 that data on cataract surgery was missing. Cataract comprised the majority of reasons for referral. Of the 74 patients that had a reason recorded, 68 (92%) were for cataract. The same proportion of the 74 cases was referred to the public surgery list at Weipa. Of the ophthalmic patients with presenting complaint and referral destination and venue recorded, 75% were similarly directed. Moreover, patients from all communities contributed to the Weipa surgical lists.

4.4 REFRACTIVE ERROR

4.4.1 Prevalence

The diagnosis of refractive error, comprising chiefly myopia, presbyopia, hypermetropia and astigmatism [Burns and Thomson, 2003; Taylor, 1997] was not specifically recorded. A crude guide to the rate of refractive error is provided by the presenting complaint 'low vision'. Hence, PR of refractive error could not be calculated.

4.4.2 Interventions

The CYREHP's optometrists dispensed 680 pairs of spectacles free of charge, of which 87 were a second pair of a different prescription, to 568 individuals. Fifty percent were Readers; 31.8% were Bifocals; and 17.9% were Distance spectacles. In addition, 457 pairs were prescribed for private supply. The optometrists also dispensed advice, half of which was for sun protection (32 of 65 recorded episodes of optometric 'general treatment').

The optometric presenting complaint was recorded for 603 pairs of spectacles dispensed free of charge. Presentations for low vision, diabetes and cataract accounted for 62.5%, 30.3% and 5.8%, respectively. Approximately half of these spectacles were Readers, a third were Bifocals and the remainder (one-sixth), Distance spectacles.

Spectacles dispensed from the private sector were for slightly different reasons. Almost all were prescribed for patients that presented for low

vision (70.5%) and for diabetic reviews (24.7%). Almost half of the spectacles prescribed for low vision were Readers; 15% each were Bifocals or Distance; and 10% each were Multifocals or required a frame only.

4.5 SUMMARY

The CYREHP made 4421 consultations with 1894 patients through 177 visits to 12 Cape York communities over 5 years. Over 80% of all presentations were for diabetes, cataract and visual impairment. The missing data on presenting complaints and diagnoses were associated with one-off visits and certain communities. The prevalence of DR was 25.0% (CI: 21.3-28.7%). The prevalence of cataract was 2.3% (CI: 1.9-2.7%). Small numbers of each disease led to significant variability in community prevalences. Half of the spectacles prescribed were Readers, a third were Bifocals and one-sixth Distance spectacles. The next chapter discusses the implications of these and other results.

Chapter 5 ~ Discussion

The original purpose of this study was to document the patterns of eye disease among Cape York's Indigenous people and the response of the CYREHP to them. The absence of Indigenous identification re-shaped the research question to include all patients, regardless of ethnicity, seen by the CYREHP. The actual study population became the entire population of the Cape York communities. However, the high proportion of Indigenous people in Cape York communities lends some validity to comparisons with Indigenous eye health data and programmes elsewhere but these are to be undertaken with caution as noted in Section 3.1.4.

This final chapter discusses the implications of the study findings reported in the preceding chapter. It begins by comparing the overall performance of the CYREHP with that of others. It then compares the prevalence and treatment of diabetes, cataract and refractive error with published data. The chapter and dissertation concludes by recommending strategies to improve data collection so that more accurate comparisons can be made in the future.

5.1 OVERALL PERFORMANCE

As noted in Section 2.5.2, only four regional eye health programmes have had their overall performance reported. They are the NSW Aboriginal Eye and Visioncare Programme [Layland *et al.*, 2004] and the eye health

programmes in the NSW South Coast, South Australia and Central Australia [Taylor *et al.*, 2003].

The majority of communities covered by the Central Australia programme was not represented in the reported data [Taylor *et al.*, 2003]. Comparisons between the remaining three programmes and the CYREHP must bear in mind their respective structures, scope and the limitations of the reported data. For example, the data span different durations (2001 for SA; the year ending May 2002 for NSW South Coast; and July 2000-July 2003 for NSW). The SA programme screened 161 patients for glaucoma and 284 patients for trachoma [Taylor *et al.*, 2003] but the CYREHP screened for neither disease. The NSW South Coast programme reported the utilisation of “1893 services” [Taylor *et al.*, 2003] but their nature is not detailed, so meaningful comparison with CYREHP in this regard is not possible.

The total number of consultations is a relatively simple, gross measure of a programme’s performance. Perhaps the simplest comparison - that of the total number of patients seen as a proportion of the target population – is the only one available here.

The NSW Aboriginal Eye and Visioncare Programme had “over 8000 consultations” (also reported as 8000 people) [Layland *et al.*, 2004] from a potential target population of 134 888 - the entire Indigenous population of

NSW [AIHW, 2004]. Thus, it saw 2.0% of its target population per year. The NSW South Coast programme saw 1015 clients out of 4273 Indigenous people in Bega, Nowra and Wollongong *ie.* 23.8% of its target [ABS, 2002a; Taylor *et al.*, 2003]. The SA programme saw 596 Indigenous patients from a target population of 4300 *ie.* 13.9% of its target [Taylor *et al.*, 2003]. The CYREHP had 5484 consultations with 2317 Indigenous and non-Indigenous patients in 5 years from a target population of 11649 (see Section 3.1.3) *ie.* 4.0% of its target population per year [ABS, 2002a].

The CYREHP performed better than the NSW-wide programme but not as well as the NSW South Coast and SA programmes. There are numerous explanations for this. Firstly, data missing from numerous visits of the CYREHP (see Section 3.3.1) would have increased the numerator here, raising the comparative performance of the programme. Secondly, the NSW South Coast and SA data span one year only, which may not reflect ongoing patterns of consultation and service delivery. Thirdly, the frequency, setting and nature of clinics would have determined the number of consultations. For example, the NSW programmes are primarily optometric and delivered from Aboriginal Community-Controlled Health Services (ACCHS), monthly in the case of the South Coast.

5.2 DIABETES

5.2.1 Screening

The SA ATSIIEHP screened 264 diabetics for DR [Taylor *et al.*, 2003] compared to the CYREHP's 489 diabetics screened for DR. This translates to 6.1% and 5.1% of their respective overall target populations (Yarrabah data excluded). The CYREHP performs comparably but the confounders underpinning the comparison noted above, must be borne in mind.

As noted in Section 4.2.1, the diabetics screened by the CYREHP over 5 years represent 92.6% of the total diabetic population of Cape York. Comparisons with other regional eye programmes is limited by lack of data [Taylor *et al.*, 2003]. A study from the Kimberley region in WA found that 58% of diabetics had been screened for retinopathy over 2 years [Mak *et al.*, 2003]. The longer span of the current study window and screening by eye health professionals, not trained health workers, may be responsible for the better performance of the CYREHP.

The NSW Visioncare Programme reported that 15% of its patients had diabetes [Layland *et al.*, 2004]. The rate of diabetes among those seen by the CYREHP was 25.8% (489 of 1894 patients). It is unlikely that this difference reflects higher diabetes prevalence in Cape York. The diabetes rate among Cape York adults is lower than the national estimate for Indigenous adults (7.2% compared to 11%) [AIHW, 2004].

This difference is more likely to stem from NSW diabetics being seen by non-ACCHS practitioners, especially in metropolitan areas where there is greater choice and accessibility. In contrast, the CYREHP is the only source for eye care for the 12 remote Cape York communities. It is also likely that the high rate of diabetics seen by the CYREHP indicates effective underlying mechanisms for the referral of diabetics by primary health care providers *eg.* general practitioners, community and Indigenous health workers. The high ratio of all Cape York diabetics that presented to the CYREHP (92.6%) is testimony to this. As noted in Section 2.4.1, compliance rates exceeding 80% translate to substantial cost savings to the government [Taylor, 1997].

There are numerous possible explanations for the absence of the 39 diabetics (7.4%) from the CYREHP. Firstly, some primary health care providers may not be complying with the recommendation that all Type II diabetics be referred for annual ophthalmologic review [Murtagh, 1998; OATSIH, 2001; Taylor, 1997]. Secondly, some diabetics may be unable to access the CYREHP for family, cultural, social, and financial or transport reasons. And thirdly, they may have been missed by poor record keeping at the CYREHP (discussed below).

The evidence for the cost-effectiveness of retinal camera-based screening for DR [Javitt and Aiello, 1996; Maberley *et al.*, 2003; Taylor *et al.*, 2003]

discussed in Section 2.4.1 is acknowledged. However, this study provided evidence for the role of manual screening in co-detecting other conditions [Taylor, 1997]. For example, approximately 20% of cataracts were diagnosed in patients presenting with diabetes (Section 4.3).

5.2.2 Prevalence

The NSW Aboriginal Eye and Visioncare Programme reported that 16% of the diabetics attending it were found to have DR [Layland *et al.*, 2004]. The CYREHP detected a DR rate of 27.0% among its diabetics. There are no data to suggest that NSW has a lower background rate of DR. As with diabetics (see Section 5.2.1), this difference is more likely to stem from DR being diagnosed through other avenues in NSW, such as mainstream health care facilities, especially in metropolitan areas with greater choice and accessibility of practitioner. Conversely, the CYREHP is the only source for eye care for the 12 communities studied here. It is also possible, though less likely, that more sensitive diagnostic criteria were used by the CYREHP; the criteria used by the NSW programme was not reported.

As noted in Section 2.2.1, there is scant data on the prevalence of DR among Indigenous people. There has never been data on the prevalence of DR in Cape York so comparisons must be sought from elsewhere in Australia [Taylor, 1997]. Prevalence was calculated on a per-subject basis in this study so comparison with the WA study that reported on a per-eye basis

is not informative [Diamond *et al.*, 1998]. Cross sectional data from Katherine NT indicate a prevalence of 21% among diabetic patients in 1996 [Jaross *et al.*, 2003]. The prevalence of 25.0% calculated in this study is comparable but slightly higher. However, it is in the range detected for mainstream Australian adults (15-35%) [McCarty *et al.*, 2003; McKay *et al.*, 2000; Mitchell *et al.*, 1998; Tapp *et al.*, 2003]. It is generally agreed that there is a similar prevalence of DR across Indigenous and non-Indigenous Australia [Burns and Thomson, 2003; McCarty, 2003].

5.2.3 Severity

The severity of DR detected in Cape York is comparable to published data. The CYREHP detected a maculopathy rate of 8.3% (Table 4.8). This is similar to the 10% detected among Indigenous people in Katherine in 1996 [Jaross *et al.*, 2003] and 13% in the mainstream Melbourne population [McCarty *et al.*, 2003]. However, the latter study also detected an overall higher retinopathy rate (38%), suggesting either more serious underlying disease or a more sensitive diagnosis of maculopathy [McCarty *et al.*, 2003]. The latter is considered more likely.

Proliferative DR lies between severe non-proliferative retinopathy and maculopathy [Batterbury and Bowling, 1999; OATSIH, 2001]. There was no proliferative DR detected in the CYREHP. Elsewhere, the rate of proliferative DR has been estimated at 2.1% [Tapp *et al.*, 2003] and 1.3%

[Jaross *et al.*, 2003]. There is anecdotal evidence that the absence of proliferative retinopathy points to an underlying “resilient retina” among Cape York indigenous people, that slides precipitously into maculopathy from non-proliferative retinopathy [Dr. Mark Loane, personal communication, 13 June 2005]. It is also likely that proliferative disease has been classified as maculopathy in the interests of more conservative diagnosis in the CYREHP.

5.2.4 Interventions

The 20 patients that had laser treatment were considered to have vision-threatening retinopathy (VTR) [Burns and Thomson, 2003]. Hence, the prevalence of VTR is 15.1% (20 of 132 DR cases). Elsewhere, the prevalence of VTR among Indigenous people in Katherine has been estimated at 8.5% and 6.7% in 1993 and 1996, respectively [Jaross *et al.*, 2003]. Two factors explain the discrepancy. Firstly, Jaross *et al.* define VTR and maculopathy analogously. Hence, the maculopathy rate detected in this study, 8.3%, is comparable to the proportion of VTR found in Katherine. Conversely and secondly, the definition of VTR used in the CYREHP took in the more mild variants *viz.* non-proliferative retinopathy, over-estimating the cases of VTR. The crude earlier estimates of VTR from Pilbara (WA) and Katherine of 10-18% probably used a similar definition [Taylor, 1997].

Diabetic eye care was considered alongside numerous aspects of primary care for Indigenous diabetics in Torres Strait (TS), Northern Territory (NT) and Cape York (CY) [McDermott *et al.*, 2004]. The names of the Cape York communities were not published but are known to be Hopevale, Napranum and Wujal Wujal [Prof. Robyn McDermott, personal communication, 15 June 2005]. Table 5.1 presents the only eye care comparators reported by McDermott *et al.*. Note that the NT column appears to suggest an anomaly – more patients had an ophthalmology review than had an eye examination (which presumably include optometric consultations and should exceed the former) – but is presented here *verbatim*. The Cape York data are shaded. Cape York diabetics were best monitored although the results were not statistically significant.

Table 5.1: Diabetic eye review rates in Northern Australian Indigenous communities (2002-3) (From [McDermott et al., 2004]).

	NT (n=194)	CY (n=252)	TS (n=921)
Eye examination in previous 12 months	27 (14%)	185 (73%)	584 (63%)
Ophthalmologist review in previous 12 months	43 (22%)	122 (48%)	373 (41%)

Data from the CYREHP indicate that 181 patients had an eye examination in the period specified by McDermott *et al* (August 2001 to February 2002), of which 104 had ophthalmology reviews. These numbers align reasonably with those in Table 5.1. However, presenting complaints

for this cohort were not recorded in the CYREHP data so it cannot be determined if they were indeed diabetics. McDermott *et al.* audited patient records directly and are likely to have more accurate results.

The McDermott *et al.* study was used to corroborate the data provided to this study on the distribution and number of diabetics in Cape York. There is reasonable correlation between the number of diabetics in the three communities selected by McDermott *et al.* (n=252) and the data available to this study (n=222). This validation of the data allowed it to be used with greater confidence in the numerous calculations in this study concerning diabetes.

These benchmarks against the McDermott *et al.* data have important ramifications. The well-known mobility of the Indigenous population [Ewald *et al.*, 2003; Lansingh *et al.*, 2001] and the vigour with which McDermott *et al.* collected their data need to be borne in mind [McDermott *et al.*, 2004]. Notwithstanding these factors, the discrepancies are in the order of tens. Hence, it may be reasonably inferred that the CYREHP data are acceptable, at least for the purposes of the current study.

5.3 CATARACT

5.3.1 Prevalence

The dominance of cataract among the non-diabetic diagnoses reflects a historical and ongoing pattern among Indigenous people [Burns and

Thomson, 2003; OATSIH, 2001; Taylor, 1997; Taylor *et al.*, 2003; Thomson and Paterson, 1998]. The prevalence of cataract detected in the CYREHP, 2.3%, is similar to the self-reported prevalence of 2-3% among Indigenous and non-Indigenous Australians [ABS, 2002b; Burns and Thomson, 2003], but lower than the crude prevalence for Indigenous people of 3.5% (age-adjusted relative risk of 2 compared to non-Indigenous Australians) calculated in the 1970s by the NTEHP [Burns and Thomson, 2003; OATSIH, 2001; Taylor, 1997; Taylor *et al.*, 2003; Thomson and Paterson, 1998]. It is unlikely that the prevalence of cataract among Indigenous people has diminished since the 1970s given that it is increasing in mainstream Australia [AE, 2004]. Differing data collection methods are more likely to be responsible for the disparity.

This study provides evidence for the diverse aetiology and presentation of cataract. It is well known that cataract represents a common ocular endpoint for a number of systemic conditions such as diabetes, corticosteroid therapy and atopy [Batterbury and Bowling, 1999; Evans, 1998]. The link between diabetes and cataract has been demonstrated here with the proportion of diabetic patients being diagnosed with cataract. This study has also provided evidence for low vision being the primary presentation of cataract [Batterbury and Bowling, 1999; Evans, 1998].

5.3.2 Interventions

The data on referrals indicates the underlying structure of the CYREHP. The flow of surgical patients from all communities to Weipa is evidence of the referral system at work. As noted in Section 3.3.1, 98% of the data on cataract operations was missing so no comment on this key outcome measure can be made. Given the cost-effectiveness of cataract surgery [Busbee *et al.*, 2002; Kobelt *et al.*, 2002; Taylor, 1997] and the presence of national guidelines [OATSIH, 2001] discussed in Section 2.4.2, this represents a significant drawback.

5.4 REFRACTIVE ERROR

5.4.1 Prevalence

No comment can be made on the prevalence of refractive error because the actual diagnosis was not recorded. This represents another weakness of the CYREHP data.

5.4.2 Interventions

Comparisons with programmes around Australia are laden with confounding factors and non-uniform parameters of measurement. In the SA programme, 114 spectacles were prescribed [Taylor *et al.*, 2003] but there is no data on how many prescriptions were actually filled. The NSW South Coast programme dispensed 759 spectacles [Taylor *et al.*, 2003] but there is no data on the number of recipients.

The NSW Aboriginal Eye and Visioncare Programme dispensed “over 6000 pairs of (free) spectacles ... to over 5000 Aboriginal people in need” [Layland *et al.*, 2004]. The CYREHP dispensed 680 free pairs of spectacles to 568 people and prescribed 457 pairs of spectacles for private dispensing. Thus, 1.2% of the 9536 people in the 12 communities received spectacles every year – the same proportion as in the NSW programme.

Given that the major challenge of addressing refractive error among Indigenous people from rural and remote settings is the delivery of services [Taylor, 1997; Wildsoet and Wood, 1997], the performance of the CYREHP is encouraging. It demonstrates the efficiency promised by the model proposed in the 1997 Review and adopted by the CYREHP [Taylor, 1997].

5.5 OTHER EYE CONDITIONS

Although trachoma has been identified in successive reports and reviews as a major threat to Indigenous eye health [OATSIH, 2001; Taylor, 1997; Taylor *et al.*, 2003; Thomson and Paterson, 1998], this study found negligible evidence of it. Only 3 patients had diagnoses of infection of which only one had trachomatous scarring. This is a plausible finding. The presence of flies, arid climate and crowded housing are all associated with high prevalence [daCruz *et al.*, 2002; Ewald *et al.*, 2003; Miller *et al.*, 2004]. These factors are considered to be in decline in Cape York and there is anecdotal evidence

that trachoma has virtually disappeared since the days of the NTEHP [Dr. Mark Loane, personal communication, 14 September 2004].

Trauma is acute and predominantly attended by primary health professionals with urgent evacuation to tertiary hospitals (*eg.* Cairns Base Hospital) if necessary. The role of CYREHP has been to provide occasional follow up care. Trauma was the third most common reason for presenting to ophthalmologists (Table 4.2) but comprised only 1.4% of non-diabetic diagnoses (Table 4.10). There are no published data on ocular trauma in Indigenous communities and this study did not examine trauma more closely. Given the frequency of presentations for trauma, there is scope for future study.

Similarly, the prevalence of pterygium was not examined. The crude prevalence is 0.3% (21 cases in 6581 people, Table 4.10) but this is unlikely to reflect the true prevalence. Pterygium is rarely vision-threatening [Batterbury and Bowling, 1999], hence the CYREHP is unlikely to see the majority of sub-clinical cases.

5.7 SUMMARY

The results of this study indicate that the prevalence of DR and cataract in Cape York is comparable to that detected in Indigenous and non-Indigenous populations elsewhere in Australia. The rate of dispensing spectacles and access to its target population is comparable to the NSW

Indigenous eye health programme. The frequency of DR screening and review is better than in other regions.

These results point to the CYREHP's successes in fulfilling its *raison d'être*. However, they are based on incomplete data. The succeeding final chapter discusses the sources of missing data.

Chapter 6 ~ Data Collection

Missing data compromised the robustness of the findings of this study and the extent of analysis possible. Consequently, the full benefits of this study listed in Chapter 1 could not be realised. This chapter aims to identify all sources of missing data by regarding each step of the clinical and administrative process. The chapter and dissertation concludes by providing recommendations to improve data collection.

There are some missing data whose collection is beyond the realm of the CYREHP, such as population statistics for Laura. The CYREHP is also not responsible for the aberrant age-distribution data for Wujal Wujal (see Section 3.1.2). The nature of missing data and recommendations to improve its collection can be regarded from two standpoints – at the level of the community visit and at the level of each consultation. Before that is done, it is instructive to consider the clinical pathway and the process through which data are collected.

6.1 COMMUNITY VISIT PATHWAY

6.1.1 Before each visit

The schedule of visits and attending personnel is finalised at the beginning of each year. This information is circulated to all primary health care providers in Cape York to facilitate referrals, which are communicated to the Regional Eye Health Coordinator (REHC). The REHC uses this and

information from previous visits to compile the list of consultations for each community clinic.

6.1.2 At each visit

Upon arrival at each community, the REHC and Community Health Worker assemble all scheduled patients and their medical documentation. Unscheduled or “walk-up” patients are slotted into the clinic list by the REHC. The integration of dedicated pages for eye health entries within individual patient records is an initiative of the CYREHP. These pages can be faxed to the community that a patient is being seen at if s/he is travelling. All data for each consultation – date, personal details, presenting complaint, consultant seen, source of referral, diagnosis, treatment, referral destination etc. – are entered from patient notes into the database after each consultation by the REHC.

6.2 IMPROVING DATA COLLECTION

6.2.1 Individual consultations

The absent demographic data was noted in Section 3.2.1. The implications of the missing data have been discussed in depth in this Chapter and the two preceding it.

Given that a well constructed electronic database and dedicated eye health records already exist, the causes of missing data are simple: either they are not being recorded adequately in patient records by the eye health

professionals or they are not being entered into the electronic database by the REHC subsequently.

The analysis of missing data undertaken in Sections 4.1.3 and 4.1.4 indicates that both probably occurred. Certain eye health professionals were better at recording data than others (The OR for numerous comparisons were 1.8-1.99 and were omitted, see Section 4.1.3). Similarly, data recording was better at some communities (*eg.* Cooktown, Wujal Wujal) than others (*eg.* Weipa, Coen). However, given that the REHC is responsible for entering the data, the variability across communities is enigmatic. Perhaps the responsibility is being delegated to local health workers who are unfamiliar with the standards of data collection required.

Patients who were seen once only were especially vulnerable to having incomplete records. It may have been felt that stricter record keeping for these cases was not necessary given its diminished future utility.

The recording of word- or phrase-based data is both an advantage and drawback for the CYREHP. The advantage lies in the fact that it has been recorded at all, given that words and phrases take time to enter electronically. However, the variability in their formatting adds to the subsequent data cleaning workload.

It is suggested that a simple template-stamp be prepared that indicates the key parameters of presenting complaints, examination findings, diagnosis

and follow-up plan (Table 5.2). This template can be stamped by the eye health professional at the end of his/ her entry to summarise the consultation. The template contents can be coded and along with demographic and other consultation details obtained from the patient's chart, entered into the database by the REHC as soon as the patient exits the consultation. This system of coding is likely to save time and increase the fidelity and uniformity of the recorded data, especially if the same person records it each time. A similar coding system based on ICD-9 was developed by Professor Hugh Taylor for the NTEHP but is yet to be assimilated into electronic data collection systems nationwide [Prof. Hugh Taylor, personal communication, 18 April 2005].

Table 6.1: Template for summarising consultation information.

Presenting complaints:	
Examination:	
Diagnosis:	
Plan:	

6.2.2 Community visits

The data missing for certain community visits may have had wide ranging implications on the findings of this study. Three of the trips were to Weipa, the most populous community visited. Mapoon and Napranum, the site of the other visits missing from the database, are smaller in comparison but contain the highest proportional Indigenous population. In addition, ophthalmic diagnoses for DR and cataract from Laura and optometric

diagnoses for cataract from Mapoon were missing. These missing data would have led to the underestimation of all prevalences calculated in this study.

The causes for these missing data are unknown but can be speculated upon. It is unlikely that the REHC who is responsible for data recording was absent as no visit is undertaken without her/ his presence. Nor is it likely that patient notes were not completed during these visits. The facilities to record the data, namely the laptop on which the database is located may not have been taken on these visits or may have malfunctioned. It is also possible that time constraints may not have permitted immediate data entry. In both of these contingencies, the back-up system of manually recording data from each consultation for subsequent electronic entry should have been implemented. It is recommended that the laptop computer be used during each community visit. In the event of equipment failure, the manual back-up should be used and data transferred to the database at the earliest opportunity.

It is also recommended that data be audited at the conclusion of each community visit. This will enable gaps to be filled before the team leaves the community. The schedule of visits should be adjusted to take this into account. However, it is hoped that efficient and prompt data collection at consultations will reduce the time required for this audit.

6.2.3 Training and feedback

Training on the importance of data and the methods of efficient and effective data collection is required. The benefits extend beyond data collection per se. A sense of empowerment and appreciation of the wider context of the CYREHP are likely to result. Face to face training is preferred but may be difficult to arrange given that staff are located in Cape York, Cairns and Brisbane. Electronic conferences with pre-prepared resource material are a reasonable alternative.

It is also important to inform local stakeholders (*eg.* Community Health Workers, GPs, community elders) of the findings of this study and the gaps identified. This will enhance their sense of participation in the programme. For example, they may be encouraged to remind patients to be more diligent with recalling and conveying clinical information.

6.3 ADDITIONAL VARIABLES AND ELECTRONIC REGISTRY

6.3.1 Additional variables

The expansion of the current electronic database to include specific diagnoses for the sub-types of refractive error (myopia, presbyopia, amblyopia, astigmatism) would enable analysis of its prevalence in the future. The introduction of a new variable to reflect this is possible and would add value to the database [Rowan Churchill, personal communication, 16 June 2004]. However, it should be devised and

introduced in consultation with the optometrists, the REHC and local health workers.

Consideration should also be given to introducing variables denoting the outcomes of ophthalmic procedures (*eg.* cataract surgery) such as complications, success and revision rates. These data can inform improvements in clinical practice and resource allocation decisions and address a significant gap in the knowledge base (see Section 2.4.2.) [Taylor, 1997].

As noted in Section 2.2.5, there is scope for a similar contribution to eye trauma literature [Burns and Thomson, 2003; Taylor, 1997]. The frequency with which eye trauma is seen by the CYREHP is a concern [Dr. Mark Loane, personal communication, 15 June 2005]. It is timely to introduce variables to monitor the patterns of eye trauma.

6.3.2 Electronic registry

Given the increases in diabetes prevalence and incidence anticipated, a diabetes registry with an inbuilt patient recall system would be an invaluable clinical and public health resource [Burns and Thomson, 2003; McCarty, 2003]. Such a registry and tracking system was proposed in the 1997 Review [Taylor, 1997] but has not been adopted across regional eye health programmes for a variety of reasons mostly to do with ease of use [Taylor *et al.*, 2003]. The diabetes registry should be linked to the CYREHP database

to provide a comprehensive electronic resource. Furthermore, it may be linked to a web-based national database, which can be updated in real time [Ron Harris, personal communication, 16 June 2004]. However, the design of the system must be undertaken in close consultation with the REHC, community health workers and others who will use it and benefit from it (*eg.* primary health professionals, local health authorities) to ensure a robust, user-friendly and acceptable system.

In addition, annual audits will ensure a more complete data set. No community visits are undertaken during December to March due to poor access precipitated by wet weather. This period presents a good opportunity to perform an annual audit of the data. Community Health Workers could electronically transfer missing data to the REHC (based in Cairns). Subsequent community visits could be used to fill in remaining gaps in the data.

6.4 SUMMARY

The CYREHP was set up to address the eye health needs of Cape York communities. This study aimed to document the patterns of eye disease in Cape York and the responses of the CYREHP to them. It did this through a retrospective audit of electronic data collected between October 1999 and October 2004.

However, data was lost at every step of the clinical and administrative process, leading to incomplete analysis of disease and service delivery patterns. Recommendations to improve data collection have been made to enhance the programme's performance and to enable it to better document its future disease challenges and responses.

6.5 RECOMMENDATIONS

1. That a culture cognisant of the importance of data collection be fostered throughout the CYREHP and its staff. Such a culture will facilitate the collection of good quality data across the communities and for each consultation.
2. That all staff be trained in data collection methods.
3. That audits of the data be conducted at the end of each community visit and annually.
4. That local stakeholders be informed of the findings of the study and be encouraged to make positive contributions to the success of the programme and its collection of data.
5. That a template-stamp summarising the four key parameters – presenting complaints, examination findings, diagnosis and follow-up plan – be applied to the end of each patient entry and completed by the attending consultant.

6. That all non-identifying data be coded to ease and standardise data entry.
7. That data be entered into the electronic database by the REHC as soon as possible after each consultation.
8. That the laptop computer containing the database be used to record data at each community visit. In the event of computer failure or absence, the manual back-up system should be used and data transferred to the database at the earliest opportunity.
9. That coded variables to specify the diagnosis of refractive error; outcomes of ophthalmic procedures; and eye trauma be added to the database.
10. That a diabetes registry for Cape York be designed and implemented and linked to the existing database. That the database be expanded into a patient tracking and recall tool.
11. That all recommendations be implemented in consultation with the personnel of the CYREHP and include local health authorities and primary health professionals where appropriate.

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Appendix 1: Map of Cape York

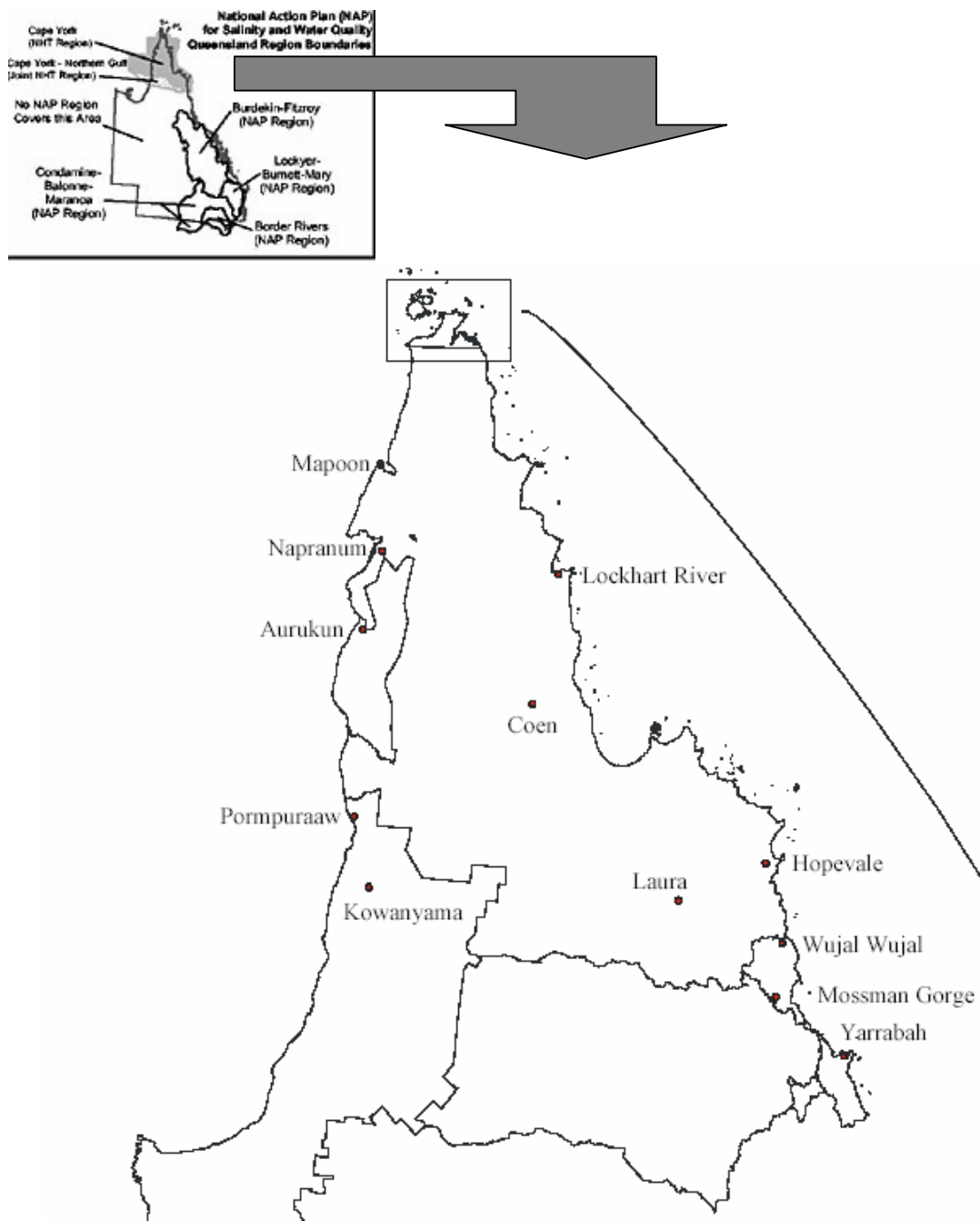


Figure A1: Map of Cape York Communities (from [QG, 2001]).

The map of Queensland is shown in the top left hand corner. Cooktown is situated on the coast approximately halfway between Wujal Wujal and Hopevale. Weipa is situated on the coast, 5km North-West of Napranum.

Appendix 2: Proposal submitted to Wu Chopperen Medical Service Management Board

The following is an excerpt from the 8-page proposal submitted to the Wu Chopperen Management Board on 13th February 2005. Only the portions pertaining to the benefits of this study and data handling are presented here. This proposal was approved verbally on 24 February 2005 and the raw data set was received on 25 February 2005.

“Describing the epidemiology of eye disease and delivery of eye health services to Indigenous communities by The Cape York Eye Programme 2001-2004”

A2.1 RESEARCH IMPLICATIONS/ HEALTH BENEFITS

The documentation of disease epidemiology and service provision quantification will have numerous public health benefits. Firstly and most importantly, it will inform effective and efficient resource allocation decisions both at local and Governmental (State and Commonwealth) levels to improve eye health services to Cape York. Secondly, in doing so, it will allow this Queensland programme to be benchmarked against others under the NATSIEHP [Jaross *et al.*, 2003; Layland *et al.*, 2004; Mak *et al.*, 2003]. And finally, it will allow assessment of the ideal underlying the Specialist Eye Health Guidelines [OATSIH, 2001]. A copy of the completed report from

this study will be submitted to the 12 Indigenous communities and Wu Chopperen Medical Service and meetings held between the REHC and community representatives to explain the findings.

A2.2 ETHICS

Utmost care will be taken with the data. The confidentiality of data will be ensured at all times. The unique identifiers will conceal all personal information from the data analysis team. Secondary data will be stored centrally at the School of Population Health with a copy at Wu Chopperen where primary data will be stored. No individual patient will be identified at any time including final publication of results in the public domain. Final publication will only be with the approval of the communities and Wu Chopperen, both represented by the REHC. The study will be underpinned by adherence to NHMRC and ACITHN guidelines [ACITHN, 2004; NHMRC, 2003].

Appendix 3: List of Variables

Variable Name	Type	Description
ClientNumber	Ordinal	Unique numerical identifier for each patient
ConsultationID	Ordinal	Unique numerical identifier for each consultation
ConsultationNumber	Ordinal	Consultation number
ConsPlaceCode	Categorical	Community at which consultation occurred
DateofConsultation	Date	Consultation date
Optometrist	Binomial	Was optometrist seen? 1=Yes, 0=No
OptomCode	Categorical	Code for name of optometrist seen
Ophthalmologist	Binomial	Was ophthalmologist seen? 1=Yes, 0=No
OphthalCode	Categorical	Code for name of ophthalmologist seen
OphPCMaj	Categorical	Primary presenting complaint for ophthalmic consultation
OphPCMin	Categorical	Secondary presenting complaint for ophthalmic consultation
OptPCMaj	Categorical	Primary presenting complaint for optometric consultation
OptPCMin	Categorical	Secondary presenting complaint for optometric consultation
OphNonDiabDiag	Categorical	Non-diabetic diagnosis recorded at ophthalmic consultation
OptNonDiabDiag	Categorical	Non-diabetic diagnosis recorded at optometric consultation
OphDiabDiag	Categorical	Diabetic retinopathy status recorded at ophthalmic consultation
OptDiabDiag	Categorical	Diabetic retinopathy status recorded at optometric consultation
OphRightDiabRetLaser	Binomial	Was laser treatment for DR delivered to right eye? 1=Yes, 0=No

OphLeftDiabRetLaser	Binomial	Was laser treatment for DR delivered to left eye? 1=Yes, 0=No
OphRefDestinationTeam	Categorical	Referral personnel requested by ophthalmologist
OphRefDestinationVenue	Categorical	Referral location requested by ophthalmologist
OphReferralReason	Categorical	Referral reason given by ophthalmologist
OptoRefDestinationTeam	Categorical	Referral personnel requested by optometrist
OptoGenTreatment	Categorical	General treatment administered by optometrist
OptoHospSpecs1	Categorical	Type of spectacles given free by optometrist – first pair
OptoHospSpecs2	Categorical	Type of spectacles given free by optometrist – second pair
OptoPvteSpecs	Categorical	Type of spectacles prescribed by optometrist