TRACHOMA AND VISUAL IMPAIRMENT IN THE ANANGU PITJANTJATJARA OF SOUTH AUSTRALIA

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Abstract

This thesis examines the epidemiology of eye disease in the Anangu Pitjantjatjara people of South Australia.

A literature review examines the methods for assessing visual disability. The major causes of blindness in the Australian Aboriginal population and the methodological problems associated with eye health surveys are discussed.

Past surveys of blindness in Australia are reviewed, demonstrating the imperfect knowledge of this area. Data relating to the Aboriginal population are presented and used in subsequent chapters for comparative purposes. The past causes of blindness in the Aboriginal population, with an emphasis on trachoma, are also reviewed.

The origin of trachoma in Australia is discussed, with the conclusion that although it may have been present in Australia for some time, the pattern of disease demonstrated by successive surveys indicates that it was not endemic in the north-west of South Australia prior to the coming of Europeans.

The design and conduct of a population-based prevalence survey is described. It examined the prevalence of trachoma, visual impairment and blindness in a sample of 1,514 individuals, aged 0-90 years of age, representing approximately 58% of the Aboriginal population in the Pitjantjatjara and Yalata lands.

Active inflammatory trachoma was found in 266/1514 (17.6%) of the sample, cicatricial trachoma in 382/1514 (25.2%) and blindness (Australian definition) in 22/1514 (1.5%) of the sample. The major causes of monocular and binocular blindness were found to be trachoma, cataracts and trauma. Women were found to have a increased prevalence of blindness and severe trachoma than males. The service role of the survey is also described.

The results are compared with those of the National Trachoma and Eye Health Program (N.T.E.H.P.) survey of 1976, which was performed in the same area. The comparison

includes a discussion of the methodological problems, and a comparison of grading schemes, the sample and source populations, and the results between the two surveys. A statistically significant decline since 1976 in the prevalence of binocular blindness, poor vision, inflammatory and cicatricial trachoma was found. These results were consistent across three sets of data.

An analysis was performed of intra-observer and inter-observer error in the survey. The use of duplicate examination sheets for this purpose is described, with the conclusion that there was only a small amount of variation between observations for trachoma grading and visual acuity testing. In another study, comparing the grading of trachoma with and without magnification, no differences between the two methods was demonstrated.

The ethical issues of research in Aboriginal communities is discussed with reference to the handling and ownership of data. Several practical problems which arose whilst performing the survey are documented and a review of the methodological issues that were apparent is undertaken. The main implications of the research findings are discussed, these include, the treatment and control of trachoma; the provision of services for women; the evaluation of inter-observer and intra-observer errors in surveys; the use of loupes for grading trachoma, and aspects of the survey that ensured its success in an Aboriginal community.

STATEMENT

This thesis contains no material which has been accepted for the award of any other degree or diploma in any University or College.

To the best of my knowledge and belief this thesis contains no material published or written by another person except where due reference is made in the text.

The author consents to the thesis being made available for photocopying and loan if applicable, if accepted for the award of the degree.

Nigel Stocks

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Chapter 1. Literature Review: Eye Health and Disease

1.1 Introduction

This thesis examines the eye health of the Aboriginal people (the Anangu Pitjantjatjara) in the north-west of South Australia. The study arose from a telephone conversation with Dr. Henry Newland early in 1989. A statewide blindness and visual impairment prevalence survey was being undertaken, it used a multi-stage sampling technique of people aged 55 and older who were listed on the electoral roll. It was felt that a concurrent survey of the Aboriginal population was both timely and necessary, because the South Australian Aboriginal Trachoma Program wanted to assess the progress of its work and obtain new base line data for the planning of future work. The eye health of the Anangu Pitjanjatjara had been documented in several eye surveys. In the mid 1960s Mann surveyed two communities in what is now the Anangu Pitjanjatjara (AP) lands (Mann and Rountree1968). Later in the same decade, Moore et al. (1965), examined people from urban and rural areas, and included two communities from the north-west of South Australia. During the 1970s the National Trachoma and Eye Health Program (N.T.E.H.P.) sponsored by the Royal Australian College of Ophthalmologists (R.A.C.O.), and financed by the Federal government, comprehensively surveyed the rural Aboriginal population of Australia and the Anangu Pitjantjatjara were amongst the first to be examined (R.A.C.O. Report 1980). Finally in 1985, a National Trachoma Program review included several A P communities in a comparison with the results of the 1976-1979 N.T.E.H.P. survey (Trachoma and Eye Health Program (T.E.H.P.) Report 1985).

These surveys, particularly the last two, demonstrated the poor eye health of Aboriginal people in Australia. The surveys also identified three common eye diseases which were responsible for the high prevalence of blindness found: trachoma, cataracts, and eye trauma. Although several cross-sectional surveys have been undertaken, only one comparative study (the 1985 review), had been attempted previously in South Australia, and it was limited to an assessment of trachoma. There has been one other comparative study in Australia (in the Northern Territory), it examined changes in trachoma from the 1940s to the 1980s (Meredith et al. 1989). No surveys have assessed visual acuity changes over time and although trachoma is a marker of eye health and socioeconomic development (section 1.3.1.), and

could be used solely to assess changes in the eye health of a population, an analysis of changes in visual impairment, adds to any comparative description.

The following literature review examines several areas of relevance to the assessment of eye health. The assessment of visual acuity, methods of obtaining data on blindness and the difficulties with international comparisons of eye disease or blindness prevalence. The biology and classification of trachoma is reviewed to establish background information on its epidemiology. These include elements of particular relevance to the affected Aboriginal population; the way it is acquired, its ability to infect multiple sites in humans, its descriptive epidemiology, transmission, and methods of treatment or prevention (section 1.3). The comprehensive picture of trachomatous infection established is used in chapter six to discuss the control and possible eradication of trachoma from rural Aboriginal communities.

Another element of the literature review concerns the methodological problems in eye disease epidemiology. The problems associated with cross-sectional prevalence surveys is discussed, and the difficulties in using this type of study for comparisons over time examined.

1.2 Assessment of Vision

In the examination of the eye an assessment of visual acuity is essential, both as an aid to clinical diagnosis and for following the progress of an eye disorder.

In eye surveys an assessment of visual acuity can be the first step in screening the population for blindness, or for ocular conditions such as cataract. Once identified, the affected people may then be examined, a cause diagnosed and treatment with follow-up arranged. It is also important to identify differences in the definition of blindness, and to recognise that the major causes of blindness, which reflect genetic, socioeconomic, climatic and ophthalmic care factors, vary between countries. Additionally in eye epidemiology, it is important to be aware of problems with blindness estimates when making international comparisons.

1.2.1. Visual Acuity

The ability to see is an important sensory function because vision shapes our perceptions of the world and affects our interaction with it. Good visual acuity is central to survival in hunter-gatherer societies, and blindness in developed countries is a feared disability. Previous surveys have documented the very good visual acuity of Australian Aboriginal people, particularly in the younger age-groups (Edwards et al. 1976). However, older Aboriginals have rates of blindness comparable to those found in developing countries (R.A.C.O. Report 1980). It is a tragedy, therefore, that a significant proportion of older Aboriginals from rural areas are condemned to years of poor vision or blindness.

Although the standard for testing visual acuity is well defined and comparable internationally, blindness has many definitions. These definitions vary from country to country, and may depend on the residual visual acuity in the better eye with correction, or the degree of impairment in the field of vision. Some countries rely on a functional definition rather than a measure of sensory capacity (Goldstein 1980). The World Health Organisation (W.H.O.) defines blindness as "a corrected visual acuity in the better eye of count fingers at one metre or worse" (W.H.O. 1973). The comparable current Australian definition is less restrictive: "a corrected visual acuity in the better eye of less than 6/60" (Social Security Department 1991).

Differences in objective definitions, and the reliance by some countries on flexible functional assessments, reflect economic, social and technological factors. The cost of providing blindness pensions or facilities allows only Western countries a liberal interpretation of blindness. Socio-cultural factors emphasizing family support may be more evident in Third World countries which lessens the need for governmental support to those with visual disability (Goldstein 1980).

1.2.2. Causes of Blindness in the World

It has been estimated that there are at least 28 million blind people in the world (Thylefors et al.1987). The majority (90%) live in Third World countries where blindness rates are 10 to 20 times higher than in developed nations. Using epidemiological models, a blindness rate of 1% occurs in developing countries with endemic trachoma, foci of xerophthalmia or onchocerciasis and insufficient eye care facilities. A rate of 0.5% has been reported in countries of intermediate development where there are problems with the provision of eye care services, particularly cataract surgery. In developed countries a rate of 0.2% is considered representative (Thylefors 1990).

Blindness is most often found in rural areas where socioeconomic conditions are poor, medical facilities meagre or non-existent, and basic services (e.g. sewerage, power) lacking. Over two-thirds of existing blindness is avoidable, either correctable with cataract surgery, or preventable as with trachoma (Sommer 1988).

World-wide, the major causes of blindness are (Thylefors 1987):

Trachoma (section 1.3.1.)

Trachoma infection commences in infancy in endemic areas, with reinfection and lack of treatment leading to progressive scarring of the conjunctiva. The eyelashes invert (trichiasis), touching the cornea, causing corneal opacity and eventual blindness.

The intensity of the inflammation in its active stage, as well as its prevalence, is important in predicting the risk of blindness. Socio-cultural, as well as economic factors affect its prevalence in a community. Whilst economic and simple hygiene changes have been noted to reduce its impact, treatment campaigns using tetracycline eye drops, systemic antibiotics, and surgery for trichiasis, are needed in areas where there is a high prevalence of trachoma.

Xerophthalmia

Vitamin A deficiency affects children up to five years of age. Because mortality is high in severe blinding disease, its impact may be underestimated. Seasonal and geographic variations occur owing to the variable availability of food containing vitamin A and to dietary habits in regional populations.

Cataract (section 1.3.2.)

Cataract is recognised as the most common cause of visual loss in the world. It is closely linked to ageing. Whilst in Western countries it is readily corrected with surgery, in developing nations an already established backlog and the lack of medical facilities combine to make cataracts a major public health problem. Risk factors for cataract have not been conclusively identified. Preventive measures or primary interventions are speculative, and therefore surgery remains the only option.

Onchocerciasis

Onchocerciasis is a parasitic disease which directly affects the eye. It is limited to savanna and forest locations in Africa and some areas of Central and South America. Chemical control of vectors is needed. Treatment requires ophthalmological review and chemotherapy.

Glaucoma

Glaucoma presents in the majority of cases in one of two forms; an acute, angle closure glaucoma with symptoms of pain and loss of vision, or in a chronic form in which the person has a progressive loss of visual fields. It is related to increasing age and is a growing problem in Western countries.

Ocular trauma (section 1.3.3.)

Trauma is often a cause of unilateral loss of vision. In developed nations it is associated with industrial and motor vehicle accidents. In Third World countries minor ocular trauma due to

foreign bodies may, if neglected, cause secondary bacterial infection and lead to corneal scarring and blindness in the affected eye.

Refractory anomalies and amblyopia

Severe myopia may functionally impair a person when suitable corrective lenses are not available. Non-correction can lead to a blindness in the affected eye.

1.2.3. **Methods for Obtaining Data for Blindness**

Sources of information on the prevalence and causes of blindness vary between countries. The theoretical methods include (Goldstein 1980):

Censuses

Although every household is approached, thus theoretically covering the whole population, problems exist with:

1. Self or proxy reporting of information.
2. Objective definitions of blindness.
3. Possible exclusion of institutionally blind, chronically or mentally ill people.
4. Inadequate or lack of recording of the cause of blindness.
5. No provision for assessing visual acuity.

It might be possible, in countries such as Australia, to obtain data on the number of people receiving blindness pensions, but difficulty has been encountered with data when the legal definition of blindness was not used consistently and no clinical examination carried out (Banks and Hutton 1985). Basic socio-demographic data could; however, be obtained, enabling better assessment of needs.

Estimates

Relatively inexpensive estimates are based on previously collected data with extrapolation, either over time, from one year or decade to the next, or over geography, from one country to another or one area to another within a country.

Extrapolation could also occur from one data source, say prevalence of diabetes, to another, such as the expected prevalence of diabetic retinopathy.

Several assumptions often need to be made regarding age, sex and racial distributions which can reduce the usefulness of the information. In addition, the known or unknown accuracy of the original source may make the accuracy of conclusions reached impossible to estimate.

Registers

Blindness Registers have several advantages (Goldstein 1980):

1. They are sources of accurate information on age, sex, race and cause.

2. They enable trends to be detected as continuous reporting is involved.

3. With continual updating (eliminating those who have died, moved on, or had their vision restored), accurate prevalence data may be estimated.

4. Service provision may be based on register data.

There are a number of disadvantages, which include:

1. Self selection of registrants may affect the applicability of the statistics to the general community.

2. Voluntary registration implies there must either be an advantage to the blind person, the referring ophthalmologist or optometrist. This is linked to the availability of services, which may be subject to variation over time, and may be applicable to certain individuals only e.g. socially disadvantaged groups.

3. Newly registered blind may not be recently blind, and may reflect a delay, either by the person or ophthalmologist, in recording the information, therefore not providing useful incidence data.

4. Registrants may differ between geographic areas, making cross-comparison difficult.

5. The function of the Register is to provide services and not data. Unless a specific effort is made to ensure the completeness and accuracy of the information, its use for statistical purposes may be invalid.

Surveys

A census survey, whilst advantageous in terms of population coverage, is impractical with large numbers of people. Sample surveys, using a random subset of individuals who are representative of the entire population, are more economical and theoretically just as accurate.

Prevalence rates may be estimated from sample surveys, and if clinical information is obtained by examination, then accurate data on visual acuity and causes of blindness may be obtained.

However, incidence data are not obtainable unless surveys are repeated at short intervals. Also institutional populations are often ignored and any degree of self selection, including refusal to participate, can bias the result.

The W.H.O. has developed survey methodology which incorporates several elements (Thylefors 1987):

1. A preliminary local census, usually on a house to house basis.

2. Preliminary screening of visual acuity at the 6/18 level, in accordance with the internationally accepted definition of low vision. Further testing is performed

if the threshold is not passed, to establish the level of visual acuity (the Snellen "illiterate E" chart is used).

3. A basic eye examination using simple x2 loupes.

4. Grading trachoma or xerophthalmia if appropriate for the country.

5. A detailed eye examination on those individuals who are blind or have low vision.

6. Assessment of the need for treatment or further care.

1.2.4. International Comparisons

Demonstration of statistical differences between countries in the prevalence or causes of blindness has its problems. Although great care may have been taken in collecting the data from registers or conducting surveys, variation may be attributable to differences in definition, classification of disease, or diagnostic acumen, or to a range of sampling problems. Goldstein outlined several areas of importance (Goldstein 1980). Problems occur due to differences in definition, in coverage and to differences in ophthalmological resources. There are also problems due to differences in classification and methods of data collection.

A careful assessment of both the results and the methodology is therefore required for valid international comparisons to be made. These comparisons can be useful in determining the aetiology of an eye disease when it is differentially distributed between countries.

Summary

Vision is an important sensory function. Visual acuity testing has been internationally standardized. Although the W.H.O. definition of blindness is well known, individual countries

adopt standards that are applicable to the socioeconomic conditions prevailing in their regions.

The major causes of blindness throughout the world vary, but most are preventable or readily treatable, indicating that there is a great burden of unnecessary blindness in the world.
There are several methods for obtaining information about the prevalence of blindness, each has methodological problems which either must be overcome or acknowledged in presenting the data. International comparisons must therefore be carefully scrutinized to ensure the validity of the conclusions.

1.3 The Major Causes of Blindness in Aboriginal Australians

1.3.1. Trachoma

Trachoma has been previously identified as an important cause of visual disability in the Australian Aboriginal population (R.A.C.O. Report 1980). Its relationship with socioeconomic development, social and cultural factors has been demonstrated (Marx 1989). An understanding of its history, biology, and epidemiology is therefore important if treatment and prevention programs are to be effective.

2.1.1. Overview

Trachoma is a term that describes both the acute infection caused by the organism *Chlamydia trachomatis*, and the long term sequelae of repeated infection which are, trichiasis or inversion of the eye lashes, and corneal opacity.

Trachoma affects approximately 500 million people world wide (M.M.W.R. 1982), mainly in the rural areas of the tropical and sub-tropical zones. Trachoma is associated with adverse living conditions and poor socioeconomic development. Although readily treatable with antibiotics the disease remains endemic in many underdeveloped nations (West and Taylor 1988, Carmichael et al. 1982). Six to nine million people are estimated to be blind from trachoma, with many more suffering partial loss of vision (Dawson et al. 1981 a). It is the leading cause of preventable blindness in the world today (Tabbara 1990).

A review of current literature on trachoma suggests that without any immediate prospect of a vaccine, or of rapid socioeconomic development, its effective eradication will rely on community-based action, with the role of the water supply, sewage disposal, and traditions of, and facilities for, personal hygiene being of equal or greater importance than the use of antibiotics (Smith 1991).

2.1.2. History

Trichiasis was known and treated in China in the 27th century B.C. and trachoma was thought to be endemic among the Sumerians of Mesopotamia before 2,000 B.C. (Duke-Elder 1965). Trachoma was demonstrated by Ebers in 1889 in evidence from papyri, to be present in Egypt 3,500 years ago (MacCallan 1913). Hippocrates included some works on trachoma and trichiasis in the Corpus Hippocraticium (Mettler 1947). An Alexandrian ophthalmologist, Heliodorus, in the 2nd century B.C., described a surgical procedure for trichiasis (MacCallan 1931). In Rome, Celsus wrote about trachoma "aspiritudo" at the time of emperor Nero. He maintained the Greek notion of trachoma as a disease causing runny eyes with inflammation and granulation of the inside of the eyelids (Mettler 1947). It appears that little progress occurred in ophthalmology from the 2nd to the 7th centuries; however, from the 8th to the 14th centuries A.D. there were at least 60 Arabic ophthalmologists who described and treated trachoma. Very little was documented in the years between the decline of Arabic science and the emergence of trachoma in Europe in the 1900s (Al-Rifai 1988).

Trachoma was probably introduced into Europe for the first time by crusaders returning from Palestine (Darouger and Jones 1983), it was reintroduced after the Napoleonic Wars in Egypt (1798-1802), being spread quickly by the returning French and English troops (MacCallan 1913), and was responsible for repeated epidemics in the early decades of the last century (Boldt 1904). Moorfields Eye Hospital was established in 1805 to treat the trachoma found in the East End of London (Jones 1980).

There was much dispute in scientific circles about its aetiology and transmission. Some held it to be non-contagious and defended the theory of a spontaneous miasmic origin. However with advances in bacteriology and other scientific knowledge, the theory that trachoma was an infectious disease spread by close contact was gradually recognised (Boldt 1904).

However primitive such theories seem in retrospect, some of the observations and experiments performed in the late 19th century were remarkably accurate. Researchers and clinicians identified family, socioeconomic and personal factors that were important in the

epidemiology of trachoma (Boldt 1904). Specific suggestions were made for improving hygiene among the troops under Napoleon (Feibel 1983), and among the people who lived in the tropics (Elliot 1920). This indicates that although the disease was not well understood, some principles of its prevention were.

2.1.3. **Trachoma Biology**

Trachoma is an infectious disease caused by the organism *Chlamydia trachomatis*. Chlamydia is an obligate intracellular bacterium which possesses a cell wall both DNA and RNA, and which divides by binary fission. The organism has two alternating forms: the elementary body which, although infective, is not metabolically active or capable of replication, and the initial body, which cannot survive outside the host cell, but can divide and is metabolically active. The organism was first grown by T'ang et al. in Peking (1957).

Infection with *Chlamydia trachomatis* has been described as occurring in two patterns reminiscent of treponemal disease, yaws and syphilis respectively (Schachter and Dawson 1981). It appears to be a pathogen specific for humans (Fletcher and Gordon 1990) and 15 serotypes have been identified (Schachter 1978). D-K, L, L_2, L_3 predominate in sexually transmitted disease and serotypes A, B, Ba, C are invariably associated with classic trachoma in endemic areas of developing countries (Schachter and Dawson 1981).

Paratrachoma (also called inclusion conjunctivitis or inclusion blennorrhea) has been used to describe the cross-over of sexually transmitted serotypes to ocular sites (Viswalingan et al. 1983), which usually occur in neonates. The signs and symptoms are typical of classical infection, and although not common this has important implications in the pathogenesis and treatment of chlamydia infections.

The clinical features of ocular infection are as follow (Darougar and Jones 1983):

Incubation Period

The incubation period is one to three weeks as demonstrated in human volunteers.

Symptoms

The usual features are: eye irritation, a foreign body sensation, itching, and a watering mucopurulent discharge with redness and swelling of the eyelids. From the experience of ophthalmologists in the field, it appears that rural populations often accept the symptoms of infection without complaint.

Signs

The signs have been described (Tabbarra 1990) as: periocular lymphadenopathy which rarely occurs, except in the early form, and a superficial peripheral and superior keratitis followed by pannus formation (Pannus is a superficial vascularization of the cornea with infiltration of granulation tissue). Limbal follicles can occur, which heal to form characteristic Herberts pits, which are scars of the semilunar area of the limbus and appear as small punched out holes. Follicles occur which may be pinhead, localized or whitish-grey elevated nodules. They occur on the conjunctiva and sometimes there is diffuse oedema and a papillary reaction associated with a conjunctivitis.

The natural history has been briefly described as an initial inflammatory stage in early childhood with diffuse papillae involving the conjunctiva, usually seen on the upper tarsal plate. Repeated infection, followed by chronic inflammation, then leads to conjunctival scars, contracture of the lids with inversion of the eyelid (entropion) and ingrowing (trichiasis) of the eye lashes. This eventually progresses to corneal scarring, corneal opacity and visual impairment. Secondary bacterial involvement can hasten the process. Blindness can be the final result if the trachomatous infection is left untreated.

2.1.4. Classification of Trachoma

One of the first trachoma classifications developed was based on MacCallan's several years of experience working in Egypt (MacCallan 1913).

Trachoma I - seen typically after *Chlamydia trachomatis* infection has occurred. Greyish follicles are seen on the upper tarsal plate.

Trachoma IIa - in which follicles predominate, often associated with ocular discharge.

Trachoma IIb - in which papillary hypertrophy coexists with the follicles

Trachoma IIc - trachoma complicated by chronic gonococcal conjunctivitis

Trachoma III - in which cicatrization (conjunctival scarring and contracture of the upper tarsal plate) is beginning.

Trachoma IV - in which cicatrization is complete.

Several other classifications have been developed (Verin et al. 1987); however, they have often been complicated and suited only to specialist interpretation . Although detailed, the reliability of these classifications has been questioned (Brilliant et al. 1983 b), and modified versions have been tried (Tielsch et al. 1987). Recently a simplified five sign system has been developed to overcome the shortfalls that were evident in previous systems (Thylefors 1987, Taylor et al. 1987). The new classification, as its name implies, has only five signs that need to be recognized as being present or absent. These are trachoma follicles (TF), trachoma intense (TI), trachoma scarring (TS), trachoma trichiasis (TT) and corneal opacity (CO). The advantages of the five sign system are: it avoids grading the severity of a particular sign and therefore is easier to use; and in inter-observer trials it was shown to reduce inter-observer errors (Taylor 1987 b). The grading system is outlined in appendix 4.

2.1.5. Acquisition of Trachoma

The early acquisition of trachoma is inferred from prevalence studies which show infection soon after birth, with peaks at 1-2 years of age (Dawson et al. 1976). Scarring has been shown to occur in 3-6 year olds, with 50% showing scarring at age 10 in endemic areas (Kupka et al. 1968). However in Tanzania, little scarring is observed in children and the peak prevalence of active disease is among 3-5 year olds (West et al. 1991). The acquisition of trachoma can therefore be seen to vary between endemic areas.

The progression of trachoma is that of a chronic infection with intermissions and relapses. Observations in animal experiments have suggested that periodic reinfection plays a role in producing the cicatrization reactions that lead to corneal scarring and lid distortion (Monnickerdam et al. 1980 a+b and Monnickerdam and Pearce 1983). A longitudinal study of trachoma incidence in three groups of school children in Taiwan showed many examples of intermittent trachoma infection, apparently due to reinfection or relapse (Woolridge et al. 1967). More recently, reinfection has been viewed as the main cause for relapse. In a ten year study, again in Taiwan, 32 households containing adults and children, were followed with repeated clinical and laboratory observations, the study demonstrated that progression of trachoma to pannus and scarring occurred only after reinfection (Grayston et al. 1985).

Epidemiological studies in South Africa, looking at household clustering and serological evidence of trachoma infection, support the idea of a multicyclic disease based on the family unit, that is, a disease that recurs in a group of people living together (Ballard et al. 1983). In Iran, Treharne showed that reinfection within households was by the same Chlamydial serotype, with the bulk of infective organisms being shed from the eyes of infants and young children (Treharne 1985).

The multicyclic nature of trachoma implies not only reinfection but spontaneous healing as an important aspect (Grayston et al. 1985). Researchers followed 877 children over several years and demonstrated reversion to normal eyes in one third of those with trachoma at entry to the study, and of the 43% who developed trachoma during the 6 years study, again one third

reverted to normal (Woolridge et al. 1967). They also demonstrated, in primary cases, that the clinical disease diagnosed as trachoma lasted from less than one to two years (average one year). In all but one case, tear antibodies disappeared close to the time classical disease ceased, but serum antibodies persisted longer. In no single case did clinical disease progress beyond trachoma stage I. In secondary cases in older age-groups, all showed signs of corneal vascularization, but when it became inactive five of nine showed no signs of trachoma. In tertiary infections in those cases with inactive stage IV trachoma, the course of infection was brief but lasted in some as long as secondary infection. There was evidence of disease transmission amongst family members in eight of the tertiary infections.

The occurrence of secondary bacterial infection of trachomatis eyes has been accepted for many years. Reports indicate that secondary bacterial infections may play a part in determining the outcome of long-standing trachoma (Jones 1980). Certainly untreated bacterial infection can cause visual impairment and blindness (Reinhands et al. 1968) and an increased rate of recovery of bacteria has been demonstrated from the lids and conjunctiva of patients with moderate trachoma (Chumbley and Thompson 1988).

2.1.6. **Trachoma as a Multisystem Disease**

Among adults *Chlamydia trachomatis* has been reported to cause cervicitis, salpingitis, endometritis, vaginitis, peritonitis, Reiter's syndrome, arthritis, endocarditis, epididymitis, urethral syndrome and urethritis (Fletcher and Gordon 1990).

Speculation that *Chlamydia trachomatis* might not only be isolated from the eyes, but may also be found at other sites, occurred in the 1950s. Abu-Jaudeh working in Lebanon, suggested that trachoma might be a generalised disease. This was supported by evidence showing inclusion bodies in other mucous membranes (Abu-Jaudeh 1953). In Australia, during several trachoma surveys in the Northern Territory, Flynn noted a chronic nasal discharge in most of the Aboriginal children with trachoma, and observed that systemic therapy was more effective

than topical therapy alone (Flynn 1957). He suggested from these observations that trachoma might be a generalized disease.

However, direct evidence that *Chlamydia trachomatis* could be cultured from extraocular sites in children from trachoma endemic areas was not available until the 1980s. In Egypt, a survey attempted to isolate *Chlamydia trachomatis* from the eyes, nasopharynx and rectum of 128 children from three villages (Malaty et al. 1983). One third of all children yielded *Chlamydia trachomatis* on a single sample. Of these 43 children, twelve (28%) with conjunctival infection had *Chlamydia trachomatis* elsewhere, and seven (16%) had negative eye cultures but had either nasopharyngeal or rectal infection.

Transmission of *Chlamydia trachomatis* from mother to child during childbirth was first demonstrated by Jones et al.(1959), *Chlamydia trachomatis* was cultured from both eyes of an infant with inclusion conjunctivitis, and from the cervix of the mother.

The importance of perinatal transmission with respect to more generalized infection was demonstrated in 1975. A case of *Chlamydia trachomatis* pneumonitis was reported in a child who had been treated for inclusion conjunctivitis of the newborn (ICN) (Schachter et al. 1975). Subsequent studies have demonstrated that *Chlamydia trachomatis* is the commonest cause of neonatal conjunctivitis (Rapoza et al. 1986), and has also been associated with acute lower respiratory tract infection in children 3-4 months of age (Paisley et al.1984). In a recent study of 3309 births in which 198 mothers had a chlamydia infection, of 174 mothers and infants followed, 43 infants were positive for *Chlamydia trachomatis.* A total of 24 had symptomatic infection and 19 asymptomatic chlamydia infection. A respiratory infection occurred in 6 (14%), conjunctivitis in 20 (46.5%), and otitis media in one. The overall incidence of *Chlamydia trachomatis* infection was calculated as 8.2/1000 live births (Preece et al. 1989). Similar results from another prospective study in America has lead to the suggestion that screening for *Chlamydia trachomatis* in pregnancy should be routine (Schachter et al. 1986 a). In trachoma endemic areas the picture may be different. A study in Kenya, demonstrated that the trachoma serovars isolated from the genital tract of mothers and the eyes of their

children, were different, and the authors concluded that perinatal transmission was not a major route of transmission. However, the validity of the study was limited by the difficulty in culturing *Chlamydia trachomatis* from the eyes of children, and the high number of mothers who declined speculum examination (Brunham et al. 1990).

Chlamydia trachomatis has also been implicated in otitis media in children. Although it is a common complication in infants with *Chlamydia trachomatis* pneumonia, and hearing loss has been associated with otitis media in adults, the contribution of *Chlamydia trachomatis* to otitis media in children 4 to 5 years of age is debatable (Schachter and Dawson 1981). In Australia, The Menzies School of Health Research, using evidence obtained from a prevalence survey of *Chlamydia trachomatis* conducted in two Aboriginal communities, found that ear perforations occurred at an earlier age in communities with: more trachoma in infants, early chlamydial infection, less passive antibody against chlamydia and less usage of antibiotics (Douglas et al. 1987 (19)). The authors concluded that the data implicated chlamydia as a cause of chronic otitis media; this was despite the fact that they isolated *Chlamydia trachomatis* in only one of 119 swabs. They remained convinced of its causal role for the following reasons: it was often grown from the nasopharynx; other studies of middle ear aspirates had been of older children after any initial damage by *Chlamydia trachomatis* infection had already occurred, culture of middle ear discharge were usually positive for other bacterial pathogens which may have prevented isolation of *Chlamydia trachomatis*; and aspirates of middle ear discharge were often positive for anti-chlamydial antibody. A second longitudinal study of Aboriginal children found the risk of ear perforation was lowest in infants born to mothers with the highest levels of anti-chlamydial antibody in the maternal serum. The inference made was that the antibody was protective against the subsequent development of chronic otitis media, supporting the hypothesis that *Chlamydia trachomatis* is important in the aetiology of chronic otitis media (Douglas et al. 1987 (20)).

Another study in Central Australia suggested that *Chlamydia trachomatis* might be implicated in chronic otitis media. Instead of using culture techniques, a direct fluorescent labelled monoclonal antibody test was applied to samples of smears taken from the eyes, throat and

middle ears of 18 children (racially European), aged 1-11 years. The results demonstrated a high carriage rate in all sites even though clinical trachoma was not evident. The author could not say whether the results indicated causation or merely commensal carriage (Banks et al.1985).

Although infection with *Chlamydia trachomatis* can occur at many extraocular sites, its importance with respect to the transmission and pathogenesis of trachoma is uncertain. Auto-inoculation from extraocular sites in an individual has been proposed (Schachter and Dawson 1981). If this form of transmission can be demonstrated, it has important implications for treatment and control. It explains treatment failures when only eye drops are used, with the reservoir of infection spilling back to the eyes from extraocular sources from either the infected individual or others. It further indicates that systemic therapy may be more appropriate in the younger age-groups, to control not only trachoma but also the respiratory, middle ear and possible diarrhoeal diseases which cause significant morbidity and mortality in trachoma endemic areas (Schachter and Dawson 1981).

2.1.7. **Descriptive Epidemiology**

The importance of *Chlamydia trachomatis* as an organism causing infectious disease is well recognised. Its distribution and prevalence, despite mass treatment programs, indicates its success as an organism. Its ability to colonize multiple sites and remain asymptomatic for long periods, indicates its adaptability and potential as a human parasite. Yet, like smallpox, it appears to have no animal reservoir of importance (Schachter 1985). Eliminating it completely is possible, at least theoretically, if not on a world scale then on the community or regional level.

Trachoma was a major cause of blindness in Europe and North America during the early part of the 19th century. As mentioned previously it is a persisting problem in developing countries. Its decline in Europe preceded the advent of antibiotics (Rienhards 1967). As with many

other infectious diseases, socioeconomic development, changes in living standards and improvements in community hygiene significantly decreased the severity and transmission of trachoma.

The interaction of the host, environment, and organism has been outlined (Jones 1975). Jones divided trachoma into three classes of infection. The first class was blinding trachoma in hyperendemic areas, with bacterial infections playing an important role in its pathogenesis. Serotypes A, B, Ba, C predominated. The second group was defined as non-blinding trachoma occurring in hyperendemic or hypoendemic areas. Serotypes A, B, Ba, C, and sometimes D, E and C were usually isolated from infected individuals. Superadded bacterial infection was not a feature of class two disease. The third classification was called 'paratrachoma' and occurred in hypoendemic areas. Serotypes D, E, P, G, H, I, J, K and sometimes B and C were all found in these areas.

The division of trachoma into classes has practical applications. In the Northern Territory differences in the intensity of trachoma between the "Top End" and Central Australia were noted as early as the 1940s (Schneider 1946). The disease was found to be mild in the North, with complications rare, but severe in the South. Schneider attributed this variation to climatic differences. The findings were repeated in 1957 when bacteriologic and virologic investigations were undertaken in the "Top End" of the Northern Territory. Practically no cicatrization or pannus was found (Crotty et al. 1959). In a more recent evaluation (Meredith et al. 1989), this initial difference in severity with latitude, was reflected in prevalence surveys over the past 40 years, with a significant decline occurring in the north, and only minor changes in the south. However, the attribution of these changes solely to climate would ignore the role of other factors in the epidemiology of trachoma.

A World Health Organisation expert committee (W.H.O. 1962) listed the following possible factors in the epidemiology of trachoma: race, climate, insect vectors, diet and nutrition, cultural and social customs, population density, general economic development, previous population movements, educational status and the presence of other ocular and general

diseases. This list has been reviewed and it was concluded that although it was comprehensive "... it did not materially advance our understanding or foster the development of specific intervention strategies ..." (Taylor and Sommer 1985). However, a review of some of these factors as follows, allows an appreciation of trachoma's epidemiology.

Distribution

Trachoma is distributed in areas of North Africa extending down to East and South Africa, into the Middle East, and into some parts of India and south-east Asia. Pockets of trachoma exist in South America, Australia and the Pacific Islands. It is a problem mainly in the rural areas (Treharne 1985).

Host Determinants

1. Age

Children are viewed as the main reservoir of infection (Treharne 1985), which has been shown to occur in young babies 2-3 months of age (Dawson et al. 1976). Active inflammatory disease in endemic areas is most commonly found in children under ten years of age. In a survey of a trachomatous region the cumulative incidence of acquired infection was 73% in pre-school children, and 2.2% in the rest of the population over a 4-year period (Treharne 1985). In endemic areas it appears that active trachoma predominates in the younger age-groups, and cicatrization in older individuals.

2. Sex

In young children there appears to be no sex difference in the rate of active trachoma (Graham et al. 1973, Jones 1975), although Hollows found a slight predominance of follicular trachoma in males aged 19 years or less in Aboriginal Australians (R.A.C.O. Report 1980). In older children and young adults; however, trachoma begins to predominate in girls (Ballard et al. 1983). Severe cicatrization is more common in older

women than men (R.A.C.O. Report 1980 and Tielsch et al. 1988) and women consequently suffer a greater loss of vision (Brilliant et al. 1985). The following environmental and behavioural factors are believed to be responsible for this difference (Kupka et al. 1968):

- Female infants receive less care than males, resulting in increased exposure to infection.
- Young girls are often given charge of younger brothers and sisters, and are therefore exposed to familial sources of infection.
- The mother has closer and more frequent contact with younger children than the father, increasing the chances of transmission.

The increased risk in women may therefore be due to repeated reinfection in early adulthood, the reinfection occurring from young children. However a study examining the risk factors for trichiasis in women conducted in Tanzania (Turner et al. 1993), found that prolonged exposure to child care as a young girl or mother showed no significant difference between cases and controls.

3. Race

Conflicting evidence has been presented on the significance of race and susceptibility to trachoma infection. Some early authors asserted that there were no differences among the races, with all suffering equally under similar conditions (MacCallan 1931). Others have found hypersusceptibility among certain ethnic groups (Guerra 1957). More recent studies in hyperendemic regions have not demonstrated differential predisposition to trachoma between racial groups (Treharne 1985).

4. Cultural Factors

Although individuals catch trachoma, they exist within a family, which is part of a surrounding community. Cultural practices can have an immediate effect on both the transmission and development of trachoma, also, cultural dislocation is common in trachomatous areas (Hollows 1985). Subtle variations in cultural practices, for example, affect the utilization of water, and the prevalence of trachoma (West et al. 1989). In a prevalence survey of trachoma on the West Bank and Gaza Strip, there was a substantial variation in the prevalence of trachoma in communities which were similar geographically and socioeconomically. The authors thought many factors such as social and hygiene practices, fly populations, water supply and the availability of medicines were very important (Chumbley and Thompson 1988).

Although personal hygiene practices have long been held to be important in the transmission of trachoma (Boldt 1904), these assessments were qualitative. The provision of washing facilities and daily baths was found to reduce the prevalence of trachomatous disease in an Aboriginal population in South Australia (Hardy et al. 1967). In another study, 1097 people in two Mexican communities were surveyed Information was gathered on personal and family hygiene practices. Twenty-five percent of children under the age of ten had significant inflammatory trachoma, and almost 100% of those older than 40 had cicatricial disease. Risk factor analysis by contingency tables and Chi-squared testing showed that a face washing frequency of greater than 7 times per week was associated with lower rates of trachoma compared to less frequent face-washing (Taylor et al. 1985). Taylor concluded that the evaluation of many different community, family, and personal practices and behaviours could be done, and interventions designed for implementation at the community level.

Direct application of these practices to other cultural settings may not have the same result, as demonstrated in a study from the Northern Territory. Face washing in

Aboriginal children in a remote settlement did not have any effect on the prevalence of trachoma (Peach et al. 1987).

Additional recent work has focussed on nasal discharge and flies rather than facial cleanliness (as measured by dust, food on face, or "sleep" in the eye), with suggestions that targeting efforts at cleaning nasal discharge and keeping flies off children's faces would produce the biggest effect on trachoma prevalence (West et al. 1991).

Another factor related to hygiene practices was assessed in a survey of an Egyptian hamlet. The absence of a pit latrine was predictive of increased trachoma prevalence. It was concluded that the construction of pit latrines, presumably by reducing the density of the fly population, could be a simple and acceptable method of reducing trachoma prevalence in some communities (Courtright et al. 1991).

Environmental

There is contradictory evidence that climate has an association with trachoma. Although trachoma is found today mainly in drier climates (West et al. 1989), 100 years ago it was common in the wetter areas of Europe, especially wherever conditions of poverty or crowding existed (Reinhards 1967). Mild trachomatous disease in Jamaica was attributed to its well watered environment (Dawson and Schachter 1967). However, seasonal differences have not been studied extensively.

In Australia; however, a strong association between follicular trachoma, humidity, evaporation rate, and bright sunshine hours was found. A weaker association was found with rainfall, ultra-violet exposure and latitude. Cicatricial trachoma was associated with low humidity, increasing evaporation rates, bright sunshine hours and rainfall (R.A.C.O. Report 1980). Control for confounding factors such as water quality was not done. The availability of water was linked to both these conditions, and also to poor sanitation, increased flies and dust. Water quality may therefore be of more importance than climatic conditions alone. However, harsh climatic

conditions fit the picture of an adverse environment, which contributes with other factors, to influence the prevalence and severity of trachomatous disease.

Socioeconomic Development

Poverty and trachoma are often seen together. Historically trachoma was found in people who were living in crowded or adverse conditions (Dunn 1985). It has persisted in developed countries, usually in socioeconomically deprived enclaves within trachoma-free communities e.g. North American Indians and Korean Tanners in Japan (Editorial Med. J. Aust. 1972). Environmental and personal factors, which play an important role in the prevalence and intensity of trachoma, are strongly associated with socioeconomic status (Treharne 1985). A review of the N.T.E.H.P. data (Tedesco 1980) showed that the environmental indices of: living conditions, housing, diet, water resources, sanitation, climate, and employment opportunities, when grouped together to form four distinct zones of socioeconomic development, correlated with geographic differences in trachoma morbidity. Adverse or poor conditions were associated with an increased prevalence and severity of the disease. This paralleled the pattern of infant mortality and crude death rates experienced by Aboriginal people in the Northern Territory. Tedesco concluded that socioeconomic initiatives, in addition to changes in government policy, were required to alleviate this burden of disease.

It has been speculated that inadequate nutrition may affect the development of immunity against trachoma (Watson 1969) and in a survey of Aboriginal health in New South Wales, trachoma was found with other diseases that were themselves associated with malnutrition and poor medical care (Kamien 1976 a, Kamien 1976 b)). However, there have been no substantial studies linking diet with trachoma.

In Tunisia, increased economic development in one village compared to another was associated with a decline in active infectious trachoma (Dawson et al. 1976). It has also been found that higher socioeconomic status within a community can be protective against trachoma (Ballard 1983, Assaad et al. 1971). Higher prevalence rates of trachoma and disease

of greater severity have been demonstrated in households with lower than average income levels and education (Winkler 1963, Mathur and Sharma 1970, Werner and Sareen 1977).

Factors related to poverty and poor socioeconomic status, such as crowding (Assaad et al. 1969), family size (Jones 1975), and number of children under ten (Ballard et al 1983), have all been associated with the prevalence of trachoma. The activity of trachoma has been shown to be directly proportional to the size of the community (Tabbara and Taylor 1988). However, improvement in any single factor is not sufficient to induce marked reductions in the prevalence of trachoma. The overall socioeconomic development within a community is important. Often the compounding effects of behavioural and environmental changes result in a marked reduction in trachoma prevalence (Prost and Negral 1989).

Water

The availability of water has been associated with the prevalence of trachoma since early observations of the disease in the 19th century (Boldt 1904). An early evaluation of the role of water, demonstrated that increasing the availability of piped water, decreased the prevalence of trachoma because of increased utilisation for personal hygiene (Marshall 1968).

Although many studies evaluating the association between trachoma and water have been reported, few have applied vigorous scientific methodology to the investigation (West et al. 1989). Most studies are cross-sectional comparisons. They may be subject to more bias and confounding that the alternative intervention studies (Henneken and Buring 1987). Either form of study may be subject to methodological problems including, inadequate control for confounding factors, problems with grading trachoma, lack of cross checks for observer variation, differences in the age structure and size of comparative populations, and questionable assumptions concerning water utilization. Problems have also arisen with cross-sectional surveys, when the survey is carried out at different times and different places (Prost and Negral 1989).

Several associations have been reported between water and trachoma. An increasing prevalence of active trachoma was found with increasing distance between houses and their water supply (Tielsch et al. 1988). The type of water supply, and possibly the water quality, was correlated with trachoma prevalence (Marshall 1968), especially in the under 20 age-group (Assaad et al. 1969). Daily bathing, when compared with infrequent bathing, was identified as protective for trachoma (Majouk 1966). In Australia both follicular and cicatricial trachoma decreased with increased water availability; however the supply of water was not isolated from other variables (R.A.C.O. Report 1980).

A further analysis of these data showed that trachoma was strongly correlated with the type and quality of water supply and sanitation. However, other variables such as climate, dwellings, diet and employment prospects were included in the analysis to create an overall measure of living conditions in four distinct zones (Tedesco 1980).

Amongst other correlates, per capita daily consumption of water showed an inverse relationship with the prevalence of trachoma (Kupka et al. 1968). An increased prevalence of trachoma was found in communities without a continuous year round supply of water, compared with communities with this facility (Chumbley and Thompson 1988).

In a recent review Prost analysed published data on water and trachoma (Prost and Negral 1989). The analysis was limited by the selection of an appropriate measure of improved trachoma status e.g. a change in severity vs absolute reduction in prevalence. There were also limitations because of the difficulty in controlling for confounding factors. However, by considering only those studies that were methodologically correct, Prost was able to conclude that improving the water supply could change the epidemiological pattern of trachoma from a severe blinding endemic disease to a relatively mild, non-blinding infection.

Whilst the provision of water appears to have a central role in decreasing trachoma prevalence, more recent work has focussed on the utilization of water. It has been shown that when water is scarce, it is used preferentially for drinking and cooking rather than for personal hygiene (Ballard et al. 1983). The value water has to a family is sometimes determined by the distance

travelled to collect it, and the perception of the way in which water should be utilized in the home (White et al. 1972). Culturally specific factors, with respect to hygiene and water utilization, are important (Taylor and Sommer 1985). Further research is needed to determine water usage in trachomatous and non-trachomatous families, and the priorities involved in the allocation of water (West et al. 1989).

2.1.8. Transmission

In 1904 Boldt wrote "It is enough to bear in mind that the family is the main channel for the spread of trachoma, and to a certain extent the incubator of the virus" (Boldt 1904 p 126). Current authors agree that trachoma is a family disease (Darougar and Jones 1983).

The mechanical means of transmission can occur by many routes, and probably varies from community to community, reflecting different social, environmental and economic conditions. Several mechanisms exist in endemic areas; spread by contaminated fingers, spread by face-cloths and clothing, spread from infective discharges on bed linen, spread by direct contact between parents and children and between children, fly transmission, and possible spread by respiratory droplets, gastrointestinal and genital contact (Treharne 1985). Dogs have been investigated as an animal reservoir for *Chlamydia trachomatis*, but a link to human infection could not be found (Rhodes et al.1987).

It has generally been accepted, although not specifically proven, that these are the principal routes of transmission. In fact, speculation about the role of flies occurred as early as the 1930s (MacCallan 1931). Later, contributors to the trachoma literature were convinced that eye-seeking flies, which often cluster about the eyes, nose and mouth of any person with an ocular or nasal discharge, were an important vector in the transmission of *Chlamydia trachomatis* (Jones 1975). In 1981, a laboratory experiment proved that fly transmission could occur (Forsey and Darouger 1981). In Tanzania a study of hygiene factors and trachoma found that household fly density was a risk factor for inflammatory trachoma and the presence of flies on the face of a child with nasal discharge was shown to increase the odds of developing trachoma almost two fold (Taylor et al. 1987). Taylor also found that active trachoma in children was significantly more common in households with high fly numbers (>5 per house), compared to a range of fly scores less than this number (Taylor 1988). In a recent study of the impact of cattle on the prevalence and severity of trachoma found that cattle droppings, by increasing the density of flies, contributed to the transmission and prevalence of trachoma (Sole 1990). However, with respect to the Taylor study, it is possible that

trachoma caused the nasal discharge and attracted the flies (West et al. 1991). Further controlled field trials have not been reported, and the actual importance of this route remains speculative.

Extraocular sites of *Chlamydia trachomatis* play an important role in transmission (Schachter and Dawson 1981). Auto-inoculation, if proven, has practical implications in trachoma treatment and control, especially in the younger age-groups.

2.1.9. **Trachoma Treatment and Prevention**

The early Egyptians, Greeks and Romans used copper to treat trachoma. This was continued through the ages, and before the introduction of sulphonamides in 1938, patients had their everted eyelids scoured daily with a pointed crystal of copper sulphate held in a wooden holder. This was often continued for years until the disease became quiescent. It was a painful and sometimes fruitless treatment; however there were more drastic measures. Inoculation of the eye with Gonococcus was practised in the early 19th century in cases with severe pannus. Later treatment methods used silver nitrate, lotions of mercuric chloride, or subconjunctival injections of cyanide of mercury. X-rays were also used, all to achieve resolution of the chronic inflammation (Duke-Elder 1965). Surgical correction by excision of the diseased areas was practised for many years and various operations were advocated (MacCallan 1913).

The introduction of antibiotics, and a better understanding of the disease, heralded a new era in the treatment of trachoma. In Australia, Flynn used sulphonamide drugs: Sulphatrial, 6 tablets or 8 grains to begin with, then 3 tablets twice a day for two weeks and Aureomycin ointment (1%) topically, twice or three times a day. He repeated the course twice at intervals of 2 weeks, and suggested the use of mass campaigns based on education and prevention as a means of controlling or eradicating trachoma (Flynn 1957).

Treatment and prevention today can be divided into five levels of intervention, and uses the basic elements of Flynn's approach:

1. Primary Prevention

Trachoma is a disease which is preventable using a primary health care approach. Historical and anecdotal data suggest that environmental factors and hygiene practices play a major role in Chlamydia transmission and endemicity (Taylor and Sommer 1985).

There has been little sociomedical research in the area of primary prevention (Dunn 1985). Observations that trachoma disappeared in Europe and most of Australia prior to intervention programs and that trachoma is unequally distributed in hypoendemic areas, clustering in family or household groups, indicate that the use of a public health approach would be useful (Taylor et al. 1987). Strategies that were non-medical were found to be effective in controlling trachoma in South Africa (Kok 1983).

In the prevention of trachoma three areas of culture have been identified as important (Hollows 1985). The first involves the "major health hardware"; the provision of water, adequate living space, elevated separated and ventilated sleeping spaces, above ground surfaces that can be cleaned and are free of animals and potential insect vectors. The second describes "software" which includes cultural change and behaviour modification and programs that are understood and designed by the participants. The third involves the "client group" which implies an understanding of the people, a commitment to the group's welfare and advancement, and an appreciation of other health-related effects that may precede or follow the development of a trachoma control program. This would involve the support and involvement of the client group at all times. Another approach emphasises the primary prevention of trachoma which includes health education, promotion of self teaching, and a recognition that socioeconomic development should be accompanied by behavioural and lifestyle changes. Three factors are crucial for

success: compliance with long term behavioural modification, integration with health care services, and eye health education (Thylefors 1985).

Both the approach outlined by Hollows and that by Thylefors have overlapping features; however, the latter emphasises the individual whereas the former incorporates physical, cultural and community aspects in an overall scheme.

In Third world countries any system that is established should be affordable, acceptable and accessible to the people (Sutter and Ballard 1988). Furthermore a clearly stated health policy needs to be formulated. This would include detailed activities and general guide-lines (Mburu and Steinkuller 1983). Currently, for example, demands for ophthalmic treatment services in Africa far exceed resources (Mburu et al. 1983). To fulfil this type of demand appropriate technology and training of health care workers is needed (Sandford-Smith 1984). During the 1980s there had been a steady increase in the incorporation of non-physician trained workers into eye care programs (Pizzarello 1990). Training programs for health workers have been described for countries such as Kenya (Sheffield 1983), and Australia (Brian et al. 1990). A distinction between teaching routine clinical procedures and teaching strategies for problem solving has been made (Goodwin 1983). The success of using health workers in trachoma control programs has been demonstrated in at least one study, a significant reduction in the severe grades of trachoma occurred with the use of primary health care workers and community action (Anderson and Bentley 1986). In Australia, workshops and courses have been established to train rural health workers in ophthalmic assessment, primary treatment and sometimes definitive care (Brian et al. 1990). Lastly, the promotion of eye health by advertising, leaflets, posters and community meetings, has been demonstrated to lead to successful cooperation by individuals with trachoma control programs (Cedrone et al. 1987).

2. *Secondary Treatment*

Secondary treatment is the use of medications to eradicate disease once it is established. In 1981, the World Health Organisation recommended twice daily treatment with tetracycline ointment for 5 consecutive days, once a month for six months (Dawson et al. 1981 a). A controlled trial demonstrated that a significant reduction in trachoma was produced. However, the effect was short-lived (Dawson et al. 1981 b).

A recent randomized controlled trial of trachoma treatment in the Northern Territory compared antibiotic eye drops, eye washing and no intervention. There was a 33% reduction in infective trachoma in those treated with eye drops, compared with a 22% and 24% reduction in the eye washing and control groups respectively. This significant result was based on screening 2852 children in 4 communities, 1164 of whom were found to have trachoma and were enrolled into the study (Peach et al. 1987). However, the overall program was criticised because under trial conditions compliance was only 60%, the effects were short term, and therefore only palliative, and *Chlamydia trachomatis* from other sites was not eliminated. Also the pool of infection which existed in pre-school children, who were heavily infected, was not reduced and there was a possibility that resistant strains could have emerged (Matthews 1987).

Recent evaluation of the efficacy of oral antibiotics in the treatment of *Chlamydia trachomatis* infection in Aboriginal children is lacking. Comparisons between topical and systemic treatment have, however, been undertaken elsewhere. A stratified double blind controlled field trial in a village in Southern Iran demonstrated no difference in the prevalence of trachoma after four weeks of treatment. The treatment consisting of the administration of topical tetracycline twice daily for 7 days once per month, versus oral doxycycline 5mg/kg once monthly (Darougar et al. 1980). After one year there was a marked reduction in the prevalence and intensity of trachoma for

both regimens. Oral doxycycline; however, was considered more practical and less expensive.

On the West Bank in Israel, a double blind stratified comparative trial was undertaken of intermittent, family based therapy for trachoma, using oral doxycycline, oral sulphametopyrazine, or topical tetracycline eye ointment. It failed to demonstrate any statistically significant difference between the 3 groups treated in the two villages (Chumbley et al. 1988). However doxycycline, given once weekly for three weeks was the easiest to administer, although compliance was high for all types of treatment.

A further study has been undertaken to examine the effect of treatment regimens. This study suggested that systemic antibiotics should only be given to children with severe or moderate intensity disease, and those individuals at significant risk of blindness (Dawson and Schachter 1985).

There is much debate about the most appropriate form of systemic therapy. In 1982, Dawson compared a topical eye antibiotic and oral erythromycin. Although erythromycin proved to be marginally more effective in eradicating trachoma, active disease did persist in many children (Dawson et al. 1982). A subsequent study of medication compliance revealed that lack of compliance was probably the cause for this difference. Erythromycin had been administered four times daily, but to achieve compliance this was reduced to twice daily during school hours. Serum levels of erythromycin were found to be negligible in the early morning, indicating rapid clearance of the drug as being the reason for treatment failures (Dawson et al. 1982).

An alternative to erythromycin is tetracycline or its longer acting derivative minocycline, which requires only one daily dosage. A double blind field trial of oral minocycline vs tetracycline ointment demonstrated equal efficacy after three weeks. However, minocycline was superior at evaluation after one year (Tabbara 1990). The once a day dosage required for minocycline was thought to ensure compliance. However, the tetracyclines are contraindicated in children under 8 years of age

because of the possible adverse effects including: (i) deposition of tetracycline in calcifying tissue such as teeth and bone, causing permanent discolouration in the former and slowing bone growth in the latter and (ii) photosensitive dermatitis (MIMS Annual 1990). This is the group which is targeted in most control programmes.

The comparative costs and benefits of using tetracyclines in trachoma endemic areas were analysed. It was concluded that oral doxycycline was at least as good as topical treatment, and that the ease and feasibility of once a day treatment was attractive for public health programs. By limiting the administration of systemic doxycycline to those children with severe intensity disease, adverse side effects would be limited to those most at risk of blindness, such effects would occur in only a small percentage of children, also it was cost effective to combine intermittent systemic treatment with an ongoing mass campaign of topical treatment (Dawson and Schachter 1985).

Sulpha agents have been used in the past (Bietti 1957) and were used extensively in the N.T.E.H.P. survey 1976-1979 in Australia (R.A.C.O. Report 1980). They are now not generally recommended because of adverse reactions including allergies, renal side effects and the severe Stevens-Johnson syndrome.

The current utilization of antibiotics can be summarised as follows:

(1) Intermittent topical therapy, which can significantly reduce the intensity of eye infections due to *Chlamydia trachomatis* (Reinhards et al. 1968), has been used in numerous anti-trachoma campaigns (Thylefors 1985). It is viewed as a prophylactic treatment because although the blinding complications of the disease are prevented, trachoma may still exist in a mild form in a community (Kupka et al. 1968). It has the secondary effect of reducing the incidence of bacterial super-infection which may lead to a reduction in the blinding complications of trachoma.

(2) The use of systemic antibiotics in individuals who either do not respond to topical treatment, or who have blinding complications, e.g. trichiasis or pannus. Tetracycline or doxycycline is used in adults, but not in pregnant women because of possible teratogenic effects (MIMS 1990), when erythromycin should be used (Schachter et al. 1986 b), and erythromycin is generally used in children.

3. *Tertiary Treatment*

Tertiary treatment involves systematic case finding and corrective lid surgery. In endemic regions mild entropian with trichiasis may be very common, the result of many years of infection. The corrective procedure is simple and can be performed by auxiliary medical personnel. A controlled trial of five operations for the correction of trichiasis has been undertaken by Reacher et al. (1990). They found that bilamellar tarsal rotation and tarsal advance were effective operations for major trichiasis, but that tarsal advance was ineffective where trichiasis and lid closure defects coexisted. Moderate cicatricial entropian with or without trichiasis, secondary blepharospasm and secondary brow ptosis require more extensive assessment and corrective procedures which have recently been evaluated in Saudi Arabia (Nasr 1991).

The progression of trachoma is such that even after active infective disease has been controlled, a lag period of 10-20 years may exist before those whose lids were scarred in childhood reach adulthood and begin to experience difficulties with trichiasis (Dawson and Schachter 1985). Therefore tertiary strategies must be maintained for a long period.

4. *Vaccination*

Chlamydia trachomatis causes not only ocular trachoma but also genital tract infection. It is one of the most common sexually transmitted pathogens in Western developed

countries, and can ultimately cause infertility in women from chronic salpingitis. Control of *Chlamydia trachomatis* is thus of importance to public health globally.

A major search for a trachoma vaccine has been in effect for thirty years. Although some short term benefits were demonstrated with live unit vaccines (Collier 1974), some vaccines produced hypersensitivity, inducing more severe disease (Monnickerdam and Pearce 1983). It is thought that the difficulty in developing an effective vaccine relates in part to the poor immune response to Chlamydia infection. Ocular infection with *Chlamydia trachomatis* induces both humoral and cell mediated immunity (Young and Taylor 1984). Although some partial protection is conferred with these responses, it also may be responsible for the tissue damage and pathology seen in trachoma (Taylor and Sommer 1985). An autoimmune mechanism may be responsible (Abu El-Asrar et al. 1989). It is clear that an effective vaccine should separate the sensitising from the protein antigens, it should be a subunit of the Chlamydia organisms, and that the problem of serotype-specific immune responses needs to be addressed (Schachter 1985).

A 'killed' vaccine would be unlikely to confer extended immunity. A desirable goal would be 4-5 years of protection; this period matches the time of peak incidence in the pre-school age-group. Protection during that period could prevent the development of changes which lead to blindness in later life. Any vaccine would be potentially effective against genital infection, conferring protection at least to the effects of salpingitis, if not from infection of the mucous membranes of the lower genital tract (Schachter 1985).

5. *Mass Campaigns*

Since the late 1950s a number of trachoma control programs have been undertaken (Thylefors 1985). Most mass campaigns have relied upon topical tetracycline, although some have utilized oral antibiotics of various types (R.A.C.O. Report 1980, Darougar et al. 1980, Dawson et al. 1981 b). Common to most campaigns have been

five main strategies : (1) early detection of cases, (2) prophylactic treatment on either a mass or selected basis, (3) topical and systemic treatment for long periods for severe infection, (4) surgical treatment of trichiasis, and (5) health education (Thylefors 1985).

It has been conjectured that the costs and benefits of topical tetracycline treatment are low, whereas benefits and costs of systemic antibiotics are higher (Taylor 1987 a).

Studies evaluating the success of campaigns are mixed. In Southern Morocco the overall prevalence of trachoma was unaffected in a mass campaign incorporating the above four steps (Kupka et al. 1968). However, a larger proportion of cases were at the "healed stage IV level", and in one region there had been a decrease in the active I to III stages in the younger age-groups. In Tunisia, an evaluation of an on-going campaign demonstrated a decline in the prevalence and severity of the disease (Dawson and Schachter 1985).

In Australia a coordinated mass campaign used oral co-trimoxazole in a method outlined by Jones (1978), of an attack phase followed by a consolidation and surveillance phase. A substantial reduction in the prevalence of trachoma follicles in children was demonstrated. Factors such as observer variation, natural remission with increasing age, seasonal changes and improvements due to changes in living conditions were taken into account (R.A.C.O. Report 1980). However, mass campaigns utilising systemic antibiotics are expensive and difficult to complete. In addition, as with the use of sulphonamides, adverse reactions to antibiotics increase with indiscriminate use. By contrast topical medication is effective in eradicating ocular *Chlamydia trachomatis*, is cheap, easy to use and has fewer side effects.

More recently campaigns have focussed on trachoma as a community or family based disease (Hollows 1985). A public health approach addresses the underlying socioeconomic and cultural factors which foster the persistence of trachoma in communities. The "natural" elimination of trachoma from Europe (Jones 1975) and

white Australia (Mann 1957 b) preceded the introduction of modern antibiotics, underscoring the need for socio-cultural and economic changes in communities if treatment campaigns are to be ultimately successful.

The discovery of a suitable vaccine to augment the immune system without damaging ocular structures would be desirable. However, it is acknowledged that the eradication of trachoma at present rests in the area of prevention and intervention (Tabbara 1990). Mass campaigns and public education strategies are urgently required in many developing countries.

Summary

Trachoma is an important cause of visual disability throughout the world. The causative organism is *Chlamydia trachomatis*, an intracellular bacterium which not only infects the eye, but also may infect other mucus membranes and organs in the body. Trachoma may be acquired at any stage in life, but in endemic regions infection often begins in the first one or two years. Recurrent infection may produce the tarsal plate scarring and lid contracture which leads to trichiasis and corneal opacity in later life. It is thought that trachoma is a multi-cyclic disease with relapses and remissions over many years; it is also, as already mentioned, a multi-system disease, which may explain treatment failures when only topical treatment is used. Trachoma thrives in crowded and unhygienic conditions and can disappear with socioeconomic development. Although all ages can be infected, inflammatory disease predominates in the young and cicatricial disease in the old. Women appear to have higher rates of infection than men. Cultural factors particularly water usage and hygiene have been identified as important in its epidemiology. Public health measures are the key to the prevention of trachoma, secondary treatment with either intermittent topical antibiotics or systemic antibiotics is the second line of defense, with tertiary procedures such as eyelid surgery, being reserved for those in whom the trachoma has progressed to its blinding stages. Currently no effective vaccination exists and so mass campaigns, which have had mixed success in the past, will only be used on a limited scale where funds and commitment are available.

1.3.2. **Cataracts**

Cataracts are an important cause of visual loss in all racial groups. Although risk factors have been identified, effective preventive strategies have not been developed. For the Aboriginal population, an understanding of cataract epidemiology is important, to identify those at risk and to be aware of the factors that favour people to seek and receive treatment when it is available. This understanding is also important for the design of strategies to reduce the prevalence of blindness due to cataract.

The lens of the eye focuses incoming light on to the retina. When the lens loses its normal transparency a cataract is said to be present. The location, distribution and density of any lens opacity determines whether the cataract impairs vision. Most are bilateral, although the rate of progression in each eye is rarely equal. The most common cause of cataract is ageing, other causes include: genetic predisposition, congenital factors, metabolic imbalances, trauma to the eye, and eye toxins (Vaughan and Ashby 1983). Approximately 17 million people worldwide are binocularly blind because of cataracts (Dawson and Schwab 1981), and it is the leading cause of blindness in the elderly (Hyman 1987).

The formation of a cataract occurs with changes in the physiology and structure of the lens. Lens edema, protein alteration, necrosis and disruption of the normal continuity of the lens filaments are characteristic. During the development of a cataract several stages are passed through each characterized by different physiological and structural changes. An immature cataract is only lightly opaque, a moderately mature cataract is edematous, a hypermature cataract is relatively dehydrated, the lens opaque and surrounding capsule wrinkled (Vaughan and Ashby 1983).

Visual acuity testing is the best clinical measure of cataract opacity, the decrease in visual acuity is generally in proportion to the density of the cataract. There are, however, individuals in whom the reduction in visual acuity is out of proportion to the degree of opacification, this is thought to be due to distortion of the visual image by a partially opaque lens. In contrast,

some people have marked opacity of the lens but are still able to carry out their normal activities.

The Epidemiology of Cataract

Several difficulties arise when considering the epidemiology of cataract. Problems with definition occur because there has not been standardization in morphology (shape, size and density) of the lens change in cataract between studies. Assessment of these changes is often subjective. Secondly, changes in visual acuity which reflect cataract development may be assessed differently between surveys, resulting in survey differences due to methodology (Leske and Sperduto 1983). Thirdly, methods of examination e.g. direct ophthalmoscope vs slit lamp, and the selection of sample groups affect the prevalence values as well (Sommer 1977). Lastly, groups that are selected for sampling have also varied; either from selected communities, or age-groups, or blindness registers, or randomized surveys of entire populations (Leske and Sperduto 1983).

In determining the descriptive epidemiology of cataract several sources may be used including:

1. Blindness registers from different countries have been used; Canada (MacDonald 1965), Great Britain (Sorsby 1966) and the USA (Kahn et al. 1977). Factors such as differential registration of blind individuals and the difficulty of comparing blindness rates between countries affect interpretation (Leske and Sperduto 1983).

2. Prevalence data is available from population based studies; for example, the Framingham Eye Health Survey. The data, however, was limited to individuals who lived in a specific community, and who had previously participated in a heart study examination (Leske and Sperduto 1983).

3. Data drawn from attendance at outpatients (Batterbury et al. 1991).

Risk Factors for Senile Cataracts

Several risk factors for age related or senile cataract have been identified in survey and case control studies. The factors can vary for each category of age related cataract viz nuclear cortical, posterior,subcapsular and mixed cataracts (Leske et al. 1991).

1. *Demographic Factors*

Increasing age has been demonstrated in numerous studies to be related to an increasing prevalence of cataract (Leske and Sperduto 1983).

A consistent difference between males and females has not been found for age-specific prevalence rates of cataract. Although studies have shown a higher prevalence of cataract in women, for instance in the Framingham National Health and Nutrition Evaluation Survey 1971-1972 (Hiller et al. 1983), and a study in Edinburgh of four hundred and eighty seven people over the age of sixty seven (Milne and Williamson 1972), a case control study of blindness in a rural Aboriginal population found that cataracts occurred as commonly in males as females (Taylor 1980 a).

Variations in the prevalence of cataract throughout the world have been demonstrated. Comparison studies have found that the age-adjusted prevalence of cataract for an area of the Punjab plains in India (Chatterjee et al. 1982), was three times higher than that obtained in the Framingham study. Differences may be due to genetic or environmental factors; however, variation in survey methodology or the availability of medical services, particularly for comparisons between developing and western nations, may account for the differences found (Leske and Sperduto 1983).

Two recent case control studies, The Lens Opacity Case Control Study (Leske et al. 1991) and The Italian-American Cataract Study Group (1991) have identified; or given further weight to several factors that affect the occurrence of age related cataracts. Table 1.3.2.1 summarizes the finding of these studies.

Table 1.3.2.1: Risk Factors for Cataracts

Type of Cataract	The Lens Opacity Case Control Study		Italian-American Cataract Group	
	Decreased Risk	Increased Risk	Decreased Risk	Increased Risk
posterior subcapsular	increased vitamins	low education diabetes	arthritis	low education family history steroid use
nuclear	increased vitamins	low education non-professional current smoking	arthritis	low education
cortical	increased vitamins	low education female sex non-white	arthritis	low education female sex family history sunlight
mixed	increased vitamins	low education diabetes	arthritis	low education family history sunlight

2. *Vitamins*

The Lens Opacity study demonstrated that individuals who had high values for an index of antioxidant vitamin intake were protected against cataract formation but the Italian-American Cataract Group, with identical methodology, failed to find an association. Both findings were valid only to the extent that current nutrient intake reflected past eating practices.

Further confirmation of the association between cataract and nutritional intake has been found in a survey conducted in India. The study demonstrated that persons with a better nutritional intake had a lesser risk of cataract. The measures of dietary intake were; however, closely correlated so an individual protective vitamin could not be identified (Mohan et al. 1989). Some studies have; however, shown no correlation with specific vitamins such as thiamine, pyridoxine or vitamin E (Bhat 1987).

3. *Sunlight*

Sunlight, or more particularly near ultra-violet (UV) light has been demonstrated in-vivo and in-vitro studies to induce opacity of the crystalline lens (Zigman 1973, Pirie 1972).

Epidemiological studies in the 1970s, indicated a relationship between cataract prevalence and high sunshine intensity (Zigman et al. 1979, Hiller et al. 1977). In Australia, a case control study of 350 Aboriginals aged 30 and over demonstrated a strong association between cataracts and latitude, increased exposure to sunlight and of high ultra-violet-B (UV-B) radiation (Taylor 1980 b). A more extensive survey of 64,307 Aboriginals revealed a positive correlation between the prevalence of senile cataract and levels of climatic UV radiation (Hollows and Moran 1981). An equally large survey in Nepal (30,565 lifelong residents), demonstrated that people who came from sites with an average of twelve hours of sunlight exposure per day, had 3.8 times the risk of cataract, compared to those from sites with an average of only seven hours of exposure (Brilliant et al. 1983 a)

More recent studies using sunlight exposure, as inferred from interview data on residency and time spent in the sun, have shown a slight relationship between increased exposure and increased risk of cataract (Collman et al. 1988).

A study using retrospective data from the 1971-1972 National Health and Nutrition Evaluation Survey and the average daily UV-B radiation at the site of the examination suggested a positive correlation with cortical cataracts (Hiller et al. 1986).

Both the Collman and Hiller studies suffer from the methodological problem of determining the true life-time exposure of an individual to UV-B radiation, as opposed to the reported or assumed exposure.

Further studies have been undertaken and these have attempted to quantify an individual's lifetime exposure by taking a careful history. In a study of Maryland watermen, a positive correlation between sunlight and cortical cataracts was demonstrated (Taylor et al. 1988). A case-control study of individuals operated on for posterior subcapsular (PSC) cataracts in

Maryland (Bochow et al. 1989), suggested that UV-B exposure may be an important risk factor for PSC cataracts. By contrast, in the Lens Opacity Case Control Study, no correlation was found for cortical or mixed cataract, and only a slight association for nuclear cataract. The authors thought that the urban population studied would have had limited sun exposure, and they were cautious about using self-reported data on sun exposure (Leske et al. 1991).

A similar study in Parma Italy, did demonstrate an association between cortical cataracts and sunlight exposure. Sunlight exposure was estimated using three variables: work location in the sunlight, leisure time in the sunlight, and use of a hat in summer. Surprisingly, use of a hat was not protective and may in fact have been a marker for increased exposure (The Italian-American Study Group 1991). Although there is evidence suggestive of an association between UV exposure and cataracts, Harding (1982) and Harding and von Heyningen (1987) have speculated that because conditions associated with sunlight exposure (e.g. pterygium and climatic droplet keratopathy) are not associated with cataract, and because in-vitro studies are not supportive of the association, that other factors are more important.

4. *Diabetes*

There is biochemical evidence that elevated sugar levels which occur in diabetes, leads to an accumulation of sorbital which can damage the lens (Kinoshita et al. 1979). An epidemiological review of cataracts (Leske and Sperduto 1983), summarised that although some studies based on extracted lens showed an increased risk among diabetics (Hiller and Kahn 1976), others based on population prevalence surveys did not (Waite and Beetham 1935).

It was hypothesized that because diabetics were more likely to seek medical attention, they would probably have their cataracts identified more often than non-diabetics, resulting in an ascertainment bias (Sommer 1977).

More extensive surveys have demonstrated a positive correlation between diabetes and cataracts (Ederer et al. 1981). Studies have also identified that the posterior and cortical

cataract types were more common in diabetics than nuclear types (Hiller et al. 1986). Confirmation of this relationship occurred in the Lens Opacity Case Control Study (Leske et al. 1991); where diabetes was associated with cortical and mixed cataracts, but not nuclear cataracts. The authors suggested that the lack of a relationship was due to the pathogenic mechanism, which they speculated predominantly affected the lenticular zones of the lens.

Several other factors have been identified as playing a role in the development of senile cataract. High doses of ionising and infra-red radiation are known to produce cataracts (Miller et al. 1967, Lerman 1980). Some drugs have cataractogenic potential including corticosteriods, phenothiazines, enzyme inhibitors, metals, organic compounds, and cancer chemotherapy agents (MIMS 1991). Blood pressure (Kahn et al. 1977), family history (The Italian American Study Group 1991), myopia (Belkin et al. 1982), eye colour (Collman et al. 1988), education (The Italian American Study Group 1991), and metabolic factors (Clayton 1984) have all been identified as potential risk factors for cataracts. Some of these, such as the role of dehydrational crisis or use of aspirin, are contentious.

A history of dehydrational crisis has been demonstrated in some studies to be associated with cataract formation (Mianassian et al. 1989), and laboratory studies have given biological plausibility to this hypothesis (Harding and Rixon 1981). However, other studies in similar populations have failed to support this hypothesis (Bhatnagar et al. 1991).

The use of low dose aspirin has been shown to be of no benefit in some studies (West et al. 1987), but observational studies support its role (Mohan et al. 1989). Methodological problems have been identified in both the West and Mohan studies, and the findings of a Physicians Health Study, although null for cataract development and not statistically significant for cataract extraction, were compatible with a small protective effect of aspirin therapy (Seddon et al.1991). The authors concluded that further investigation was warranted with the Health Study's cohort. They also argued, that a possible reduction in the number and therefore cost of cataract extractions in the U.S. using drugs (by slowing the development of

cataract), should be balanced against the potential side effects of any agent used. This would require careful evaluation of risks and benefits before a public policy was formulated.

Blindness due to Cataract

Cataract has been identified as the leading cause of blindness in the world (Sommer 1988). Developing nations bear the brunt of this burden (Schwab 1990 a), and in Africa the shortage of manpower and material resources is recognized as the cause of an increasing backlog of treatable blindness (Foster 1987), a backlog that grows by 160,000 per year (Steinhuller 1983).

Various strategies have been proposed to help overcome this problem. These include: fostering the political will to support a blindness prevention program, obtaining resources, and using cost efficient techniques,which might include using non-physician ophthalmic practitioners to perform cataract operations (Schwab 1990 a).

Several factors are important in considering any program (Foster 1987). Firstly the patient must be motivated to seek help. Past experience or the experience of friends or relatives with cataract surgery may affect this, as would lengthy travel time, expense, and unfamiliarity with physicians. Secondly three steps should occur in the provision of services within a program, screening, the selection of those likely to benefit from surgery, and surgery that utilizes available resources. Thirdly issues such as the availability of manpower, the use of materials, the mobility of patients, and the management of any program are all important.

Although the shortage of ophthalmological manpower is acute in developing countries (Smith 1990), backlogs of patients can occur in places such as the UK due to an ageing population (Batterbury et al. 1991). Local initiatives, expansion of day-case surgery and managerial changes are seen to be important in clearing this backlog (Drummond and Yates 1991). Another issue that can arise even when surgery is available, is underutilization

(Venkataswarmy and Brilliant 1981). Geographical isolation, education and economic cost have been identified as contributing to this (Brilliant and Brilliant 1985)

Summary

Cataracts are an important cause of blindness throughout the world. Several associations for cataract have been found including increasing age, female sex, diabetes, lower education, and increased exposure to U-V radiation. A decreased risk of cataract has been noted in individuals with increased vitamin intake and those having arthritis.

Although these associations may be viewed as risk factors, intervention studies have not been concluded, and so prevention must rely on surgical cataract extraction. The availability and use of these tertiary treatments may vary, and strategies have been developed to overcome these problems.

1.3.3. **Eye Trauma**

Eye injuries are a common and often preventable. Although not a major cause of binocular blindness in either developed or underdeveloped countries, eye injuries are a major cause of monocular blindness in developing nations (Schwab 1990 b).

In Aboriginal communities the contribution of eye trauma to monocular blindness has already been identified (R.A.C.O. Report 1980); however, little work has been published on using prevention to alleviate this burden of visual disability.

Causes of ocular injury

The causes of ocular injury vary throughout the world, and it appears that social background influences the aetiology and severity of ocular trauma (Adala 1983). Currently in western developed nations, sport, work, children at play and assault predominate as major causes (Schein et al. 1988). To this list could be added ocular injuries during intrauterine life or birth, injuries due to travel, agricultural eye injuries and war injuries (Duke-Elder 1965).

Surveys in Africa have identified domestic activities as being the major source of ocular injury (Islar et al. 1982, Olurin 1973), the causes were: chopping wood, sharp and blunt instruments, falls, and burns. In a survey of eye disease in the Navajo Indians in the United States of America, trauma from assaults was the leading cause of monocular blindness, the assaults were often associated with alcohol ingestion (Friederich 1982).

Trauma was identified as being responsible for 2.4% of all bilateral blindness in a Nepalese eye survey (Brilliant et al. 1985). Bilateral blindness may also be caused by: thermal burns, when a person falls into a fire (e.g. during an epileptic fit); road accidents, where the person is thrown through the windscreen, and chemical burns in industrial workplaces (Roper-Hall 1978).

The distribution of ocular injury within a population is said to be bimodal, with young and old most affected (Tielesh et al. 1989). Although this probably relates to the timing of the injury

and not the crude prevalence. Men have been found in a Stockholm study to bear the burden of perforating injuries (Blomdahl and Norell 1984), and men attended for the treatment of eye injuries more frequently than women (Schein et al. 1988).

Types of injury

The three most common vision threatening emergencies are chemical burns, ruptured globes and hyphemas (Shingleton 1991). The first requires immediate irrigation with water followed by ophthalmic assessment; the second may be missed, as up to 20% of patients with ruptured globes do not have readily apparent signs of perforation; the third may be complicated by a further bleed, and 30% of patients with a hyphema have associated glaucoma, corneal damage, cataract, choroidal rupture or posterior-segment bleeding (Shingleton 1991).

Prevention

The evaluation of eye injuries, coupled with advanced surgical techniques and a better understanding of the mechanisms of injury have improved the prognosis for eye injuries (Shingleton 1991). However, because of the high cost of medical and surgical intervention efforts should be directed at prevention. This is particularly so in developing nations where factors such as the distance to treatment facilities, scarcity of eye trained staff, lack of transport and cultural barriers affect treatment (Schwab 1990 b).

In developed countries prevention can be focussed on face and eye protection in sport (Vinger 1981), an increasing awareness of the hazards in industry (Schein et al. 1988), and the reduction of hazards in the home (Grin et al. 1987). In developing countries strategies to reduce blindness from trauma could include: eye safety programs utilizing government agencies, private volunteer organizations and health professionals (Schwab 1990 b). Programs to improve basic eye care facilities in rural areas have also been suggested; as have policy changes, such as, by-laws requiring that motorists wear seat belts (Adala 1983).

Summary

Eye trauma is an important cause of monocular blindness throughout the world. Preventive strategies have been evaluated and implemented in developed countries. However, in third world nations, although the causes of eye trauma are well documented, only limited interventions have been achieved. There are also differences between developed and developing nations in the provision of advanced surgical techniques to treat eye trauma, with developing countries sometimes being unable to provide even basic accessible eye care facilities.

1.4 Methodological Problems in Eye Disease Epidemiology

Although a cross-sectional prevalence survey of eye health and visual impairment may seem to be a simple counting exercise, there are a number of methodological problems which must be considered. By recognising their importance, procedures can be instituted to eliminate or minimize their effect. If they cannot be altered the results may be reported with appropriate acknowledgement of possible inaccuracies. Only by addressing the methodological problems, which are more controllable than confounding and bias, can a study achieve its stated purpose (Hennekens and Buring 1987).

The Number of Subjects

Other factors being equal, as the number of subjects increases in a study, so does the accuracy of any estimates. This is not a linear relationship, and depending on the prevalence of a condition, increasing the number of subjects beyond an accepted limit contributes little to the precision of the estimate. A law of diminishing returns means there will always be a trade-off between the additional benefit and the effort required to obtain number of subjects.

Of importance in ophthalmological investigations is whether we count eyes or subjects. Either eyes or individuals may be counted and the paired eyes of individual subjects, and the unpaired eyes of different people must be distinguished (Ederer 1973). Put simply, the correlation between the right and left eye is very high for some parameters, and therefore the results for each eye cannot be considered independently. For example, the trachoma status of the right eye will very likely be correlated with the trachoma status of the left eye because both have been subject to the same physiological and environmental conditions. In data analysis positively correlated values provide more information when considering the difference between paired measurements and less information when considering the sum or average of paired measurements. Negative correlation would have an opposite effect (Ederer 1973).

The coefficient of correlation is a mathematical construct indicating the degree of sameness between two parameters. Its value ranges between -1 (perfect negative correlation) through zero (absence of correlation) to +1 (perfect positive correlation).

If, for example, both left and right eyes were perfectly positively correlated (r = +1) no more information would be gained from considering 60 pairs of eyes from 60 individuals than from 60 individual eyes, left or right, from 60 people. Alternatively, if the left and right eyes were independent (r = 0), we could consider only 30 individuals to collect the equivalent amount of information i.e. 60 eyes worth. Generally the correlation coefficient does not lie at these extremes, and it is evident that the degree of information provided by a pair is inversely related to (1 - r). Analysis may require comparison of left and right eyes, or if they are highly correlated, tabulation of only the left or right eyes may be sufficient in presenting data as the other eye adds little information.

In summary, it is important to distinguish between the number of eyes or subjects. In ophthalmology, ocular parameters between paired eyes are usually positively correlated. When pooling or averaging positively correlated parameters or measurements, the greater the "r" correlation coefficient, the less information obtainable when compared with two independent measurements. No additional information is obtained from pooling if the parameters are perfectly correlated. However, it is sometimes desirable to tabulate left and right eye measurements separately. Statistical methods are available to adjust for the intraclass correlation between eyes (Rosner 1982).

Disease Definitions and Classifications

In general clinical practice definitions of disease tend to be broad, subject to interpretation and subject to re-evaluation over time. In epidemiology this is unsatisfactory because national, international and longitudinal comparisons need to be made. Standardized disease definitions are required which rely on reproducible measures. This may mean narrower categories and an emphasis on objective measures.

Ophthalmic Observations and Measurements

Diagnosis in ophthalmology is often based on observations, which by themselves are subjective. The conditions under which an observation is made, the training and experience of the observer and the cooperation of the patient all may influence the final diagnosis (Leibowitz et al. 1980). Reproducibility and good observer agreement have been established for a number of ophthalmic measures but there are still problem areas, and even when standards exist they are generally not followed (Ederer 1983).

Visual Acuity Testing

Central to any eye survey is an assessment of visual acuity. Both examiner and subject can have an effect on the accuracy of this test. Double masking, when feasible, can help eliminate the bias (Ederer 1975).

Examiner masking when visual acuity is an outcome variable, is possible in therapeutic trials or controlled studies, but is not applicable in general survey epidemiology because a particular outcome can not be anticipated. Masking in a survey would be difficult, and would involve the examination of people not included in the survey. This would create additional work without improving the accuracy of the survey. Standardising procedures and equipment (see below), then evaluating differences between examiners would be a more effective strategy to pursue. Subject masking is important only in trials when study treatments are identifiable by the subject. Subject compliance, effort and deception cannot be entirely eliminated by study design. It can be minimized by encouraging maximum effort in reading lines, and by continuing the examination until two or more mistakes are made per 8 letter line (Aiello et al. 1974). Repeat testing to reveal inconsistency, at the same or a different time, and adequate explanation of the importance of the examination, also help to reduce subject bias in a survey.

Physical constraints have been identified as additional sources of inaccuracy (Ferris and Ederer 1979):

1. Location of the light for the eye chart, or front, rear (through glass), or projected image.

2. Amount of chart illumination.

3. Distance of the patient from the chart.

4. Degree of black-white contrast between letters and background.

5. Degree of reading difficulty of letters (some letters are more difficult than others).

6. Printing style of the letters.

In survey work it would appear that consistency of an approach to visual acuity testing is as important as limiting the physical sources of inaccuracy. Surveys in remote areas, although acknowledging difficulties, have not attempted to evaluate the magnitude of any inaccuracy. It would appear each should be examined independently and a broader range of error accepted, thus reflecting the constraints of the physical environment (Ederer 1975).

Reproducibility of Observations

Intra-observer and inter-observer variation are important in survey work which is not performed under controlled conditions, and may involve diverse locations, several examiners and an extended time period. In data collection it is important to distinguish between systematic and non-systematic error. Non-systematic error, tends to average to zero over large samples, whilst systematic error can lead significant bias in results (Cochrane and Gemmel 1977).

Only recently have ophthalmic studies recognised that variations in clinical assessments can occur either between observers or between observations made by the same observer on different occasions. In trachoma studies an awareness of the importance of systematic observer variation occurred in the 1960s. The first study of the subject occurred in Taiwan (Assaad and Maxwell-Lyons 1967). They concluded from the results of a survey which

examined 35,000 persons, that variations were inevitable if based on clinical examination alone. It was better to have two observers and it was possible to assess and reduce systematic observer bias. Other studies to account for observer variation were conducted by Hollows and Graham (Gibson and Sanderson 1980) and the Framingham Eye Survey of 1975 (Kahn et al. 1977)).

Trachoma has been the subject of frequent population-based surveys; however only a few have reported strategies for reducing inter-observer and intra-observer error. Brilliant reviewed four surveys and presented Table 1.4.1 (Brilliant et al. 1983 b)

Table 1.4.1 : Inter-observer agreement on the diagnosis of trachoma: comparison of results from four population surveys

Survey (reference)	Trachoma measure	No. of subjects	No. of examiners	% agreement	Kappa
Taiwan (Assaad 1969)	Absent/ present	574	2	80.5	0.59
Morocco (Kupka 1968)	Nonactive/ active [1]	200	2	77.0	0.53
Australia (RACO 1980)	Absent/ present [2]	172	2	83.1	0.53
Nepal (Brilliant 1983)	Absent/ present	507	5	80.5	0.60

1. Nonactive trachoma = stages O, D and IV; active trachoma = stages I - III (see Kupka for definition of stages).

2. Follicular trachoma.

Although the % agreement appears to be excellent, the Kappa (K) statistic (see below), showed only fair to good concordance in trachoma grading. This may reflect the complexity of

the old trachoma grading system, It may be concluded that because the K values were similar, with consistency between surveys conducted in different locations with different grading personnel, that study design, including standardization procedures, could not overcome the inherent problems with the complex grading system. The new five sign trachoma grading system was designed to overcome these deficiencies (Taylor 1987 c).

The Kappa statistic is a standardised measure of agreement which corrects observed agreement between examiners for that expected by chance. A three category ranking provides a measure of agreement (Fleiss 1981).

K = 1.00 - 0.75 excellent agreement

K = 0.74 - 0.40 fair to good agreement

K = 0.39 - 0.0 poor agreement

The Kappa statistic was used in the 1989/90 survey to assess the degree of agreement for the presence or absence of trachoma, and the effect of magnification vs non-magnification on trachoma grading (section 5.2.2 and 5.2.3)

Cross-sectional Prevalence Surveys

Cross-sectional surveys may be concerned with: the presence of disorders, such as diseases or disabilities within a population; measures of health, such as blood pressure, fitness or diet; and factors associated with health and disease, such as socioeconomic status and demographic data (Abramson 1991).

Cross-sectional prevalence surveys are most often used to learn about risk factors for diseases of slow onset and long duration (Kelsey 1986). Other uses include: the promotion of health in a specific group or population studied; the enhanced clinical care of individuals; and the provision of new knowledge, with inferences that could be applied beyond the population studied (Abramson 1991).

Cross-sectional surveys have two principle advantages; they are relatively cheap compared to other types of surveys and the sample is taken from the general population, not a small sub-group (e.g. hospital patients), and therefore the results are generalizable. There are three major difficulties (Kelsey 1986). Firstly, it may be difficult to separate cause and effect. Secondly, a series of prevalent cases will have a higher proportion of cases with diseases of long duration than a series of incident cases, (That is, people who either recover or die from a disease quickly have less of a chance of being included in the disease group). If there are differences between long or short term sufferers in certain characteristics, the association of these characteristics with exposure and incidence may be obscured. Thirdly, there are possible problems with definition, for instance, should a treated person be counted or should a person in remission not be counted.

Weighing up the advantages and disadvantages of cross-sectional prevalence surveys it appears that they are cost effective and useful for both descriptive and analytical work, including hypothesis testing (Abramson 1991). They are also often used to provide base-line information for more detailed planning of curative and preventive work (Minassian 1988). There are, however, several issues that must be addressed if comparisons are to be made between cross-sectional surveys.

Comparison Between Surveys

Although there are difficulties in comparing results from different eye health surveys, an appreciation of change over time is greatly enhanced by the utilization of quantitative rather than qualitative data, even if they are generated by several cross-sectional surveys rather than cohort or longitudinal studies. Anecdotal evidence submitted as fact can be misleading rather than informative and can also be subject to bias and misrepresentation. Quantitative data can also be interpreted selectively, but if the methodology, assumptions and analysis are clearly stated, conclusions can be checked and challenged.

Several factors may influence the interpretation of differences between ocular surveys (Meredith et al. 1989). For example, there may be differences in the ability of workers to

identify trachoma. This may be due to differences in the level of experience, or it may reflect levels of expertise, personal motivation and expectations, environmental conditions, facilities for testing and fatigue.

The classification of trachoma is another factor which may influence the results of comparative research. Over many years the grading system for trachoma has changed, reflecting both the evolution in the understanding of the disease caused by *Chlamydia trachomatis* and a realization that a complicated system added little to the interpretation and application of the results. A simplified system has the added benefits both of being useful for non-specialized health workers who could be instructed in its use, and of being interpretable by non-medical personnel.

When comparing surveys which have used different grading schemes difficulties arise. For instance, although the terminology may be similar, the definitions for disease may be different and could result in significant errors. For example, in the 1985 National Trachoma and Eye Health Program Review (T.E.H.P. Report 1985), a new diagnostic criteria for trachoma was devised by the investigators because it was felt that the old system failed to pick up genuine cases of follicular trachoma, and whilst the classification of limbal follicles could have been used to diagnose follicular trachoma, it could not be used to assess the severity of follicular trachoma. When the investigators examined the 1985 results and those in the 1980 R.A.C.O. Report, they found that by applying the new diagnostic criteria to the 1980 results, a 16% increase in the follicular trachoma rate occurred, with a 22% increase in the prevalence of severe follicular trachoma. A change in the diagnostic criteria had resulted in a significant increase in the 1980 trachoma prevalence rates.

When comparing two surveys, factors that influence selection of a participant in a survey may be distributed differentially between the survey populations leading to a response bias. It would be difficult to predict and correct response bias if it had occurred in a past survey and had not been documented. Differences between surveys could then be due to differences in response rather than actual differences in prevalence rates. A practical example of this

would be a survey of the prevalence of blindness in a community, in which an eye health survey might identify 90% of all blind people. A second survey two years later may not attract the same interest as the first, with 50% of all blind people knowing that being seen again would not help them. The results of the second survey would falsely show a fall in the prevalence of blindness.

Differences in the age structure of two survey populations may also lead to errors when estimates of disease prevalence are compared. This may occur for two reasons. Firstly, with trachoma, active infection is found predominantly in the young, a survey population which has a higher proportion of young people will have an apparently higher crude rate of infection due solely to the higher proportion of infected young people. This may be overcome by giving age-specific rates or by age adjustment, in which a single summary rate is calculated that takes into account any difference in the population structure, a procedure called age-standardization. Secondly, an increase in population density may increase the prevalence of trachoma. When two populations are compared each having the same population distribution, an equivalent result may be accepted as indicating equivalent socioeconomic or infrastructure development, the true result possibly being confounded by the different population densities. Again, procedures should be implemented to adjust for the confounding factor, or the difficulties with the comparison acknowledged.

Differences in the way the results of a survey are reported may make comparisons with other surveys difficult or impossible. For instance, if the source population is not defined or the methodology not described fully, it may be inaccurate to compare the survey results because differences may be due to differences in survey design rather than disease prevalence.

Surveys can be used for surveillance, which permits the identification of changes in health status. For example, changes in risk factors for cardiovascular disease have been monitored by repeated cross-sectional surveys in the Multinational Monitoring of Trends and Determinants in Cardiovascular Disease (Monica Project) sponsored by the W.H.O. (Pisa 1989). Case registers may be used for the purpose as well (Thompson 1989). When

changes in the prevalence of a disease is noted from repeated cross-sectional surveys care must be taken in interpretation. For example, incident data should be used to indicate changes in the risk of developing a disease because changes in the demographic characteristics of the population e.g. an ageing population or migration of affected people away from the survey area, may explain changes in prevalence data. Also, as explained above changes in the method of case identification, survey methodology, or disease definitions may all affect the results and their subsequent interpretation (Abramson 1991).

It has been shown that when performing repeated cross-sectional surveys there are advantages in using separate sample (between surveys) designs, these are (Salonen et al. 1986): 1. differential re-examination response bias is avoided (individuals do not change their response because they have been examined before) 2. the representiveness of the sample remains the same. Similarly re-examination of the same cohort has advantages, especially if the communities are small, these advantages include : 1. the ability to adjust for base-line differences between communities on an individual level 2. sample sizes may be smaller 3. there are increased opportunities to explain interactions between base-line characteristics and risk factor changes. The major disadvantages are that as the cohort ages and dropouts occur, its representiveness of the total community is lost, and the survey may affect the behaviour of the participants.

Lastly, the evaluation of intervention programs for diseases that have epidemics (e.g. measles) and therefore have swings in incidence that are naturally high and low, may not be usefully monitored using repeated prevalence surveys, because it would be difficult to attribute changes to the program or to natural fluctuation (Cutts 1988).

Summary

There are several methodological problems associated with eye disease epidemiology. These include: sample size considerations, standardization of disease classifications, the minimisation of errors due to ophthalmic measurement (e.g. in visual acuity testing), the reproducibility of observations (inter-observer and intra-observer error), and the selection of an appropriate survey or study design. When surveys are compared these issues must be considered; also, when the study is a cross-sectional survey several other factors must be considered. Chiefly, differential participation, the representativeness of the samples and the natural fluctuations of the disease being monitored.

1.5 Conclusion

It is clear from the foregoing chapter that a review of eye health within a community is reliant on the accurate assessment of visual acuity. A sample survey can be the most practical method of achieving this aim. However, because sample surveys are cross-sectional, comparisons with previous literature can be difficult. Comparisons with international data are also problematical and therefore may only be useful for illustrative purposes.

The major causes of blindness in the Aboriginal Australian are trachoma, cataract and trauma. Trachoma is a readily preventable cause of blindness and lends itself to intervention at primary, secondary and tertiary levels of treatment. The prevalence and severity of trachoma reflects the environmental and socioeconomic conditions prevailing in Aboriginal communities. An assessment of the prevalence of trachoma could therefore yield information about the general health status of a community and the level of its socioeconomic development. Additionally, if comparisons could be made with previous evaluations of eye health, conclusions about progress in a community might be possible.

Chapter one also indicates that there are several methodological problems when assessing eye disease in a community. Any study has to define the number of individuals to be examined and make a choice between counting subjects or eyes. Standardization of disease definitions and ophthalmic measures is important, especially if comparisons are to be made with previous surveys. Also, observer variation needs to be acknowledged, with the measurement of observer variation is best made using the Kappa statistic.

Although it appears that there are disadvantages with cross-sectional surveys when they are used to monitor change over time, if adjustments are made for changes in disease classification, population age structure, survey design, result reporting and cohort representation, then for many diseases there are many advantages in using this type of study design.

If a sample survey was to be undertaken the literature indicates that the following interventions would be of benefit to the community being surveyed: case identification followed by individual treatment (Individuals with trichiasis could be offered epilation or surgical

intervention, those with cataracts, surgery in a major centre); increasing the awareness in both the community and medical services of preventive and treatment measures for eye disease; and specific training of community health workers in eye care.

Chapter 2. Blindness and Trachoma in Australia with Reference to the Anangu Pitjantjatjara of South Australia

2.1 Introduction

In this chapter the causes of blindness in Australia are reviewed. The literature relating to the Aboriginal population is more comprehensive than that available for the white population, mainly because of the contribution the N.T.E.H.P. survey 1976-1979. It is important to understand the differences in eye health between white and Aboriginal Australians because the equitable distribution of health resources is dependent on the accurate assessment of need.

Trachoma is an important cause of blindness in the Aboriginal population and has been historically important to their eye health. Furthermore, its origin in Australia has been subject to speculation for many years, with no firm epidemiological basis for definitively ascribing its introduction to the coming of Europeans in the 18th and 19th centuries. A review of the historical evidence and epidemiological data allows further conclusions about its origins in Australia to be made.

The literature review is also used to construct a picture of Aboriginal eye health in South Australia from the earliest recordings by explorers in the 19th century through several surveys of Aboriginal people in the north-west of South Australia from the 1960s to the 1980s. No other group in Australia has had its eye health recorded and published as much as the Anangu Pitjantjatjara of S.A.. It provided a unique opportunity to make descriptive comparisons between surveys over time and to draw conclusions about the development of trachoma in their communities.

2.2 Blindness In Australia

Probably more work has been done to establish the prevalence of blindness in the Australian Aboriginal population than amongst the white population. Early reference to Aboriginal ocular disease and blindness occurs in anthropological review articles by Cleland (1928) and later Packer (1961). The first major ophthalmological surveys began in the 1940s with Flynn (1957) in Central Australia. These were followed by work in Western Australia by Mann (1954 a, 1954 b, 1957 a) in the 1950s and several smaller surveys in S.A. and the N.T. in the 1960s by Moore et al.(1965), Mann and Rountree (1968) and several unpublished workers. In the 1970s the most extensive survey carried out was by the National Trachoma and Eye Health Program (N.T.E.H.P.), whose Chief Ophthalmologist and director was Professor Fred Hollows. Beginning in 1976, in the arid areas of central Australia, 62,116 Aboriginal and 38,616 non-Aboriginal people were examined (R.A.C.O. Report 1980).

Presentation of the results for some of these surveys allows qualitative comparisons to be made. For instance comparison of the causes of blindness in the white and Aboriginal population highlights that there will be differences in the strategies for prevention in each group. The estimates of blindness prevalence for each population demonstrate the order of magnitude separating the two populations in terms of their eye health. Tables 2.1.1, 2.1.2 and 2.1.3 summarise the results of some of these surveys of Aboriginal and non-Aboriginal people.

Table 2.1.1: Visual system abnormalities in the blind by racial group

(rates per thousand) R.A.C.O. Report 1980

Site	Rates per 1000 blind			
	Aborigines		Non-Aborigines	
	Rate	Rank	Rate	Rank
Site				
lens	641	1	516	1
cornea	555	2	83	4
eyeball	149	3	33	11
conjunctiva	118	4	50	6
eyelids	87	5	33	10
iris, ciliary body	47	6	66	5
refraction	46	7	183	3
strabismus	24	8	50	7
retina and choroid	18	9	250	2
optic nerve	17	10	-	-
lacrimal system	16	11	-	-
vitreous	1	17	-	-
sclera	1	18	-	-
Cause				
glaucoma	16	12	33	-
visual disturbances	9	13	16	13
general disorders	5	14	50	8
congenital abnormalities	4	15	16	14
neoplasm	3	16	16	12

The table shows that for many blind individuals one or more sites or causes of blindness were recorded by the examining ophthalmologist. This is not unusual, because multiple pathology often exists, and it is difficult to attribute the reason for blindness to one cause. Therefore the numerators of the rates given may add up to more than a thousand.

The table demonstrates that for both populations diseases of the lens (e.g. cataract), were the leading cause of blindness. Corneal (e.g. trachoma) and "eyeball" disease were then the next two most important diseases for Aboriginal people, but for non-Aboriginal people diseases of the retina or choroid and refractive problems follow lens disease. This is an important difference, for while corneal and eyeball disease may be preventable, retinal and choroidal disease (e.g. macular degeneration) is more a function of ageing and not preventable with current knowledge.

The data for the Eastern Goldfields survey of Aboriginal blindness (Table 2.1.2) were derived from a smaller sample (2,203 vs 100,732 for the R.A.C.O. Report of 1980), and Mann choose to define the causes of blindness explicitly. She also choose to provide information about both eyes. Twenty three individuals had a single cause of blindness listed (e.g. cataract), but five individuals were listed as having two causes (e.g. trachoma and cataract or cataract and injury). Whilst it is often necessary to narrow the cause of blindness to one disease, it can be useful and more accurate to list the cause of blindness in each eye, preserving the detail of the data.

Table 2.1.2: Causes of Blindness in the Eastern Goldfields
(based on 2203 people surveyed) (Mann 1957 a)

Cause of Blindness	No. of Cases	Rate per 1000 in those surveyed
Trachoma	16	7.3
Cataract	4	1.8
Cataract and injury	3	1.4
Trachoma and cataract	2	0.9
Ophthalmia neonatorum, corneal scars and bilateral phthisis bulbi	3	1.4
Total	**28**	**12.8**

Mann found trachoma to be the principal cause of blindness, with cataract being the next most important cause. The survey was small; however the data, in particular that relating to trachoma and the high prevalence of blindness, was of great interest at the time.

The data in Table 2.1.3 were a sub-set of that previously discussed (Table 2.1.1). However, it gave specific disease categories rather than sites of visual system abnormalities, and provided information for both eyes. It was a larger sample than that for the Eastern Goldfields, and had several disease categories. The results tend to mirror those of its larger data group rather than those of Mann's work. Taylor (1980 a) found that almost half of Aboriginal blindness was due to cataract, one third to corneal scarring and one twelfth to phthisis or enucleation. Only one twelfth was attributable to retinal disease. He concluded that blindness in Aboriginal people was environmentally related and therefore preventable. Trachoma contributed to only 18.1% (9/55) of all binocular blindness, a finding consistent with the N.T.E.H.P. data, but less than that obtained by Mann. Mann's and Taylor's work were completed in different geographical locations, and this may account for the observed differences. The R.A.C.O. Report found considerable variation between the 13 zones it had chosen, which reflected both climatic and socioeconomic conditions (R.A.C.O. Report 1980).

Table 2.1.3: Causes of Blindness In 138 Aborigines Over The Age Of 60 Years; n = 339 (Taylor 1980 a)

	Binocular No.	Monocular No.
Trachoma	7	5
with cataract *	1	-
with enucleation *	1	-
Corneal scars	8	15
with cataract *	2	-
with phthisis *	1	-
Senile cataract	32	25
traumatic *	1	-
with pt. *	1	-
with enucleation *	2	-
Traumatic cataract	-	5
Climatic droplet keratopathy	4	3
with corneal scar *	1	-
Bilateral phthisis	1	12
Other	3	8
All causes	**65**	**73**

* In these cases of binocular blindness, one eye was affected by the condition listed in the major entry; the other eye was affected by the condition in the sub-entry.

In contrast, very little literature appears for the urban white population. Anderson (1939) reported the prevalence of blindness and its causes among private practice patients in Melbourne. He conducted an analysis of the medical records of 12,240 ophthalmology patients. The definition of blindness used was vision of less than 6/36, or a field loss reduced to within 10^{o} in the other. The survey was acknowledged as incomplete as it did not sample from the whole community. He found binocular blindness in 2.2% of the sample and monocular blindness in 5.5%. Of more interest were the listed causes of blindness. In order of importance they were: glaucoma; congenital and hereditary diseases, myopia, vascular lesions, syphilis, diabetes, focal sepsis and trachoma. The results reflect the type of patient seen in private practice, the treatment available at that time (e.g. for glaucoma or syphilis), and

the exclusion of people with cataract, as they were classified as "amenable to treatment" (Anderson 1939 p680).

In his discussion of the results, Anderson concluded that 50% of blindness was preventable with the then current knowledge, and a further 30% possibly preventable in the future. He was concerned at the implication of the results for monocular blindness, particularly the greater risk of complete blindness and the impairment of efficiency if the other eye was not good. The presentation of the results for blindness from trauma was comprehensive, and gave a detailed picture of events and objects that had caused monocular or binocular blindness. Motoring accidents, chopping wood, shooting and hammering steel being the predominate causes. Although the study was acknowledged as being limited, it was hoped that the work would encourage a more systematic investigation of blindness in Australia.

During the Second World War (1939-1945) the results of a blindness survey conducted in Tasmania were published, with a final review in 1948 (Hamilton 1950). It presented the results of a private practice audit in Hobart, with a comparison to similar data collected in 1938. The work was criticized by ophthalmologists of the day for not being representative of the total incidence of blindness in Tasmania, as it only concerned private patients in Hobart, further, there were potential problems with double counting of patients between practices and the total number of blind patients seen (106), which was thought to be small. The comparison with earlier work was seen as interesting; however, other explanations for the observed changes were not explored. For instance, although the decline in blindness from diabetes may have been due to the introduction of insulin, other factors such as the referral of diabetic patients to Dr. Hamilton may have been important (Hamilton 1950 : Discussion).

In 1949 Redmond presented the findings of a review, in which the records of 10,000 patients (from a ten year period) were examined, and the causes of bilateral and unilateral blindness described. The study was not presented as a paper on blindness, but as a stimulus for other

ophthalmologists and the government to consider both the lack of data on blindness in Australia and the prevention of unilateral blindness (Redmond 1949).

Following on from this early work, the Ophthalmological Society of Australia proposed to evaluate data from the compulsory registration of blindness. A form, the SA 47, was designed for the certification of people seeking the invalid pension. It was introduced in an effort to obtain accurate statistical information on the causes of blindness. A survey was run for five years from 1953 to 1958 inclusive (Yates 1963). Although the data was subject to bias, it was useful as a guide to the causes of blindness in Australia. The principle causes were: cataract 17.78%, glaucoma 16.02%, diabetes 6.89%, and all other causes 11.38%. Trachoma was found to cause 2.17% of all blindness (it was not clear whether Aboriginal people were counted in the data). Yates compared the prevalence rates with those obtained by Sorsby in England, and Mann in the Kimberleys and Eastern Goldfields. He found that the causes of blindness were similar to those found by Sorsby in England. However, when he reviewed Mann's results from the Kimberley and Eastern Goldfields it was apparent that none of blind individuals from these areas appeared on the SA47 forms.

A later survey estimated major causes and prevalence of blindness based on four sources (Banks and Hutton 1981):

1. Records of the Department of Social Security.
2. The National Trachoma and Eye Health Program.
3. Australian Bureau of Statistics.
4. The Royal Blind Society.

Aboriginals were not included and methodological problems were found with each source of information. The estimated prevalence of binocular blindness was of the order of 7 to 10 per 1000 (0.14-0.19%). Of these, only half were receiving a blindness pension. Banks concluded that the although an absolute value for blindness prevalence could not be obtained from pension data, the % contribution of any cause could be readily available with

cooperation from the Department of Social Security, and by adopting interactive coding for diagnosis in the Department's records. The causes of blindness so obtained were listed by site of pathology, making comparisons difficult. In order they were: macular degeneration 37.2%, anterior segment 28.8%, neurological (including optic nerve) 11.2%, and other 19.5%. Acquired cases made up 67% of all blindness, with congenital 10% and genetic 15.5%. He concluded that accurate information could only be obtained from extensive population based surveys.

The presentation of these results for blindness in Australia demonstrates the difficulty of obtaining accurate prevalence data and while the causes of blindness were more easily identified, the percentage contribution of each was subject to ascertainment bias, particularly for data obtained from private practice or social security records. The former eliminates those who cannot afford private health insurance, and the latter those ineligible or unwilling to obtain the blindness pension.

2.3 Origins of Trachoma in Australia

The ancestors of today's Aboriginal Australians crossed a land bridge between Asia and Australia somewhere between 60,000-40,000 years ago. They migrated south through a land which was wetter and greener than it is today (Abbie 1976 pxviii). With rising sea levels, they were then effectively isolated until the coming of Europeans in the 17th and 18th centuries. From what is known of the Aboriginal lifestyle prior to white settlement, it appears they were nomadic or semi-nomadic, hunting and gathering in small groups (Berndt and Berndt 1977). If trachoma had been endemic in Australia it would have necessarily survived 40,000 years of changing environments, as Australia became drier, and maintained itself by carriage and transmission in small groups of scattered people, who it appears had few other infectious diseases, and were physically fit and healthy. Given these constraints, and the fact that trachoma is difficult to catch and only thrives in crowded communities with poor hygiene, it

appears that the presence of trachoma as a blinding disease did not occur until the advent of the socio-cultural and bacteriological changes associated with the coming of white man. There were ethno-historical accounts of eye disease in Aboriginals from the 19th century (Sturt 1833, Eyre 1854, Stirling 1894). Also, a number of anthropologists have speculated that trachoma was present prior to white settlement (Abbie 1960, Barnes 1970), and some authors on Aboriginal life have used statements attributed to explorers to suggest that trachoma may have been present prior to white settlement (Cleland 1928).

The first known European explorer to visit Australia was William Dampier (1688). He wrote " ... the miserablest people in the world, their eyelids are always half closed to keep the flies out of their eyes, they being so troublesome here that no fanning will keep them from coming to one's face so that from infancy, being thus annoyed with these insects, they do never open their eyes as other people, and therefore they cannot see far unless they hold up their heads, as if they were looking at somewhat over them". The Professor of Pathology at the University of Adelaide speculated that the above passage referred to trachoma (Cleland 1928). It may, however, have been another form of eye disease (R.A.C.O. Report 1980). In contrast, during the voyage of the "Endeavour" in 1776, the English explorer Captain James Cook (1788), did not observe any sign of disease among the Aboriginals encountered. Further corroborating evidence from early settlement is currently not available, but it appears that there is no indication in the traditions or folk lore of Australian Aboriginal people, as to the origin of trachoma (Mann 1957 b). Such information might be expected if it had been present for 40,000 years.

With the colonization of Australia after 1778, trachoma was acknowledged as occurring in both the white and Aboriginal population (Cleland 1928). Confusion has arisen between endemic trachoma and epidemics of conjunctivitis, with the Australian term "Sandy Blight" once thought to describe trachoma (Editorial 1972), now being recognised as a non-trachomatis conjunctivitis (Hollows 1989). Whatever the terminology, several authors have speculated on the origin of trachoma. In 1904 a European author, in a review of trachoma throughout the world, supported the contention of its European introduction (Boldt 1904), " It is probable

that the disease was introduced by the convicts who were transported". Boldt observed that trachoma was prevalent amongst the inmates of prisons and other institutions in England at the beginning of the 19th century, from which the early convicts transported to Australia would have been drawn.

Mann, an ophthalmologist from Western Australia, conducted several trachoma and eye health surveys in Australia and Papua New Guinea during the 1950s (Mann 1954 a, Mann 1954 b, Mann 1957 b, Mann 1967). She found strong epidemiological evidence from the distribution of trachoma in New Guinea to support the hypothesis of its recent introduction there. By contrast, in Australia she found trachoma to be widespread in all the areas surveyed. Although acknowledging that it may have been endemic, she speculated that Western Europeans (settlers, convicts or goldminers), Japanese or Malay pearl fishers, Afghan camel drivers, imported Chinese labourers, natives from other Pacific Islands, and Central and Eastern European migrants, could have introduced trachoma in more recent times (Mann 1957 b).

If trachoma was introduced by the early explorers and settlers, its transfer and early disastrous effects on the Aboriginal population went unnoticed. In addition, the socio-cultural disintegration seen when large groups of Aboriginal people were forced into crowded communities probably enabled the disease to flourish (R.A.C.O. Report 1980).

An opportunity arose in the 1960s to examine a group of Aboriginals from W.A. who had no previous association with Europeans (Elphinstone 1971). He reported that of 88 individuals, half had signs of active or healed trachoma, with one case of trichiasis and two cases of corneal opacity due to trachoma. It could be concluded that this finding provided evidence of trachoma's ancient origins in Australia. However, it was known that this group had had some contact with Aboriginal people from surrounding areas. These Aboriginals were infected with trachoma. It could be argued that the lower prevalence of trachoma, and its severe complications (of trichiasis and corneal opacity), when compared with results from the adjacent Warburton area (from Mann's 1957 survey), indicated a more recent introduction into this

group, with insufficient time for the disease to infect all susceptible individuals, or run a chronic course, in order to produce the blinding complications so characteristic of trachoma in endemic areas.

The only other evidence concerning the origins of trachoma in Australia, comes from the examination of the skeletal remains of prehistoric Aborigines (Webb 1990). Skulls 1,000 to 14,000 years old, were examined for a small round hole in the orbital plate of the frontal bone. Webb speculated that a chronic infection of the lacrimal glands was the most likely cause and that trachoma was the most probable agent. The lesion was positively correlated with age and was distributed in trachomatous regions. However, males were affected more than females (a reverse of the epidemiology today), and practising ophthalmologists doubt the association between the lesion and active trachoma, they think it may have been due to post morbid trauma. (Personal communication Dr. J. Crompton 1991, Adelaide, South Australia)

2.4 Past Surveys In South Australia

The first observations of the eye health of Aboriginal people in South Australia (S.A.) were made by explorers from the 1880s to the 1920s. They recounted anecdotal evidence of eye disease. For instance, the use by Adelaide Aboriginal people of masticated gum leaves for sore eyes caused by "Sandy Blight" was described by Stephens in 1889 (Cleland 1928). Ophthalmia was stated to be prevalent amongst the natives in Central Australia encountered on the Horn Expedition (Stirling 1894). In 1916 several old Aboriginals were met in the north of South Australia and found to be blind (Waite 1916). The Professor of Pathology at the University of Adelaide later ascribed this to " ... the results of trachoma or sandy blight. " (Cleland 1928 p219).

Trachoma was also noted to occur in the white population. In a review of trachoma throughout the world Boldt (1904), reported on the findings of a Dr Bennett. He was a general practitioner for 8 years in a small town called Crystal Brook, which is located in the mid-north of South

Australia, an area known for its farming and low rainfall. An imaginary line had been drawn across the state of South Australia, delineating arable from non-arable land. Known as Goyder's Line, it reflected the average rainfall across the state, with the area north of the line receiving less than 200mm of rain per year. Enough rain fell south of the line to produce crops consistently. Dr Bennett found trachoma to be twenty times more frequent north of Goyder's line than south of it, despite the fact that the farmers were otherwise healthy, had adequate diets and lived in spacious houses.

In 1928, the Professor of Pathology at the University of Adelaide reported on the eye disease of Aborigines. Ophthalmia, gonorrhoeal conjunctivitis, corneal opacities, trachoma, glaucoma and senile cataract were discussed with reference to previous observations from the 19th and early 20th centuries (Cleland 1928). A Dr. Basedow, was acknowledged on several occasions, for his work in the N.E. of South Australia during three medical relief expeditions in 1919-1920. The article was descriptive, and gave no indication of the prevalence or incidence of disease. While of historical interest, it may or may not be an accurate picture of Aboriginal eye health at the turn of the century.

Doctor Basedow in 1932 contributed further information on the "Diseases of the Australian Aborigines" when he wrote as the former Chief Medical Inspector and Chief Protector of the Aborigines of the Northern Territory. He lamented the fact that more had not been done to document the diseases of the "pure blooded" Aboriginal Australians, despite ample opportunity by medical officers in the past. He also presented personal observations of Aboriginal customs, behaviour and health beliefs. He emphasised the influence of traditional Aboriginal ideas of health and sickness on western diagnosis and treatment of disease (Basedow 1932). He was aggrieved, that despite suggestions, "no systematic treatment whatsoever has ever been inaugurated in Australia for checking the alarming spread of trachoma among the natives. To placate the prevailing sentiment at the time he added "if for no other reason, this should have been done long ago in the interest of the white settlers" (Basedow 1932 p132)

Contributions to the limited amount of knowledge of diseases in Aboriginal people continued in the 1930s with an expedition to Nepabunna in the Flinders Ranges of South Australia, and to the 'Granites', 380 miles north-west of Alice Springs (Black and Cleland 1938).

Only "full blood" Aboriginals were examined, nine from Nepabunna and fifty from the Granites. Corneal opacity was found in four of the nine from Nepabunna, and three of the eighteen in the Granites. The author commented that corneal opacity was common and was severe in the three, and had reduced substantially the vision in each eye in one woman from Nepabunna. Grey and Cleland (1933) had previously considered that the corneal ulcers preceding the opacities were due to injury from three sources: fights, mulga twigs or other during passage through dense scrub, and fire or fire-sticks, especially in the case of children. Some of the cases from Nepabunna were thought to be of gonococcal origin. Three subjects from the Granites were thought to have scarring of the upper lids, possibly due to trachoma. Signs of trachoma were not noted in the individuals from Nepabunna.

Blindness was not remarked upon except for the woman from Nepabunna with "very little vision in either eye". Vision testing was found to be unsatisfactory because "it was difficult to get them to rivet their attention on what you want them to see" (Grey and Cleland 1933 p81). Refraction was estimated on six using homatropine and cocaine. All showed some degree of hypermetropia except one, a young women aged 22 years who was emmetropic.

Although the N.W. areas of South Australia were not visited, the Aboriginal people in both the N.W. of S.A. and around Nepabunna may have been living under similar conditions and it could be expected that the pattern of trachoma would be the same.

Flynn conducted several eye surveys in the 1940s. These were the first modern assessments of eye health amongst the Aboriginal population of central Australia. He commented in 1942: "At this time it appeared to be the generally held contention that little or no active trachoma existed in Australia" (Flynn 1957 p 269). When he conducted a survey in 1944 he found severe disease in the area around Alice Springs, with 90% of those examined infected with trachoma, and with 7% blind in one or both eyes (Flynn 1957).

During the 1950s, Mann conducted Aboriginal eye health surveys in the Kimberley District of Western Australia and in the Goldfields area (Mann 1954 a, 1954 b, 1957 a). The results from these surveys showed that trachoma was a major problem in the Aboriginal population and that a large differential existed between the eye health of Europeans and Aboriginals. Treatment programs did not reduce the prevalence of trachoma appreciably, and Mann concluded " ... little impression will be made on the trachoma rate unless the standard of living of the infected groups can be substantially raised (Mann and Rountree 1968 p1020).

In the mid 1960s Mann conducted a survey in the Pilbara and the north-western part of South Australia (Mann and Rountree 1968). These large regions were chosen because of the paucity of white inhabitants, and the fact that traditional tribal life continued for the Aboriginal population.

In this report no details were given of the methodology involved in the survey, but a descriptive account of the people, their customs and living conditions were given with summary tables of the results. Two communities were visited. At Ernabella, 377 "full blood" Aboriginal individuals were examined from an estimated 400-500 members of the tribe. At Indulkana which was little more than a temporary camp with no amenities, with buildings and nursing services some miles away, 118 individuals were examined.

The results of the Ernabella survey indicated a high prevalence of trachoma, 90% overall, with 53% of the under-20 age-group having active trachoma (the under-20 age-group comprised 50% of the total population). Visual acuity was tested on only 77 individuals, 61 of whom had 6/6 vision or better. Three elderly people with lens changes read 6/36. It was of note that only one person over 60 years of age was "economically blind", and only five showed visual disability due to trachoma. However, these data may be imprecise, only 20% of the population underwent visual acuity tests and it is unclear how the blind or visually impaired individuals were identified. Certainly blindness in older individuals was not a major feature of the survey in Ernabella. In contrast the survey in Indulkana, although examining only 118 Aboriginals, found trachoma in 84%, with a "pattern of distribution which was similar to other surveys of

W.A. and S.A." Mann and Rountree commented that most had healed by middle-life with no impairment of vision, the only sign being scarring of the tarsal plate, Herberts pits and mild pannus. Eight persons had corneal opacity with five being "economically blind" as a result. No other causes of blindness were mentioned. Tables 2.4.1 and 2.4.2 detail Mann's and Rountree's results for trachoma status and eye disease.

Table 2.4.1: Ernabella and Indulkana - Trachoma Status by Age (Mann and Rountree 1968)

Age-group	Total examined	No Trachoma	Trachoma[1] I-II (A)	Trachoma III (A)	[2]Trachoma[3] IV (A)	Trachoma[4] IV (C) & IV (D)
<1	19	12	7	0	0	0
1-4	83	20	56	6	1	0
5-9	68	2	22	39	5	0
10-19	78	1	4	48	25	0
20-59	190	15	0	45	126	4
60+	57	1	0	3	44	9
Total	**495**	**51**	**89**	**141**	**201**	**13**
% of total		**10.3%**	**17.9%**	**28.4%**	**40.5%**	**2.8%**

Mac Callam's Stages of Trachoma (Mac Callam 1931)

1. Trachoma I-II(A): Follicular Trachoma

2. Trachoma III(A): Where cicatrization has commenced

3. Trachoma IV(A): Where cicatrization is complete and healed with good vision

4. Trachoma IV(C) and IV(D): Where cicatrization is complete and either healed with impaired sight or is economically blind

Table 2.4.2: Distribution of Other Eye Diseases in Ernabella and Indulkana (Mann and Rountree 1968)

Disease	Ernabella	Indulkana
Perforating injuries	18	7
Non-perforating with infection	7	0
Lens changes (cataract)	10	1
(nuclear sclerosis)	6	0
Eye excised	2	-
Ruptured sphincter	1	-
Total examined	44	8

Mann and Rountree summarised their findings as showing that trachoma was the most important eye disease throughout the areas. Perforating injuries to the eye from trauma were more commonly found in Aboriginal than non-Aboriginal people, and despite the high number of perforating injuries, no sympathetic ophthalmitis was found.

Several limitations affected the accuracy of the survey, principally the representativeness of the sample. The two major settlements were visited; however, it was not known how many individuals existed away from these areas, leading nomadic lives. A total of 400-500 may be a reasonable estimate by locals familiar with the Pitjantjatjara. However, with people ranging up to 300 km from the population centres, any estimate was likely to have been a guess.

In South Australia during the 1960s trachoma was noted to be "extraordinarily rare" in the white population. Little was known about its prevalence in the Aboriginal population in the state (Mann's work had not been published). After isolated reports of active trachoma in

Adelaide, and a meeting of interested groups, it was decided to perform a survey of trachoma in urban and rural populations (Moore et al.1965).

The urban white samples in Adelaide and Salisbury were highly selected. They were either patients of ophthalmologists in whom follicular conjunctivitis had been diagnosed, or, in the latter township, ex-servicemen, many of whom had served abroad. Musgrave Park (Amata) and Mt. Davies (Pipalyatjara and Kalka) in the far N.W. of S.A., and Cooper Pedy were selected as rural localities. The survey was conducted in 1963-64.

All the rural areas were visited again in 1976 -1979 N.T.E.H.P. survey, with Mt Davies and Musgrave Park included in the 1989/90 survey. The results for these two communities (for 1963) are summarised in Table 2.4.3. Trachoma was found in 96% of the 163 individuals examined in the 1965 survey. Corneal opacities were present in 18 subjects (11.0%), with 13 (72.2%) of these considered to be trachomatous. Three subjects showed severe visual loss (1.8%), two being occupationally blind in both eyes (1.2%). Trichiasis and severe lid deformity had occurred in two subjects. Moore concluded that his findings indicated a high prevalence of trachoma, as in previous reports in W.A. and the N.T., but with low rates of severe lid deformity and blindness.

Table 2.4.3: Musgrave Park and Mt Davies (Moore et al.1965)

Age-group vs Trachoma Status

Age-group (Years)	total examined	No Trachoma	Stage[1] I	Stage[2] II	Stage[3] III	Stage[4] IV	Complication[5]
0-1	10	2	4	4	-	-	-
2-4	10	-	-	10	-	-	-
5-9	19	-	1	11	3	2	2
10-14	14	-	3	5	4	1	1
15-19	11	-	1	1	6	3	-
20-29	16	-	-	1	8	6	1
30-50	62	-	4	1	19	30	8
51+	21	-	3	-	2	13	3
Total	163	2	16	33	42	55	15

1. Stage I -Early stages of pinhead follicles.

2. Stage II -Follicular trachoma.

3. Stage III -Where cicatrization has commenced:often non contagious.

4. Stage IV -Where cicatrization is complete: non- contagious.

5. Complications - corneal opacity and trichiasis.

A study on the effect of improved hygiene and treatment with oxytetracycline and systematic sulphormethoxine was conducted by Hardy (Hardy et al. 1967). Aboriginal school children at Yalata in South Australia were initially surveyed in March 1965. Conjunctival smears were taken for cytology. Improved washing facilities were provided in May 1965 and a second survey undertaken in July that year. Because of the high prevalence of trachoma, treatment with oxytetracycline eye drops for 3-4 weeks and sulphormethoxine (one dose/week for 12 weeks) was undertaken until a third survey was conducted in October 1965.

It was concluded that improved hygiene produced a significant change towards a normal cytological picture. Further significant change was produced by treatment with oxytetracycline eye drops and oral sulphormethoxine. This study provided evidence from an appropriately

organised intervention that hygiene was linked to trachoma, reinforcing previous evidence that simple primary health care intervention could be significant in decreasing infectious disease. Additional improvements in the rate of trachoma with medical intervention heightened the need for a two-pronged strategy, to maximize the effectiveness of any intervention program.

A survey of visual acuity and retinal changes in South Australian Aborigines was carried out in 1975 (Edwards et al. 1976). Four Aboriginal communities were visited and 361 adults examined. The examination for eye health was performed during a general health survey. Visual acuity and retinal vascular defects were specifically assessed. Good response rates were obtained at three of the four communities. Arterio-vascular changes were seen in 26% of all subjects but only rarely observed in those from Ernabella (7%). Severe changes in the retina such as haemorrhage/exudates and papilloedema associated with hypertension and diabetes were not seen although some individuals had been diabetic or hypertensive for 15 or more years. Only 64 (18%) had a visual defect (visual acuity of 6/9 or worse), and an additional 79 (22%) had a similar loss of acuity in one eye only, these were found mostly in the non-traditional community of Konnibba. Causes of poor vision were not reported.

The largest and most comprehensive survey in Australia was undertaken by the Royal Australian College of Ophthalmologists with the National Trachoma and Eye Health Program (R.A.C.O. Report 1980). Starting in South Australia in 1976 and finishing with a rescreening of the Pilbara region of Western Australia in 1979, approximately 100,000 people were screened, some of whom were examined on two occasions. For the purposes of the report, 62,116 were considered to be Aboriginal and 38,616 non-Aboriginal. All the states on mainland Australia were covered, with mainly rural or semi-urban Aboriginal communities being visited. To assist in the collation and integration of the collected data, rural Australia was divided into 13 zones, these having been chosen because of a relative similarity in geographic, climatic, industrial and demographic features. Although the population sample was not random, the investigators thought the sample obtained was representative. Lastly,

efforts were made to standardize the examination and reduce both inter-observer and intra-observer variation.

The results detailed age-specific prevalence rates by zones, and collectively, for trachoma and blindness, visual system abnormalities, and for infections of the ear, nose, skin and respiratory system. Results were cross-tabulated with a selection of environmental variables, such as climatic conditions (normal relative humidity, annual rainfall, latitude, intensity of ultra-violet radiation, annual evaporative and average daily sunshine hours) and hygiene (water access, sewerage systems, housing, nutritional status). Composite scores were allocated for each hygiene and climatic variable. The prevalence rates for several disease and visual function categories were tested for the strength of association with the climate and hygiene variables.

In the following discussion the N.T.E.H.P. data dealing with the "Red Centre" zone will be presented and used later for comparison with the 1989/90 survey (Tables 2.4.4 and 2.4.5). Comprehensive results were presented for thirteen zones across Australia in the original report. The N.W. communities of the Pitjantjatjara were included in the "Red Centre" zone of the N.T.E.H.P. survey in 1976, an area that represented 16% of the total population for that zone. Yalata was included in the "Arid Eastern" zone, which extended into western N.S.W. and north into Queensland and which included communities in Pt. Augusta and Cooper Pedy (S.A.) Bourke and Wilcannia (N.S.W.), and Longreach (Qld.). Yalata contributed only 211 out of 8671 (2.4%) individuals to this zone.

Table 2.4.4: Age Distribution of Aboriginals in the "Red Centre" zone

	Age							
	0-9	10-19	20-29	30-39	40-49	50-59	60+	Total
Number	2944	1997	929	614	486	335	692	7997
%	36.8%	25.0%	11.6%	7.7%	6.1%	4.2%	8.7%	100%

Table 2.4.5: Rates (per 1000) for visual acuity in the "Red Centre" zone

Age in Years	0-9	10-19	60+	All ages 0-60+
Good Vision[1] Rate/1000	994	987	361	908
Satisfactory Vision[2] rate/1000	999	997	555	952
Poor Vision[3] rate/1000	1	2	220	26
Monocular Blindness[4] rate/1000	3	5	227	37
Binocular Blindness[5] rate/1000	-	-	225	23

(1) **Good Vision**: Corrected visual acuity of 6/12 or better in both eyes

(2) **Satisfactory Vision**: Corrected visual acuity of 6/12 or better in one eye

(3) **Poor Vision**: Corrected visual acuity of 6/12 or 6/24 or 6/36 in the better eye.

(4) **Monocular Blindness**: Corrected visual acuity of no better than 6/60 in the worse eye and vision better than 6/60 in the best eye

(5) **Binocular Blindness**: Corrected visual acuity in the better eye of 6/60 or worse.

Follicular trachoma was found in 26% of the 7982 Aboriginal people surveyed in the "Red Centre" zone. In the 0-9 age-group the prevalence of follicular trachoma was 50%. The peak prevalence occurred in 2-3 year olds (66.3%). The lowest prevalence was found in the 18-19 year olds (12.0%). Cicatricial trachoma was found in 5149 Aboriginals (65%) overall, and in 95% of Aboriginal people aged 60+ years.

The results demonstrated the poor eye health of Australian Aboriginal people. The report also indicated the impact made by trachoma on the Aboriginal people living in Australia, and the relationship between trachoma and poverty. Several recommendations were made relating to the provision of adequate housing, water and sewerage, and to the future role of the N.T.E.H.P. in providing trachoma and ophthalmic services to rural communities.

In October 1985 the National Aboriginal and Islander Health Organisation presented a report on Trachoma and Eye Health to the Hon. Clyde Holding, Minister for Aboriginal Affairs. Its terms of reference were (i) to report on the current ocular health status of Australian Aboriginals in a manner comparable with that provided in the R.A.C.O. Report of 1980, (ii) to assess the effectiveness of the existing anti-trachoma program, and (iii) to promote plans to effectively deal with the trachoma and eye disease found.

Approximately 2000 Aboriginal people were examined across S.A., the N.T., and northern W.A. The communities of Amata, Fregon and Indulkana in the north-west of S.A., and Yalata to the south, were visited.

In the Anangu Pitjantjatjara communities the prevalence of follicular trachoma, which had fallen after a treatment program in August 1976, had risen by 1985 to levels higher than those found in the first screening in June 1976. Severe scarring in the up to 19 years age-group; however, had shown a drop in prevalence. The reviewing ophthalmologist concluded that the prevalence rate for trachoma was of clinical concern, but formed only a part of a matrix of ill health. The results for Yalata were similar but not statistically significant because of the small numbers surveyed (T.E.H.P. Report 1985).

2.5 Discussion

From the foregoing review it appears that the high prevalence of blindness in Aboriginal Australians arises from causes that are currently preventable. The three sets of results (Tables 2.1.1.-2.1.3.) also demonstrate the different ways data may be presented, each revealing complementary aspects of the data.

The review also demonstrates the paucity of knowledge about the causes and prevalence of blindness in the white population in Australia. The difficulty in obtaining accurate prevalence data appears to be the principle reason for inaccuracy and population based cross-sectional surveys appear to be the most accurate way of obtaining information. However, the qualitative data presented does demonstrate differences between white and Aboriginal populations in Australia, both in the prevalence and causes of blindness. Amongst the preventable causes of blindness in the Aboriginal population, trachoma and cataract appear to be the most important.

It has been speculated, but not proven, that trachoma was endemic in Australia before European settlement. In South Australia the earliest recorded observations of trachoma in the white population were reported by Dr. Bennett (Boldt 1904). Anecdotal descriptions of Aboriginal eye health in the 1880s were used by authors in the 1930s as evidence of trachoma infection, unpublished observations by Dr Basedow did give some confirmation that trachoma existed in the "native" population of South Australia at that time (Cleland 1928). But it wasn't until the 1930s that an anthropological expedition to Nepabunna in the Flinders Ranges described in more detail the eye health of some Aboriginal people. No trachoma was found (Black and Cleland 1938).

In the 1940s and 1950s Flynn and Mann conducted eye health surveys in Central and Western Australia respectively. Widespread and severe trachoma was found in both regions. Only in the 1960s were the N.W. areas of South Australia visited. Although a high prevalence of trachoma was found, few individuals showed visual disability because of trachoma (Mann

and Rountree 1968). Mann recorded that most of the trachoma had healed by mid-life with only fine tarsal scarring and some Herberts pits and minimal pannus.

Similarly in the same area, Moore found a high prevalence of trachoma but a low prevalence of severe lid deformity and blindness secondary to trachoma (Moore et al. 1968).

It was not until 1976 that a high prevalence of trachoma accompanied by a high rate of trichiasis and corneal opacity was identified in the N.W. of South Australia (R.A.C.O. Report 1980). Trachoma was also found to be the major cause of visual disability and blindness. After another 14 years trachoma was still thought to be endemic in the Aboriginal communities that comprise the A P lands. However, its severity and contribution to blindness, after several years of intervention, was unknown.

To answer these questions quantitative data needed to be obtained. Although there have been numerous attempts to quantify blindness in Australia it appears only the N.T.E.H.P. surveys have provided comprehensive data adequate for statistical analysis. Chapter three describes a population based prevalence survey used to obtain data in 1989-1990. This data is then utilized in chapter four to make quantitative comparisons with the N.T.E.H.P. survey (R.A.C.O. Report 1980) and the N.T.E.H.P. review (T.E.H.P. Report 1985). Methodological problems with the selection of the samples, grading and reporting of results precluded the use of other survey information other than for qualitative descriptions.

Chapter 3. A Survey of Trachoma and Blindness in the Anangu Pitjantjatjara: The 1989/90 Survey

3.1 Introduction

To assess the current eye health of the Anangu Pitjantjatjara a cross-sectional population based prevalence survey was designed.

Although a prevalence survey does not require a hypothesis, it was hoped to make a comparison between the results obtained, with those of the National Trachoma and Eye Health Program survey of 1976 conducted in the same area. A testable hypothesis was therefore framed as

> "The age-specific prevalence rates of blindness and trachoma in the Anangu Pitjantjatjara population of South Australia have shown a statistically significant decline since the N.T.E.H.P. survey of 1976".

Specific aims and objectives were formulated, including service roles which were to be important to the success of the survey:

1. To re-establish base-line data on the prevalence of blindness and visual impairment in the Anangu Pitjantjatjara of South Australia.

2. To identify the causes of blindness in this population.

3. To identify trends in the prevalence and population distribution of eye disease.

4. To assist in the education of community health workers and the people in the Aboriginal communities about common eye conditions.

5. To identify individuals with blindness and eye disease and facilitate their treatment and review.

6. To analyse and distribute the accumulated data to:

   a. The Aboriginal communities (Anangu Pitjantjatjara).

   b. Nganampa Health Council (see section 3.2.3.).

c. The South Australian Aboriginal Trachoma Program (see section 3.2.3.).

These aims corresponded with the strategies for working with Aboriginal communities, outlined in the report of the National Health Strategy Working Party (1989).

3.2 Methods

3.2.1. Geographic and Climatic Description of The Study Area

Two distinct areas were visited. Although separated by 1,500 km, they were similar in climate and culture (Fig. 3.2.1.1 and appendix 6).

Anangu Pitjantjatjara (A P) Lands

The Anangu Pitjantjatjara lands comprise 10,190,000 hectares of semi-arid land or approximately 10% of South Australia (see figure 3.2.1.1). The lands are part of a central plateau that extends from the far north-west of South Australia into the Northern Territory and across into Western Australia. The plateau is approximately 700 metres above sea level. The Anangu Pitjantjatjara lands are dissected by four principal ranges: the Musgrave, Mann, Tomskin and Everard, all of which run East-West and rise to 1,300 metres, with some peaks over 1,600 metres. Mt Woodroofe in the Musgrave Range is the highest peak in South Australia. The area receives, on average, 20-25cm of rain per year, so the watercourses are generally dry, and until the provision of bores water was only available from rock holes and soaks found in the ranges. The summer is usually hot with temperatures averaging 35+^{o}C, winters are typically cool by day with cold nights.

In 1976 the Pitjantjatjara, Yankunyatjara and Ngaanyatjara people formed the Pitjantjatjara Council Incorporated to represent their collective interests. It operated

across state borders, administered some human and essential services and oversaw land management systems. In 1981 the South Australian Government, under the Pitjantjatjara Lands Rights Act, gave freehold title of the land to the Anangu Pitjantjatjara (Nganampa Health Council 1987).

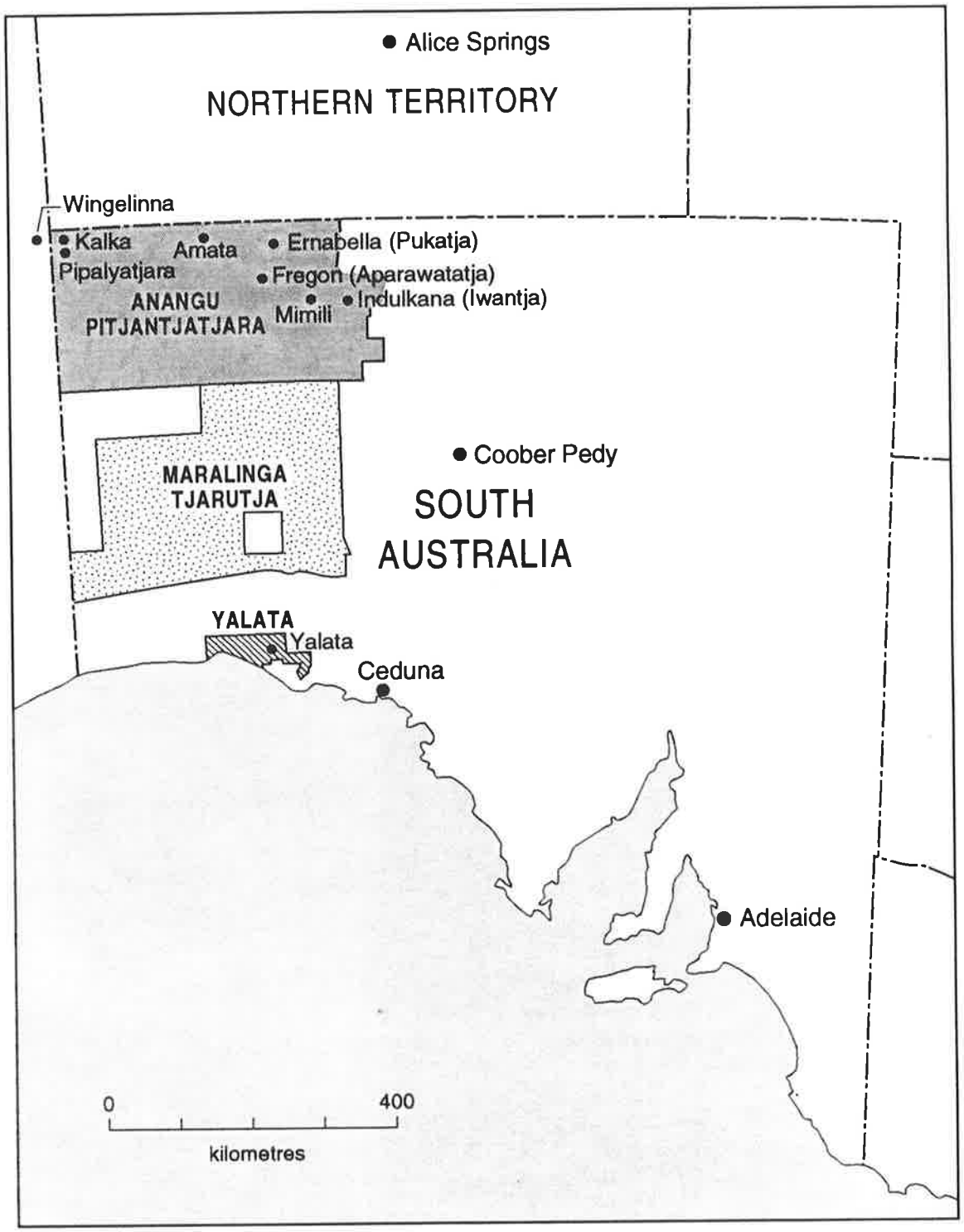
Yalata Lands

Lying some 1,500 kilometres to the south of the Anangu Pitjantjatjara lands lie the Yalata lands. The community of Yalata lies a few kilometres off the Eyre Highway and approximately 170 km west of Ceduna, on the edge of the Nullabour Plain. The plain has an even and treeless surface, is noted for its deep flooded sinkholes and caves, and for high cliffs and sand dunes on its coast.

The other half of the Yalata lands extend north to Oldea and further to the Maralinga lands (taking in some of the Great Victoria Desert). These areas contain open mallee, some grassland and scrubland typical of the semi-arid zones which receive less than 200-300 mm of rain a year. Like the A P Lands the summers are hot and dry with the temperature during the winter being moderate in the daytime but cold at night. There are oceanic influences in the southern areas such as coastal fogs (Atlas of South Australia).

Figure 3.2.1.1

The Anangu Pitjantjatjara and Yalata Lands 1990



3.2.2. Description of the Study Population

The population of the Anangu Pitjantjatjara and Yalata lands is predominantly Aboriginal. However, a significant population of white people provide services in health, education, maintenance and management. Although some are permanent residents in the communities, most spend only 1 - 3 years on the lands.

In the Anangu Pitjantjatjara lands the majority of the Aboriginal population live in the major communities; however, a proportion live in "homeland" settlements scattered around the major communities. These homelands often have specific associations with the families who occupy them, and have been established over the past 10-15 years at the instigation of the Anangu Pitjantjatjara.

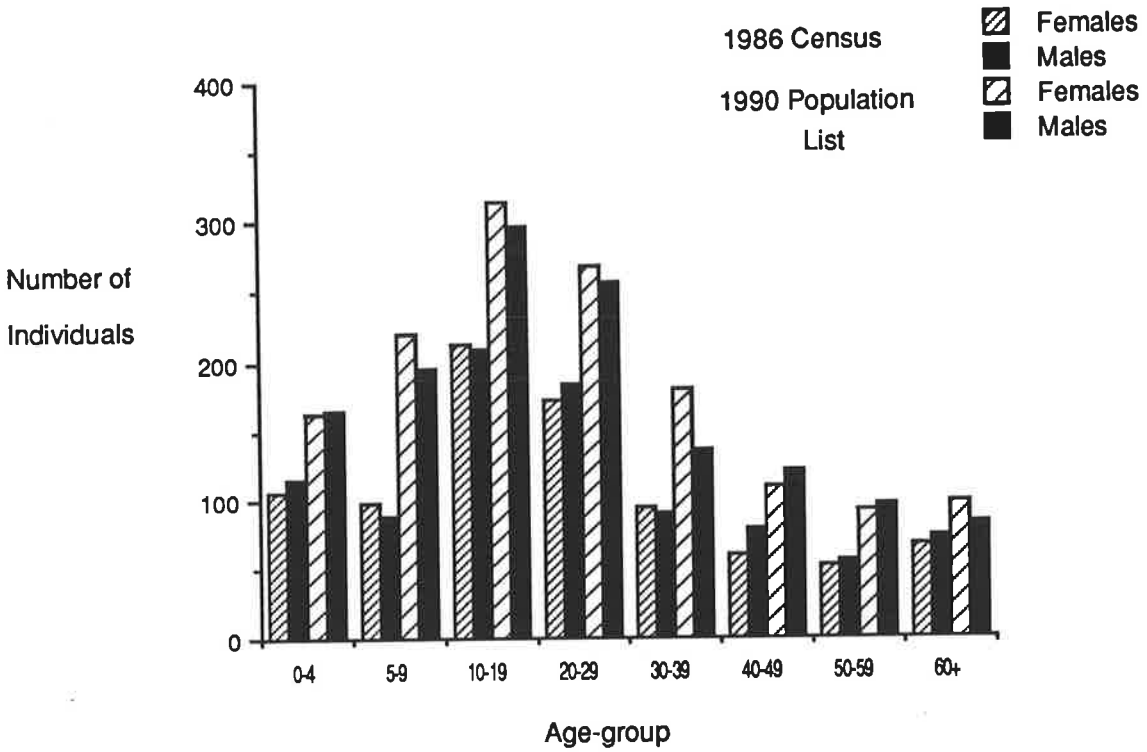
The population of the communities and the lands as a whole is dynamic. Movement of people between the communities and homelands, and further away (such as west to Warburton, north to Alice Springs, or south to Port Augusta) occurs frequently. Although families identify strongly with a given area, individuals may spend months or years in other communities. This mobility can interfere with the accuracy of single census. Table 3.2.2.1 details the population distribution in the two areas according to the 1986 census (Australian Bureau of Statistics 1986 Census), an estimate based on population lists compiled by Nganampa Health Service (section 4.3), the population distribution of the sample from this study, and a projection of the 1986 census data from 1986 to 1990 (Fig. 3.2.2.1). The projected distribution assumed no net migration, an even distribution of individuals within an age-group, used the population list estimate for the 0-4 age-group and used an estimate for the mortality rate in the 50+ age-group from the Australian Bureau of Statistics (appendix 2). The chief purpose of the projection was to indicate the difference between the population estimate as derived by Nganampa Health Service and that obtained by the census. Either there had been considerable net migration into the lands, or the 1986 census underestimated the population total, or the population list estimate was exaggerated. Given the difficulties, both with the single census estimate due to the mobility of the population, and the methodological

problems associated with the population estimate from the Nganampa Health Service, the population total for 1990 probably lies somewhere between the two estimates. However, a survey in Ernabella found that only 10% of the population list was no longer associated with that community (section 3.3.2.). Therefore, the population list compiled by Nganampa Health Service, is probably the most accurate estimate of the true total for the source population and was used in data calculations.

Table 3.2.2.1: Population Distribution of the A P and Yalata lands.

	1986 Census		1986 Census data projected to 1990		Population List 1990		1989/90 Survey	
Age-group	M	F	M	F	M	F	M	F
0-4	115	106	165	162	165	162	99	95
5-9	88	98	110	126	195	220	121	152
10-19	208	212	196	206	297	313	125	174
20-29	184	172	194	188	256	267	86	135
30-39	89	94	127	126	135	180	55	92
40-49	78	60	82	74	121	110	65	67
50-59	56	52	51	49	96	92	52	60
60+	73	67	71	76	83	97	62	74
	891	861	996	1006	1348	1441	665	849
total	1752		2002		2789		1514	

Figure 3.2.2.1.: Population distribution for the A P lands



3.2.3. Description of the Collaborative Organisations

The South Australian Aboriginal Trachoma Program

The South Australian Aboriginal Trachoma Program (Trachoma Program) was established in 1981 as the S.A. Eye Care Program. It was formally constituted in 1983 and now has a full-time coordinator and administrator, with a voluntary executive body of five members and a chairperson. Once a year there is a general meeting between it and the representatives of the Aboriginal communities it services.

The program provides ophthalmic care services to Aboriginal communities throughout South Australia, usually by annual visits of ophthalmologists or eye health educators. They also conduct school screenings and individual examinations to detect trachoma and other eye disease, and conduct training programs for Aboriginal health care workers.

Nganampa Health Service

The Nganampa Health Service is controlled by the Anangu Pitjantjatjara people through the Nganampa Health Council (N.H.C.). It provides health services to the communities of the A P lands in the north-west of South Australia. Although based in Alice Springs it runs medical and dental services in the communities. It provides a culturally sensitive service with a mixture of Aboriginal health care workers and usually non-Aboriginal medical and nursing staff. The N.H.C. also determines what research related to health can be performed on the A P lands.

Aboriginal Health Organisation

The Aboriginal Health Organisation (A.H.O.) is an incorporated body under the South Australian Health Commission Act of 1981.

It has a principal objective of increasing the health status of Aboriginal people in South Australia, and has specific policy goals which include: understanding the health needs of Aboriginal people in S.A.; the creation and maintenance of health care services to the

Aboriginal community, and the involvement of Aboriginal people in the provision of these health services.

The A.H.O. has adopted several initiatives to achieve its objectives these include: the establishment of community-controlled health services; the training of Aboriginal Health Workers, the provision of hospital liaison officers; the establishment of a comprehensive data base of all aspects of Aboriginal health in S.A.; and the provision of assistance and advice to departments organisations proposing to carry out medical research in the Aboriginal community. A formally constituted Ethics Committee was established in 1991.

The A.H.O. is not formally connected with either the Nganampa Health Service or the Trachoma Program but does liaise with both organisations. The Trachoma Program meets regularly with representatives of the N.H.C. and coordinates through the Nganampa Health Service, visits of ophthalmologists to the Anangu Pitjantjatjara lands.

3.2.4. Study Design

The study was divided into four phases:

1. Planning and Facilitation
2. Fieldwork
3. Collation and Data Processing
4. Information Distribution

In a study of this kind the choice of survey type was limited. Ophthalmic disorders are well suited to epidemiological studies (Rosenthal 1988), and a descriptive cross-sectional survey was chosen as the most appropriate form. The most comprehensive picture would be obtained from a census-type survey, in which every member of a community is enumerated and his/her ocular status recorded. A less comprehensive, but still standard method, uses a simple random sample which assumes that there is a way of identifying individuals within a community e.g. electoral rolls or school lists. The lists should be as comprehensive and up to date as possible. A sample size is calculated on the basis of the estimated prevalence for the condition under consideration, and people are picked at random from the list to make up the sample. A third way to conduct a survey is to use a random cluster technique, which assumes that there are distinct groups of people with homogeneity in the factor of interest between, and heterogenity within, clusters. Groups are picked at random from a total population representing, for example, communities, schools or other easily identified groups. This smaller sub-set of the population is then surveyed and the results extrapolated to the total population. It is assumed that the clusters are representative of the population from which they are drawn.

It was apparent in this study that there were not enough distinct communities that were sufficiently comparable to rely on cluster sampling. A simple random sample could not be performed because population lists were not known to exist. The census style of survey was chosen because it was theoretically achievable and previous surveys had used the same technique. The results would thus be comparable, and it also enhanced the service role of

the research in case identification and treatment. The service role and educational aspects of the research project were key elements in the survey's eventual approval by the Aboriginal communities.

Previous research had sometimes led to misunderstandings and ill feeling when work of little direct benefit to the people was performed. Communities, or organizations representing them, began to evaluate any research project for its immediate and long term benefit. The Anangu Pitjantjatjara had been subjected to numerous surveys and research in the 1970s and early 1980s. A renal survey had been conducted in the north-west of South Australia in 1982/83 by The Aboriginal Health Organization of South Australia (A.H.O. Renal Survey 1988). It was culturally sensitive, provided a significant service role and gave continuing feedback to both the individual participants and the communities. The design and conduct of the Renal Survey provided a basis for the formulation of this eye health survey.

The research proposal was originally written as an exercise for course work in a Masters of Public Health Degree (University of Adelaide), and was produced in the format of a National Health and Medical Research Grant (N.H.&M.R.C.) grant proposal. It was subsequently reworked after comments from the markers to make it more relevant to the ethical and health council committees. It included a review of the relevant trachoma and blindness literature, as well as a study design and research plan.

Funding was not sought for the project as it was being performed under the auspices of the S.A. Aboriginal Trachoma Program, which had agreed to provide travel expenses, as well as logistical and specialist back-up. The survey was conducted as an extension of the normal trachoma program work.

As part of the initial work, and prior to the survey, the principal investigator spent several sessions in the eye outpatients' department of Flinders Medical Centre, refreshing basic ophthalmology skills and knowledge. The new trachoma grading system (5 sign system) was reviewed utilizing photographs and slides (W.H.O. 1989). A pilot survey was conducted at Point Pearce, an Aboriginal community on Yorke Peninsula, South Australia, in April 1989.

Examination techniques, trachoma grading, data collection and recording procedures were evaluated. These data were not included in the subsequent survey.

3.2.5. **Ethical Approval**

Ethical approval was sought from four bodies. The Committee on the Ethics of Human Experimentation (University of Adelaide) and the Clinical Investigation Committee at Flinders Medical Centre (the place of employment of the investigator), were approached. An advisory committee of the Aboriginal Health Organisation, although not formally organized as an ethics committee at that time, provided a vetting and advisory role which was invaluable. Finally and most importantly, Nganampa Health Committee, a body that acted for Nganampa Health Council and the Anangu Pitjantjatjara was approached for approval. Only with the Nganampa Health Committee's approval could the survey be undertaken, and permits to enter the Anangu Pitjantjatjara lands obtained.

Separate approval to visit and perform the survey on the Yalata lands was obtained from the Yalata Community Council.

Approval was given by each organisation with minimal alterations to the protocol (appendix 5).

3.2.6. **The Survey**

Description

The source population was the Aboriginal population of the Anangu Pitjantjatjara and Yalata lands in South Australia.

Initial target population estimates were based on 1986 Census data. On reaching the communities it was found that more recent population lists had been prepared and then updated in 1989/1990 by Nganampa Health and Yalata medical service staff. Medical records,

pension and social security recipient records, school lists, community work records and the knowledge of local Aboriginal health workers were combined to provide alphabetical lists of the people in each community (Table 3.2.6.1).

A cross-sectional survey was undertaken. Using the population lists all members of the community were approached to participate in census style. Each person who agreed to participate was examined and had their visual acuity tested. Those with specific visual problems were referred to an ophthalmologist (see The Examination).

Population Lists

As previously described, this study could not check the accuracy of the population lists; however, the lists were useful adjuncts to the study. They were rearranged into sex and age-specific categories and used:

1. as a check-list for individuals, names and ages;
2. as a guide to the population distribution;
3. to identify individuals not previously seen in a community.

In each community the lists were updated by Aboriginal health workers to identify people who had moved either into or away from the community. The names of newly born children were added to the list and, although infrequent, those who had died were removed from the list.

Table 3.2.6.1: Total population in the communities:1981 census, 86 census and 1989/90 population list data

Community	1981 Census	1986 Census Data	1989/90 Population List
Ernabella	322	364	586
Fregon	203	268	307
Indulkana	301	237	360
Mimili	132	144	215
Amata	180	276	437
Kalka/Pipalyatjara	[1]123	105	330
Yalata	281	222)	
Oak Valley	[2]----	118)	554
Half Way Camp	[3]15	18)	
Total	1557	1752	2789

1. Estimate from available 1976/1981/1986 data.
2. No census figures for 1981 Oak Valley (not populated then).
3. Estimate based on 1989/90 figures.

Sample Size

Although the survey was to be of a census type, a sample size calculation was required to confirm that the source population was large enough to give adequate precision to an estimate of the prevalence of trachoma and visual impairment. It would also act as a guide to the effort, time and cost involved. A sample size was calculated using the following formula (Schaeffer et al. 1990).

$$n = \frac{4.N.(P).(1 - P)}{(N - 1)\,B^2 + 4.(P).(1 - P)}$$

where n = sample size

N = population size

B = 2 standard error bound on the estimate of P

P = population proportion of interest

The population size was estimated using 1986 Census data projected to 1990, a figure of 2002 was derived (Table 1.1). The error bound of 0.5% was selected and the population proportion of interest was the rate of binocular blindness in the "Red Centre" zone of the N.T.E.H.P. survey, which was 2.3% for all ages (R.A.C.O. Report 1980). Substituting

$$n = \frac{4.2002.(0.023).(0.977)}{(2002).(0.005)^2 + 4.(0.023).(0.977)}$$

$$n = \frac{179.9}{0.1399}$$

$$= 1286$$

A sample size of 1,286 individuals would be required to estimate the proportion of individuals binocularly blind in the population with an error of 0.5%.

A similar calculation for trachoma was performed using N = 2002, B = 5.0%, P = 65% (taken from the R.A.C.O. Report 1980 for cicatricial trachoma). A sample size of 439 individuals was required to estimate the proportion of individuals with trachoma with an error of 5.0%.

Transportation and Dates of Field Trips

Dates for individual field trips were made after discussion with each community health service and the S.A. Aboriginal Trachoma Program. Entry permits for the Anangu Pitjantjatjara lands were then obtained. In the case of Yalata, permission was obtained directly from the community council.

Chartered aircraft or the Royal Flying Doctor Service (Pt. Augusta)[1] were used to transport personnel and equipment to the communities.

The survey team comprised the survey researcher, an ophthalmologist, and one or two helpers (e.g. Aboriginal nurse educator, trachoma program coordinator, medical student, or additional ophthalmologists).

A total of eight field trips were undertaken.

Date	Community	Duration
1989 July	Ernabella	5 days
1989 August	Pipalyatjara/Kalka	5 days
1989 September	Indulkana and Mimili	12 days
1989 October	Yalata	9 days
1990 May	Ernabella and Amata	18 days
1990 June	Fregon and Kalka	14 days
1990 August	Yalata	5 days

These were the major communities for the Anangu Pitjantjatjara in these areas. Smaller satellite homelands around these population centres were also visited, and included in the data collected for these communities.

1. Using a S.A. Health Commission funded aircraft for specialists visiting remote areas.

The Examination

Prior to the arrival of the survey team, the community's health service advertised by posters and word of mouth that the Trachoma Program team would be visiting. All the community members were encouraged to attend.

A suitable area was found at each clinic, either outside in a sheltered position or in a room with adequate illumination. Another area was found to provide an area suitable for ophthalmic, slit lamp or fundoscopic examination of the eye.

On their arrival participants would be greeted and introduced to the researcher. The survey and testing procedures would be explained. Verbal consent would then be sought. Either the participant or researcher would write the participant's name in the top left hand corner of the data sheet, their age and sex were then entered. If either the age or name were unclear, the population lists were consulted, with either the Aboriginal health worker or the individual participant identifying the appropriate information.

An illiterate Snellen E chart was used for visual acuity testing, with the subject at six metres. Covering first the left eye then the right eye, the subject indicated by a hand movement the direction in which the legs of the E pointed. The tester noted any signs of strabismus. A corrected vision with glasses or pin hole was also obtained if required.

Using x2 loupes the eyes were examined for basic eye problems using a bright torch or ophthalmoscope. External signs of trichiasis or corneal opacity were sought. The lids were then everted, and examination of the upper tarsal plate performed to look for active trachoma, or trachoma scarring according to the five sign system (see Appendix 4).

Referral to the ophthalmologist occurred if:

1. repeat testing of corrected visual acuity was worse than 6/18 in any eye;

2. refraction was required;

3. signs of trichiasis or corneal opacity were evident;

4. there was any abnormality of the eye which was thought to require a specialist opinion;

5. the participant had any chronic disease which might have ocular consequences (e.g. diabetes or hypertension);

6. the participant requested a specialist opinion.

The ophthalmologist repeated the previous examination, dilated both pupils, and used a portable slit lamp and direct or indirect ophthalmoscopy to make a diagnosis, based on one of several categories (Appendix 3).

3.2.7. **Data Handling**

Recording Data

At the time of the examination data relating to an individual were entered on pre-printed forms (Appendix 3). The forms were adapted from a concurrent eye survey of blindness in South Australia.[2] Some questions were redundant and the information not sought. Names were added for the Aboriginal population to assist in cross-checking participants between communities, and to ensure that the sheet could become part of an ocular medical record for that individual when it was returned to the community medical service.

Data were recorded in the following sequence: name, age, sex, past ocular history, vision, basic eye examination, previous eye surgery, trachoma, and then optional examination results if seen by the ophthalmologist. Causes of low vision and the current action required were also noted.

---

2. Conducted by Dr. H. Newland.

At the end of each day, all forms were checked to ensure all boxes had been ticked, names entered clearly, and age and sex recorded. At times it was found that ages had to be corrected after examination of the population lists or medical records. Running totals were kept in age-specific groups for trachoma and causes of blindness.

At the end of a community visit, the medical service was provided with a list of all individuals requiring:

1. treatment for trachoma;

2. surgery for cataract or other conditions;

3. follow up for certain conditions, e.g. trichiasis, trachoma scarring, diabetic retinopathy.

The community council was also given non-identifying clinical information and tabulated data; including the total number seen, grouped by age and sex, and the number requiring trachoma treatment, surgery or the prescription of spectacles.

Data sheets were given community and individual identity numbers and entered onto a data-base using Epi-Info (5), a software package for the analysis of epidemiological survey data.

Data Checking

There were several stages of data checking:

1. Field checks were undertaken during the survey.

2. Data sheets were arranged alphabetically for each community and checked for duplicates.

3. Printouts of all information entered into the computer were obtained and compared with individual data sheets after computer data entry, and appropriate corrections were made.

4. Cross tabulations and frequency tables were used to identify outlying data points and missing data. Comparison with field (manually calculated) data was also performed.

5. If missing age or sex data could not be obtained, the information for that individual was not entered. Missing values for visual acuity, eye abnormality or trachoma status were left as missing but any other information was entered.

When duplicate examinations were compared the most recent data sheet was retained for data entry, and the first sheet used to assess inter-observer and intra-observer error (section 5.2).

Data Analysis

Analysis was performed using Epi-info 5.0 (a statistical package), including simple frequency tabulations for descriptive assessment of the results. Age/sex standardisation to allow comparison between communities and between different surveys. Odds ratio calculations using Mantel-Haenszel X^2 for trend to quantitate and test differences between serial surveys, age-groups and the sexes. The Fisher exact test was used to estimate the P value when the expected cell frequency in one or more cells of a 2x2 table was below 5.

Logistic regression analysis was performed using Systat (a statistical package) to investigate the effect of several variables on the prevalence of trachoma.

Community Liaison

In several communities the community council would be consulted on the first or second day of the visit. The survey team would be introduced and the purposes and expected benefits of the survey explained. Advice would be taken from the council concerning visits to houses within the community, and visits to outlying camps or homelands. This was of particular relevance when there had been a recent death in the community and people might be in mourning, or if there were special sites that could not be visited. Also, the occurrence of

religious ceremonies in the latter months of the year were able to be discussed, to minimize any interference by the researchers and facilitate the accomplishment of the aims of the survey.

3.2.8. Information distribution

Information distribution occurred at three levels. At the end of each visit, the health service was given clinical information pertaining to individual participants, and the community council was given non-identifying tabulated data. On the investigator's return to Adelaide the South Australian Aboriginal Trachoma Program (Trachoma Program) was given copies of all aggregated data for each community. Summary reports were prepared at intervals during the survey period.

When the survey work was completed, an interim report was produced and given to Nganampa Health Council (N.H.C.). After consideration by N.H.C. the report was passed to the Trachoma Program and the S.A. Aboriginal Health Organisation (A.H.O.). A brief summary of the survey work was given to the ethical committees of the University of Adelaide and Flinders University of South Australia.

A final report, detailing all results and comparisons with previous surveys, was given to N.H.C., the Trachoma Program, and the A.H.O.

Any future articles written for publication will be forwarded to N.H.C. for comment and approval.

3.3 Results

3.3.1. Description of the Sample

A total of 1514 individuals were examined out of the entire source population; approximately 200 were seen twice (and in the case of one school age boy, inadvertently, four times) either on the same or a subsequent visit to the community, or at another community on a different occasion. The duplication was established either at the time of the examination or subsequently at the time of the data sheet checking. The age and sex distribution of the sample (the study population)obtained is outlined in Table 3.3.1.1 and fig.3.3.1.1

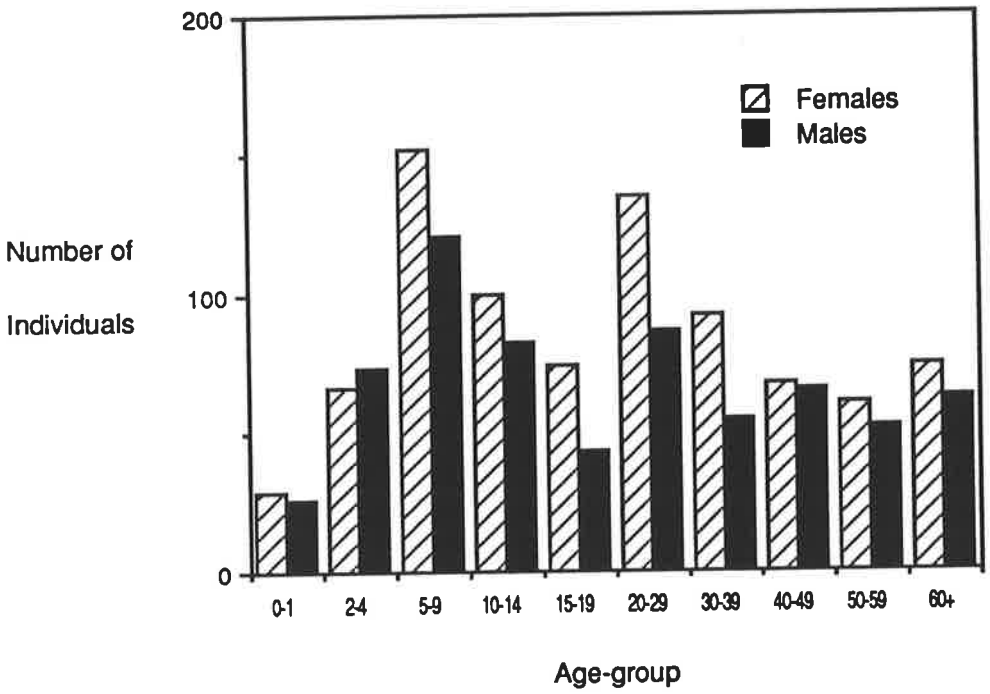
Table 3.3.1.1: Age and sex distribution for the 1989/90 survey sample

Age-Group	Females	Males	Total	% Total
0-1	29	26	55	3.6
2-4	66	73	139	9.2
5-9	152	121	273	18.0
10-14	100	82	182	12.0
15-19	74	43	117	7.7
20-29	135	86	221	14.6
30-39	92	55	147	9.7
40-49	67	65	132	8.7
50-59	60	52	112	7.4
60+	74	62	136	9.0
Total	**849**	**665**	**1514**	**100**
% of total	56.1%	43.9%		

The table shows that 42.8% of the sampled population was under 15 years of age, and that females formed 56.1% of the total sample. The largest participation rate difference between males and females occurred in the 15-19 and 30-39 age brackets. The distribution should be

compared to the underlying source population (section 3.2.2.), in which females comprised 51.7% of the total.

Figure 3.3.1.1: The population distribution of the sample



3.3.2. Participation Rates

Participation rates in each community varied due to several factors: the duration of the visit, the occurrence of ceremonies, business or sporting events and the importance the community and individuals placed on the survey (section 5.2.1.).

Table 3.3.2.1. outlines the percentage of the source population surveyed in each community. It was never expected that all the names on the population list would be found in any community at a given time. Rather the population list reflected the number of people who identified with that community, stayed there for much of the year or utilized the shopping and other facilities on a regular basis (e.g. people from the surrounding homelands).

A small population survey was conducted in Ernabella in 1990 to check the validity of the population list. Utilising the knowledge of the local health workers, the investigators examined the population lists. Individuals who had not been seen were identified, and their whereabouts ascertained. Particular care was taken to ensure only those who had moved away for a "long time" were counted. It identified 61 individuals, or 10.4% of the population list as having moved away permanently or semi-permanently, usually to Alice Springs, Port Augusta or to other communities within the Anangu Pitjantjatjara lands.

During the survey a small number of individuals (approximately 20) were examined who were visiting from adjacent communities or towns. Although checked for eye disease and offered treatment, their results were not included in the survey. There was another group identified, those who lived permanently on the lands and did not appear on the population lists. They were added to the lists when found and therefore were included in the population list totals used in this and other chapters. No attempt was made to quantify how many individuals were added to the lists; however the majority were babies and young infants who had been born in the previous year. There were only 15 adults who had to be added to the lists, usually people who had recently moved onto the lands.

Table 3.3.2.1.: Community participation rates

		1990 Population Lists	1989/90 Survey	%
Yalata	F	274	151	
	M	280	144	
	Total	**554**	**295**	**53.3**
Fregon	F	153	107	
	M	154	87	
	Total	**307**	**194**	**62.9**
Ernabella	F	321	224	
	M	265	171	
	Total	**586**	**395**	**67.4**
Indulkana	F	182	108	
	M	178	74	
	Total	**360**	**182**	**50.5**
Amata	F	223	103	
	M	214	81	
	Total	**437**	**184**	**42.1**
Mimili	F	116	60	
	M	99	33	
	Total	**215**	**93**	**43.3**
Kalka/ Pipalyatjara (Pip)	F	172	96	
	M	158	75	
	Total	**330**	**171**	**51.8**
All Communities	F	1441	849	
	M	1348	665	
	Total	**2789**	**1514**	**54.3**

The poorest response occurred in the two communities in which the least amount of time was spent, Amata (4 days) and Mimili (3 days). The best response occurred in Ernabella where a total of 19 days were spent.

The male to female ratio of the source population across communities was approximately the same, the exception was Fregon, where there were more males than females. Mimili showed the largest female to male participation rate difference of 65% vs 35% respectively.

Of interest was the variation in participation across age-groups Table 3.3.2.2 demonstrates this variation.

Table 3.3.2.2 (A): Participation rates across age-groups

Females

Age-Group	Yalata	Fregon	Ernabella	Indulkana	Amata	Mimili	Kalka/Pip	Total
0-4	15/23 65%	11/16 69%	24/37 65%	15/28 54%	11/26 42%	11/17 65%	8/15 53%	**95/162 59%**
5-9	28/32 88%	11/17 65%	50/55 91%	18/32 56%	17/37 46%	10/18 56%	18/29 62%	**152/220 69%**
10-19	40/76 53%	24/38 63%	47/74 64%	24/31 77%	17/42 40%	8/17 47%	14/35 40%	**174/313 56%**
20-29	21/46 46%	17/26 65%	41/62 66%	18/31 58%	17/45 38%	12/27 44%	9/30 30%	**135/267 51%**
30-39	18/46 39%	14/20 70%	22/35 63%	8/16 50%	13/32 41%	4/11 36%	13/20 65%	**92/180 51%**
40-49	10/18 56%	8/12 67%	14/23 61%	7/14 50%	6/10 60%	6/12 50%	16/21 76%	**67/110 61%**
50-59	10/14 71%	8/10 80%	17/23 74%	8/17 47%	8/14 57%	3/6 50%	6/8 75%	**60/92 64%**
60+	9/19 47%	14/14 100%	9/12 75%	10/13 77%	14/17 82%	6/8 75%	12/14 86%	**74/97 76.3%**

Participation by females varied from 100% in Fregon in the 60+ age-group, to a low of 30% in 20-29 age-group in Kalka/Pipalyatjara. The best participation occurred in the 60+ age-group which had the most eye problems and therefore was interested in participating in the survey. The school age-group 5-9, also showed above average participation, probably because they were easily found at school. The differences between the participation of older age-groups and the middle years probably reflected the mobility of the younger people and their relatively good eye health.

Table 3.3.2.2 (B): Participation rates across age-groups

Males

Age-Group	Yalata	Fregon	Ernabella	Indulkana	Amata	Mimili	Kalka/Pip	Total
0-4	17/27 63%	12/20 60%	19/25 76%	12/26 46%	17/35 49%	9/16 56%	13/16 81%	**99/165 60%**
5-9	24/36 67%	17/25 68%	37/51 73%	9/16 56%	12/26 46%	7/17 41%	15/24 63%	**121/195 62%**
10-19	32/68 47%	9/29 31%	44/58 76%	15/41 37%	8/49 16%	3/17 18%	14/35 40%	**125/297 42%**
20-29	23/56 41%	11/23 48%	28/55 51%	8/34 24%	8/38 21%	2/20 10%	6/30 20%	**86/256 34%**
30-39	12/33 36%	7/11 64%	8/22 36%	10/20 50%	10/23 43%	5/10 50%	3/16 19%	**55/135 41%**
40-49	18/24 75%	13/20 65%	7/18 39%	7/20 35%	5/13 38%	2/8 25%	13/18 72%	**65/121 46%**
50-59	11/23 48%	7/13 54%	17/23 74%	4/10 40%	7/12 58%	3/6 50%	3/9 33%	**52/96 54%**
60+	7/13 54%	11/13 85%	11/13 85%	9/11 82%	14/18 78%	2/5 40%	8/10 80%	**62/83 75%**

For males the participation rates varied from a high of 85% in Fregon and Ernabella (60+ age-group), to a low of 10% in Mimili (20-29 age-group). Overall the pattern paralleled that for females, with greatest participation occurring in the 60+ and 5-9 years age-groups. The differences between the 60+ and 20-39 age-groups was greater than that which occurred in females, probably due to the greater mobility of the young men compared to young women.

3.3.3. Overview

Visual acuity was tested in all individuals except children less than 6 years of age. The illiterate Snellen E chart was used at 6 metres, with the subject using hand movements to indicate the direction of the E. Visual acuity better than 6/6 was not tested for.

A pinhole or glasses were used to obtain the corrected visual acuity, which was recorded for all individuals with less than 6/6 vision in either eye.

Visual acuity was divided into ten categories for coding purposes.

0	6/6	uncorrected
1	6/6	corrected
2	6/12	corrected
3	6/18	corrected
4	6/36	corrected
5	6/60	corrected
6	3/60	corrected
7	CF	corrected (Count figures at 1 metre)
8	PL	corrected (Perception of light)
9	NPL	corrected (No perception of light)

Visual acuities for males and females are presented in Tables 3.3.3.1 and 3.3.3.2. The tables represent the best vision obtained by each individual participant. Children under the age of 6 were assumed to have 6/6 vision in both eyes unless the ocular examination was abnormal.

Table 3.3.3.1: Right vs left eye corrected visual acuity for males

	LCORRECTED										
	6/6 Uncorr.	6/6 Corr.	6/12	6/18	6/36	6/60	3/60	CF	PL	NPL	**Total**
RCORRECTED											
6/6 Uncorr.	559	0	0	0	0	0	0	0	0	0	**559**
6/6 Corr.	0	15	6	2	3	1	0	2	1	1	**31**
6/12	0	5	14	2	2	1	0	0	2	0	**26**
6/18	0	2	2	4	2	3	0	1	0	2	**16**
6/36	0	1	1	2	1	3	0	1	1	1	**11**
6/60	0	0	0	1	2	1	0	0	0	1	**5**
3/60	0	0	0	0	0	0	0	0	0	0	**0**
CF	0	5	0	0	0	0	0	3	0	0	**8**
PL	0	0	1	1	1	0	0	1	0	1	**5**
NPL	1	1	2	0	0	0	0	0	0	0	**4**
Total	**560**	**29**	**26**	**12**	**11**	**9**	**0**	**8**	**4**	**6**	**665**

Corrected visual acuity of 6/12 or better in both eyes was achieved by a total of 599 of 665 males (90%). Only five or 0.75% of males were binocularly blind. (W.H.O. definition: count fingers at 1 metre or worse). Broadening the definition to less than 6/60 (Australian blindness definition) did not add any more individuals to the total.

Table 3.3.3.2: Right vs left eye corrected visual acuity for females

	LCORRECTED										
	6/6 Uncorr.	6/6 Corr.	6/12	6/18	6/36	6/60	3/60	CF	PL	NPL	**Total**
RCORRECTED											
6/6 Uncorr.	711	0	0	0	0	0	0	0	0	0	**711**
6/6 Corr.	1	18	2	2	0	2	0	2	1	2	**30**
6/12	0	5	8	5	1	2	0	1	1	1	**24**
6/18	0	5	8	6	0	1	0	1	2	1	**24**
6/36	0	2	0	2	2	1	0	4	3	0	**14**
6/60	0	0	1	1	4	1	1	1	0	0	**9**
3/60	0	0	0	1	0	0	0	1	0	1	**3**
CF	0	5	3	1	3	0	0	5	0	2	**19**
PL	0	0	0	2	1	1	0	2	2	1	**9**
NPL	0	0	1	0	2	0	0	1	1	1	**6**
Total	**712**	**35**	**23**	**20**	**13**	**8**	**1**	**18**	**10**	**9**	**849**

By comparison with the male results 15 women were binocularly blind (W.H.O. definition), representing 1.77% of the total (cf 0.75% in males). Corrected visual acuity of 6/12 or better was found in 745 individuals or 87.7% (cf 90% in males). These differences were not explained by variations in age structure and must relate to some other factor. The prevalence of severe trachoma, eg. trichiasis and corneal opacity was greater in women than men, and probably accounted for much of this difference (Tables 3.3.7.4 and 3.3.7.5). The prevalence of sight limiting cataract (Tables 3.3.4.2 and 3.3.5.2) which again was greater in women than in men, would also be a cause of this difference.

3.3.4. Binocular Blindness

Two definitions of binocular blindness were used; the first to allow comparison with Australian data, and the second to meet W.H.O. criteria.

Australian definition - those individuals whose vision in their better eye was less than 6/60 (Social Security Department 1991).

W.H.O. definition - those individuals whose vision in their better eye was no better than count fingers (C.F.) at one metre (W.H.O. 1979).

Table 3.3.4.1 gives the number of individuals binocularly blind by age-group and sex.

Table 3.3.4.1: Binocular blindness sex by age-group

Australian defn.:

Age-Group	Females	%	Males	%	Total	%
0-19	0/421	0.0	0/345	0.0	**0/766**	**0.0**
20-29	2/135	1.5	0/86	0.0	**2/221**	**0.9**
30-49	0/159	0.0	0/120	0.0	**0/279**	**0.0**
50-59	1/60	1.7	0/52	0.0	**1/112**	**0.9**
60+	14/74	18.9	5/62	8.1	**19/136**	**14.0**
Total	**17/849**	**2.0**	**5/665**	**0.8**	**22/1514**	**1.5**

W.H.O. defn.:

Age-Group	Females	%	Males	%	Total	%
0-19	0/421	0.0	0/345	0.0	**0/766**	**0.0**
20-29	2/135	1.5	0/86	0.0	**2/221**	**0.9**
30-49	0/159	0.0	0/120	0.0	**0/279**	**0.0**
50-59	1/60	1.7	0/52	0.0	**1/112**	**0.9**
60+	12/74	16.2	5/62	0.1	**17/136**	**12.5**
Total	**15/849**	**1.8**	**5/665**	**0.8**	**20/1514**	**1.3**

A total of 20 individuals, or 1.3% of the sample population were binocularly blind using the W.H.O. definition of blindness.

The estimate of the age-standardized odds ratio (Mantel-Haenzel weighted OR) of blindness, using the Australian definition, when females were compared to males was: OR=3.22, 95% C.I.: 1.03 to 10.43, (X^2=4.04 (p=0.045)).

(a) Causes of Binocular Blindness:

The causes of binocular blindness were grouped. Only the major categories have been presented; when two or more causes have been given for binocular blindness the major contributing cause has been recorded (Table 3.3.4.2).

Binocular blindness was caused by trachoma in nine of twenty individuals (45%). Cataract accounted for another eight blind individuals (40%), trauma, infection and congenital problems the remaining 15%.

Diabetic retinopathy, although causing visual impairment in some individuals, was not severe enough yet to classify these individuals as blind by W.H.O. standards.

Table 3.3.4.2: Causes of binocular blindness (W.H.O definition)

Female

Age-Group	Cause: Absent or phthisical globe	Cataract	Trachoma	Other	Total Blind
10-14	-	-	-	-	**0**
20-29	1	-	-	1[1]	**2**
30-39	-	-	-	-	**0**
40-49	-	-	-	-	**0**
50-59	-	-	1	-	**1**
60+	1	4	7	-	**12**
Total	**2**	**4**	**8**	**1**	**15**

1. Right total retinal detachment and left congenital ectopic pupil with cataract.

Male

Age-Group	Cause: Absent or phthisical globe	Cataract	Trachoma	Other	Total Blind
20-29	-	-	-	-	**0**
30-39	-	-	-	-	**0**
40-49	-	-	-	-	**0**
50-59	-	-	-	-	**0**
60+	-	4	1	-	**5**
Total	**0**	**4**	**1**	**0**	**5**

Cross-tabulation of the cause of blindness for left and right eyes reaffirms that trachoma and cataract were the leading causes of blindness for individual eyes (Table 3.3.4.3). The causes of blindness for those with visual acuity of 6/60 or less in both eyes is also presented for comparison with the 1976-1979 N.T.E.H.P. survey.

Table 3.3.4.3: Causes of blindness right vs left eye for visual acuity of CF at 1 metre or worse (6/60 or worse in brackets).

		Left Eye			
		Absent or phthisical	Cataract	Trachoma	Other
Right Eye	Absent or phthisical	-	-	1	-
	Cataract	-	7(2)[1]	(1)	1[3]
	Trachoma	3(1)	1(1)	5(2)	-
	Other	1[2]	-	-	1[4](2)[5,6]

1. One case of presumed radiation induced bilateral cataract
2. Right corneal opacity
3. Left corneal opacity due to trauma
4. Right total retinal detachment, Left congenital ectopic pupil and cataract
5. Bilateral labrador keratopathy
6. Diabetic retinopathy

(b) *Prevalence Rates for Binocular Blindness*

Age specific prevalence rates for binocular blindness were calculated to allow comparison with previous Australian surveys. Table 3.3.4.4 presents rates using both the Australian definition of blindness and W.H.O. criteria. Two sets of rates were calculated, first using the sample as a denominator and second using the source population, as estimated from the 1990 population lists, as a denominator. An assumption was made that no other blind individuals existed in the source population. The validity of the source population relied on two factors:

1. The accuracy of the population lists (section 3.2.6 and section 5.3).

2. The ability of the survey to identify and examine blind individuals.

Identification of blind individuals utilized two methods. During the survey, community health workers with local knowledge were utilized to identify blind individuals who might not have otherwise attended the clinic to be examined. Sometimes trips to remote homelands or outstations were undertaken to meet and examine these blind individuals. Even if some individuals were missed on one trip to a particular community, they often presented to another community on a subsequent trip.

A second method utilized the medical records available in each community clinic. The records of people aged 40 years or more, who had not been examined in the survey, were reviewed. Although two additional cases of monocular blindness were found, no binocularly blind individuals were identified. The limitation of using the medical records as a check of visual status are:

1. Records may not have existed, particularly if the person was healthy or was new to the community.

2. The case notes may not have recorded visual acuity or visual problems. This was unlikely for someone who was blind and had been in the community for a few years, as there had been regular annual or 6 monthly visits to the communities for the past ten years by the Trachoma Program.

3. The accuracy of the record could be questioned; however, only notes made by ophthalmologists, qualified doctors or hospital discharge summaries were accepted.

It was the opinion of the investigators that although it was possible that a blind individual had been missed, it was unlikely. Therefore estimates of the prevalence of blindness using data from the sample as a numerator and the source population as a denominator were reasonable.

Table 3.3.4.4: Prevalence rates for binocular blindness by age-group

Australian defn.

	Sample group	Assuming no other blind individuals in unexamined population
Age-group	Rate per 1000	Rate per 1000
20-29	2/221 = 9/1000	2/524 = 3.8/1000
50-59	1/112 = 8.9/1000	1/118 = 5.3/1000
60+	19/136 = 140/1000	19/179 = 106/1000
Overall	22/1514 = 14.5/1000	22/2789 = 8.0/1000

W.H.O. defn.

	Sample group	Assuming no other blind individuals in unexamined population
Age-group	Rate per 1000	Rate per 1000
20-29	2/221 = 9.0/1000	2/524 = 3.8/1000
50-59	1/112 = 8.9/1000	1/118 = 5.3/1000
60+	17/136 = 125.0/1000	17/179 = 95.0/1000
Overall	20/1514 = 13.2/1000	20/2789 = 7.2/1000

As expected, the highest prevalence rate for binocular blindness occurred in the 60+ age-group. Using the sample group as a denominator, and the Australian definition of blindness, the prevalence rate was 140/1000 in this age-group. If projected 1986 census data were used for the denominator the crude rates were :

	proportion	Rate per 1000
Australian defn.:	22/2002	11/1000
W.H.O. defn.:	20/2002	10/1000

The results using projected 1986 data were approximately intermediate between the two previously presented rates.

3.3.5. Monocular Blindness

Monocular blindness was defined as: vision in the worse eye of CF at 1 metre or worse, and vision in the better eye of 3/60 or better (W.H.O. defn.).

From a sample of 1514, 66 or 4.4% were monocularly blind. The proportion for each sex and age-group is outlined in Table 3.3.5.1.

Table 3.3.5.1: Monocular Blindness: Age-Group by Sex

Age-Group	Females No. Monocularly Blind	%	Males No. Monocularly Blind	%
0-1	0/29	-	0/26	-
2-4	1/66	1.5	0/73	-
5-9	0/152	-	0/121	-
10-14	0/100	-	1/82	1.2
15-19	0/74	-	0/43	-
20-29	1/135	0.7	1/86	1.2
30-39	4/92	4.4	1/55	1.8
40-49	2/67	3.0	3/65	4.6
50-59	6/60	10.0	4/52	7.7
60+	27/74	36.5	15/62	24.2
	41/849	**4.8**	**25/665**	**3.8**

The age-standardized odds ratio of monocular blindness, when females were compared to male was: OR=1.55, 95% C.I.:0.81 to 2.56, (X^2=1.46 (p=0.227)). The causes of monocular blindness are given in the Table 3.3.5.2 (A) and (B) for females and males and respectively.

Table 3.3.5.2 (A): Causes of monocular blindness. Age-group by cause.

Females

Age-Group	Cause					
	Phthisical or absent	Cataract	Trachoma	Corneal Opacity	Other	Total
0-4	-	1	-	-	-	1
10-14	-	-	-	-	-	-
15-19	-	-	-	-	-	-
20-29	-	-	-	1	-	1
30-39	3	-	1	-	-	4
40-49	-	2	-	-	-	2
50-59	-	2	-	1	3[1,2,3]	6
60+	4	13	6	3	1[4]	27
Totals	**7**	**18**	**7**	**5**	**4**	**41**

1. Dense right posterior capsule fibrosis

2. Vitreous haemorrhage

3. Amblyopia

4. Pseudophakia (post surgical complication)

Table 3.3.5.2 (B): Causes of monocular blindness. Age-group by cause.

Males

Age-Group	Cause					
	Phthisical or absent	Cataract	Trachoma	Corneal Opacity	Other	Total
10-14	-	-	-	-	1[1]	1
15-19	-	-	-	-		-
20-29	-	-	-	-	1[2]	1
30-39	-	-	-	1	-	1
40-49	2	-	-	1	-	3
50-59	1	2	-	-	1[3]	4
60+	4	5[5]	4	1	1[4]	15
Totals	**7**	**7**	**4**	**3**	**4**	**25**

1. Ambylopia
2. Right traumatic mydriasis and optic atrophy (trauma)
3. Retinal detachment (trauma)
4. Complications of cataract extraction
5. Traumatic cataract and optic atrophy (trauma).

Of the 66 people with monocular blindness, 52 (78.8%) were aged 50 or more years. In those individuals aged 60+ years 42/136 (30.9%) were monocularly blind. Individuals in this age-group tended to have poor vision in their remaining eye, whereas vision in the non-blind eye was good for individuals younger than 50 years.

(a) *Causes of monocular blindness:*

Cataract: 25/66 (37.9%). The cataracts were predominantly of the senile type. All but three cases occurred in the 50+ age-group. One in a child aged 4 years was congenital.

Phthisical or Absent Globe: 14/66 (21.2%). Trauma, at least as an initiating event, was found to be the cause of 11 cases of phthisical or absent eyes. Other causes were not determined. Trauma also caused two cases of optic atrophy, one case of retinal detachment and 5 cases of corneal opacity. Trauma made up a total of 19/66 (28.8%) of all monocular blindness.

Corneal Opacity: 8/66 (12.1%). Corneal opacity, not due to trachoma, was found in eight individuals. The underlying cause was attributed to either trauma or infection; however a precise determination of cause was often difficult.

Trachoma: 11/66 (16.6%). Trachoma caused monocular blindness from corneal opacity in eleven individuals. Because there is a high correlation between paired eyes for trachoma severity, the individuals who were monocularly blind from trachoma, were at greater risk of binocular blindness, compared to those individuals monocularly blind from other causes. Table 3.3.5.3 identifies the individuals with monocular blindness at risk of binocular blindness from trachoma.

Other: 8/66 (12.1%). The categories included ambylopia, optic atrophy and iatrogenic causes.

(b) *Individuals at risk of binocular blindness:*

Corneal opacity or trachoma trichiasis can lead to blindness if neglected. There were fourteen individuals who were monocularly blind and had no signs of trachoma, but there were fifteen individuals (23.0%) who were monocularly blind and were at an immediate risk of further visual impairment because of trachoma (Table 3.3.5.3). The majority were aged 60 or more years; however one female was in the 30-39 age-group. There was also a group of thirteen people aged 59 or less who had trachoma trichiasis and although not yet being monocularly or

binocularly blind, were at risk of visual impairment if adequate ophthalmic care were not available (Table 3.3.7.4).

Table 3.3.5.3: Individuals with monocular blindness, at risk of binocular blindness from trachoma

Age-Group	Trachoma status in the non blind eye						Total
	Normal		Trachoma scarring		Trachoma Trichiasis or Corneal Opacity		
	F	M	F	M	F	M	
1-4	1	-	-	-	-	-	**1**
5-9	-	-	-	-	-	-	**0**
10-14	-	1	-	-	-	-	**1**
15-19	-	-	-	-	-	-	**0**
20-29	1	1	-	-	-	-	**2**
30-39	1	1	2	-	1	-	**5**
40-49	2	1	-	2	-	-	**5**
50-59	2	1	4	3	-	-	**10**
60+	-	2	18	8	9	5	**42**
Total	**7**	**7**	**24**	**13**	**10**	**5**	**66**
% of total	10.6%	10.6%	19.7%	36.4%	7.6%	15.2%	100%

3.3.6. Visual Acuity

Visual acuity was grouped into the World Health Organization categories for adequate and low vision (W.H.O. 1979). Tables 3.3.6.1 and 3.3.6.2 outline these categories of vision. Another category of visual acuity is also presented for completeness (6/6 vision in both eyes).

Table 3.3.6.1: Age-group vs sex for 6/6 vision in both eyes and category (1) visual acuity W.H.O. defn.

	6/6 Vision in both eyes				Between 6/6 and 6/18 vision in both eyes			
Age-group	females	%	males	%	females	%	males	%
0-1	29	100.0	26	100.0	29	100.0	26	100.0
2-4	65	99.4	73	100.0	66	100.0	73	100.0
5-9	152	100.0	121	100.0	152	100.0	121	100.0
10-14	100	100.0	81	98.8	100	100.0	82	100.0
15-19	73	98.6	43	100.0	74	100.0	43	100.0
20-29	130	92.3	84	97.7	133	98.5	86	100.0
30-39	81	88.0	51	92.7	92	100.0	55	100.0
40-49	52	77.6	50	76.7	66	98.5	65	100.0
50-59	34	56.6	32	61.5	54	90.0	52	100.0
60+	14	18.9	13	20.9	42	56.8	45	72.6
Total	**730**	**86.0**	**574**	**86.3**	**808**	**95.1**	**648**	**97.4**

The proportion of individuals with visual acuity of 6/6 in both eyes was found equally in males and females. In the age-group 0-19 years almost every individual had 6/6 vision. There was a small decline in the proportion of individuals with 6/6 vision until the 50+ age-group was reached where less than 60% of all individuals had 6/6 vision. However, if those individuals in the next category of visual acuity were included (between 6/6 and 6/18 in either eye), the decline was evident only in the 60+ age-group, indicating the poor visual status in older individuals.

Table 3.3.6.2: Age-group vs sex for categories (2) and (3) of low vision W.H.O. defn.

Age-group	Between 6/24 and 6/60 vision in both eyes				3/60 vision in both eyes			
	female	%	male	%	female	%	male	%
0-1	0	-	0	-	0	-	0	-
2-4	0	-	0	-	0	-	0	-
5-9	0	-	0	-	0	-	0	-
10-14	0	-	0	-	0	-	0	-
15-19	0	-	0	-	0	-	0	-
20-29	0	-	0	-	0	-	0	-
30-39	0	-	0	-	0	-	0	-
40-49	1	1.5	0	-	0	-	0	-
50-59	5	8.3	0	-	0	-	0	-
60+	18	24.3	12	19.4	2	3.2	0	-
Total	**24**	**2.8**	**12**	**1.8**	**2**	**0.2**	**0**	**0.0**

Low vision categories (2) and (3) occurred mainly in the 60+ age-group. Women had a greater prevalence of low vision in the younger age-groups, but the numbers were small. This finding was consistent with the prevalence data for binocular blindness (section 3.3.4). If the categories for low vision and blindness were combined the crude odds ratio of visual impairment when women were compared to men was: OR=1.93, 95% C.I.:1.06 to 3.58, (X^2=4.63 (p=0.031)). In the 60+ age-group the odds ratio was: OR=2.02, 95% C.I. 0.92 to 4.44, (X^2=3.01 (p=0.083)).

3.3.7. **Trachoma**

The trachoma grading system used in this study was based on the presence or absence of five selected "key" signs. Outlined by Thylefors et al. (1987), it was devised for use by the non-specialist to produce a simplified grading system for the assessment of trachoma at the community level. Studies have shown that this system produces good observer agreement, and that the interpretation of findings recorded generally corresponds to that of the more detailed grading system (section 1.4).

Tables 3.3.7.1 - 3.3.7.5 give age-specific results for each of the five trachoma signs, follicular trachoma (TF), trachoma intense (TI), trachoma scarring (TS), trachoma trichiasis (TT), corneal opacity (CO).

Follicular trachoma:

Table 3.3.7.1: Prevalence of trachoma follicles by age-group and sex

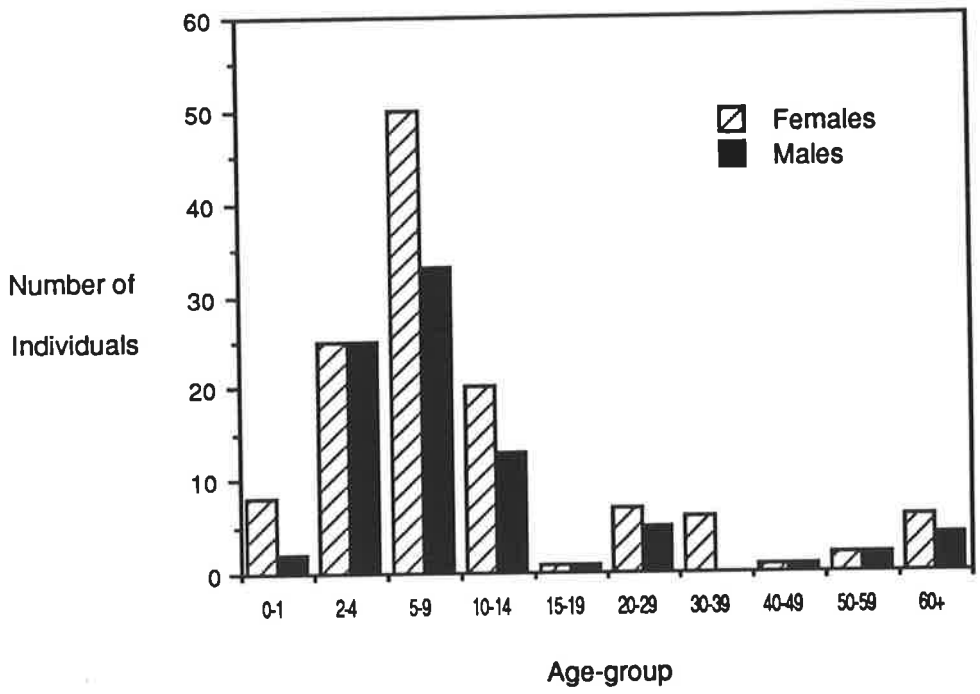
Age-Group	females No.	% of age-group	males No.	% of age-group	Total	% of age-group
0-1	8/29	27.6	2/26	7.7	**10/55**	**18.2**
2-4	25/66	37.9	25/73	34.2	**50/139**	**36.0**
5-9	50/152	32.9	33/121	27.2	**83/273**	**30.4**
10-14	20/100	20.0	13/82	15.9	**33/182**	**18.1**
15-19	1/74	1.4	1/43	2.3	**2/117**	**1.7**
20-29	7/135	5.2	5/86	5.8	**12/221**	**5.4**
30-39	6/92	6.5	0/55	0.0	**6/147**	**4.1**
40-49	1/67	1.5	1/65	1.5	**2/132**	**1.5**
50-59	2/60	3.3	2/52	3.8	**4/112**	**3.6**
60+	6/74	8.1	4/62	6.5	**10/136**	**7.4**
Total	**126/849**	**14.8%**	**86/665**	**12.9%**	**212/1514**	**14.0%**

Follicular trachoma (TF) is a measure of infective disease in a community (W.H.O. 1989). The peak prevalence occurred in the 2-4 age-group, closely followed by the 5-9 age-group. The lowest prevalence occurred in the 15-19 and 40-49 age-groups. The youngest age-group, 14 years and less, had the bulk of the disease burden, 176 out of 212 cases or 83% of the total.

Sex differences in the follicular trachoma rates were observed in the 0-1 and 30-39 age bracket, but the numbers were small and the differences were not significant. The difference in the 5-9 age-group between males and females, although having larger numbers, was also not significant: Mantel-Haenszel X^2=1.0 (p=0.317). The age-standardized odds ratio of follicular trachoma for females relative to males was: M-H weighted OR=1.36, 95% C.I. 0.98 to 1.89, (X^2=3.30 (p=0.069)), using the five age-groups from 0-19 and the aggregate total of the 20+ age-groups.

The relationship of follicular trachoma with age is best appreciated graphically Fig 3.3.7.1 .

Figure 3.3.7.1: Individuals with folliclular trachoma by age-group



Trachoma intense:

Table 3.3.7.2: Prevalence of trachoma intense by age-group and sex

Age-Group	females No.	females % of age-group	males No.	males % of age-group	Total	% of age-group
0-1	2/29	6.9	4/26	15.4	**6/55**	**11.0**
2-4	2/66	3.0	2/73	2.7	**4/139**	**2.9**
5-9	6/152	3.9	0/121	0.0	**6/273**	**2.2**
10-14	1/100	1.0	0/82	0.0	**1/182**	**0.5**
15-19	0/74	0.0	0/43	0.0	**0/117**	**0.0**
20-29	6/135	4.4	3/86	3.5	**9/221**	**4.1**
30-39	5/92	5.4	5/55	9.1	**10/147**	**6.8**
40-49	6/67	8.9	3/65	4.6	**9/132**	**6.8**
50-59	4/60	6.7	3/52	5.8	**7/112**	**6.2**
60+	4/74	5.4	7/62	11.3	**11/136**	**8.1**
Total	**36/849**	**4.2%**	**27/665**	**4.1%**	**63/1514**	**4.2%**

The table demonstrates the low prevalence of trachoma intense (TI) in the 15-19 age-group, and the variable but overall low prevalence in older age-groups. The prevalence in the younger age-groups was also low except among children aged less than one year who had the peak prevalence of 11.0%.

The relationship of TI with age was the reverse of follicular trachoma (TF), (in which 83% occurred in individuals younger than 14 years), with 73% (46/63) of TI occurring in individuals over the age of 14.

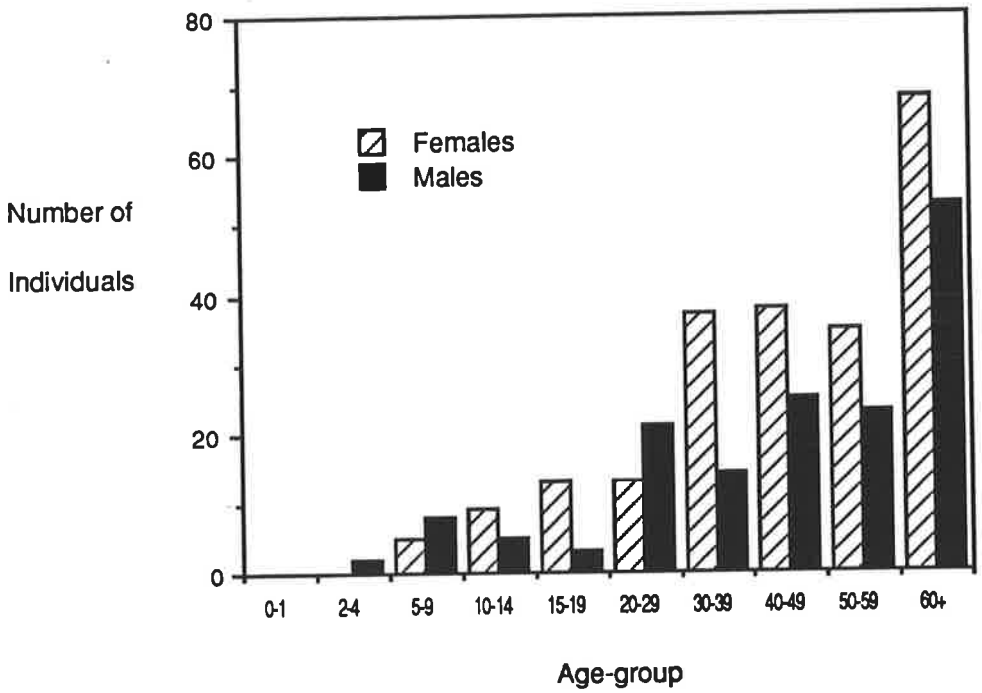
Trachoma scarring:

Table 3.3.7.3: Prevalence of trachoma scarring age-group by sex

Age-Group	females No.	% of age-group	males No.	% of age-group	Total	% of age-group
0-1	0/29	0	0/26	0.0	**0/55**	**0.0**
2-4	0/66	0	2/73	2.7	**2/139**	**1.4**
5-9	5/152	3.3	8/121	6.6	**13/273**	**4.8**
10-14	9/100	9.0	5/82	6.1	**14/182**	**7.7**
15-19	13/74	17.6	3/43	7.0	**16/117**	**13.7**
20-29	23/135	17.0	21/86	24.4	**44/221**	**19.9**
30-39	37/92	40.2	14/55	25.5	**51/147**	**34.7**
40-49	38/67	56.7	25/65	38.5	**63/132**	**47.7**
50-59	35/60	58.3	23/52	44.2	**58/112**	**51.8**
60+	68/74	91.9	53/62	85.5	**121/136**	**89.0**
Total	**228/849**	**26.9%**	**154/665**	**23.2%**	**382/1514**	**25.2%**

Trachoma scarring is a measure of past infection in the community. As expected the peak prevalence occurred in the older age-groups. The age-standardized odds ratio of trachoma scarring for females relative to males was: M-H weighted OR=1.15, 95% C.I.: 0.96 to 1.79, (X^2=2.843 (p=0.091)), using the aggregate total of the 0-19 age-groups and the five age-groups in the 20-60+ age bracket. The prevalence increased with age, reflecting either the past burden of trachoma disease or the diminishing prevalence of active infection in recent years. Figure 3.3.7.2 highlights the age effect and demonstrates the steep increase of scarring with age.

Figure 3.3.7.2: Individuals with trachoma scarring by age-group



Trachoma Trichiasis:

Table 3.3.7.4: Prevalence of trachoma trichiasis by age-group and sex

Age-Group	females No.	females % of age-group	males No.	males % of age-group	Total	% of age-group
0-19	0/421	0.0	0/345	0.0	**0/766**	**0.0**
20-29	2/135	1.5	1/86	1.2	**3/221**	**1.4**
30-39	2/92	2.2	0/55	0.0	**2/147**	**1.4**
40-49	3/67	4.5	1/65	1.5	**4/132**	**3.0**
50-59	4/60	6.6	0/52	0.0	**4/112**	**3.6**
60+	21/74	28.4	5/62	8.1	**26/135**	**19.1**
Total	**32/849**	**3.8%**	**7/665**	**1.1%**	**39/1514**	**2.6%**

Trachoma trichiasis is the consequence of years of trachoma infection with scarring and inturning of the eye lashes.

One in five individuals aged 60 or over had trichiasis (19.1%). The overall prevalence of trichiasis in the sample group was 2.6% (39/1514). The age-standardized odds ratio of trichiasis for females relative to males was: M-H weighted OR=4.49, C.I.: 1.81 to 11.83, (X^2=12.17 ($p<0.001$)), using the age-groups in Table 3.3.7.4. The increased risk of trichiasis for women occurred despite similar prevalence rates for active disease (TF or TI) in men and women (Tables 3.3.7.1 and 3.3.7.2).

The occurrence of trichiasis in younger age-groups, although small, is a cause for concern because these individuals are at risk of corneal opacity and eventual blindness if adequate ophthalmic care is not available.

Corneal Opacity:

Table 3.3.7.5: Prevalence of trachoma corneal opacity

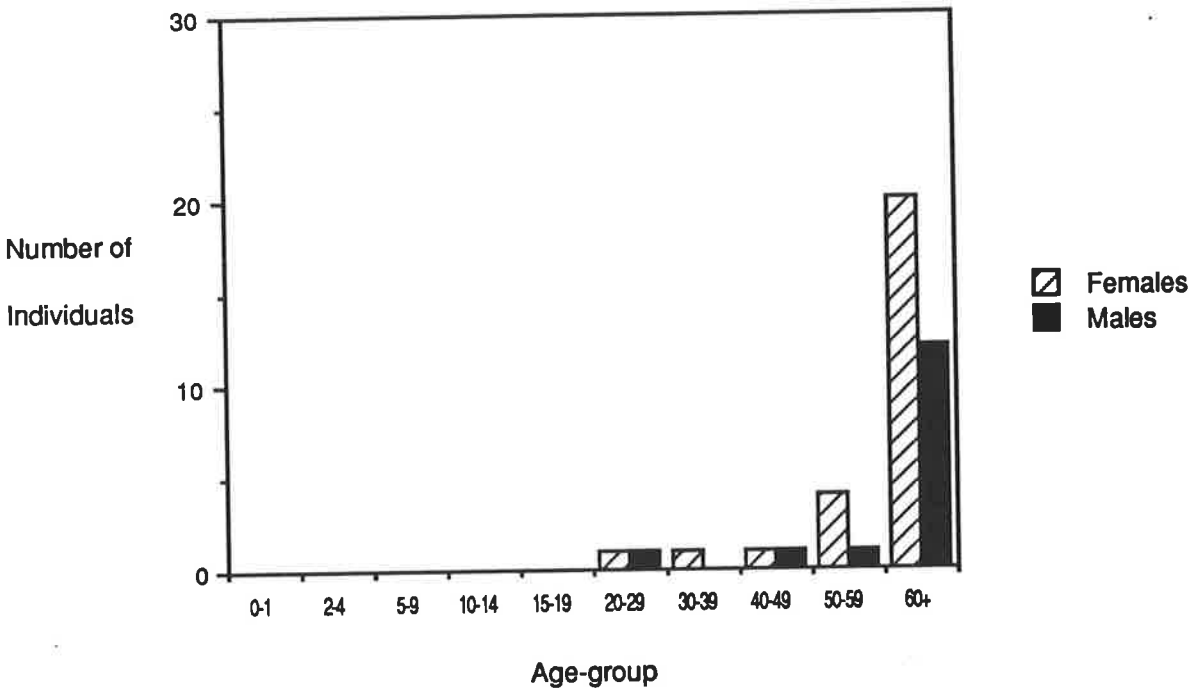
by age-group and sex

Age-Group	females No.	% of age-group	males No.	% of age-group	Total	% of age-group
0-19	0/421	0.0	0/345	0.0	**0/766**	**0.0**
20-29	1/135	0.7	1/86	1.2	**2/221**	**0.9**
30-39	1/92	1.1	0/55	0.0	**1/147**	**0.7**
40-49	1/67	1.5	1/65	1.5	**2/132**	**1.5**
50-59	4/60	6.7	1/52	1.9	**5/112**	**4.5**
60+	20/74	27.0	12/62	19.4	**32/136**	**23.5**
Total	**27/849**	**3.2%**	**15/665**	**2.3%**	**42/1514**	**2.8%**

The results for corneal opacity were virtually the same as for trichiasis. This was expected as those with trichiasis usually have some degree of corneal opacity. The age-standardized odds ratio of corneal opacity when females were compared to males was: M-H weighted OR=1.64, C.I.: 0.77 to 3.48, (X^2=1.48 (p=0.224)), using the age-groups in Table 3.3.7.5. The difference between the sexes was less marked, but when the outcome of blindness was considered, women were disproportionately represented (Table 3.3.4.1).

The relationship of corneal opacity with age is demonstrated in Figure 3.3.7.3 .

Figure 3.3.7.3: Individuals with corneal opacity by age-group



Inflammatory Trachoma:

Table 3.3.7.6: Active Inflammatory Trachoma (TF+TI) by age-group and sex

Age-Group	females No.	females % of age-group	males No.	males % of age-group	Total	% of age-group
0-1	10/29	34.5	6/26	23.0	**16/55**	**29.1**
2-4	26/66	40.9	27/73	37.0	**53/139**	**38.1**
5-9	52/152	36.8	33/121	27.2	**85/273**	**31.1**
10-14	21/100	21.0	13/82	15.8	**34/182**	**18.7**
15-19	1/74	1.4	1/43	2.3	**2/117**	**1.7**
20-29	12/135	9.6	6/86	9.3	**18/221**	**8.1**
30-39	11/92	12.0	5/55	9.1	**16/147**	**11.0**
40-49	7/67	10.4	4/65	6.2	**11/132**	**8.3**
50-59	6/60	10.0	5/52	9.6	**11/112**	**9.8**
60+	10/74	13.5	10/62	17.7	**20/136**	**14.7**
Total	**156/849**	**18.9%**	**110/665**	**16.5%**	**266/1514**	**17.6%**

Note: individuals with both TF and TI have only been counted once

The addition of the trachoma intense and follicular trachoma gives an overall impression of the distribution and extent of active inflammatory disease in the sample.

Reflecting the results for trachoma follicles (Table 3.3.7.1) the highest prevalence of infective disease occurred in the younger age-groups, although the 60+ age-group had almost 1 in 6 individuals with active disease. Male to female differences occurred; however, the age-standardized odds ratio of infective trachoma for females relative to males was; M-H weighted OR=1.29, C.I.: 0.97 to 1.72, (X^2=2.92 (p=0.087)), using the age-groups in Table 3.3.7.6.

Summary of the Trachoma Results:

The findings for trachoma demonstrated a changing pattern of disease across age-groups.

In the young (0-14 age-group), active inflammatory disease (TF+TI) predominated, affecting 29.0% (188/649) of this group. Trachoma scarring, by contrast, was only found in 4.5% (29/649) of this group.

The adolescent and young adult years (15-29 age-group), had a lower prevalence of active inflammatory trachoma (21/338 or 6.2%), but a higher prevalence of trachoma scarring (60/338 or 17.8%). There was in fact a steep increase in trachoma scarring with age (Figure 3.3.7.2).

For the middle years (30-59 age-group), active inflammatory trachoma was found in 9.7% (38/391). However, whereas TF had predominated in the younger age-groups, TI now contributed more to the total of infective disease than TF (approximately 68% of all infective trachoma in this group).

Trachoma scarring was found in 44.0% (172/391) of the 30-59 age-group. Additionally, trachoma trichiasis and corneal opacity began to be found, the percentages being 2.6% (10/391) and 2.0% (8/391) respectively.

In the oldest age category (60+), both TF and TI were found in greater proportions compared to the middle years, 7.4% (10/136) and 8.1% (11/136) respectively; the total prevalence of inflammatory trachoma was 14.7% (20/136). The proportion of trachoma scarring was the greatest of any group (89%) and the greatest burden of TT and CO also fell in this group (66% and 76% of the totals respectively).

In summary, the pattern of disease across age-groups was characterised by; a steep increase of trachoma scarring with age, a high prevalence of inflammatory trachoma in the young, with a smaller but significant increase in inflammatory trachoma (compared to preceding age-groups) in the 60+ age-group. A feature of this increase was the reversal of the relative proportions of

TF and TI compared to the 0-14 age-group. Trachoma trichiasis and corneal opacity were predominantly found in the middle (30-59) and old years (60+). For all trachoma trichiasis, 77% was found in individuals aged 50+ years, and for corneal opacity this percentage was 88.0%.

The burden of severe trachomatous disease appears to fall on individuals aged 60+ years. It was found that even though the young had high rates of inflammatory disease this was not translated into a high proportion of secondary scarring, trichiasis or corneal opacity, as found in trachoma endemic regions overseas (section 1.3.1). The middle years had less inflammatory infective disease and although having an increasing proportion of scarring with increasing age, this again was not translated into high rates of trichiasis and corneal opacity. Only in the 60+ age-group was there a large proportion of scarring and an high prevalence of trichiasis and corneal opacity. The burden of trachomatous disease in the 60+ age-group was also reflected in the prevalence of visual disability for this group (section 3.3.3 to 3.3.6).

3.3.8. Service Role

Although not a part of the research, the service role was important to the survey's acceptance by the communities visited.

The number of spectacles prescribed totalled 131. These were mainly for presbyopia or aphakia in the older individuals, although a few were prescribed for myopia or hypermetropia.

It appeared that although many of the individuals had been given glasses by previous trachoma program trips, these were easily lost or broken and therefore had a short life in the bush. One suggestion to increase the lifetime of the spectacles was the provision of restraining straps for all glasses. Although corrective glasses were welcomed by the older age-groups in the communities, young people who had poor vision often chose not to wear them, presumably because of a sense of shame or because of peer group pressure. At least

two individuals were seen who were monocularly blind due to amblyopia, probably as a consequence of not wearing prescribed lenses.

Referrals for eye surgery either to Adelaide or Alice Springs also were made. A total of 54 people were given the opportunity to have either cataract surgery (44), or lid surgery for trichiasis (5), or laser treatment for diabetic retinopathy (4), or for one person, rehabilitation.

3.4 Discussion

3.4.1. Participation Rates

In the context of a census type survey, participation is defined as the proportion of the source population who were approached and agreed to participate in the survey. Approximately 54% of the total population identifiable from the 1990 population lists for the Anangu Pitjantjatjara lands were examined; if projected census data were used the figure was 76%. This may be compared to the approximate participation rate of 80.4% from the N.T.E.H.P. survey for the AP lands in 1976, using 1976 census data and the R.A.C.O. Report (1980). Although 100% participation in a survey is desirable if the group which participates is representative of the source population the results obtained will be applicable to the larger total population.

In the 1989/90 survey all the communities were sampled with variable participation rates (42.1% to 67.4%). Females were seen more often than men in all age-groups except those aged 0-4 years. Age categories with the highest participation were the 60+ (76%) and the 0-9s (63%) age-groups. Coincidentally these were the age-groups in which the major ocular pathology occurred, blindness and trachoma respectively. The participation in the 60+ age-group was comparable to the response (86.2%) in a prevalence survey of ocular disease in a New Zealand town of people aged 65+ years (Martinez et al. 1982). Participation in the other age-groups varied from 41% to 60%, which was adequate for statistical purposes.

The variation in participation reflected several factors including:

(a) The time spent in the communities. The longer the stay the greater the participation, but as the stay lengthened fewer individuals were seen each day (a law of diminishing returns), this limiting the "efficiency" of a prolonged visit.

(b) The perception by individuals of a need for eye care and assessment. Older individuals with visual problems usually sought examination earlier than those with

good visual acuity. Therefore young males and females in good health were less likely to participate on the basis of individual need.

(c) The appreciation by the community and individuals of the survey's value influenced many who participated. For those without visual disability the perception of the survey benefiting the community as a whole increased participation.

(d) The occurrence of ceremonies or business.

Factors that were important in fostering the communities positive perception of the survey were, pre-visit advertising, liaison with health service staff and community leaders, and the formation of relationships with families and individuals within the community. Often the encouragement by one family member who had participated in the survey induced others to attend for examination. The increased participation with time spent in each community, was due to both the time spent in the field, and the gradual growth in relationships with members of the community.

Even with a participation rate of 76% potential biases could be introduced into the results if the examined proportion of the population were systematically different from the unexamined. It was established from medical records and health workers that all binocularly blind individuals were examined (section 3.3.4. b). Generally those not examined tended to be aged 20-39. A group, in those examined, which showed little eye pathology and only some inflammatory trachoma. The symptoms of trachoma did not appear to influence presentation to the health clinics at other times and identification of trachoma in these communities appears to occur with opportunistic screening by health staff. It could therefore be concluded that trachoma status would not influence presentation to survey personnel and that an individuals presence in the community was the main determining factor for participation (see section 5.3).

Previous surveys of eye health in Australia had not attempted to estimate the underlying source population from which the sample was taken. Therefore, the prevalence rates presented were from the study population (sample). Extrapolation from this rate to the

population may be inaccurate because the residual or unexamined proportion of the population may have more or less disease than the sample. The 1989/90 survey attempted to see as many individuals as possible and to estimate the size of the underlying source population. Also, at least for blindness, the 1989/90 survey sought to identify the visual acuity of individuals not examined (section 3.3.4 (b)). Despite methodological difficulties, the prevalence rates presented (Table 3.3.4.4) gave a more accurate estimation of the eye health of the total population than the sample prevalence rates themselves. If a properly randomised survey could have been done, the sample would have yielded more accurate prevalence data for the population as a whole. With the availability of the population lists, this may be possible in the future.

3.4.2. Visual Acuity Results

Binocular Blindness

In the 1989/90 survey 1.3% of the sample was binocularly blind (W.H.O. defn.), or using the Australian definition 1.5%. The source population prevalence rate was 7.2/1000 (W.H.O. defn.), which was comparable with blindness rates of 1% in "typical" developing countries (Thylefors 1990). The prevalence of blindness derived from the sample was also comparable with the figure of 1.4% (visual acuity 6/60 or worse, N.T.E.H.P. defn.) for the Aboriginal population from a series surveyed by Taylor (1980). By contrast, an estimate for the state of New South Wales (N.S.W.) was 1.4 - 1.9/1000 or less than 0.2% (Banks and Hutton1985); and using population based data from a multi-stage random cluster eye health survey for people aged 50+ years in South Australia, a rate of 1.0 /1000 or 0.1% (personal communication with Dr. H Newland 1991). These rates that were similar to those obtained from major surveys in developed countries around the world (Sorsby 1966, Kahn et al. 1977), and highlight the gap between Aboriginal and white eye health in Australia.

A comparison of the causes of binocular blindness may be made using a sub-set of data from the N.T.E.H.P. survey. Using the N.T.E.H.P. blindness definition twenty eight people were blind in the 1989/90 survey. The causes of binocular blindness were in order, trachoma (12/28), cataract (11/28), absent or phthisical globe (3/28), bilateral labrador keratopathy (1/28) and retinal detachment with congenital ectopic pupil and cataract (1/28). These may be compared to the results of a sub-sample of the N.T.E.H.P. survey (Taylor 1977), in which again by coincidence, twenty eight individuals were binocularly blind. The causes were cataract (14/28), corneal scars (4/28), phthisis (3/28), labrador keratopathy (3/28), trachoma (2/28), pterygium and cataract (1/28) and interstitial keratitis (1/28). The crude prevalence of blindness was similar, 1.8% vs 2.2% respectively. Age-specific prevalence rates were not given in the results, nor was an age/sex distribution recorded. However, it was established that examination of the sample occurred on the A P lands (Personal communication with Prof. Taylor 1992), therefore it could be assumed that the sample included a large proportion of the

Anangu Pitjantjatjara. The equivalence of both the sample and source population is established in chapter 4 (section 4.3), comparisons of prevalence rates and causes of blindness would therefore be valid. Cataracts were a major cause in each survey, trachoma predominated in the 1989/90 survey but not in the 1977 study. However, adding diseases of the anterior segment (corneal scars, labrador keratopathy, trachoma and interstitial keratitis) together in each survey, demonstrated that these preventable diseases had approximately equal proportions in each year (13/28 vs 10/28).

Comparison of the results with a larger sample of Aboriginal people in Central and Western Australia reported by Taylor (1980), found consistency in the causes of blindness with the 1989/90 survey. Just over half the blindness in Taylor's second study was due to cataract, one third to corneal disease and one twelfth to loss of the globe. Again trachoma was not as important in causing blindness in the earlier work compared to the 1989/90 survey. However, he found using a case control method that blindness was correlated with increasing age, trachoma and history of trauma, findings that were consistent with the 1989/90 survey.

The results of the N.T.E.H.P. survey (R.A.C.O. Report 1980), demonstrated that disease of the lens and cornea were the most common visual system abnormalities in the blind (Table 2.2.1). Trachoma although being important did not predominate as in the 1989/90 survey, but preventable causes of the anterior segment were important for Aboriginal people. A further analysis of this finding occurs in the discussion of the trachoma results.

The prevalence of blindness in males and females was significantly different in the 1989/90 survey (section 3.3.4). This had been found before in the "Red Centre" zone in the 1976-1979 survey. A difference which was not significant in the other twelve zones (R.A.C.O. Report 1980 p62).

Bilateral blindness was mainly found in the 60+ age-group, 86% (19/22) of the total blindness (Australian definition). This is roughly comparable to the risk of blindness in America, where

people over the age of 65 years have a 10 fold risk of blindness, compared to those aged less than 65 years (Pizzarello 1987).

Monocular Blindness

In the 1989/90 survey the crude prevalence rate per thousand for monocular blindness (N.T.E.H.P. defn. of 6/60 vision or less in one eye) was 56/1000 (85/1514 using data from table 7 appendix 1). This can be compared with a crude prevalence rate of 37/1000 for the "Red Centre" zone in the R.A.C.O. Report (1980). If the source population was used as a denominator the rate was 30/1000 for the 1989/90 survey data . When the 60+ age-group was considered the rate for the "Red Centre" zone was 227/1000 in the R.A.C.O. Report, compared to the 1989/90 result of 353/1000 (48/136 using data from table 6 appendix 1) for the sample. For the source population the rate was 267/1000. A direct comparison for the Anangu Pitjantjatjara lands or Yalata could not be done because age-specific data was not available.

It was difficult to explain the apparent increase in monocular blindness (from 1976 to 1989/90), when the sample was considered. The fall as it occurred for the source population was more in keeping with the trend demonstrated for both poor vision (Table 4.3.4) and binocular blindness. The high prevalence rate in the 60+ age-group may have been due to a cohort effect, with a group of monocularly blind individuals in 1976-1979 being counted again in 1989/90. The results for monocular blindness may also reflect an increased identification of monocularly blind people in the 1989/90 survey compared to the N.T.E.H.P. survey, or the differences in the population distribution between the 1989/90 survey and the sample in the "Red Centre" zone (see Table 4.3.6).

Comparison of the causes of monocular blindness in the 1989/90 survey with the 1977 Taylor study demonstrates that cataracts were the most important cause in each survey 39.4% vs 48.6% respectively, anterior segment disease was next 39.4% vs 24.3% and trauma as an

underlying cause, was responsible for approximately a third of all monocular blindness 28.8% vs 43.2%.

Comparison with international studies highlight factors that contribute to monocular blindness. Firstly, an eye health survey of a rural Appalachian community in Kentucky (USA) gave the causes of monocular blindness as cataract, trauma, amblyopia, and macular degeneration. Infectious causes were not important (Dana et al. 1990). In the 1989/90 survey cataract and trauma were the major causes with infection third. Geographically and racially the surveys were dissimilar, but both areas were rural and socioeconomically disadvantaged, with restricted access to ophthalmic services.

Secondly, an eye health prevalence survey among the Turkana tribe in north-west Kenya, an area which was climatically and socioeconomically similar to the 1989/90 survey was reported in 1990 (Loewenthal and Pe'er 1990). The crude prevalence of monocular blindness was 6.8%. Trauma contributed significantly to monocular blindness (21%) compared to the figure for the 1989/90 survey of 28.8% (19/66). Senile cataract was a cause in 13.1% (8/61), cf 37.6% (25/66), trachoma 14.8% (9/61) cf 16.6% (11/66), and corneal opacity 22.9% (14/61), cf 12.1% (8/66) of all monocular blindness. For corneal opacity a precise cause was hard to determine because the histories were imprecise. A difficulty found in other surveys in undeveloped regions (Potter 1991).

The comparisons are qualitative, but, the first study demonstrates that cataract can be an important cause of blindness in developed countries, with factors such isolation and economic disadvantage possibly contributing. The second study shows that despite climatic and economic similarities with Central Australia, and although the causes of monocular blindness were the same, the relative importance of the causes may be different for each region. This has implications for the prevention and treatment of blindness and trachoma (section 6.2)

Visual Acuity

The results of the 1989/90 survey for visual acuity were similar to those from previous surveys conducted in Central Australia. The majority of the population (86%), had visual acuity of 6/6 in both eyes. "Good" vision (Visual acuity of 6/12 or better in both eyes (N.T.E.H.P. defn.)) was found in 88.5% of the sample, this was comparable to the prevalence rate of 908 per thousand found for the "Red Centre" zone in the R.A.C.O. Report (1980). The results of a survey conducted in the 1970s, showed that visual acuity of 6/6 or better in at least one eye was found in 82% of the population from Yalata and 91% from Ernabella (Edwards et al. 1976). Visual acuity of 6/9 in both eyes or worse was found in 17% of people from Yalata and 9% of people from Ernabella, cf. 10% for the 1989/90 survey (appendix 1 Table 7).

3.4.3. Trachoma Results

The five sign system simplified the trachoma grading procedure (section 1.3.1 (2.1.4)). Although some difficulties were experienced with the current W.H.O. grading scheme, it appears to reflect inflammatory and cicatricial trachoma accurately. It is also subject to less intra-observer and inter-observer errors than previous more complicated schemes (Tielsch et al. 1987). However, some difficulties were found in grading trachoma intense (TI) in older individuals. They often had scarred tarsal plates, with no normal blood vessels and irritated eyes from smoky fires, their everted upper lids were therefore similar in appearance to trachoma intense.

This was reflected in the results when the age distributions of individuals with follicular trachoma (TF) and TI were compared. TF was found predominantly in the young; for those aged 14 years or less the prevalence was 27% (176/649) and for individuals more than 14 years 4.2% (36/865). Of all individuals affected by TF, 83% were in the less than 14 age-group. This finding was consistent with the literature, in which trachoma is acquired soon after birth (section 1.3.1 (2.1.5)). In contrast, TI had a reverse relationship with age, with 73% occurring in individuals aged 15 or more years, although the peak age-specific prevalence rate occurred in the 0-1 age-group 6/55 (11.0%), which was consistent with previously published results. The prevalence in those aged less than 14 was 2.6% (17/649) and in those aged more than 14 years 5.3% (46/865). These results were unexpected and require further explanation.

A high prevalence (over 15%) of severe tarsal conjunctival inflammation (TI) in age-groups less than 10 years of age indicates a continuing involvement of a new cohort in the trachomatous blinding process (Darougar and Jones 1983). The low prevalence of TI in 1989/90 survey for this age-group suggests they will not progress to the blinding complications of trachoma.

The differences in the age distribution of TF and TI for the 1989/90 survey may be due to a changing pattern of disease or systematic grading error. Other surveys have not noted such a relationship with age, but the prevalence of the active inflammatory disease in the Anangu

Pitjantjatjara lands has declined since 1976. It may be that susceptible individuals continue to suffer poor eye health due to both old scarring and neglect, whereas the younger age-groups have grown up with improved housing, different hygiene practices and better access to treatment services. The two groups, each forming a cohort, would therefore be expected to have different patterns of disease.

Systematic grading errors might also explain the differences. Misclassification may have occurred in grading when tarsal plate scarring with diffuse fibrosis or formation of a fibrovascular membrane obscured the large deep tarsal vessels, giving the appearance of inflammatory thickening (Thylefors et al. 1987). Eye irritation from dust and smoky fires (which the older Aboriginal people often spend much time around) would have confused the clinical assessment further. A study on the reliability of photographs for grading trachoma in field-studies demonstrated problems with the photograph grader over diagnosing TI when TI was not observed clinically (West and Taylor 1990). A reliance on not identifying deep tarsal vessels when grading TI appeared to be the cause. The same reason for misclassification of TI could have occurred in the 1989/90 survey.

Although this type of misclassification was not analysed, on review, the results for individual communities showed significant variation in the prevalence of trachoma intense in the 60+ age-group. This variation could not be accounted for by the presence of different graders and therefore the high prevalence of TF in the 60+ age-group may be due to outbreaks of active trachoma in different communities during the survey, with individuals most susceptible because of previous scarring demonstrating signs of active disease.

The prevalence of trachoma scarring reflects past disease in the community (W.H.O. 1989). The almost exponential relationship with age demonstrates this well (Figure 3.3.7.2). Although scarring may take years to develop, other surveys in endemic regions have found that scarring can occur early, predisposing the individual to repeated infection and scarring over many years (section 1.3.1(2.1.5)). The finding that only 5.9% (45/77) of those aged 19 years or less have any scarring (and most of it mild), reflects both the low prevalence of TF and

TI, and the probable influence of treatment programs. The higher prevalence in age-groups above 20 probably reflects infection prior to 1976 when living conditions were poorer and treatment programs unavailable.

The results for trachoma trichiasis (TT) and corneal opacity (CO) were very similar, and again reflect many years of severe disease. Prevalence rates had declined in the period from 1976 to 1989/90 (section 4.4). A cohort effect may have occurred, with a group of individuals aged in their 40s, 50s and 60s in 1976 who had severe disease, ageing by 15 years and being re-counted in the 1989/90 survey. Although this cannot be proven, it could explain the persistence of severe disease despite the diminishing prevalence of active inflammatory disease.

Some individual data sheets are still in existence in Ernabella (as a collected set) and Yalata (incorporated into the medical case notes of the clinic). A retrospective longitudinal study would give a more accurate picture but follow-up of individuals would be difficult.

There is some evidence of severe disease in younger individuals, 33% percent of trichiasis occurs in the age-group less than 60 and 24% of the corneal opacity. However, when comparisons were made with surveys overseas, the absence of TT and CO in the < 19 age-group indicate a pattern of less severe disease (Jones 1975).

Two other results were important. The increased prevalence of trachoma trichiasis in females, with an odds ratio of 4.49 compared to males (across all age-groups), has important implications. Males and females had non-significant differences in prevalence rates for active inflammatory disease and tarsal scarring, so why did women have more trichiasis? The increased risk of trichiasis for women has been observed in other surveys (section 1.3.1 (2.1.7)). A recent survey in the Nile delta found 75% of older women had trichiasis compared to 57% of males. Severe conjunctival scarring was more common (84% vs 58% respectively). Inflammatory disease was found to be equally distributed between the sexes (Courtright et al. 1989).

Several explanations have been offered in the past. The most plausible is that young women have greater contact with young children who have high infectivity rates, thereby acquiring trachoma more often (section 1.3.1 (2.1.7 b)), an explanation which accounted for a higher prevalence of cicatricial trachoma in girls compared to boys (10% vs 6%) in a study from Mexico. There was also a higher prevalence of active trachoma in girls (29% vs 19% respectively) (Wilson et al. 1987).

There are two other explanations of why trachoma is more severe in women than men. Women may have poorer eye hygiene, or may have decreased access to treatment programs. There is no supporting evidence concerning eye hygiene, nor has differential access to treatment been identified in trachoma studies as a cause for a higher prevalence rates; however, the public health literature has looked at the social determinants of health and disease. Among the many factors known to have have some effect on health status, access to medical care for disadvantaged groups, eg. migrants, unemployed, the poor, can add to the burden of disease (Syme 1986). Women were found to have more binocular blindness than men (17/849 vs 5/665) with the causes being trachoma and cataract, (X^2=4.04 p=0.045). The results for monocular blindness also appear to support this, with 24.4% (10/41) of monocularly blind females being at risk of binocular blindness due to trachoma compared 20.0% (5/25) males OR=1.29 ,95% C.I.: 0.34 to 5.53 (Table 3.3.5.3). This finding is in agreement with the Nepal Blindness Survey (Brilliant and Brilliant 1985) where all the people bilaterally blind from trachoma were women (2.4% of all blindness) and a survey in the Transvaal region of South Africa where women were more likely to be blind or have impaired vision from trachoma than men (Ballard et al. 1983).

The hypothesis of differential access to treatment appears to be supported by data for the prevalence of sight-limiting cataract in males and females. Case control studies examining age-related cataract (cortical cataract) have determined the following odds ratios (female risk of cataract compared to male risk), OR=2.20, 95% C.I.: 1.56 to 3.12 (The Italian American Cataract Study Group 1991), OR=1.51, 95% C.I.: 1.07 to 2.12 (Leske et al. 1991). In the

1989/90 survey monocular blindness due to cataract was found in 28% (7/25) of males compared to 44% (18/41) of females OR=2.01, 95% C.I.: 0.61 to 6.75, but again the difference was not significant at the $p<0.05$ level.

Why women are at greater risk of cataracts or are less likely to access ophthalmic care is an important question. Socio-cultural processes may be the determining factor. Two studies have identified that in traditional societies men are more likely to use physician services than women (Lieban 1978, Morsey 1980). A study of those blind from cataract in the Nepal Blindness Survey found that men were more readily provided with cataract surgery regardless of wealth or access to care, whereas women received surgery if barriers such as distance to treatment and cost were minimal (Brilliant and Brilliant 1985). Another study in the Northern Transvaal (Bucher and Ijsselmuiden 1988), found that women were 1.6 times less likely to have undergone cataract surgery than men. However, a sex difference found in a prevalence survey of blindness in a rural Appalachian community could not be ascribed to the prevalence of cataract or the use of surgical services (Dana et al. 1990); and in a survey of blindness in Saudi Arabia there was a strong indication that women formed cataracts earlier than men and had more procedures for cataract removal (Tabbara and Ross-Degan 1986).

In conclusion, it appears that data from the 1989/90 survey and the literature supports differences in the prevalence of trachoma between females and males. Although a precise reason is unknown, the data from the survey supports differential access to treatment as being a possible factor. The answer is not clear and will only be determined by further study.

Chapter 4. Changes in the Prevalence of Trachoma and Blindness in the Anangu Pitjantjatjara: A Quantitative Comparison Between the 1989/90 Survey and Previous Surveys

4.1 Introduction

Although the qualitative descriptions of past surveys can be used to make comparisons, a quantitative analysis would be more accurate. Cross-sectional comparisons have been used before to quantitate changes over time. Firstly, the N.T.E.H.P. review in 1985 (T.E.H.P. Report 1985), compared the results of trachoma screenings in twenty Aboriginal communities with the results from the same communities during the 1976-1979 N.T.E.H.P. survey. Whilst the methodology of this comparison allowed for differences in disease definition, often only small numbers were sampled in the second survey (the 1985 review), leading to reduced confidence in the differences observed. Secondly, a review of trachoma surveys in the Northern Territory was undertaken in the late 1980s, trachoma was shown to have declined in coastal areas but not in the inland (Meredith et al. 1989). The study by Meredith utilized data from many surveys which were not standardized for methodology, and therefore may be inaccurate, although the statistical methods used appear to have smoothed out this inaccuracy allowing crude comparisons and deductions to be made. Neither of these comparisons had attempted to assess changes in visual acuity.

4.2 Methods

(a) The Hypothesis

To test the hypothesis:

> "The age-specific prevalence rates of blindness and trachoma in the Anangu Pitjantjatjara of South Australia have shown a statistically significant decline since the N.T.E.H.P. survey of 1976".

Data which had been collected in a similar way to the 1989/90 survey had to be found. Three sets of data were identified. Original reports from the N.T.E.H.P. 1976-1979 survey called the interim reports, data for the "Red Centre" zone in the R.A.C.O. Report 1980, and data from the 1985 N.T.E.H.P. review (T.E.H.P. Report 1985).

Three major difficulties arose in the comparison between the 1989/90 survey data and the 1980 R.A.C.O. Report. Firstly, no community-specific data were available from the 1980 report. Interim reports compiled during each community visit in 1976 were; however, obtained from Professor Fred Hollows in Sydney. Unfortunately reports were not found for the communities of Ernabella and Fregon. The information contained in the interim reports included:

1. The age distribution of individuals with poor vision (defined by the survey as visual acuity in the better eye of 6/18 or 6/24 or 6/36, with similar or worse vision in the other eye).

2. The number of blind individuals (defined as visual acuity of 6/60 or worse in the better eye).

3. The age distribution of individuals with trachoma follicles.

Secondly, comprehensive results were available from the R.A.C.O. Report of 1980, but the data for the communities in the N.W. of South Australia, the Anangu Pitjantjatjara lands, were pooled with other communities from Central Australia to form a distinct zone called the "Red Centre", one of thirteen such zones that were created in the report to aggregate data based on geographical and demographic features. The communities from the Anangu Pitjantjatjara lands made up 16% (1011 individuals) of the "Red Centre" zone total population of 6321 individuals (Appendix 2 R.A.C.O. Report 1980).

It could be assumed that the averaged results for the "Red Centre" zone were an accurate estimate for the results of the Anangu Pitjantjatjara communities. Some differences would be expected but the general characteristics of the communities throughout the "Red Centre" zone including environmental, socio-demographic and cultural factors were relatively homogeneous (R.A.C.O. Report 1980). In contrast, the community of Yalata was pooled with 37 other country towns and Aboriginal reserves to form the "Arid Eastern" zone. The characteristics of the communities in this region were less homogeneous and the Yalata

population comprised only 2.4.% of the total sample. Comparisons between the 1980 R.A.C.O. Report pooled data and the 1989/90 survey results could therefore be inaccurate.

Another source of inaccuracy was the actual data contained in the R.A.C.O. Report. In 1985, a review of the Trachoma Program was undertaken, with approximately 2000 Aboriginal people being examined (T.E.H.P. Report 1985). It was established that certain discrepancies and inconsistencies existed in the 1980 R.A.C.O. Report (section 6.2.3.1 T.E.H.P. Report 1985), both in the report itself and between the data base and the report. For instance, zone tallies for follicular trachoma in the text of the report differed inconsistently with the zone tallies in appendix 2 of the report. A suspected source of discrepancy was the addition of rescreening data (in most cases following a treatment program) to the tally for the data represented by tables in the main text.

Although this may affect the interpretation of some results based on the "Red Centre" zone data (section 4.3.3), the comparisons based on the interim reports and 1985 N.T.E.H.P. review are not affected because the interim and 1985 review reports used first screening data to calculate their results.

In summary the three sources of 1976 survey data available for comparison with the 1989\90 survey results were:

1. The Interim Reports

These unpublished reports provided 1976 data for the communities of Yalata, Amata, Indulkana, Mimili and Pipalyatjara. These data were compared with those for the same communities in the 1989/90 survey. The data available included the prevalence of follicular trachoma, the prevalence of poor vision by age and the total number of blind people.

2. The "Red Centre" Data from the 1980 R.A.C.O. Report

The results for the "Red Centre" zone in the 1980 R.A.C.O. Report were compared with the 1989/90 pooled results for the communities of Ernabella, Amata, Indulkana, Mimili, Pipalyatjara, Kalka and Fregon, communities that are in the Anangu Pitjantjatjara lands.

3. The Results of the Trachoma and Eye Health Program Review of 1985

Prevalence data for active inflammatory trachoma in the communities of Yalata, Indulkana, Amata and Fregon for the years 1976 and 1985 were available. Descriptions used in a grading manual from the 1976 survey and the 1980 R.A.C.O. Report were applied to the 1990 five sign system. In some cases the same photographs had been used to illustrate grades of trachoma, facilitating the cross-matching of grading.

(b) Comparison of Trachoma Grading and Diagnostic Criteria

The system for trachoma grading has evolved and changed in the fourteen years since the 1976 survey. It has been simplified to incorporate fewer categories and to avoid grading particular signs by their severity. Also, previously well known signs such as Herberts pits, papillae and pannus have been deleted from the new grading system. Therefore, direct comparison of results between surveys spanning these years is difficult. However, clearly defined criteria are available for each category enabling some comparisons to be made.

The diagnostic criteria are outlined below. Abbreviations used are the same as appeared in the 1985 Trachoma and Eye Health Program Report. The criteria for 1989/90 are based on the five sign system. The diagnostic criteria for trachoma follicles and trachoma intense are defined using the description found in the 1985 N.T.E.H.P. review (T.E.H.P. Report 1985).

Diagnostic Criteria for trachoma

New diagnostic criteria for follicular trachoma were devised by the investigators in the 1985 N.T.E.H.P review for the purpose of analysis.

The following abbreviations were used (T.E.H.P. Report 1985):

FOL = Follicles

LF = Limbal follicles

PAP = Papillae

HP = Herberts pits

SC = Scarring

PAN = Pannus

TR = Trichiasis

0=sign absent

1=sign just present

2=sign obviously present

3=sign grossly present

Example:

"FOL=2+" means "Follicles grade 2 or more"

Follicular Trachoma

1980 Criteria

	FOL/LF = 2 +		
or	(1) FOL/LF = 1	combined with	PAP = 1 + (same eye)
		or	HP = 2 + (same eye)
or	(2) FOL = 1	combined with	LF = 1 (same eye)

1985 Criteria

As above, plus two new categories

FOL/LF = 1 in both eyes

FOL/LF = 1 combined with SC = 1 + (same or other eye)

1990 Criteria

Trachoma follicles (TF) FOL = 1+ (i.e. grades 1, 2 or 3) with any combination of LF, HP, SC, PAN or TR in one or both eyes.

It was apparent that the 1989/90 criteria were broader, encompassing all the criteria described for 1980 and 1985 and including infection in only one eye. Although limbal follicles, Herberts pits or pannus were not specifically looked for, if follicles were present, it was graded as TF Therefore, the 1989/90 criteria could overestimate TF in the community relative to the 1980 or 1985 criteria.

Severe Follicular Trachoma

1980 Criteria

Using the same abbreviations as above.

Severe follicular trachoma (Severity A and B combined)

FOL/LF = 3

or (1) FOL/LF = 2 Combined with PAP=1+ (same eye)

or (2) FOL/LF = 1 combined with PAP=2+ (same eye)

1985 Criteria

Limbal follicles were excluded.

FOL = 3

or FOL = 2 combined with PAP = 1+ (same eye)

or FOL = 1 combined with PAP = 2+ (same eye)

plus two new categories:

FOL = 2 combined with PAN = 2+ (same eye)

or SC = 2+ (same eye) (same eye)

or TR = 1+ (same eye)

or FOL = 1 combined with PAP = 1 and PAN = 2+ (same eye)

2+ or SC = 2+ (same eye)

or TR = 1+ (same eye)

1989/90 Criteria

The 1990 survey had no equivalent for severe follicular trachoma as the grading of severity is avoided in the Five Sign System. Some elements were equivalent to trachoma intense discussed below.

Trachoma Intense

Trachoma intense (TI) was a 1989/90 grading sign, equivalent to papillae grade 3 in the 1980 grading system. It was possible to score grade 2 papillae, especially with trachoma scarring, as trachoma intense in the 1989/90 survey (usually in older individuals). Also individuals scored as TI in 1989/90 could have also been scored as trachoma follicles (TF) in the five sign system. To avoid double counting, these individuals were designated as having TI only, they were not included in the TF data.

Therefore trachoma intense overlapped with trachoma follicles and papillae (with the addition of any combination of LF HP SC PAN or TR), and a comparison between the prevalence of trachoma follicles in the 1980 Report, the 1985 review and the 1989/90 survey requires the addition of TI to the TF data. Note: (The data presented in the interim reports for TF grades 1, 2 and 3 could be directly compared to the TF results for the 1989/90 survey because the definitions were the same.).

Summary

The grading systems for the 1980 report, 1985 review and 1989/90 survey are different. An evaluation of the diagnostic criteria was made allowing comparison of active inflammatory trachoma between the surveys (TF + TI in 1989/90 survey). The broader definition in the more recent five sign system probably overestimates the prevalence of trachoma in a community relative to the 1980 and 1985 definitions.

4.3 Comparison with the 1989/90 Survey using three data sets

Three sets of data were used to make comparisons between previous surveys and the 1989/90 survey (section 4.2). For each data set the sample and source populations are compared between surveys to ensure that they were approximately equivalent. Crude and age-standardized prevalence rates are then compared. The results are tested using either X^2 stratified analysis, or for two sets of data, logistic regression analysis.

(1) Interim Reports

(a) Comparison of the populations for the interim reports 1976 and the 1989/90 survey.

Table 4.3.1. compares the source populations for the communities surveyed for the 1976 interim reports with the same communities in the 1989/90 survey. The figures were derived from 1976 census data, 1986 census data, and 1989/90 population lists.

Table 4.3.2. compares the sample, in the 1976 interim reports and the 1989/90 survey.

Interim report data was available for the communities of Yalata, Amata, Indulkana, Mimili and Pipalyatjara.(Note: Kalka was not officially recognised in either the interim reports or the 1976 census.)

Table 4.3.1.: Comparison of the source populations: 1976 interim reports (1976 census data) and 1989/90 survey (1986 census data and 1989/90 population list data)

Age-Group (Years)	1976 Census Data	% of Total	1986 Census Data	% of Total	1989/90 Populations List	% of Total
< 2	41)	13.4	130	11.2	192	11.4
2-5	100)					
6-10	140	13.3	120	10.3	232	13.8
11-20	234	22.2	266	22.8	379	22.6
21-30	173	16.4	268	23.0	310	18.5
31-40	160	15.2	128	11.0	206	12.3
41-50	90	8.5	89	7.6	138	8.2
51-60	60	5.7	65	5.8	107	6.4
60+	54	5.1	99	8.5	115	6.8
Total	**1052**	**100%**	**1165**	**100%**	**1679**	**100%**

Each set of data had been compiled in a different manner. The 1976 census data were collected using 4 collector districts and an unknown number of collectors. The collectors enumerated the number of individuals present in the communities at a defined point in time. In 1976 the communities were more clearly defined than in subsequent years and there were few if any homelands.

The 1986 census was more difficult because the population was scattered across communities and homelands. Additionally, the collection of data was interrupted for several weeks in one area because of a dispute between a collector and a community (Personal communication with M. Stratton of the Australian Bureau of Statistics). The 1989/90 population list by comparison was compiled over several months by an examination of medical records, school lists, pension records, social security benefits and local knowledge. It had been updated prior to its use.

Whatever the limitations set by the collection of data, the three population distributions were the best estimates available. Comparison by age-group indicated that the populations were very similar in structure over the years.

Table 4.3.2.: Comparison of the samples: 1976 interim reports with the 1989/90 survey

Age-Group (Years)	1976 survey	% of Total	1989/90 survey	% of Total
< 2	36	5.2	32	3.5
2-5	67	9.6	96	10.4
6-10	135	19.3	158	17.1
11-20	155	22.2	175	18.9
21-30	89	12.8	124	13.4
31-40	72	10.3	96	10.4
41-50	63	9.0	90	9.7
51-60	23	3.3	63	6.8
60+	58	8.3	91	9.8
Total	**698**	**100%**	**925**	**100%**

Although the 1989/90 population was larger than the 1976 sample the overall structure was similar across the age-groups listed. There were more people examined in the 1989/90 survey in the 51-60 age-group, approximately double the proportion seen in 1976. However, this was the only age-group in which a large difference was found between 1976 and 1989/90. The proportion sampled in this age-group was 38.3% (23/60) and 58.9% (63/107) respectively. A difference that was significant (X^2=6.5 (p=0.01)).

(b) *Comparison of the interim reports with the 1989/90 survey: Follicular trachoma*

The follicular trachoma prevalence for the interim reports was compared with the 1989/90 survey (Table 4.3.3.).

Table 4.3.3.: Comparison of the follicular trachoma (TF) prevalence by age-groups: The interim reports and 1989/90 survey

	1976			1989/90		
Age-group	foll.[1] trach.	Total seen	% of age group	foll.[1] trach.	Total seen	% of age-group
Less than 2	17	36	47.2	6	32	18.7
2-5	47	67	70.1	27	96	28.1
6-10	68	135	50.4	34	158	21.5
11-20	34	155	22.0	14	175	8.0
21-30	1	89	1.1	5	124	4.0
31-40	1	72	1.4	9	96	9.4
41-50	2	63	3.8	6	90	6.6
51-60	0	23	0.0	6	63	9.8
61+	0	58	0.0	9	91	9.9
Total	**170**	**698**	**24%**	**116**	**925**	**12.5%**

1. Trachoma follicles (TF), graded 1, 2 or 3 (section 4.3.2.)

The interim reports gave results for trachoma follicles graded as 1, 2 or 3, therefore the interim report results could be directly compared with the TF results of the 1989/90 survey. By contrast, in the R.A.C.O. Report of 1980, the results were given in broader categories which grouped various diagnostic features. Therefore a comparison based on these results required grouping of the categories TF and TI in the 1989/90 survey (Table 4.3.7.).

There was a decline in the crude prevalence rate of follicular trachoma from 24% in 1976 to 12.5% in 1990. The difference was statistically significant. The age-standardized odds ratio of follicular trachoma when 1976 was compared to 1989/90 was: M-H weighted OR=2.34, 95% C.I.: 1.77 to 3.20, (X^2= 35.54 ($p< 0.001$)), using the four age-groups in the 0-20 age bracket and the aggregated results for the 21-61+ age-group.

The difference was greatest in individuals aged 0-20 years, where the prevalence rate for each of the two surveys was 42.0% and 23.6% respectively. There was an increase in the prevalence rate of TF in the 20+ age-group from 1.3% (4/305) to 7.5% (35/464) which was a significant increase (X^2=14.82 ($p<0.001$)).

(c) Comparison of the interim reports with the 1989/90 survey : Poor Vision

The definition of "Poor Vision" was taken from the 1980 R.A.C.O. Report and applied to the 1989/90 survey data. That is: Persons whose vision in their better eye was 6/18 or 6/24 or 6/36. The vision in their other eye might be similar or worse. Table 4.3.4. compares "Poor Vision" between the surveys.

Table 4.3.4.: Comparison of poor vision

by age-groups, for the interim reports with the 1989/90 surveys

	1976			1989/90		
Age-group	Poor Vision	Total Seen	% of age-group	Poor Vision	Total Seen	% of age-group
Less than 2	0	36	0.0	0	32	0.0
2-5	0	67	0.0	0	96	0.0
6-10	0	135	0.0	0	158	0.0
11-20	4	155	2.6	0	175	0.0
21-30	6	89	6.7	3	124	2.4
31-40	8	72	11.1	2	96	2.1
41-50	16	63	25.4	5	90	5.6
51-60	10	23	44.0	7	63	11.1
61+	36	58	62.1	52	91	57.1
Total	**80**	**698**	**11.5**	**69**	**925**	**7.5**

Poor vision was the only measure of blindness which had age-specific data in the 1976 interim reports. Table 4.3.4. shows a decline in the individual age-specific prevalence rates, with the smallest change occurring in the 61+ age-group. After grouping some of the age categories the significance of this reduction was tested.

Age-Group	1976 RACO report	1989/91 survey	Odds Ratio	X^2 (Yates corrected)	P value
0-40	18/554	5/681	4.54	9.24	0.002
41-50	16/63	5/90	5.79	10.70	0.001
51-60	10/23	7/63	6.15	9.18	0.002
61+	35/58	52/91	1.14	0.05	0.828
Overall (crude)	80/698	69/925	1.61	7.71	0.001

The age-standardized odds ratio of poor vision when 1976 was compared to 1989/90 was: M-H weighted OR=2.86, 95% C.I.: 1.86 to 4.75, (X^2=23.2 ($p< 0.001$)), using the age-groups in the 21-61+age bracket and the aggregated results for the 0-20 age-group.

If the source population was used as a denominator, the results did change (assuming no other people with poor vision in the unsampled population).

Age Group	1976 RACO report	1989/91 survey	Odds Ratio	X^2 (Yates corrected)	P value
0-40	18/848	5/1319	5.70	13.33	0.000
41-50	16/90	5/138	5.75	11.40	0.001
51-60	10/60	7/107	2.86	4.28	0.070
61+	35/54[1]	52/115	2.42	4.89	0.026
Overall (crude)	80/1052	69/1679	1.92	14.65	0.001

1. The 1976 Census gave a total in the 60+ age-group of 54 but the interim reports gave 58 as the number seen.

Two changes occurred, the difference in the 51-60 age-group was no longer significant at the 0.05 level and the difference for the 61+ age-group became significant. This demonstrates the importance of defining the denominator accurately.

Binocular blindness was reported as occurring in 19 of the 698 (27/1000) in the 1976 interim reports, compared with 21 out of 925 (or 23/1000) in the 1989/90 survey. The difference was not statistically significant, (X^2 = 0.18 (p = 0.675)). If the source population was used as a denominator the values became 19/1052 and 21/1679 respectively, (X^2=1.02 (p=0.311)). This result should be compared with the results found for the "Red Centre" zone, when a significant reduction was found for the source population estimates.

(2) "Red Centre" zone data

(a) Comparison of the populations for the "Red Centre" zone data in the N.T.E.H.P Report 1980 and the 1989/90 survey.

Table 4.3.5. compares the source population for the Anangu Pitjantjatjara lands in 1976 (when the data for the 1980 report was collected) and 1989/90 using 1976 census data, 1986 census data and the 1989/90 population lists.

Table 4.3.6. compares the samples for the two surveys. The age structure of the "Red Centre" zone was projected from the sample total for the communities of the Anangu Pitjantjatjara lands as recorded in the interim reports.

The communities included in the "Red Centre" zone were Amata, Ernabella, Indulkana, Mimili, Kalka, Pipalyatjara and Fregon.

Table 4.3.5.: Comparison of the source populations: N.T.E.H.P Report 1980 "Red Centre" zone (1976 census data) with the 1989/90 survey (1986 census data and 1989/90 population list data)

Age-group (Years)	1976 Census Data	% of Total	1986 Census Data	% of Total	1989/90 Population List	% of Total
0-4	156	12.4	190	13.3	277	12.4
5-9	205	16.3	145	10.1	347	15.5
10-19	277	22.0	360	25.2	466	20.9
20-29	198	15.5	275	19.2	422	18.9
30-39	174	13.9	132	9.2	236	10.6
40-49	122	9.7	123	8.6	189	8.5
50-59	58	4.6	88	6.2	151	6.8
60+	78	6.2	116	8.1	147	6.6
Total	**1265**	**100%**	**1429**	**100%**	**2235**	**100%**

Comparison between the three source populations in 1976, 1986 and 1989/90, indicated that the age structure had not changed. The source population for the original "Red Centre" zone of the 1980 report could not be calculated because the data were not readily available. The total derived is for the A P lands only, whereas the distribution of the sample was taken from the overall "Red Centre" zone which included towns or communities such as Yuendemu, Napperby, Santa Terasa etc. (R.A.C.O. Report 1980, appendix 2 p186).

Table 4.3.6.: Comparison of the samples: R.A.C.O. Report 1980 "Red Centre" zone (1976 data) with the 1989/90 survey

Age-group (Years)	1976 "Red Centre" Sample	% of Total	1989/90 Survey Sample	% of Total
0-4)	2944	36.8	) 162	31.4
5-9)			) 221	
10-19	1997	25.0	227	18.6
20-29	929	11.6	177	14.5
30-39	614	7.7	117	9.6
40-49	486	6.1	104	8.5
50-59	335	4.2	91	7.5
60+	692	8.6	120	9.8
Total	**7997**	**100%**	**1219**	**100%**

Of all the population comparisons, the "Red Centre" zone 1976 sample was the least comparable with the 1989/90 survey, despite having a similar source population (Table 4.3.5.). It should be noted that the population total for the "Red Centre" above was 7997, this was taken from the text of the 1980 report, whereas the figure previously given in section 4.2. (6321) was taken from the appendix of that report. A possible explanation was given in the 1985 T.E.H.P. Report. The authors thought that the higher percentage of individuals aged less than 20 and a proportionately lower percentage of people in the greater than 20 age-group, when compared with the 1985 sample, was accounted for by the rescreening of people after treatment (ie. these individuals had been double counted). Those rescreened were included in the results for the 1980 R.A.C.O. Report. In the Anangu Pitjantjatjara lands, this second screening occurred in November 1976. In the communities of Amata, Indulkana and Fregon only individuals under the age of 20 were included (T.E.H.P. Report 1985). This probably occurred for two reasons: the people treated tended to be younger (see the results

for trachoma follicles in 1976, Table 4.4.6) and when rescreened, the school age population was often the easiest to find and examine. Yalata was rescreened in June 1977 and included individuals aged 20+. It was not clear from the 1980 R.A.C.O. Report whether this data was included in the final result.

When the sample was compared for the community specific data based on the 1976 interim reports (which separated out the initial and rescreening population) the samples resembled one another more closely (section 4.3 (1)).

(b) Comparison of the Trachoma Follicle Prevalence Rates, by age-group, for the "Red Centre" zone with the 1989/90 survey.

Although the "Red Centre" data had shortcomings (section 4.2), they were of value in indicating the trend of trachoma prevalence. The results for poor vision and blindness were only marginally affected by including rescreening data, those re-screened in the A P lands were aged less then 20 years, an age-group that had low rates of blindness. However, by increasing the denominator (with people who were not blind) the prevalence rates for blindness and poor vision would be decreased.

Inflammatory Trachoma

The prevalence of follicular trachoma (TF), from the R.A.C.O. Report was compared to the inflammatory trachoma prevalence rate (TF+TI) for the 1989/90 survey. A comparison was done using the results for the "Red Centre" zone. Data for individuals aged 19 years or less. in 1976 and the 1989/90 surveys were used (Table 4.3.7).

Table 4.3.7.: Inflammatory trachoma - comparing the prevalence rates for infective trachoma, by age-group for the N.T.E.H.P.Report 1980 and 1989/90 survey - "Red Centre" zone

	Age-Groups										
	0-1	2-3	4-5	6-7	8-9	10-11	12-13	14-15	16-17	18-19	Total
1976											
TF	122	318	401	337	300	237	160	88	36	31	2030
No TF	378	480	676	679	721	648	492	350	248	259	4931
%of TF	32%	66%	59%	49%	41%	36%	32%	25%	14%	12%	41%
1989/90											
TF	10/51	28/73	37/83	32/99	21/77	19/64	7/50	3/50	0/27	2/36	159/610
TI	6/51	4/73	1/83	3/99	1/77	0/64	1/50	0/50	0/27	0/36	16/610
TI+TF	16/51	32/73	38/83	35/99	22/77	19/64	8/50	3/80	0/27	2/36	165/610
%	31%	44%	46%	35%	28%	30%	16%	6%	0%	5%	29%
Odds Ratio and X^2											
Odds Ratio	1.04	2.37	1.73	1.80	1.78	1.37	2.53	8.62	-	2.31	1.89
X^2 (Yates connected)	0.00	11.1	5.01	6.50	4.39	0.92	5.04	16.6	3.3	0.74	44.65
p=	.976	.001	.025	.011	.036	.337	.027	.000	.068[1]	.38[2]	.000

1. As cell value < 5 Fisher exact 1 tailed test used p = 0.02

2. As cell value < 5 Fisher exact 1 tailed test used p = 0.18

TF = trachoma follicles

TI = trachoma intense

Comparison between the two surveys showed an overall reduction in the prevalence of follicular trachoma in the less than 20 age-group from 41% in 1976, to 29% in 1990.

Reductions occurred in all age-groups. The differences were statistically significant ($p < 0.05$) for all ages except the 0-1, 10-11 and the 16-19 age-groups.

It should be reiterated that the addition of TF and TI for the 1989/90 result encompassed a greater range of disease than the 1976 definition of TF, consequently the 1989/90 result would be expected to overestimate inflammatory trachoma relative to 1976 (section 4.2).

Using logistic regression analysis a model was derived to fit the data presented above. Follicular trachoma was found to vary by age-group and year.

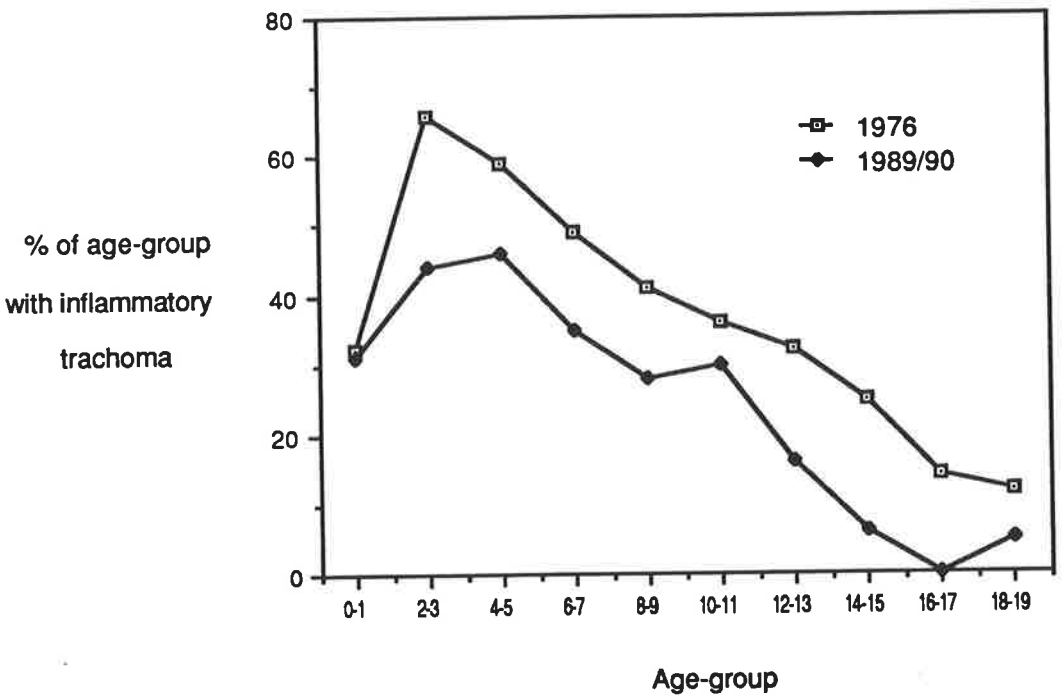
The model had the following estimates.

	Estimate	SE	t statistic
Constant	-2.239260	0.1218586	-18.376
Group 1	0.878363	0.1321429	6.6471
Group 2	2.193173	0.1209089	18.139
Group 3	1.945486	0.1102825	17.641
Group 4	1.549272	0.1091487	14.194
Group 5	1.222579	0.1092529	11.190
Group 6	1.030494	0.1132677	9.0979
Group 7	1.133989	0.1279830	8.8605
Group 8	0.0	0.0	0.0
1976	0.6866309	0.0979333	7.0112

Where group represented one of 8 age categories (average age = 1, 3, 5, 7, 9, 11, 13, 17).

A decline in the prevalence in follicular trachoma was found. An odds ratio for 1976 compared 1989/90 was OR = 2.0, 95% C.I. 1.64 to 2.41. The differences between the years are presented graphically in Figure 4.3.1 .

Figure 4.3.1: Inflammatory trachoma 1976 compared to 1989/90



(c) *Prevalence of Blindness: A Comparison between the prevalence rates of Blindness for the R.A.C.O. Report and the 1989/90 survey :"Red Centre" zone data*

The prevalence rates for blindness were compared using R.A.C.O. Report 1980 definition for blindness (visual acuity in the better eye of 6/60 or worse. Table 4.3.8. outlines the age /sex distribution of blind individuals in the "Red Centre" zone.

Table 4.3.8.: Number of Blind Individuals for the "Red Centre" zone using 1989/90 survey data (N.T.E.H.P. defn.)

Age	F	M	Total
0-19	0	0	0/610
20-29	1	0	1/177
30-59	0	0	0/312
60+	16	5	21/120
	17	**5**	**22/1219**

Four comparisons were made of the blindness prevalence rates using the 1980 R.A.C.O. Report and the 1989/90 survey data. Crude proportions were used in testing the significance of the changes. Prevalence rates per thousand are also presented (Table 4.3.9).

Table 4.3.9.: Prevalence of blindness: A comparison between the 1980 R.A.C.O. Report and the 1989/90 Survey

Type of Comparison	Prevalence Rates			
	1980	1989/90	X^2	P
Crude prevalence from from survey data	183/7997	22/1219	1.09	0.29
Rates per 1000	23	18		
Prevalence using the source population as a denominator	23/1265	22/2386	4.76	0.03
Rates per 1000	18	10		
Prevalence in the 60+ age using 1976 census data	157/692	21/120	1.32	0.25
Rates per 1000	227	172		
Prevalence in the 60+ age using the source population as a denominator	20/78	21/147	3.77	0.05
Rates per 1000	256	143		

The results indicate a reduction in the prevalence of blindness in the population as a whole (using the source population as a denominator), if assumptions about the unsampled population were correct.

When just the 60+ age-group was considered, male/female data was available from the R.A.C.O. Report (1980 p62). In the "Red Centre" zone 58/313 (185/1000) males were binocularly blind compared to 98/379 (259/1000) females. A difference that was significant (p=0.025). These rates can be compared to the 1989/90 data: 5/55 (91/1000) and 17/65 (261/1000) respectively (using the source population as a denominator 5/70 (71/1000) and 17/75 (218/1000)). A significant reduction in the prevalence of blindness occurred for males using the source population (p=0.02), but not for females with either the sample or source denominators.

(3) 1985 N.T.E.H.P. Review Data (T.E.H.P. Report)

(a) Comparison of the populations for the 1985 N.T.E.H.P. review and the 1989/90 survey.

Table 4.4.0 compares the source population for the communities surveyed in the 1985 N.T.E.H.P. review with the same communities in each of the years 1976, 1985 and 1989/90. As estimated from 1976 census data, 1986 census data, and 1989/90 population lists.

The communities surveyed in the 1985 N.T.E.H.P. review were Yalata, Indulkana, Amata and Fregon.

Table 4.4.0.: Comparison of the source population : N.T.E.H.P. review 1985 (1976 and 1986 census data) with the 1989/90 survey (1989/90 population list data).

Age-group (Years)	1976 Census	% of Total	1986 Census	% of Total	1989/90 Population List	
0-4	153	13.8	129	11.4	201	12.1
5-9	145	13.1	109	9.6	221	13.3
10-19	230	20.1	277	24.4	376	22.7
20-29	181	16.4	228	20.1	300	18.1
30-39	180	16.3	137	12.1	201	12.1
40-49	99	8.9	90	7.9	131	7.9
50-59	62	5.6	73	6.4	113	6.8
60+	56	5.1	93	8.2	117	7.0
Total	**1106**	**100%**	**1136**	**100%**	**1660**	**100%**

Note: In 1976 the communities of Amata, Fregon and Pipalyatjara were part of one collector district. Adjustment was necessary using 1981 census data to obtain an approximate total for the communities of Amata and Fregon alone.

Comparing the population structures of the source population it appears they were very similar.

Table 4.4.1.: Comparison of the samples : N.T.E.H.P. Review 1985 with the 1989/90 survey

Age-group (Years)	1976 Sample	% of Total	1985 Sample	% of Total	1989/90 Sample	% of Total
0-4	94	12.9	28	11.4	110	13.0
5-9	151	20.7	59	24.1	136	15.9
10-14	101	13.8	82	33.5	94	11.1
15-19	65	8.9	14	5.7	75	8.9
0-19	**411**	**56.2**	**183**	**74.7**	**415**	**48.6**
20-39	162	22.2	24	9.8	215	25.2
40-59	89	12.2	19	7.8	136	15.9
60+	69	9.4	19	7.8	88	10.3
Total	**731**	**100%**	**245**	**100%**	**854**	**100%**

The sample totals for the 1976 and 1990 surveys were similar: 731 and 854 respectively. In the 1985 survey, only 245 individuals were examined. The majority were in the 0-19 age bracket. The age structures of the 1976 and 1989/90 surveys were comparable, but the 1985 sample differed from both the 1976 and 1989/90 surveys.

(b) Comparisons Based on the 1985 Trachoma and Eye Health Program Review (N.T.E.H.P.Review) : follicular trachoma

The prevalence of follicular trachoma for the communities of Yalata, Indulkana, Amata and Fregon for 1976, 1985 and 1989/90 were compared.

Tables 4.4.2. - 4.4.5. give the results for individual communities and Table 4.4.6. for the communities combined. The definition of follicular trachoma was standardized for the 1985 report (section 4.2.), the results for 1976 and 1985 are therefore directly comparable. The definition of follicular trachoma (TF) used in 1985 included a category that would overlap with the current grading of trachoma intense (section 4.2). The results for the 1989/90 survey were for total active inflammatory trachoma (trachoma follicles and trachoma intense), and included an additional category of trachoma grading for single eyes. The 1989/90 result would therefore overestimate the prevalence of trachoma compared with the 1976 results.

Table 4.4.2.: Follicular trachoma in Yalata by year and age

	1976			1985			1989/90		
Age-Group	Foll. Trach.	Total Examined	%	Foll. Trach.	Total Examined	%	TF/TI	Total Examined	%
0-4	10	24	41.6	1	2	50	5	32	15.6
5-9	18	43	41.8	13	32	40.6	10	52	19.2
10-14	8	28	28.6	4	27	14.8	4	45	8.8
15-19	3	22	13.6	0	1	0	0	27	0
0-19	**39**	**117**	**33.3**	**18**	**62**	**29**	**19**	**156**	**12.2**
20-39	1	43	2.3	0	1	0	7	74	9.5
40-59	0	24	0	0	1	0	4	49	8.2
60+	0	23	0	0	5	0	3	16	18.8
Total	**40**	**207**	**19.3**	**18**	**69**	**26.1**	**33**	**295**	**11.2**

Yalata showed an overall decline in the crude prevalence of TF from 19.3% in 1976 to 11.2% in 1990. The difference was statistically significant. The age-standardized odds ratio of follicular trachoma when the results for 1976 were compared to 1989/90 was: M-H weighted

OR=1.86, 95% C.I.: 1.08 to 3.27, (X^2 = 5.05 (p = 0.025)), using the age-groups in the 0-19 age bracket and the aggregate results for the 20-60+ age-group. The increase in 1985 was based on a small sample of young people, and was therefore not directly comparable with the other years.

Age specific rates showed a statistically significant decline in 0-19 age-group from 33.3% in 1976 to 12.2% in 1990 (X^2 = 16.64 (p < 0.001)). Conversely an increase in inflammatory trachoma (TF + TI) occurred in the 20+ age-group in 1989/90 (X^2= 5.78 (p=0.016)). This may have been artefactual, due either to the inclusion of trachoma intense in the definition, or to grading TF when TS was possible. Alternatively it may reflect a true change in the age distribution of the disease. This was supported by data from the interim reports where results for follicular trachoma (without the addition of TI) showed an increase in the 20+ age-group in the 1990 survey compared with the 1976 survey.

Table 4.4.3.: Follicular trachoma in Indulkana

	1976			1985			1989/90		
Age-Group	Foll. Trach.	Total Examined	%	Foll. Trach.	Total Examined	%	TF/TI	Total Examined	%
0-4	7	12	58.3	6	6	100	4	27	14.8
5-9	31	42	73.8	7	15	46.6	10	27	37.0
10-14	18	35	51.4	2	13	15.4	5	21	23.8
15-19	3	5	60.0	0	3	0	0	18	0
0-19	**59**	**94**	**62.7**	**15**	**37**	**40.5**	**19**	**93**	**20.4**
20-39	1	42	2.4	0	1	0	3	44	6.8
40-59	2	22	9.1	0	3	0	5	26	19.2
60+	0	11	0	0	0	0	3	19	15.8
Total	**62**	**169**	**36.7**	**15**	**41**	**36.6**	**30**	**182**	**16.5**

Indulkana had a high prevalence of follicular trachoma in 1976, particularly in the 5-9 age-group. This had fallen by 1985, although only age-specific rates were comparable.

The prevalence of follicular trachoma also had fallen in 1989/90. The difference was statistically significant. The age-standardized odds ratio of follicular trachoma when the results for 1976 were compared to 1989/90 was: M-H weighted OR=2.55, 95% C.I.: 1.54 to 5.25, (X^2 = 11.92 ($p < 0.001$)), using the age-groups in the 0-19 age bracket and the aggregate results for the 20-60+ age-group. But again an increase in the crude follicular trachoma prevalence was seen in the 20+ age-group, but this was not significant (X^2 = 2.65 (p=0.100)).

Table 4.4.4.: Follicular trachoma in Amata

	1976			1985			1989/90		
Age-Group	Foll. Trach.	Total Examined	%	Foll. Trach.	Total Examined	%	TF/TI	Total Examined	%
0-4	18	27	66.6	6	7	85.7	15	28	53.6
5-9	24	37	64.8	7	9	77.7	9	29	31.0
10-14	7	18	38.8	6	14	42.8	2	9	22.2
5-19	2	26	7.7	2	6	33.3	0	16	0
0-19	**51**	**108**	**47.2**	**21**	**36**	**58.3**	**26**	**82**	**31.7**
20-39	0	41	0	0	11	0	2	48	4.2
40-59	0	22	0	0	5	0	1	26	3.8
60+	1	13	7.7	0	7	0	1	28	3.6
Total	**52**	**184**	**28.3**	**21**	**59**	**35.6**	**30**	**184**	**16.3**

The results for Amata, like Indulkana, showed a decline in the crude follicular trachoma prevalence The difference was statistically significant. The age-standardized odds ratio of follicular trachoma when the results for 1976 were compared to 1989/90 was: M-H weighted OR=2.18, 95% C.I.: 1.12 to 4.33, (X^2 = 5.24 (p = 0.02)), using the age-groups in the 0-19 age bracket and the aggregate results for the 20-60+ age-group. But, Amata unlike Fregon and Indulkana did not show a large increase in crude follicular trachoma prevalence in the 20+ age-group and the difference was not significant (X^2 = 1.08 (p=0.29 Fisher exact test)). If the increase was solely due to systematic grading error, or differences in definition, the variation would be expected to be similar across all communities. Therefore a changing pattern of disease may explain at least some of this increase.

Table 4.4.5.: Follicular trachoma in Fregon

	1976			1985			1989/90		
Age-Group	Foll. Trach.	Total Examined	%	Foll. Trach.	Total Examined	%	TF/TI	Total Examined	%
0-4	15	31	48.4	10	13	76.9	9	23	39.1
5-9	11	29	38.0	0	3	0	5	28	17.8
10-14	7	20	35.0	11	28	39.2	2	19	10.5
15-19	1	12	8.3	0	4	0	1	14	7.1
0-19	**34**	**92**	**37.0**	**21**	**49**	**43.7**	**17**	**84**	**20.2**
20-39	0	36	0	0	11	0	2	49	4.1
40-59	0	21	0	0	10	0	2	35	5.7
60+	0	22	0	0	7	0	2	25	8.0
Total	**34**	**171**	**19.8**	**21**	**76**	**27.6**	**23**	**193**	**11.9**

Fregon had almost identical overall results to those of Yalata, but, the observed decline in crude follicular trachoma from 34/171 to 23/193 was not statistically significant. The age-standardized odds ratio of follicular trachoma when the results for 1976 were compared to 1989/90 was: M-H weighted OR=1.15, 95% C.I.: 0.77 to 2.99, (X^2 = 1.25 (p = 0.263)), using the age-groups in the 0-19 age bracket and the aggregate results for the 20-60+ age-group. For the 0-19 group the decline from 34/92 to 17/84 was statistically significant (X^2 = 5.18 (p = 0.023)). As with Amata, the increase in the older age-group was less than that occurring in Yalata and was not significant (X^2 = 1.27 (p=0.13 Fisher exact test)) The persisting high prevalence in the 0-4 age-group was a cause for concern. The difference between the years was not significant (X2= 0.45 (p=0.502)). A similar picture occurred in Amata but not in Yalata or Indulkana.

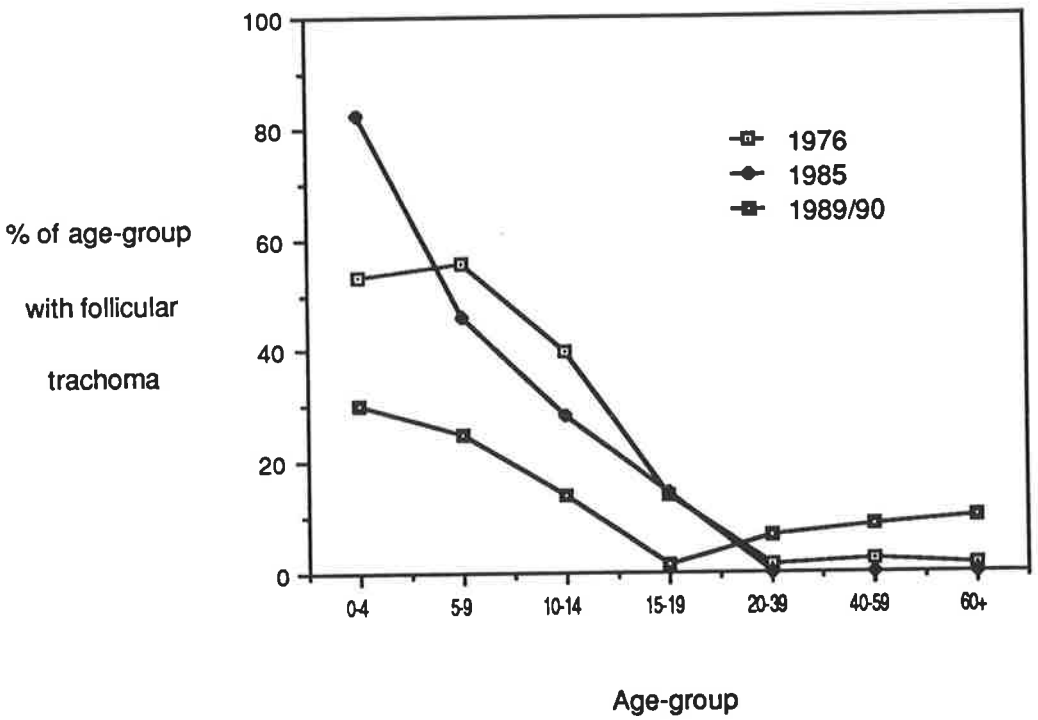
Table 4.4.6.: Follicular trachoma in all the communities combined

	1976			1985			1989/90		
Age Group	Foll. Trach.	Total Examined	%	Foll. Trach.	Total Examined	%	TF/TI	Total Examined	%
0-4	50	94	53.2	23	28	82.1	33	110	30.0
5-9	84	151	55.6	27	59	45.8	34	136	25.0
10-14	40	101	39.6	23	82	28.0	13	94	13.8
15-19	9	65	13.8	2	14	14.3	1	75	1.3
0-19	**183**	**411**	**44.5**	**75**	**183**	**41.0**	**81**	**415**	**19.5**
20-39	2	162	1.2	0	24	0	14	215	6.5
40-59	2	89	2.2	0	19	0	12	136	8.8
60+	1	69	1.5	0	19	0	9	88	10.2
Total	**188**	**731**	**25.7**	**75**	**245**	**30.6**	**116**	**854**	**13.6**

The combined results averaged the observed variation between communities. There was a statistically significant decrease in the crude trachoma prevalence in the 0-19 age-group (X^2=58.24 (p <0.001)) and an increase in the 20+ age-group (X^2 = 13.98 (p <0.001)). Overall there was a decline in the prevalence of trachoma follicles. The age-standardized odds ratio of follicular trachoma when the results for 1976 were compared to 1989/90 was: M-H weighted OR=2.24,95% C.I.: 1.62 to 2.90, (X^2= 28.76 (p <0.001)),using the age-groups in Table 4.4.6.

As has already been discussed for the individual communities, the inclusion of TI with TF may explain some of this increase. However, a change in the pattern and distribution of inflammatory disease cannot be excluded as a cause. The differences between the years is demonstrated in figure 4.3.2 .

Figure 4.3.2: Follicular trachoma by year (1976,1985 and1989/90)



Using logistic regression analysis a model was derived of the results for the three years. Follicular trachoma was found to vary by group and year.

For this model we have the following estimates.

	Estimate	SE	t statistic
Constant	-3.383102	0.183777	-18.409
Group 1	2.741640	0.209946	13.059
Group 2	2.518410	0.196422	12.821
Group 3	1.368844	0.2032537	6.7347
Group 4	0.0	0.0	0.0
1976	0.713983	0.1426969	5.0035
1985	0.9155231	0.1880173	4.8694
1989/90	0.0	0.0	0.0

Where group was representative of 4 age categories (2, 7, 15, 45).

A reduction in the prevalence of follicular trachoma was demonstrated. An odds ratios between the years 1976-1989/90 was: OR = 2.04, 95% C.I.: 1.54 to 2.68.

Summary

Four sets of data were used to review the changes in eye health in the Anangu Pitjantjatjara, for the years from 1976 to 1989/90.

(1) The interim report data.

(2) The "Red Centre" zone data from the R.A.C.O. Report of 1980.

(3) The data from the N.T.E.H.P. review 1985.

(4) The 1989/90 survey data.

Trachoma

The prevalence of follicular trachoma was found to have decreased significantly in the young, in the years from 1976 to 1989/90, for both the crude or overall rates and for the age-standardized rates. However, there was an increase in the prevalence of inflammatory trachoma in the older age-groups.

(1) *Interim reports* : A reduction in the crude and age-standardized follicular trachoma prevalence rates from 1976 to 1989/90.
: An increase in the prevalence of follicular trachoma in the 20+ age-group from 1976 to 1989/90.

(2) *T.E.H.P. Report* : A decrease in the age-specific prevalence of follicular trachoma as measured by, TF in 1976 and TF+TI in 1989/90. Age-specific rates were shown to have decreased in all age-groups except the 0-1, 10-11 and 18-19 age-groups.
: Logistic regression analysis confirmed the observed decline in follicular trachoma for the 0-20 age-group in the years from 1976 to 1989/90.

(3) *1985 Review* : A reduction in the age-standardized prevalence of follicular trachoma as measured by, TF in 1976 and TF+TI in 1989/90, was

found in the communities of Yalata, Amata and Indulkana, but not in Fregon.

: An increase in the crude follicular trachoma prevalence for the 20+ age-group, in the community of Yalata, but not for the other communities.

: A decrease in the age-standardized prevalence rate of follicular trachoma for the combined communities. However, an increase was found in the 20+ age-group.

Visual Acuity

Visual acuity was compared using data available from the interim reports and the T.E.H.P. report (1985).

(1) *Interim reports* : A decrease in the age-standardized prevalence of poor vision was found in results for the communities combined.

: A decrease in all the age-specific prevalence rates of poor vision, except in the 61+ age-group.

: No reduction in the crude prevalence of blindness for the combined communities

(2) *R.A.C.O. Report* : A reduction in the source population prevalence of blindness (N.T.E.H.P. defn.), but no significant decrease found for the sample.

: A reduction in the prevalence of blindness in males but not females using the source population as a denominator.

: A significant difference in the proportion of males and females binocularly blind. Which was consistent with the results of the 1976-79 N.T.E.H.P. survey.

4.4. Discussion

Although there were methodological problems when the 1976 N.T.E.H.P. survey was compared to the 1989/90 survey, there was consistency in the results obtained from the three comparisons used.

The two principal methodological problems were the different grading systems and the selection of the sample. Although the grading systems differed comparisons could be made, acknowledging that the 1990 criteria of the 5 sign system would overestimate TF relative to the 1985 and 1980 definitions (section 4.2.), especially when for comparative purposes TI + TF were combined to generate rates for 1989/90 data.

The sample and source population of the surveys were compared and found to be approximately equivalent (section 4.3.). This could be expected because although the population had grown there had been no documented net migration. The communities were basically the same, except for the growth of homeland settlements and the participation by people in the survey would be expected to be the same because the need for eye care was unchanged. Additionally the purpose and extent of each survey was similar.

The following hypothesis was tested.

"The age-specific prevalence rate of blindness and trachoma in the Anangu Pitjantjatjara of South Australia have shown a statistically significant decline since the N.T.E.H.P. survey of 1976".

The results of the comparisons (section 4.3) between 1989/90 and 1976 indicate that for follicular trachoma, a statistically significant reduction was found for all age-standardized prevalence data from the interim reports, from the "Red Centre" data for the 0-20 age-group, and from the 1985 Trachoma and Eye Health report for all the individual communities (except Fregon) . The decline was also evident from the comparisons using logistic regression analysis. However, it was noted that the age-specific prevalence rates for inflammatory

trachoma in the older age-groups (20+) increased. As mentioned previously this may be due to the inclusion of TI with TF, or the differences in grading TF between the surveys (e.g. individuals with TF in one eye only were counted as having TF in the 1989/90 survey but not in the N.T.E.H.P. survey or the 1985 review). Alternatively it may represent a change in the distribution of disease, such that, a cohort of individuals severely affected by trachoma in the 1970s have grown older and continue to suffer from poor eye health in the 1990s, whilst a younger generation grows up with less severe disease. A reduction in inflammatory trachoma in the younger age-groups has been found before in the "Red Centre" zone. A review found a statistically significant reduction in TF from 1976 to 1985 for the 0-9 age-group in the Warburton Range of Western Australia (Cooper et al. 1986). The authors thought the availability of water in the region may have contributed to the decline. The 1985 N.T.E.H.P. review found no statistically significant difference in the prevalence of trachoma in Indulkana, Fregon and Amata when 1976 was compared to 1985 screenings (although there was an apparent rise in Amata and Fregon with a reduction in Indulkana). Other studies of Aboriginal communities in Central Australia by Meredith et al. (1989), have not demonstrated a decline in active inflammatory trachoma.

Recalculation of the trachoma rates for the source population were not performed, as was done for poor vision and blindness, because there was no evidence that the rate of infection in the unsampled population was any different from the sampled group.

Unfortunately, due to problems of disease definition and access to original age-specific data, prevalence rates for trachoma scarring, trachoma trichiasis and corneal opacity were not compared. Comparison of the crude cicatricial trachoma rates (TS + TT + CO) for the "Red Centre" data gave a guide to the trend. For all ages the rate were 661/1017 in 1976 versus 334/1218 in 1989/90, a statistically significant reduction ($X^2 = 315.3$ ($p < 0.00$)).

From the qualitative examination of past surveys in South Australia (section 2.4 and section 2.5), it appears that there was an initial rise in the prevalence and severity of trachoma during the 1960s and 1970s, followed by a decline in the 1980s. Such a rise and than a fall in the

prevalence and severity of trachoma could be consistent with a late introduction of trachoma into these N.W. communities, with trachoma initially causing a high rate of infective disease in a community not previously exposed, but with little secondary severe disease detectable. Then over time some individuals develop the blinding complications of chronic untreated disease. The surveys in the late 1970s may have detected this phase of the process. A gradual improvement in economic development, living conditions and treatment programs produces a decline in the active infection rate, but with a residual pool of severely affected people, who form a cohort, and are detected by each subsequent survey in the 1980s.

A similar but reverse pattern of disease occurred in Southern Malawi, where high rates of trachomatous inflammation in children and high rates of cicatrization in adults was accompanied by the absence of trachomatous blindness. It was hypothesized by the authors that in the valley studied, dramatic changes in the local ecology towards desertification had produced a cohort effect; a group of older people, previously not affected by trachoma, now existing in an environment favouring infection with trachoma. This group had survived to have the first changes towards blindness (cicatrization), but had not had time to progress to more severe complications. If high rates of infection had been present for 30 or more years a greater prevalence of blindness due to trachoma would have been found (Tielsch et al. 1988).

The comparisons between 1989/90 and 1976 demonstrated a statistically significant decline in poor vision and blindness. Two assumptions were made in deriving prevalence rates for comparison. The first assumption was the extrapolation of the "Red Centre" data from the R.A.C.O. Report of 1980, to a sub-set of data for the Anangu Pitjantjatjara lands. The second assumption was that there were no additional blind individuals in the unexamined population. Support for both these assumptions was found in:

(a) The rate for binocular blindness recorded for the interim reports that were available for the 1976 survey. Blindness was found in 19 of 698 people (a prevalence rate of 27/1000 for the sample or 18/1000 for the source population, assuming no additional blind individuals). This may be compared with the rates for the "Red

Centre" zone data of 23/1000 and 18/1000 respectively. The similarity of these figures supports the assumption that the "Red Centre" zone data could be used to form a set of data for comparison with the data for the Anangu Pitjantjatjara lands.

(b) The assumption that all or most of the binocularly blind individuals were seen was based on the high sampling in the at-risk group aged 60+ (79%), examination of medical records for individuals not seen in the survey but identified by the population lists, and the use of local health workers to identify blind individuals.

Similar assumptions could be made about the 1976-1979 survey; however, it was not known whether a thorough search was made for blind individuals. But, using 1976 census data, the interim reports demonstrated an overall participation of 66% (668/1052), with a 100% participation[1] in the 60+ age-group, the group with the greatest proportion of blindness. Although it could be speculated that most of the blind choose to be examined, and the cooperation of the communities in enabling this to happen was effective, Prof. Hollows did comment "the blind were often immobile while those with visual impairment were often unable or unwilling to attend, whether because of diffidence or shame, or because they had accepted their disability and were pessimistic about the prospects of improvement" (R.A.C.O. Report 1980 p13).

If all blind individuals were examined in the 1976-1979 survey any prevalence figures based on the sample would be an overestimate of the true prevalence, only by using the source population as a denominator would the estimate be accurate. Conversely, if many blind individuals were not examined the estimate using the sample could underestimate the true prevalence of blindness, and using the source population would reduce the estimate further.

Comparing the prevalence of blindness using the above assumptions demonstrated that the reduction in the prevalence of blindness, from 1976 to 1989/90, was statistically significant

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[1] More people were examined than seen in the 1976 census.

using the source population as a denominator, but not for the sample (section 4.3.). However, the source population estimate for 1989/90 may be an overestimate of the true population. If the estimate for the source population was reduced by 10%, (the figure derived from the survey in Ernabella (section 3.3.1) the results change but were still significant (for the source population 23/1265 vs 22/2147, (X^2=3.85 ($p<0.05$))). If projected 1986 census data was used the result was not significant ($p<0.05$ level). When the 60+ age-group for the "Red Centre" zone was considered (section 4.3. (2)), a significant reduction had occurred for males but not females.

The difference found in the source population prevalence rates for blindness was supported by the data for poor vision. When the two surveys were compared (section 4.3.) the crude prevalence of poor vision for the sample showed a statistically significant difference between the years, the age-standardized odds ratio between the years being OR=2.86, 95% C.I.: 1.86 to 4.75, (X^2= 23.2 ($p<0.001$)), using the age-groups in the 21-61+ age bracket and the aggregated results for the 0-20 age-group. Statistically significant differences were also found for all bar the 60+ age-group for the sample, or for the 50+ group using the source population as a denominator. The 60+ age-group was aged 45+ in 1976, and probably had a high rate of visual impairment then, although individuals who were blind or severely visually impaired in 1976 may have had higher mortality rates than those with good vision, a cohort effect could be maintaining the prevalence rates for this group at a high level.

The overall reduction demonstrated across all age-groups was not due to an increasing proportion of young people (who have good visual health). In fact the proportion of "aged" (50+) to "young" (0-49) had increased from 1976 to 1989/90, (10.8% to 13.7% (source) and 11.6% to 16.6% (sample) respectively).

The cause for the decline in visual disability may be related to the decline in inflammatory trachoma, with fewer young individuals progressing to poor vision and blindness because of repeated infection. This was demonstrated in the table showing individuals at risk of binocular blindness from trachoma (Table 3.3.5.3.). Of 15 individuals at high risk of blindness from

trachoma out of 66, only 1 was aged less than 60. Of those individuals with binocular blindness of whom nine were blind due to trichiasis, again, only one was aged less than 60. Additionally, trichiasis and corneal opacity were found in only a small percentage of the young (less than 40). For ages less than 50 the proportion were 9/1134 (0.79%) and 5/1134 (0.44%) respectively. Indicating that few individuals were at risk of blindness due to trachoma in the < 50 age-groups.

The decline may also have been due to better living conditions and changed lifestyles which might decrease the risk of traumatic visual loss. Trauma accounted for 28.8% of monocular blindness but its contribution overall to binocular blindness was probably small (Table 3.3.4.3.). Another factor which could have a major impact on the prevalence of visual impairment, would be the availability of surgery for cataract and trichiasis, two areas of tertiary treatment which had been provided more consistently since the 1976 survey. However, it was alarming that cataract accounted for 37.9% of monocular blindness and 40% of binocular blindness. If the survey were repeated in 1991 many of the 33 individuals severely visually impaired because of cataract diagnosed in the 1989/90 survey would have been operated on, and would no longer contribute to the poor vision or blindness prevalence rates, decreasing the rates further. A review of the cataract operations and their outcome, using medical records at the Royal Adelaide Hospital and Flinders Medical Centre (the principal centres for tertiary treatment), would provide useful incidence data on these aspects of Anangu eye health.

Why has this decline occurred? The survey was not designed to identify specific factors; however, several explanations, including cultural, environmental and socioeconomic factors, can be advanced (section 1.3 (2.1.7 (b) and (c))). Declines have been found in areas of previously high endemicity. One survey of hospital outpatients statistics in Nigeria (42,399 cases) demonstrated a prevalence of trachomatous blindness of 0.5% and ocular morbidity of 0.5% in 1986 compared to figures of 21-44% and 23% respectively thirty years ago (Babalola 1988). The author acknowledged the shortcomings of an outpatient survey but suggested the decline in the importance of trachoma may have been due to the availability of topical

antibiotic medication and improved living standards. Another survey in Papua New Guinea which was compared to the results of Mann in 1955, found that although trachoma was still endemic, it was reduced in prevalence and severity. It was thought improvement in standards of personal care and community hygiene contributed to the decline (Dethlefs 1982).

In a similar fashion, community and socioeconomic development on the Anangu Pitjantjatjara lands may have contributed to the decline. Events such as the granting of the free-hold title of the lands to the Anangu Pitjantjatjara, the establishment of a self-governing body (Pitjantjatjara Council Inc.) and the organization of an independent health service (Nganampa Health Council) may have helped. An increase in the quality of housing has occurred, and there has been a trend to the settlement of homeland areas, which promote traditional Anangu ways, and a decentralization of the population. Employment opportunities have increased (although still small by comparison with large cities) and educational opportunities have also broadened. The availability and access to water has improved, with more homes having reticulated supplies. This has probably been combined with a change in personal hygiene practices, epitomized by recent advertisements aimed at children on the local Central Australian Aboriginal television (C.A.A.M.A.), of the fun and importance of showering and washing faces. The world literature supporting the role of increased access to water in decreasing the prevalence of trachoma, with hygiene factors also being important (section 1.3 (2.1.7 (e))). Access to medical facilities has also improved with the opening of clinics in all the major settlements, which can also provide referrals for tertiary treatment at Alice Springs or Adelaide. Of importance to eye care specifically has been the South Australian Aboriginal Trachoma Program visits which have identified and initiated trachoma treatment, particularly in children.

Chapter 5. Research Issues

5.1 Introduction

The preceding chapters have detailed the formulation of a population based cross-sectional prevalence survey in the Anangu Pitjantjatjara, and the results of comparisons with previous surveys.

There were three principal research issues. These were:

1. The issues associated with the 1989/90 survey. Firstly, the practical problems encountered in performing the survey were not unique to research in Aboriginal communities and have ramifications for research in any defined community. Specifically, it requires researchers to be aware of cultural differences and to allow for them in study design. Secondly the 1989/90 survey analysed observer error in a manner different from previous eye surveys. Thirdly, the effect of non-magnification on trachoma grading was assessed because loupes were occasionally difficult to use in the field and it was some health workers were noted not to use them when assessing trachoma.

2. The methodological problems of the survey and the comparison was another issue which was important to the validity of the conclusions.

3. The issue of medical and public health research in Aboriginal communities was both topical and evolving during the course of the study. Additionally, there were specific ethical considerations associated with the performance of the survey and the distribution of the results.

5.2 1989/90 Survey Issues

5.2.1. Practical Problems in the Communities

During the survey several practical problems arose, which although they affected the conduct of the survey, did not significantly affect the results. The problems reflected the cultural differences between the survey team and the Anangu Pitjantjatjara, and the priorities of the local communities. At all times both groups were patient and co-operative enabling the survey to proceed with minimal disruption.

Deaths in the Communities

On at least two trips to communities, a recent death adversely affected participation in the survey . A death would often involve the whole community and mean the movement of people away from either the house or area where someone died, with perhaps the establishment of "sorry camps" where the process of mourning would occur. An "expected" death of either a very old person or sick individual usually resulted in less disruption to the community than the sudden and tragic loss of a child or formerly healthy adult. However, a unique combination of factors occurred on each occasion, and although some generalisations could be made about outcomes, these were not strictly predictable. For example, although a community might be in mourning, participation in the survey might could still occur.

Football

Australian Rules Football was played with enthusiasm by many young men. Each community had a team and games were played on earthen playing fields during the winter months. Matches were played between communities within the Anangu Pitjantjatjara lands, but could also involve Aboriginal people from other Central Australian areas. The activities were often broadened to include other games such as basketball.

Families would accompany the playing members of a team and the occasion was a significant social event. The population of a community could double or treble if it was a weekend game. Conversely, the other communities could lose a significant proportion of their population in the days leading up to a carnival and those following it. Therefore, the timing of a survey team visit to a particular community was important, avoiding if possible an away match, or at least staying for a longer period. Unfortunately the timetable for matches was difficult to ascertain in advance, and could change at short notice. Therefore, it was necessary to stay for as long as possible and have a flexible attitude to the inevitable changes in timetable.

Ceremonies

Throughout the calendar year but perhaps more towards October and November, important ceremonies were conducted throughout the Anangu Pitjantjatjara/Yalata lands. These ceremonies were central to the functioning of the community and had precedence over other activities. The conduct of the survey at these times was difficult but not impossible. The communities and individuals were very co-operative and helpful when the survey visits coincided with initiation or other ceremonies. During interludes from the ceremonies, when people returned to the central community, individuals were often happy to be examined; and on one occasion the survey team was invited to visit a camp of several hundred people to examine anyone who wished to be tested.

Again, although it is easy to generalise, each occasion was different and the team was guided by discussion with health service staff, the community council, and the elders who lived in the community. Consultation was the key element in obtaining permission to continue the survey at these times.

Absence of Young Men

An observation concerning the relative absence of young men was confirmed in the final statistics. Although it was evident from the population lists that about as many young men aged 20-30 lived in the communities as did young women, their participation in the survey was

limited. Several reasons can be proposed for this. Most young men had good eye health and probably did not feel the need to have their eyes tested. The young men were also often involved in football or ceremonies. There may have been some element of embarrassment or shame in having their eyes tested or being compared to others. Lastly, anecdotal evidence suggested that they tended to move around the communities more frequently than other age-groups. They were also away hunting or visiting regional centres such as Uluru, Alice Springs or Port Augusta, and therefore not be available to be approached for testing.

Although it was disappointing not to sample this group comprehensively, because of their generally good eye health they would have contributed little to the morbidity statistics for trachoma or blindness, and by using rates based on the source population the contribution of this age-group was taken into account.

Nomadic Lifestyle

Prior to white settlement, the Anangu Pitjantjatjara moved across the landscape visiting known water-holes, hunting areas and ceremonial sites according to the time of year. Although most people now identify with a particular community, time is often spent at other communities or on the homelands with extended family members. These periods away could last several months, therefore it was not uncommon to find several individuals visiting or spending extended periods in other communities during survey visits.

It was important, therefore, to establish which community individuals identified with, identify them on the population list and avoid duplication. Double counting, particularly of those with eye disease, theoretically could have led to significant inaccuracies in the data.

Weather

In general the weather was mild; however, both extreme heat and cold had negative effects on participation in the survey. On one survey trip, the cold and harsh weather reduced the number of people visiting the clinic. Because testing occurred outside participation was further curtailed and the examination made more difficult because of the windy conditions.

Rain on another occasion had a similar effect, despite having a large and well equipped clinic and being able to conduct the examination inside . People were unwilling to leave their house or camps and brave the elements just for an eye survey. Extreme heat had a similar effect and sapped the energy and enthusiasm of the survey team.

Cultural

There was an obvious gap between the culture, expectations and aims of the survey team on the one hand and the Aboriginal people on the other. Although the survey had a strong service element, the underlying aim was to see and examine as many people as possible. The survey and its role was discussed with the community council and explained to people attending for examination. The involvement of the council was the key to the success of the survey in any community. Also it was found that a multiplier effect occurred when a single family member was examined and the importance of the survey explained to him or her. Often s/he would then encourage other family members to attend for examination. It was the establishment of a relationship with the first person which facilitated the participation of others. The importance of relationships to Aboriginal people recurred again and again, with grandparents for whom spectacles had been prescribed encouraging younger family members to attend, or with brothers and sisters bringing siblings. Sometimes people would attend not out of any perceived self-need but because they thought the survey was important for the community. On other occasions they did so because they wanted to help the survey team as people not as researchers.

Eventually, after several trips some of the survey team became well known and friendships developed on previous visits helped participation on subsequent trips.

Resources

Although the survey team was effectively self-contained in terms of equipment, it was reliant on a clinic or other space for the examination. The quality of the accommodation varied enormously from spacious air conditioned clinics, to open areas under trees. It would have

been useful to be completely self-contained to avoid disrupting the clinic routines; however, the resources for the survey could not be extended to meet such requirements..

Timetables

Timetables were perhaps the greatest source of frustration in organising the survey. Of first priority was the communities' preferences, each of which had a number of important programs occurring throughout the year, along with events such as football, business and ceremonies. The dates given then had to be coordinated with the Trachoma Program, the Royal Flying Doctor Service (R.F.D.S.), who provided transport, and the ophthalmologists. Occasionally trips had to be cancelled or rearranged. However, as long as sufficient time was eventually spent in each community problems did not arise. The best participation rates occurred in communities which either had extended visits, such as Ernabella (1990), or communities which were visited on at least two occasions. In each case the survey team became familiar with the physical surroundings, health personnel and the people. Similarly, the people had time to familiarize themselves with the survey team and had time to make their own way to the clinic for review. On such trips, repeated visits to the schools often increased the numbers in the younger age-groups significantly, because some children attended school intermittently or were away for short periods with their families.

Personal Details (names/ages)

Age was a basic demographic detail which was usually easily obtained. However a proportion of older Aboriginal people did not know their age. If the population list was not available the age would be guessed, with a correction occurring at the data checking stage. A check of forty such data sheets revealed wide variation in the accuracy of the predicted age, based on appearance or "detective work". The biggest difference was twenty five years with a mean difference of -/+ six years. The accuracy of the population list was assumed for all people born from 1935 on, the period of mission settlement. Ages for people prior to this must have been guessed by the early mission staff based on the physical appearance of the then child or young adult. The oldest person examined was 89 years of age.

As described in the methodology section, names were recorded on the examination sheets and usually crossed off a population list. Some difficulties arose with (1) phonetic vs actual spelling of names, eg Charlie Tjampu being recorded as Charlie Jumbo by survey team members. This was overcome by allowing people to write their own names or obtaining the assistance of a health worker. Correct spellings and identification avoided later problems with the data sheets. (2) Another problem arose with data sheets of people having similar sounding names, sometimes the sheets were incorrectly assigned as duplications. (3) Lastly nicknames and "white" vs Aboriginal names often caused confusion and only with experience, and the use of the population lists to cross-check people's names, were errors avoided.

Finally, the Anangu custom of changing their name when a person sharing either a Christian or surname died required both sensitivity and some detective work, because the name was not allowed to be spoken. For example, if someone in the community called John died, a person named John Smith would become Kumana Smith. After a period of time they would take a new name and become Jim Smith, the name John would usually not be spoken, although a name could be pointed out on a population list. An extension of this custom would be to both names, e.g. Kumana Kumana, which provided no direct clue to the survey team of the persons former name as recorded on the population list.

Language

Although most Aboriginal people who participated in the survey spoke English, a few, particularly older individuals, relied on relatives or health workers to interpret for them. For the simple questions asked in the survey (eg. age, sex, name), and the simple tasks performed (e.g. using the Snellen E chart), no problems were encountered. However, more detailed histories or examination were occasionally difficult because of the language barrier. Difficulty in the way ideas are expressed could also lead to misunderstandings. From many years of interpreting in Pitjantjatjara, Edwards (1990), has found that asking questions in the negative form can lead to confusion as to the correct yes/no answer. This has been called the "yes

person" syndrome (Mobbs 1986). Confusion also exists because comparisons are not expressed easily in Aboriginal language, e.g. bigger or better may not be easy to interpret (Edwards 1990).

5.2.2. Analysis of Intra-Observer and Inter-Observer Error

The 1989/90 survey utilized the services of two principal investigators, AB being a doctor and CD being an ophthalmologist. Five sessional ophthalmologists were also employed (DM,M,ND,RS,DG). The approximate proportions of the total population graded for trachoma by each investigator were

AB	- 60%
CD	- 30%
DM/M/ND/RS/DG	- 10%

For the assessment and diagnosis of visual impairment (when the visual acuity was 6/36 or worse in the better eye) the six ophthalmologists saw 97% of all individuals, (CD seeing approximately 67 % of that total) and AB seeing the remaining 3%.

Although standardization of trachoma grading was performed using slides, grading manuals and comparison in the field, no formal inter-observer testing was performed due to the small numbers being examined by most of the examiners. The two principal researchers (AB and CD) graded 90% of all examined individuals and conferred regularly on grading problems in the field and prior to each trip

Duplicate Examination Sheets

To achieve a measure of intra-observer and inter-observer error, 110 duplication examination sheets were randomly collected from those generated by repeat examination on the same individual (approximately half the duplicated total). The repeat examination had occurred either on the same visit or on a subsequent visit to the same or different community, and was only discovered during the data checking procedures as outlined in section (3.2.6). As such they represented a completely unbiased check of inter-observer or intra-observer error. Although not evaluated in the literature, formalized testing could have "anticipatory bias" as a factor. The knowledge of a test biasing the results towards closer agreement because the

participants know they are being evaluated. Because active trachoma could vary over time, only trachoma scarring and abnormalities of the eye were assessed. Trachoma scarring could have arisen over several months but this was felt to be unlikely, and abnormalities of the eye would also be unlikely to evolve over a short time span and not be commented on in the examination sheet.

Of 110 duplications, 60% were female and 40% were male. Concordance was found for virtually all visual acuity testing allowing for a variation of one line between tests. Only three individuals varied more than one line, each for two lines only, all the visions were no worse than 6/36. Table 5.2.2.1 outlines four eye conditions which were found among the 110 individuals, concordance was found between examination for the conditions' presence or absence.

Table 5.2.2.1.

Condition	Number of individuals	Examination agreement
Diabetic retinopathy	3	present or absent
Cataracts	5	present
Corneal injury	3	present
Absent globe	3	present

The presence or absence of scarring, trichiasis or corneal opacity was recorded for every individual. Table 5.2.2.2. outlines the age distribution, trachoma grading and concordance and non-concordance between tests. Table 5.2.2.3 compares the grading of trachoma between the first and second examination.

Table 5.2.2.2.: Concordance and non-concordance in 110 duplicated examinations

Age-Group	Concordance			Non-concordance		
	N	TS	TT/CO	TS	TT/CO	Total
0-1	4	-	-	-	-	4
2-4	4	-	-	-	-	4
5-9	21	-	-	-	-	21
10-14	11	-	-	1	-	12
15-19	4	-	-	1	-	5
20-29	10	3	-	-	-	13
30-39	11	2	-	1	-	14
40-49	5	4	2	5	-	16
50-59	1	2	2	1	-	6
60+	-	9	3	2	1	15
Total	**71**	**20**	**7**	**11**	**1**	**110**

N = Normal

TS = Trachoma scarring

TT = Trachoma trichiasis

CO = Corneal opacity

Table 5.2.2.3.: Grading of trachoma: First vs Second examination

		Second examination		
		N	TS	TT/CO
First Examination	N	71	7	-
	TS	4	20	1
	TT/CO	-	-	7

The analysed data indicated that 98 of 110 or 89% of all duplications were concordant for trachoma status. Only 12 of 110 or 11% were non-concordant, but in that twelve, seven had changed from normal to TS and five had changed from TS to normal. One had changed from TS to TS and trichiasis. The effective, or net change in the trachoma scarring was therefore 2 of 110 or 1.8% (assuming TT/CO would still be graded as TS). This occurred in a group with an overall trachoma prevalence (TS + TT + CO) of 39/110 or 35.5% (assuming the non-concordance group to all have trachoma signs). A Kappa (K) statistic was calculated using the following data (Table 5.2.2.4).

Table 5.2.2.4 : Presence or absence of trachoma scarring: Time 1 vs Time 2

		Time 2		
		Absent	Present	
Time 1	Absent	71	7	78
	Present	5	27	32
	Total	76	34	110

$$Pe = (0.691 \times 0.709 + 0.309 \times 0.291)$$

$$= 0.580$$

$$K = (0.891 - 0.580)/(1.0 - 0.580)$$

$$= 0.74$$

The value of K (0.74), indicates that the agreement between the duplicate examinations was good.

5.2.3. Effect of Magnification vs Non-Magnification

To assess the impact of non-magnification on trachoma grading, a separate test/re-test survey was performed in Oak Valley during 1990.

A total of 116 individuals were examined over a three day period. Only one examiner and one recorder were involved. The first examination was performed with the naked eye only. The second examination, using x 2 loupes, occurred either later on the same day or on a subsequent day, the examiner being unaware of the previous examination result. Only trachoma grading was performed.

The age and sex distribution is outlined in Table 5.2.3.1. to indicate the similarity of the Oak Valley survey to the 1989/90 survey..

Table 5.2.3.1.: Age and sex distribution

test/re-test at Oak Valley 12/10/90

Age-Group	Females	Males	Total	% of Total
0-1	1	0	1	0.9
2-4	7	2	9	7.8
5-9	2	18	30	25.9
10-14	6	11	17	14.7
15-19	7	3	10	8.6
20-29	10	5	15	12.9
30-39	4	3	7	6.0
40-49	3	8	11	9.5
50-59	1	4	5	4.3
60+	6	5	11	9.5
Total	**57**	**59**	**116**	**100**

The sex distribution was more equal than in the 1989/90 survey sample. However, the age distribution was quite similar (section 3.2.1). The prevalence of trachoma in the population given in Table 5.2.3.2. were the results of grading by naked eye examination only. Trichiasis and corneal opacity were not included.

Table 5.2.3.2.: Trachoma status of individuals in Oak Valley September 1990

naked eye evaluation only

	Normal		Trachoma follicles		Trachoma scarring		Trachoma intense	
Age-group	F	M	F	M	F	M	F	M
0-1	1	0	-	-	-	-	-	-
2-4	3	2	4	-	-	-	-	-
5-9	8	10	2	8	2	-	-	–
0-14	4	7	2	4	-	-	-	-
15-19	7	3	-	-	-	-	-	-
20-29	6	3	-	-	3	2	1	-
30-39	4	1	-	-		2	-	-
40-49	2	4	-	1	1	3	-	-
50-59	1	2	-	-	-	1	-	1
60+	0	2	-	-	5	3	1	-
Totals	**36**	**34**	**8**	**13**	**11**	**11**	**2**	**1**

Active inflammatory trachoma was found in 24 (20.7%) individuals, predominantly in the under 15 age-group. Trachoma scarring was found in 22 (18.9%) of individuals predominantly in the 20+ age-groups. Table 5.2.3.3 outlines the changes in trachoma grading in going from naked eye to loupe examination.

Table 5.2.3.3.: Trachoma grading, naked eye vs x2 loupe examination.

	Naked eye examination						
	N	TF	TI	TS	TT	CO	Com[1]
Loupe examination							
N	70	2	-	-	-	-	-
TF	4	14	-	-	-	-	2[3]
TI	-	-	1	-	-	-	-
TS	3	-	-	13	-	-	-
TT	-	-	-	-	1	-	-
CO	-	-	-	-	-	1	-
Com[1]	-	1[2]	-	-	-	-	4

1. Com is any combination of trachoma follicles, trachoma intense or trachoma scarring.

2 Trachoma scarring and trachoma follicles.

3. (1) One case of trachoma scarring and trachoma follicles.

(2) One case of trachoma intense and trachoma follicles.

Concordance in the trachoma grading occurred in 104 individuals in going from naked eye to x2 loupe examination. A Kappa statistic was calculated using the following data (Table 5.2.3.4).

Table 5.4.3.4: Trachoma grading naked eye vs x2 magnification

		x2 Magnification		
		Trachoma Absent	Trachoma Present	Total
Naked eye	Trachoma Absent	70	4	74
	Trachoma Present	8	4	42
	Total	78	38	106

$$Pe = (0.736 \times 0.698 + 0.358 \times 0.396)$$

$$= 0.655$$

$$K = (0.98 - 0.655)/(1-0.655)$$

$$= 0.942$$

The value of K (0.942) indicates that there was excellent agreement between naked eye and x2 loupe examination.

It appeared that although the trachoma grading changed in 12 (10.6%) individuals, the changes resulted in a net difference of one in trachoma scarring and of two in inflammatory trachoma (either TF or TI). Relating these differences to the trachoma data for naked eye grading (Table 5.2.3.2), a net change of 1 in a total of 22 individuals represented an error of 4.5% and a net change of 2 in a total of 24 individuals with TF or TI represented an error of 8.4%. Both changes were towards normality, indicating that naked eye examination could produce a higher prevalence of inflammatory or scarring in trachoma grading compared to loupe examination.

Summary

In the 1989/90 survey an analysis of inter-observer and intra-observer error was undertaken using duplicate examination sheets. The data was grouped together so inter-observer and intra-observer comparisons could not be made separately. The results demonstrated good agreement in trachoma grading of TS, TT,and CO. The results for visual acuity and major eye pathology were almost unchanged between examinations.

The results are applicable to the general survey if it is assumed that those who underwent a second examination are representative of the general population. The data presented for the age distribution, prevalence of trachoma and eye disease is consistent with this hypothesis. Therefore, there is no reason to believe that those individuals seen twice have different characteristics from those presenting only once.

A study comparing magnification (x2 loupes) with non-magnification demonstrated excellent agreement between examinations. It was also concluded that non-magnification tended if anything, to over estimate the prevalence of inflammatory trachoma.

5.3 Methodological Problems in the Survey and with the Comparisons

The methodological problems associated with eye surveys was presented in section 1.4. Some issues of specific concern to the 1989/90 survey were:

The Number of Subjects

The total number of people surveyed was more than that required, as calculated from the sample size (section 3.2.6.). There were several reasons why a complete survey was attempted. A comparison of the results with the N.T.E.H.P. survey 1976-1979 (R.A.C.O. Report 1980) was to be made, and it was felt that the study design should be similar. Secondly, a simple randomized survey could not be effectively conducted because population lists were not known to exist when the design of the survey was completed. Thirdly, the survey was to have a service role and individuals could not be refused assessment and treatment. The larger sample was fortuitous because the original number calculated for trachoma did not include an adjustment for household clustering. A factor that has been recently identified as necessitating an increase in sample size to maintain a reasonable variance of prevalence estimates (Katz et al. 1988).

Several problems could arise in the conduct of a survey. A reliance on data generated from short visits to each community, or from only one or two communities could result in selection bias. Only those with eye problems may have presented to be examined, or if several hundred people had been seen in one community during a football weekend those who were blind may have been excluded. All communities needed to be included, as there was variability in both participation rates and disease prevalence between them (section 3.3). A study comparing self-selection and random sampling methods has demonstrated an under-estimation of blindness of 130%, suggesting self-presentation may grossly underestimate the prevalence of blindness (Said et al. 1973). To avoid this problem a pro-active role was adopted by the survey team to encourage participation by as many people as possible. An attempt was made to sample evenly across all age-groups, although the participation rates (section 3.3.2.) demonstrate the difficulty in achieving this. Although only a 54% participation

rate was achieved overall, based on the population list denominator, using projected 1986 census data the figure was 76%. It was the impression of the research team that in each community, at the time of the visit, up to 90% of the population was examined. When Ernabella was visited in 1990, 10% of the population was identified as being away permanently or semi-permanently (section 3.3.2). Many others, usually in the 20-39 age-group were also absent. Therefore, the study was probably as successful as it could be in obtaining a complete survey.

Within the limitations described above, those who were blind may have chosen not to be examined or because of diffidence or shame not presented to the survey team. The high response from the 60+ age-group, which had a high prevalence visual impairment, could lead to a higher estimate for blindness if the sample population only was used to generate prevalence rates.

Disease Definitions and Classifications

A review of the methodological problems of the old trachoma grading system (section 4.2.) and the apparently good intra-observer and inter-observer agreement with the new 5 sign system, has already been presented (section 2.1.4). The standardization procedures for the eye survey in this thesis have been outlined (section 3.2.6). These were similar to other surveys which had equivalent methodology. At the time it was felt unnecessary to test for intra-observer and inter-observer agreement because the literature had already demonstrated good agreement between graders with the new 5 sign system (Taylor et al. 1987 c). Retrospectively, duplicate examination sheets were examined to test for intra-observer and inter-observer agreement for grading trachoma scarring and visual acuity testing (section 5.2.2.). Formal testing of the grading for trachoma follicles and trachoma intense perhaps should have been undertaken, particularly because of the difficulty with the grading of TI in the older age-group (section 3.4.2). In previous surveys it seems that although adjustment of the final prevalence rates based on the test results was not performed, some benefit was presumably derived from the process to help standardize the results between graders. A

process in the 1989/90 survey which was achieved by the principal graders, AB and CD, by their review of slides and consultation in the field.

Ophthalmic Measures

Visual acuity testing was performed under varying conditions inside and outside clinics, with and without other people present. However, the subject was always at six metres and care was taken to avoid prompting. Classification of individuals into good vision and blindness was relatively quick and was also accurate. People who had corrected visual acuity of 6/18 or worse in the better eye were re-checked once by the first examiner and secondly by an ophthalmologist. Retrospective examination of duplicate examination sheets showed good reproducibility between testing. Another method of checking results could have been employed. As used in a larger survey in Egypt, a random sample of screened individuals who had "good vision" could have been re-examined to check for false negatives, those who had visual impairment but who were not identified as such (Said et al. 1970). A process achieved in the 1989/90 survey with the duplicate examination sheets.

Within the constraints set by the local environment and the ability to communicate with the participants, the results for visual acuity obtained would have accurately classified individuals into the four categories of visual acuity mentioned in the results (section 3.3.6), some variation may have occurred within these groups, but as demonstrated by the review of duplicate examination sheets this was only a minor problem. Other studies have demonstrated good inter-observer agreement in field survey work for visual acuity, with Kappa's between 0.80 and 0.88 (Brilliant et al. 1983 b). However, in clinic settings statistically significant variations have occurred in visual acuity data collected by clinicians and nurses for patients with cataracts (Gibson and Sanderson 1980).

One area for which standardization was difficult to achieve was the cause of visual impairment. The small size of the survey limited the extent to which formal testing of the ophthalmologists could be achieved for the range of conditions seen. This problem has been observed in studies designed to assess inter-observer agreement, with adequate evaluation impossible

for rare causes of visual impairment and variable agreement for other more common causes of blindness (Brilliant et al. 1983 b). Even surveys that have emphasised quality assurance e.g. The Framingham Eye Survey, had problems with diagnostic standardization, with considerable variation between examiners (Kahn et al. 1975). Several problems could arise. Firstly, when determining the principal cause of blindness there may have been several conditions affecting the eye at the same time. In the 1989/90 survey for example, the most usual being trachoma and cataract in combination. Secondly, trachomatous corneal opacity could co-exist with corneal opacity from other causes e.g. labrador keratopathy. Although it is possible to distinguish corneal opacity due to trachoma from that due labrador keratopathy (McGuiness et al. 1972), when the two conditions coexisted, the attribution of blindness to a particular cause was difficult. Additionally when non-trachomatous corneal opacity was identified the underlying cause was sometimes difficult to identify; medical records did not necessarily document the original injury or infection, and many initiating events occurred in childhood; the passage of time blurring the memory of the true cause. Thirdly, it was also possible for one condition to obscure the diagnosis of another; for example, a treatable cataract might obscure an untreatable optic atrophy or retinal detachment. Therefore, although many cataract extractions could be expected to relieve blindness, in some instances a secondary condition might preclude the restoration of good vision, leading to disappointment for both the individual and the treating ophthalmologist.

Comparison of Results

The methodological problems associated with comparing the 1989/90 survey with the 1976-79 N.T.E.H.P. survey (R.A.C.O. Report 1980) has already been discussed (section 4.2).

Two factors which would be expected to increase the accuracy of the comparison were; the same communities were visited in both surveys, with the populations examined having similar age structures, secondly the study designs were similar. However, the 1976 survey probably had better pre-visit organisation than the 1989/90 survey, although the latter built upon the previous trachoma program visits. Other differences included the amount of time spent in

each community, and the time span of the total survey. The 1989/90 survey spending more time in each community and using two years to complete the survey work.

The extension of the survey over two years could theoretically lead to some methodological problems. 1. Differences in the weather might affect the prevalence of trachoma, e.g. via the prevalence of flies. 2. The occurrence of ceremonies, with the influx of a large group of people, could have produced an epidemic of trachoma or other infective conjunctivitis eg. an outbreak of gonococcal conjunctivitis was followed across Central Australia in 1991 and was linked to the movement of people associated with ceremonial activity (Condon 1991). 3. People could more easily be double counted in the same or different settlement. The data checking procedure in fact identified over 200 duplications after examination and several dozen before the second examination took place. 4. The effect of seeing and treating many individuals in the first year may have altered the prevalence of disease in the second, with the greater awareness of trachoma and eye health that the first round of examinations engendered. The awareness leading to greater self-identification of disease or greater case finding by health workers. A mitigating feature of the 1989/90 survey in this regard was its resemblance to the usual South Australian Aboriginal Trachoma Program trips which had visited the communities once or twice a year during the 1980s. The survey therefore reflected the usual pattern of visits.

It may be concluded that although a prevalence survey of trachoma is a "snap shot" or a cross-section in time of the actual eye health picture, the degree to which the length of a survey; be it 2 weeks, 2 months or 2 years, creates a different result is difficult to assess. Certainly if significant interventions occur between the start and finish of a survey the results may be biased; however, if the environmental features, socioeconomic factors and medical facilities of the communities remained the same, there would be no reason to suspect that the results of a 2 week survey would be and different from that taking 2 years as long as the coverage of the population was the same.

One of the hardest methodological problems to resolve was the choice between using the sample or source population as a denominator for prevalence rate calculations. The sample would be subject to bias, because relatively, the older age-groups were oversampled, increasing the crude prevalence of visual impairment, and the younger age-groups 0-15 years were also disproportionately represented, possibly leading to an over estimation of crude trachoma prevalence. Although age-specific prevalence rates would not be greatly affected, presentation of crude proportions could give inaccurate results for the population as a whole. A simple random survey could not be conducted for the reasons already given. The choice then became which estimate of the source population was most accurate. Both the population lists and projected 1986 census population distribution had flaws. The latter having problems with its collection and not allowing for net migration and the former being subject to double counting between communities and increasing the estimate by not being regularly updated for people leaving the communities. Whatever the drawbacks, the crude prevalence rates derived for blindness and poor vision using the population list estimates were thought to be a more accurate reflection of disease than those based solely on the sample proportions. Again, age-specific rates using the sample denominator would have reasonable validity, the high sampling in some age-groups (60+ and 0-15) closely approximating the source population reducing the difference between the estimated rates.

Finally, the advantages and disadvantages of using cross-sectional surveys to monitor change in a defined community have already been discussed (section 1.4). The surveys used in this thesis have been population based, have had similar survey design and study procedures, have studied diseases or ophthalmic measures with standardized definitions, and the diseases studied do not have large swings in prevalence. Therefore, like comparisons in cardiovascular disease (Dobson 1987), the results of the comparisons are probably valid.

5.4 Ethical Issues: Research In Aboriginal Communities

Several ethical considerations were identified prior to the survey, these were addressed in submissions to the four ethical bodies consulted. In addition, ethical problems arose during the survey and after the conclusion of the field work. Many of the issues were not specific to Aboriginal health and research, and relate to the conduct of any research in a definable population. These issues included:

1. The risks for researchers and trachoma program personnel in travelling to remote areas. Additionally, there were risks for the subjects to be screened in travelling to the examination centres. The eye examination itself had minimal risks associated with it. Every effort was made to ensure the cleanliness and safety of the equipment used.

2. The potential disruption to a small community caused by a survey or research project with its influx of people and equipment. However, all the communities visited had previous Trachoma Program visits, and the survey work was integrated into the normal service provision of the Trachoma Program, as such the survey was well received by the communities.
The eye examination was non-invasive and participation did not appear to be affected by the gender of the examiners (it was gender neutral). Further, personal data were kept to a minimum to avoid alienating participants.

3. Informed verbal consent was obtained from all adults or parents of participating children. Written consents proved to be unwieldy for field use, and unnecessary for the simple examination performed. The administration of eye drops for diagnosis or treatment was governed by the normal medical consent procedures of a Trachoma Program trip.

4. There was no coercion in obtaining community or individual consent, their freedom of choice was respected at all times. Although the participating communities from the A P lands were represented on the Nganampa Health Council, (which reviewed the research proposal), additional meetings often took place prior to the commencement of work, between the community council and the medical research personnel. The extent and benefits of the

survey were outlined, and its methodology explained. Information was received from the community concerning the social and cultural imperatives which were important, and questions were answered.

5. The confidentiality of both the communities and individuals was maintained during and after the survey. Although names appeared on data sheets, personal information was known only to the researchers. Individual clinical details (e.g. for treatment purposes) were only given to the health workers for each respective community. Aggregated data only were given to community councils, personal information was not released.

6. At all times the welfare of the individual participants and communities were paramount in any conflict arising from the research. For example, trips were scheduled to avoid conflicts with business or ceremonies when this was known in advance.

During the survey several issues arose which had ethical ramifications.

1. The use of medical records had not been specifically requested in the original submission for ethical approval, although it was implied from the integration of the service and research roles. The principal investigator therefore had two responsibilities, the first to the research project, which had not specifically requested the use of medical records, and secondly to the Trachoma Program as a doctor. In that role he would normally, and ethically, utilize the medical records to obtain and update information.

It was only on reflection by the principal investigator that the use of records for people not seen (to identify blind individuals) was seen to be unethical in terms of the original submission. However, it had been justified as part of the Trachoma Program work, which sought to identify those in need of treatment and follow up.

2. During the survey, the research team became aware of several socio-cultural constraints to the research process. When a death occurred within a community prior to a visit, many people would leave the immediate area. Although some individuals were happy to participate in the survey the wishes of others not to participate were respected. Similarly, with

ceremonies or "business", only if the community was happy for the survey to continue, did the survey work progress. On a personal level, the research team respected the wishes of health workers either not to be involved at all, or not to approach certain members of the community, to whom, according to Aboriginal law they could not speak (avoidance relationships).

Additionally, the family/community structure and the role of parents or guardians was respected at all times. This extended to the role of the traditional Aboriginal medicine men or Ngangkere, whose healing powers in Aboriginal society were acknowledged by the survey team.

3. The service role of the research has been previously described. This was extended during the survey period to include workshops in eye care and treatment for Aboriginal health workers. Skill sharing occurred with the health workers, nursing staff and medical personnel. Discussions were also held with community members on strategies to improve eye health using a primary health care approach.

4. No problems arose from the type of physical examination (eversion of the eyelids) performed. Most individuals were happy to be examined in front of others; however, some preferred to be tested privately. This was respected and provision for it was generally available in most locations.

5. The survey team comprised of two or three, and sometimes four individuals. Because of the teams small size, the exploitation of community resources was not a major issue. Usually an area of the medical clinic was used which avoided disrupting the day-to-day routine of the service. The survey team utilized visitors' accommodation for which a fee was payable (often waived), but sometimes research personnel shared or were given quarters used by the medical service staff. This occurred not from necessity but friendship. Food was purchased from the local community store, thus in a small way, the researchers supported the local economy.

Although community health workers were diverted from their usual roles to assist the survey team, the strong service focus ensured that the health return for the time spent was worthwhile for both the health service and the community.

At the conclusion of the survey two issues were important.

1. The ownership of the data and the publication of research material was an ethical issue of great importance to the Aboriginal people.

During the survey interim reports were given to the communities. At its conclusion a summary report was given to Nganampa Health Council (N.H.C.) of data for the Anangu Pitjantjatjara lands. Data from Yalata were not included. After consideration by N.H.C. the report was forwarded to the A.H.O., the Trachoma Program, and the director of the Yalata Health Services.

A final report which detailed all the results and the comparisons with the 1976 survey was prepared and given in the same sequence to these organisations.

The N.H.C. saw the data and conclusions first, to allow approval to be given for its further distribution. A co-ownership model was developed to ensure that the form and presentation of the data was acceptable to both the communities from whom the data were derived, and the researchers who collected it. It is hoped that data for publication will also be handled in the same way, ensuring that the interests of the Aboriginal people are respected and that the distribution of public information is by mutual agreement.

2. The use of research material beyond the research process will occur for the original data sheets. Although not specifically outlined in the original submission to the ethical bodies it was mutually agreed that the data sheets eventually be returned to the communities after use by the Trachoma Program. The Trachoma Program would utilize transcribed sheets as individual medical records, for recall and follow-up purposes. The data sheets would then be returned to the communities for incorporation into the clinic medical records.

5.5 Discussion

This chapter has examined three principal research issues which related primarily to the conduct of the eye health survey and the evaluation of comparisons with previous work. However, of particular importance were the ethical issues associated with research in Aboriginal communities and the specific issues faced by the the 1989/90 survey in working with the Anangu Pitjantjatjara.

The practical problems encountered in the 1989/90 survey have not been documented in previous eye studies, and so comparisons can not be made. However, cultural factors and the implementation of western medicine have been discussed by some authors. Firstly, Maddocks and Maddocks (1991), found that in a Papuan village population, western ideas and structures, including medical concepts, could deprive people of the control they once assumed. The relevance of any intervention should therefore be measured by the degree of control the particular society maintains. Knowledge and autonomy should be encouraged. For the Anangu Pitjantjatjara some control is already exercised by the Aboriginal controlled health service. But, we still do not understand the Anangu concept of eye disease (particularly trachoma). It seems that trachoma is viewed as a "white man's" disease, and therefore treatment with antibiotics is accepted. However, socio-cultural attitudes to hygiene (e.g. face washing) is less clear and anecdotally there was some resistance to these measures because they were "white man's" ways. This superficial analysis requires further exploration and could lead to a greater understanding of Aboriginal culture.

Secondly, attitudes to education and hospitalisation have been identified as barriers to accessing health care (Watson 1987). However, the involvement of Pitjantjatjara women in the management of chronic diseases such as diabetes and hyperlipidemia has been achieved when they were given autonomy (Mulvey and Endean 1991).

Thirdly, the whole concept of western medicine and its application to Aboriginal people has been questioned. Medical treatment is thought to reflect and reproduce the cultural, socioeconomic and political forces of a wider society. Additionally, western medical practice is

seen as particularistic, biophysical, mechanistic and disease orientated, whereas Aboriginal health beliefs and practices are holistic (Nathan and Japanangka 1983). However, although the gulf between them is culturally wide simple changes have occurred and the acceptance of western treatments indicates an evolution in both European and Aboriginal thinking.

The analysis of observer error demonstrated that the simplification of the five sign system for trachoma grading ensured good agreement between observers or observations. The use of duplicate examination sheets has not been described before, although descriptions of standardization procedures occur in the literature as do evaluation of intra-observer and inter-observer errors. The feature of both these procedures is the possibility of "anticipatory bias", where those being tested know that an evaluation is taking place. They would then increase their effort to maximize their score, this maximal effort could not be sustained throughout a survey, and therefore the evaluation can not be truly representative of the survey. The method used during the 1989/90 survey was an evaluation of duplicate examinations that occurred by chance. The graders and subjects were unaware that a particular examination would be subsequently used for intra-observer and inter-observer error, freeing the test from any "anticipatory bias".

The effect of non-magnification on trachoma grading has again not been described in the literature before, and the evaluation was undertaken because it was observed in the field that some health workers didn't use loupes when assessing trachoma. Rather than enforce the use of loupes for the clinical assessment of trachoma, the evaluation of their use demonstrated that under test conditions no significant differences were observed between magnification and non-magnification. Health workers could therefore be confident that their diagnosis would not be affected by not using loupes.

The methodological problems encountered in the survey were similar to those encountered in other surveys; however, population lists have not been used in Australia before to define a population (although their use overseas is documented (Thelefors 1987)). Their use contributed to the accuracy of the 1989/90 survey. The simplification of disease definitions made the trachoma grading easier and although comparisons with previous surveys was more difficult, satisfactory adjustments could be made for inflammatory trachoma. Comparison for

trachoma scarring was not performed because it was felt that the 1989/90 survey scored TS grade 1 (N.T.E.H.P. review definition) much more than the 1976-1979 survey , and the results obtainable for that survey (from the 1985 review) were for TS grade 2+(ie did not include TS grade 1).

Finally, there were several ethical issues raised during the course of the survey. Medical and public health research involving Aboriginal communities has undergone important changes in the last five years (Houston and Legge 1992). The adoption of the National Aboriginal Health Strategy (National Aboriginal Health Strategy 1989), and the publication by the National Health and Medical Research Council (N.H.M.R.C.) of a statement on ethics in Aboriginal research (N.H.M.R.C. 1992), have highlighted the need to work with Aboriginal communities in solving issues identified by Aboriginal people, and not, as has occurred in the past, performing research on Aboriginal people. These guidelines also encourage the use of informed consent from the group as well as the individual and suggest that a high level of control by the group in the conduct of the research, or use of the results, is a worthwhile feature (Maddocks 1991). Community participation should encompass setting priorities for research, joint ownership of the project, involvement in the actual process, and the right to withdraw if there is a break of social, cultural or project protocol (Wyatt 1991).

The 1989/90 eye health survey complied with most of the guideline's set down in the report of the National Health Strategy Working Party (1989), recommendations 11.1.1. to 11.1.9.. Only in one area did the study not involve the community, the initial formulation of the study. However, the Trachoma Program was involved very early in the planning process.

Chapter 6. Conclusions and Implications

6.1 Introduction

The unacceptable health status of Aboriginal people in South Australia has been documented previously (Easterman et al. 1988). On a range of general indices, including, education, employment status, and economic status, the Aboriginal population is disadvantaged compared to non-Aboriginals. Further, health indicators such as: fertility, mortality, and rates of hospitalization, are all substantially worse in Aboriginal people than in non-Aboriginal people (Thompson and Briscoe 1991).

Contemporary issues in the health of Aboriginal people have been documented recently (Torzillo and Kerr 1991), and reflect not only specific diseases, but general issues such as: management and planning in community controlled services, environmental health, the provision of health hardware and the use of health promotion. Although trachoma is one of many diseases, the approach to its control can be used as a model for other problems, incorporating, as it does, primary through tertiary levels of intervention.

6.2 Discussion

The results of the 1989/90 survey have several implications. From its genesis as a population based prevalence survey of trachoma and visual disability in an Aboriginal population, the research developed into a review of the historical and epidemiological aspects of the eye health in the Anangu Pitjantjatjara.

The literature review revealed that the Anangu Pitjantjatjara have been the subject of several published trachoma and eye health surveys since the 1950s. Additional information relating to the eye health of the Aboriginal population had been noted in anthropological and exploratory expeditions since the 1880s.

Assessment of the available literature and the results of all the published survey work, including the 1989/90 survey, suggest a changing pattern of disease consistent with the late introduction of trachoma into the north-west of South Australia. Its initial absence in Central Australia does not imply that Aboriginal people in the rest of Australia were not afflicted by trachoma before the coming of white man. Trachoma may have been endemic in some areas but its carriage and transmission in Central Australia, amongst a people who knew few other infectious diseases and lived in small nomadic groups, would not have favoured an organism that thrives in crowded, unhygienic conditions.

The review of the literature relating to trachoma demonstrated the comprehensive but incomplete knowledge about both preventive strategies and treatment programs (section 1.3 (2.1.8.-2.1.9). For example, hygiene practices such as face washing were identified as an intervention strategy to reduce trachoma (Taylor et al. 1989); however, further studies suggest that cleaning nasal discharge and keeping flies off children's faces was more important (West et al. 1991). Application of face washing to an Australian Aboriginal community had no effect on the prevalence of trachoma (Peach et al. 1987). The differing results indicate that although overseas research could suggest areas for primary prevention, local experience and evaluation are necessary to justify cultural and other changes.

The treatment of trachoma in the individual using either oral or topical therapy is well documented and accepted. The effectiveness of treatment on a mass scale is less clear (section 1.3 (2.2.9)). The use of a campaign style approach is likely to meet some political resistance if attempted on a scale which would have a beneficial effect. Nevertheless, the application of a culturally appropriate and systematic treatment program, in a group of communities served by one health service (e.g. Nganampa Health Service) could be successful, as demonstrated by overseas experience. Such a strategy has already been proposed in the Northern Territory by the Menzies School of Health Research (Matthews 1987). Reintroduction of trachoma from other communities would occur but the chronic cycle of closely spaced repeated infection could be broken, leading to a reduction in the severity if not the prevalence of trachomatous disease. Another approach could utilize systematic case finding and treatment of families by Aboriginal health workers. This should have been occurring; however, it appears that the demands of multiple problems had limited the ability of the health services to respond.

The last implication, and perhaps the most important of the literature review was that socioeconomic development, infrastructure improvement and some attendant cultural change was the most effective means of decreasing or eliminating trachoma (section 2.2.7). However, to wait for this to occur in rural Aboriginal communities could condemn many individuals to years of blindness.

The results of the eye health survey presented in chapter 3 indicate that trachoma is still endemic among the Anangu Pitjantjatjara of South Australia, and that whilst visual acuity is good in the younger age-groups, a considerable burden of blindness already exists in the old. It appears, although this is by no means certain, that these younger age-groups, as they get older, will not progress to the same levels of visual disability as their mothers and fathers.

Trachoma is an indication of socio-economic development, community and health infrastructure (Marx 1989); that trachoma still exists demonstrates that despite positive changes within the communities, improvement can still be made. For example, an

improvement in the prevalence of follicular trachoma in Western Australia was found to be associated with improvements in school hygiene and housing (Cooper et al. 1986). Socioeconomic development would not only benefit eye health but would also address the identified matrix of disease which had been documented previously (Hollows 1982)

The high prevalence of blindness has implications for the communities beyond the immediate provision of treatment services. There is a personal cost to the individual and costs to family for the additional care of a blind person. Much of the blindness identified in the 1989/90 survey was either preventable as with trachoma or easily remediable as with cataracts. A backlog of blindness from cataracts does occur in developed countries (Drummond and Yates 1991); however, the high prevalence of sight limiting cataracts found in the 1989/90 survey, indicates some deficiencies in the provision of treatment services. Either the Trachoma Program has been unable to encourage attendance at its clinics and ensure completed treatment, or the local health services have had an uncoordinated approach to the identification and follow-up of individuals with eye health problems. Again, the difficulties of servicing a remote region which has significant socioeconomic disadvantage, and a broad spectrum of ill health, determines the distribution of finite resources.

The results also demonstrate that more eye disease is found in females; as measured by sample prevalence rates of cataracts and trachoma trichiasis. Other surveys have found similar differences between the sexes (section 3.4.3) but an adequate explanation has not been found, differential access to treatment may be the most important factor. A biological explanation for the difference based on sex has not been expounded, and sex therefore may be a confounding variable.

For the Anangu Pitjantjatjara, perceived barriers in treatment services for women need to be reduced and socio-cultural expectations examined. Possible problems could arise from the perception of invasive procedures being carried out by male doctors; it is reported that the attendance by women on men can be difficult, and it is preferable for women to treat women and men to treat men (Edwards 1990). There may also be cultural expectations concerning

the role of male and female elders vis. the subsequent need for good eyesight. It has been found in other surveys that in traditional societies, sex roles have implications for knowledge about access to health resources (Brilliant and Brilliant 1985), and this may require further exploration in Anangu Pitjantjatjara culture.

The comparison of the 1989/90 survey with the results of the R.A.C.O. Report of 1980 demonstrate a statistically significant decline in both inflammatory and cicatricial trachoma. Two recent evaluations of trachoma in Central Australia suggested that in some coastal Aboriginal communities the prevalence of trachoma has been reduced, whilst it has remained the same in inland communities (Freeman et al 1985; Meredith et al 1989). The 1989/90 survey therefore demonstrates for the first time that the eye health of Aboriginal people in Central Australia may be improving. However, isolated reports of gonococcal conjunctivitis in Central Australia (Brennen et al. 1989), and more recently in the Anangu Pitjantjatjara lands (Dr. Mulvany personal communication 1991) indicate that eye hygiene still needs to be improved.

The findings of the survey and analysis require explanation. What changes have occurred in the communities in the last 15 years? Have the changes reduced the prevalence of other diseases? What further positive changes can be initiated to continue the improvement of eye health? The changes that might have occurred may be an improvement in water supplies, nutrition or shelter, the influence of an Aboriginal controlled medical service, the intervention of the Trachoma Program or simply hygiene changes. A retrospective study would be methodologically difficult, but prospective cohort studies, although expensive, could yield valuable and accurate data if conducted properly (Rosenthal 1980).

The 1989/90 survey identified two areas of the study design which may have implications for future studies of trachoma and eye health. The first related to the standardization and error assessment of grading trachoma or testing vision. In future surveys repeat examination could be incorporated randomly into the study design to evaluate both intra-observer and inter-observer error. The second related to the grading of trachoma using x 2 loupes. A small study of 110 individuals demonstrated no significant differences between grading and TF and TS

both with and without magnification. Although not in accordance with W.H.O. guide-lines it demonstrated that grading could occur without magnification with results being comparable to that obtained with magnification.

The success of the survey in seeing a large proportion of the population and a willingness of the communities to participate indicate that a prominent service role should if possible be incorporated in future studies. The review of ethical considerations reinforces the co-ownership model for research within Aboriginal communities. Participation by Aboriginal people in the development, implementation and distribution of the results is important. Aboriginal people should have the right to review work and be able to suggest appropriate changes.

6.3 Future Directions

Although Australia cannot be classified as a developing country the resources available to Aboriginal communities are limited. It has been suggested that for areas of limited means evaluation of personal and family factors should be undertaken to identify risk factors which are amenable to intervention (Tielsh et al. 1988).

Risk factors for inflammatory trachomatous disease have been identified in many studies (Tielsh et al. 1988). Consistently and of relevance to the conditions encountered in the Anangu Pitjantjatjara and Yalata lands are socioeconomic status, distance to primary water source, presence of trachoma among siblings and presence of a latrine. These conditions have been identified and given priority on the A P lands (Nganampa Health Council 1989).

In Africa a shortage of ophthalmologists has been identified (Foster 1987), and the solution to high rates of cataract blindness found in various surveys in Africa was to train more ophthalmologists or medical assistants who were capable of performing surgery (Faal et al. 1989). By contrast, even though the per capita number of ophthalmologists in England is not very different from that in India or China, the level of access and affordability is important in

determining who gets operated on for cataract in those countries (Sommer 1988). The results from this survey indicate that the distribution and motivation of skilled practitioners was just as important as total numbers in providing eye care to disadvantaged communities. The enthusiasm of the Trachoma Program and Community Health Service personnel are essential in developing better access to treatment programs.

When the results for trachoma were aggregated it appears that there is a high rate of active inflammatory trachoma in the younger age-groups with a high rate of cicatricial trachoma in the older age-groups. Superficially this would fit Jones' epidemiological classification of a class 1 region, an area of blinding hyperendemic trachoma (Jones 1975). However, this definition applies to a steady state situation and with the demonstrated decline over 15 years, the situation in this study appears to be in transition, and a class 2 region (non-blinding trachoma) appears to be emerging.

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Appendices

Table 1: Right vs left eye corrected visual acuity in the 0-19 age-group

		LCORRECTED										
RCORRECTED		6/6 Uncorr.	6/6 Corr.	6/12	6/18	6/36	6/60	3/60	CF	PL	NPL	Total
6/6	Corr.	756	0	0	0	0	0	0	0	0	0	**756**
6/6	Uncorr.	1	6	0	0	0	0	0	0	0	1	**8**
6/12		0	1	0	0	0	0	0	0	0	0	**1**
6/18		0	0	0	0	0	0	0	0	0	0	**0**
6/36		0	0	0	0	0	0	0	0	0	0	**0**
6/60		0	0	0	0	0	0	0	0	0	0	**0**
3/60		0	0	0	0	0	0	0	0	0	0	**0**
CF		0	1	0	0	0	0	0	0	0	0	**1**
PL		0	0	0	0	0	0	0	0	0	0	**0**
NPL		0	0	0	0	0	0	0	0	0	0	**0**
Total		**757**	**8**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**1**	**766**

Table 2: Right vs left eye corrected visual acuity in the 20- 29 age-group

		LCORRECTED										
RCORRECTED		6/6 Uncorr.	6/6 Corr.	6/12	6/18	6/36	6/60	3/60	CF	PL	NPL	Total
6/6	Uncorr.	211	0	0	0	0	0	0	0	0	0	**211**
6/6	Corr.	0	3	0	0	0	0	0	0	0	0	**3**
6/12		0	0	0	0	0	0	0	0	0	0	**0**
6/18		0	0	2	1	0	0	0	0	0	0	**3**
6/36		0	0	0	0	0	0	0	0	0	0	**0**
6/60		0	0	0	0	0	0	0	0	0	0	**0**
3/60		0	0	0	0	0	0	0	0	0	0	**0**
CF		0	1	0	0	0	0	0	1	0	0	**2**
PL		0	0	0	0	0	0	0	0	1	0	**1**
NPL		1	0	0	0	0	0	0	0	0	0	**1**
Total		**212**	**4**	**2**	**1**	**0**	**0**	**0**	**1**	**1**	**0**	**221**

Table 3: Right vs left eye corrected visual acuity in the 30-39 age-group

RCORRECTED		LCORRECTED 6/6 Uncorr.	6/6 Corr.	6/12	6/18	6/36	6/60	3/60	CF	PL	NPL	Total
6/6	Uncorr.	125	0	0	0	0	0	0	0	0	0	**125**
6/6	Corr.	0	7	2	0	0	0	0	1	0	2	**12**
6/12		0	1	3	1	0	0	0	0	0	0	**5**
6/18		0	1	1	1	0	0	0	0	1	0	**4**
6/36		0	0	0	0	0	0	0	0	0	0	**0**
6/60		0	0	0	0	0	0	0	0	0	0	**0**
3/60		0	0	0	0	0	0	0	0	0	0	**0**
CF		0	1	0	0	0	0	0	0	0	0	**1**
PL		0	0	0	0	0	0	0	0	0	0	**0**
NPL		0	0	0	0	0	0	0	0	0	0	**0**
Total		**125**	**10**	**6**	**2**	**0**	**0**	**0**	**1**	**1**	**2**	**147**

Table 4: Right vs left eye corrected visual acuity in the 40-49 age-group

RCORRECTED		LCORRECTED 6/6 Uncorr.	6/6 Corr.	6/12	6/18	6/36	6/60	3/60	CF	PL	NPL	Total
6/6	Uncorr.	99	0	0	0	0	0	0	0	0	0	99
6/6	Corr.	0	3	2	3	2	3	0	1	0	0	14
6/12		0	2	3	1	0	1	0	0	0	0	7
6/18		0	0	1	2	1	1	0	0	0	0	5
6/36		0	2	0	1	0	0	0	0	0	0	3
6/60		0	0	0	0	0	0	0	0	0	0	0
3/60		0	0	0	0	0	0	0	0	0	0	0
CF		0	2	0	0	0	0	0	0	0	0	2
PL		0	0	0	0	1	0	0	0	0	0	1
NPL		0	1	0	0	0	0	0	0	0	0	1
Total		**99**	**10**	**6**	**7**	**4**	**5**	**0**	**1**	**0**	**0**	**132**

Table 5: Right vs left eye corrected visual acuity in the 50-59 age-group

		LCORRECTED										
RCORRECTED		6/6 Uncorr.	6/6 Corr.	6/12	6/18	6/36	6/60	3/60	CF	PL	NPL	Total
6/6	Uncorr.	56	0	0	0	0	0	0	0	0	0	**56**
6/6	Corr.	0	10	3	1	0	0	0	0	2	0	**16**
6/12		0	3	8	2	1	1	0	0	1	0	**16**
6/18		0	5	3	0	0	2	0	0	0	1	**11**
6/36		0	0	0	0	1	0	0	0	0	0	**1**
6/60		0	0	0	2	3	0	0	0	0	0	**5**
3/60		0	0	0	0	0	0	0	0	0	0	**0**
CF		0	3	2	0	1	0	0	0	0	0	**6**
PL		0	0	0	0	0	0	0	1	0	0	**1**
NPL		0	0	0	0	0	0	0	0	0	0	**0**
Total		**56**	**21**	**16**	**5**	**6**	**3**	**0**	**1**	**3**	**1**	**112**

Table 6: Right vs left eye corrected visual acuity in the 60+ age-group

		LCORRECTED										
RCORRECTED		6/6 Uncorr.	6/6 Corr.	6/12	6/18	6/36	6/60	3/60	CF	PL	NPL	Total
6/6	Uncorr.	23	0	0	0	0	0	0	0	0	0	**23**
6/6	Corr.	0	4	1	0	1	0	0	2	0	0	**8**
6/12		0	3	8	3	2	1	0	1	2	1	**21**
6/18		0	1	3	6	1	1	0	2	1	2	**17**
6/36		0	1	1	3	2	4	0	5	4	1	**21**
6/60		0	0	1	0	3	2	1	1	0	1	**9**
3/60		0	0	0	1	0	0	0	1	0	1	**3**
CF		0	2	1	1	2	0	0	7	0	2	**15**
PL		0	0	1	3	1	1	0	2	1	2	**11**
NPL		0	0	3	0	2	0	0	1	1	1	**8**
Total		**23**	**11**	**19**	**17**	**14**	**9**	**1**	**22**	**9**	**11**	**136**

Table 7: Right vs left eye corrected visual acuity for all age-groups combined

		LCORRECTED										
RCORRECTED		6/6 Uncorr.	6/6 Corr.	6/12	6/18	6/36	6/60	3/60	CF	PL	NPL	Total
6/6	Uncorr.	1270	0	0	0	0	0	0	0	0	0	**1270**
6/6	Corr.	1	33	8	4	3	3	0	4	2	3	**61**
6/12		0	10	22	7	3	3	0	1	3	1	**50**
6/18		0	7	10	10	2	4	0	2	2	3	**40**
6/36		0	3	1	4	3	4	0	5	4	1	**25**
6/60		0	0	1	2	6	2	1	1	0	1	**14**
3/60		0	0	0	1	0	0	0	1	0	1	**3**
CF		0	10	3	1	3	0	0	8	0	2	**27**
PL		0	0	1	3	2	1	0	3	2	2	**14**
NPL		1	1	3	0	2	0	0	1	1	1	**10**
Total		**1272**	**64**	**49**	**32**	**24**	**17**	**1**	**26**	**14**	**15**	**1514**

The projected 1986 Census data was estimated approximately using 1986 census data. It was assumed that the population was equally distributed in each age group, there would be no net migration which would affect the population distribution and the population list for 1990 could be used to estimate the size of the 0-4 age group. An estimate for the total number of births could have been used, but there were several problems with birth and death registration data (Australian Bureau of Statistics 1988).

An estimate for the death rate was used (7.2/1000), which was the rate for the Aboriginal population in the Far North of South Australia in 1988, age-specific rates for the state were used to apportion deaths among the age-groups (Australian Bureau of Statistics 1988). As the projected data was only a crude approximation, only deaths in the 45+ age groups were calculated and adjusted for.

The number of deaths in the four year period were calculated as

	M	F
50-59	14	16
60+	24	12

The increase in size for each age group was calculated by "moving" four years of one age category individuals into the next age-bracket until all age-groups were adjusted. Deaths were adjusted for last of all.

IDENTITY NO.

AGE ☐☐ M/F ☐ ABORIGINAL Y/N ☐

OCCUPATION _____ COUNTRY OF BIRTH _____

P.O.H. ☐

_____

_____

_____

_____

ACTION TAKEN ☐

_____

_____

_____

_____

B. VISION

	R	L
UNAIDED	☐	☐
CORRECTED (P.H. or Glasses)	☐	☐

C. BASIC EYE EXAMINATION

	R	L
NO ABNORMALITY:	☐	☐
ABNORMALITY		
EYELID:		
Inturned margin/trichiasis	☐	☐
Neoplasm	☐	☐
GLOBE:		
Phthisical/disorganized/absent	☐	☐
CORNEA:		
Central corneal opacity	☐	☐
Pterygium (corneal)	☐	☐
LENS:		
No view of lens	☐	☐
Obvious opacity	☐	☐
Aphakia	☐	☐
Pseudophakia	☐	☐
NOT EXAMINED	☐	☐

D. PREVIOUS EYE SURGERY

	R	L
NO EVIDENCE OF SURGERY	☐	☐
TYPE OF PREVIOUS SURGERY:		
Eyelid	☐	☐
Cataract	☐	☐
Glaucoma	☐	☐
Retinal	☐	☐
Other	☐	☐
NOT ASSESSED	☐	☐

E. TRACHOMA

	R	L
NO SIGN	☐	☐
SIGN OF TRACHOMA:		
TF	☐	☐
TI	☐	☐
TS	☐	☐
TT	☐	☐
CO	☐	☐
NOT EXAMINED	☐	☐

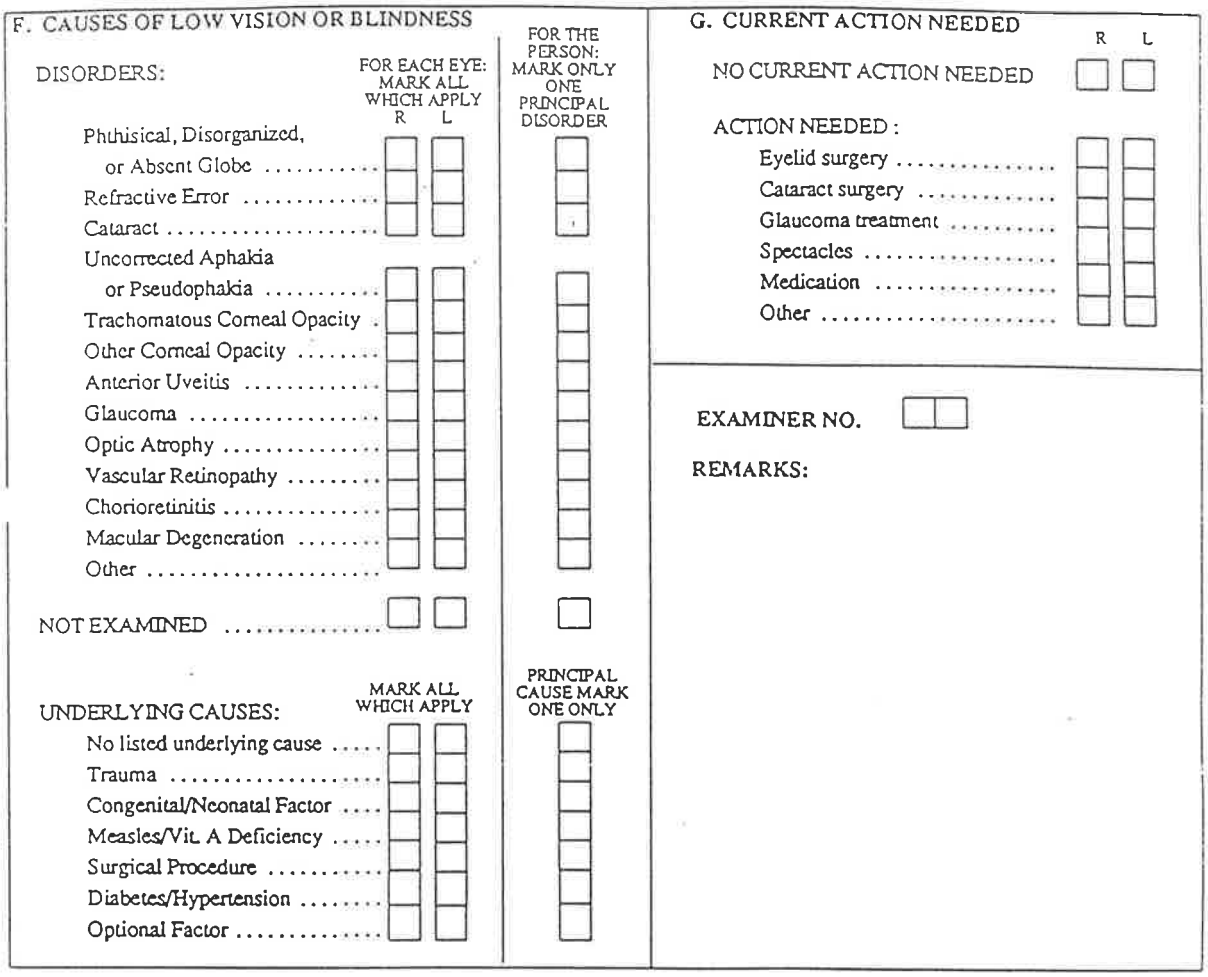
INTRAOCULAR PRESSURE

	R	L
IOP in mm Hg	☐	☐
NOT EXAMINED	☐	☐

OPTIONAL EXAMINATION (<6/18 either eye best corrected)

	R	L
DILATED FUNDUS	☐	☐
NOT EXAMINED	☐	☐

REMARKS



F. CAUSES OF LOW VISION OR BLINDNESS

DISORDERS:

	FOR EACH EYE: MARK ALL WHICH APPLY R	L	FOR THE PERSON: MARK ONLY ONE PRINCIPAL DISORDER
Phthisical, Disorganized, or Absent Globe	☐	☐	☐
Refractive Error	☐	☐	☐
Cataract	☐	☐	☐
Uncorrected Aphakia or Pseudophakia	☐	☐	☐
Trachomatous Corneal Opacity	☐	☐	☐
Other Corneal Opacity	☐	☐	☐
Anterior Uveitis	☐	☐	☐
Glaucoma	☐	☐	☐
Optic Atrophy	☐	☐	☐
Vascular Retinopathy	☐	☐	☐
Chorioretinitis	☐	☐	☐
Macular Degeneration	☐	☐	☐
Other	☐	☐	☐
NOT EXAMINED	☐	☐	☐

UNDERLYING CAUSES:

	MARK ALL WHICH APPLY		PRINCIPAL CAUSE MARK ONE ONLY
No listed underlying cause	☐	☐	☐
Trauma	☐	☐	☐
Congenital/Neonatal Factor	☐	☐	☐
Measles/Vit. A Deficiency	☐	☐	☐
Surgical Procedure	☐	☐	☐
Diabetes/Hypertension	☐	☐	☐
Optional Factor	☐	☐	☐

G. CURRENT ACTION NEEDED

	R	L
NO CURRENT ACTION NEEDED	☐	☐
ACTION NEEDED :		
Eyelid surgery	☐	☐
Cataract surgery	☐	☐
Glaucoma treatment	☐	☐
Spectacles	☐	☐
Medication	☐	☐
Other	☐	☐

EXAMINER NO. ☐☐

REMARKS:

BETTER VISION FOR ALL

The Five Sign System for Trachoma and Age Specific Prevalence Rates

This system is a simple direct method of listing trachoma in a group of people. It avoids severity grading of particular signs and does not list some well known signs (eg. Herberts Pits, Papillae and Panus). This method is efficient, rapid and accurate. When these five signs are entered into an **age table** the trachoma status of the examined group is easily seen. This makes decisions regarding the need for treatment and comparisons with previous trachoma situations possible in an organised way.

The five signs are:

(1) **TF** Follicular trachoma is scored whenever follicles are seen in the conjunctiva of the everted upper lid.

(2) **TS** Trachoma scarring is scored when scars are seen in the conjunctiva of the everted upper lid.

(3) **TI** Trachoma intense is scored when no normal tarsal vessels are seen in the everted upper lid.

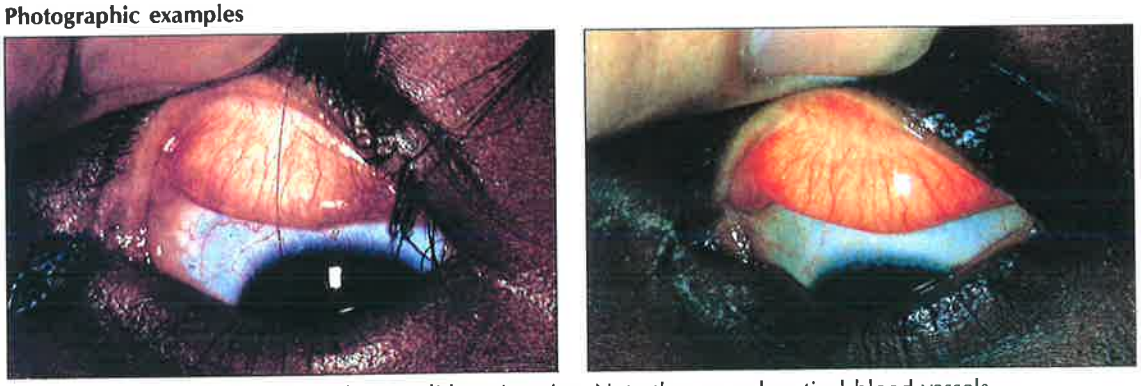
(4) **TT** Trachoma trichiasis is scored when one or more eyelash touches the eyeball.

(5) **CO** Corneal Opacity is scored when any opacity of the cornea dense enough to obscure a view of the pupil (were it so placed) is seen.

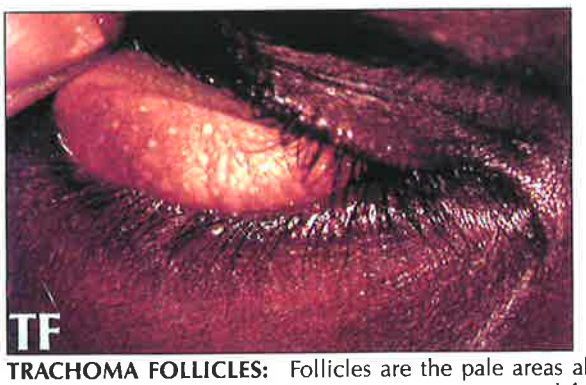
An eye may be scored for one or more of these signs

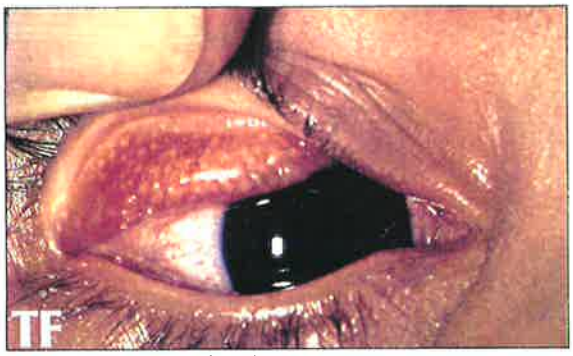
Procedure:
(1) Magnification in day light or torch light.
(2) Only the upper lid conjunctiva is graded, excluding lateral and medial corners.
(3) The presence of a sign in one or both eyes categorises the patient as positive for that sign.
(4) The right eye is examined and recorded first.
(5) Tally is entered thus: 𝍸 = 5 𝍸 ||| = 8
𝍸 𝍸 ||| = 13 etc

Photographic examples

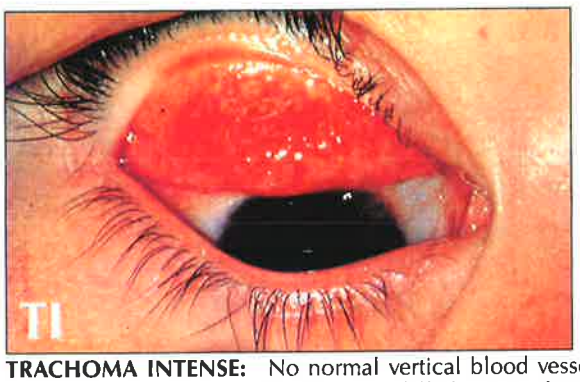


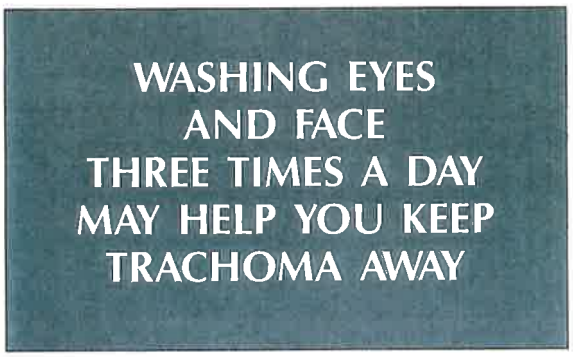
NORMAL Normal upper lid conjunctiva. Note the normal vertical blood vessels. Not scored for TF, TS or TI.



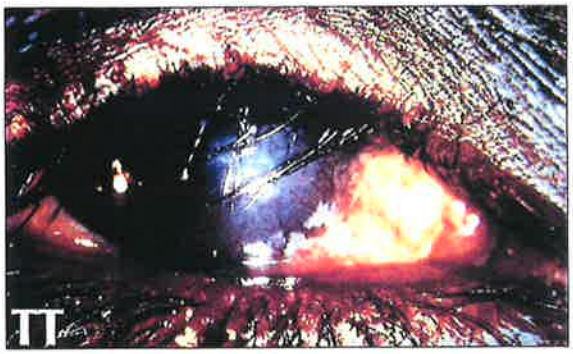


TRACHOMA FOLLICLES: Follicles are the pale areas about the size of a pinhead. These two eyes are scored for TF.

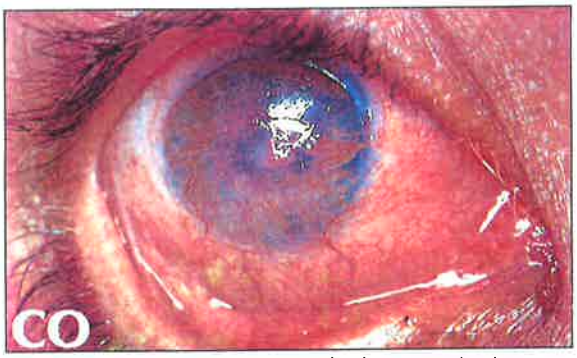




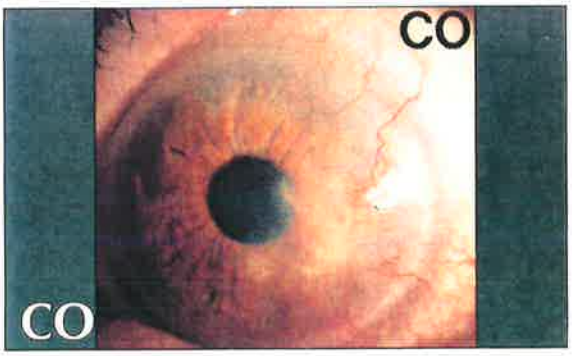
TRACHOMA INTENSE: No normal vertical blood vessels seen, TI (in this case follicles (TF) obscure the vessels). Scored for TF and TI.



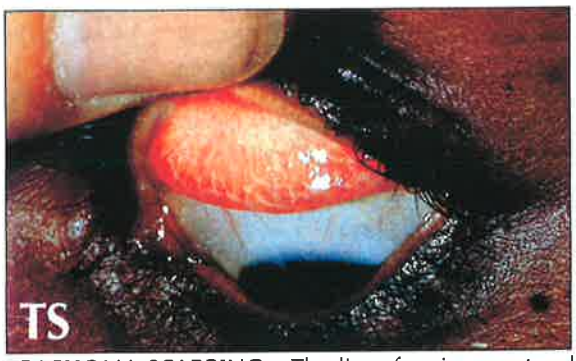
TRACHOMA TRICHIASIS: Eye lash or lashes touching the eyeball. Scored TT.



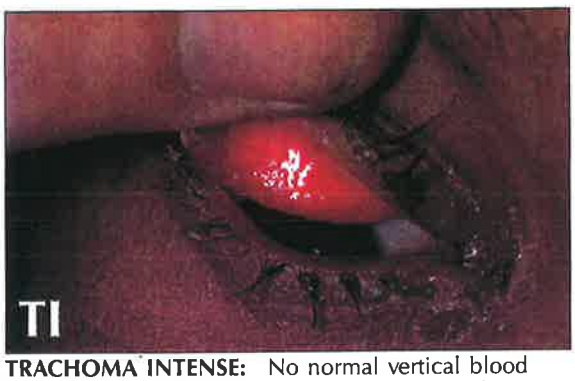
CORNEAL OPACITY: Is scored when opacity is dense enough to prevent a view of the pupil. In this case the whole cornea is opaque.



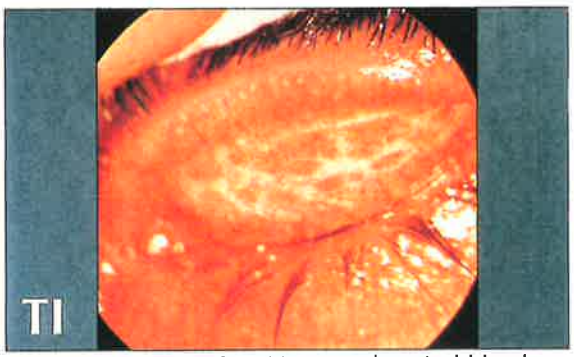
CORNEAL OPACITY: In this case of CO the opacity although not over the pupil is dense enough to obscure it if it were so placed. Scored CO.



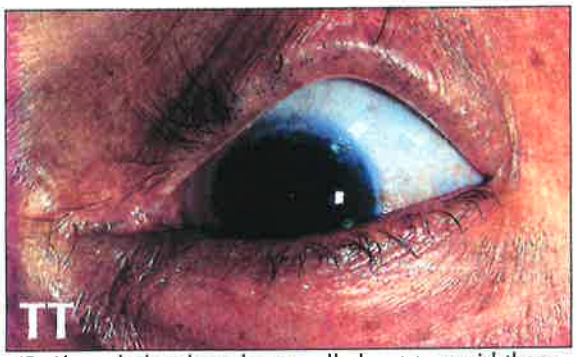
TRACHOMA SCARRING: The lines forming a network are scars. These two eyes are scored for TS.



TRACHOMA INTENSE: No normal vertical blood vessels seen, TI (in this case due to papillae obscuring vessels). Scored for TI only.



TRACHOMA INTENSE: No normal vertical blood vessels seen. TS (in this case scars (TS) obscure the vessels). Scored for TS and TI.



NB: If eye lashes have been pulled out to avoid them touching the eyeball TT is scored.

CORNEAL OPACITY:
From above (panus) also grades case as CO if dense enough, as in this case.

REQUIREMENTS FOR DOMICILIARY HYGIENE

1. Water reticulated into the dwelling available at 100 litres/person/day.
2. Means of heating water for body/clothes washing.
3. Showers to enable every person to shower at least once per day. One shower per 10 persons.
4. Washing machine for clothes and linen.
5. Sleeping surfaces that are elevated, separated and ventilated.
6. No more than 2 persons for each 3 × 3 metre square sleeping room.
7. Fly screens on all exterior doors and windows.
8. Cleanable surfaces inside dwellings.
9. Living space free of animals.
10. One toilet per 10 persons.

"TRACHOMA GOES WHEN HOME HYGIENE IS GOOD"

ABORIGINAL HEALTH ORGANISATION OF S.A.

Head Office:
62 Beulah Road, Norwood, S.A. 5067
P.O. Box 285, Norwood, S.A. 5067
Telephone: [redacted]
Telex: 87165 333 7300
Fax: 363 1514
In reply please quote: 14/95/04

Dr Nigel Stocks
Dept of Primary Health Care
Flinders Medical Centre
BEDFORD PARK SA 5042

Dear Dr. Stocks,

RE: PROPOSED VISUAL IMPAIRMENT STUDY IN ABORIGINAL COMMUNITIES

I apologise for this late response.

As the Committee had indicated to you when you presented your proposal, the Study is supported by the Aboriginal Health Research Committee. The Committee felt that the action-oriented research approach of combining a survey with providing service to the people examined is commendable.

It would be appreciated if you could provide the Research Committee some feedback on the Pilot Study phase of the Project.

Enclosed is a copy of the environmental health report "Uwankara Palynyaku Kanyintjaku" for your perusal.

Best Wishes

M. HAMPTON
CHAIRPERSON
ABORIGINAL HEALTH RESEARCH COMMITTEE

CDB:MH:LD

22nd August, 1989

Flinders Medical Centre
BEDFORD PARK SOUTH AUSTRALIA 5042
TELEPHONE 2759911

27 September 1989

MEMORANDUM

TO: Dr. N. Stocks, Department of Primary Health Care

FROM: Dr. A. Vedig, Chairman, Committee on Clinical Investigations

TOPIC: **Research Application 71/89**

Your attention is drawn to the following extract from the Minutes of the Committee's meeting held on 25 September 1989.

1899.1 Research Application 71/89 - Dr. N. Stocks
A population based prevalence survey of visual impairment in the rural Aboriginal population of South Australia.

Letter from Dr. Stocks outlining the information this Committee requested was received and the application approved.

A. Vedig
Intensive Care Unit,
Extension 4324

ANANGU PITJANTJATJARA
SOUTH AUSTRALIA
PITJANTJATJARA LAND RIGHTS ACT, 1981.

PERMIT TO ENTER ONTO AND REMAIN ON ABORIGINAL LAND

Pursuant to Division II

GENERAL CONDITIONS OF ISSUE:

1. This permit does not authorise the entry of a person to a dwelling or living area of a camp occupied by or belonging to an Aboriginal without the consent of the owner or occupant.
2. This permit is subject to the special conditions (if any) set out below.
3. Special conditions

4. Issue of this permit does not imply that notice of intention to visit the Aboriginal land specified has been served upon the traditional owners concerned. The permittee is responsible to ensure that Aboriginal communities are informed of his intention to visit.
5. This permit is valid only to enable the permittee to perform the duties associated with his or her stated purpose.
6. This permit must be carried at all times while the holder is on the Aboriginal land and produced for inspection on demand.
7. The permittee must comply with any laws currently in force concerning the sale and possession of liquor on the Aboriginal land.
8. This permit may be revoked at any time.
9. In the event of revocation of a permit or its ceasing to be valid for any reason, the permittee shall immediately leave the Pitjantjatjara freehold land.

Executive Members and the Field Officer of A.P. may inspect permits and may at any time give direction to permit holders in relation to their conduct and activities on the Freehold Lands.

No. 9250

NAME DR NIGEL STOCKS

ADDRESS SA ABORIGINAL TRACHOMA & EYE PROGRAMME BOX 760 ADELAIDE SA

AREAS INVOLVED AMATA, FREGON & ERNABELLA

PURPOSES OF ENTRY DOCTORS TRIP

DATES: from 25/11/89 to 8/12/89

Issued at Alspnngs this 27 day of Oct 1989

Signed by

Signature

The University of Adelaide
BOX 498, G.P.O., ADELAIDE, SOUTH AUSTRALIA 5001

Ref: LDZ
D.2603/75
Enquiries: Ms. L. D. Zeitz
Secretary,
Committee on the Ethics of
Human Experimentation
Phone: (08) 228 5184

THE REGISTRY
21 September 1989

Dr. N. Stocks
Department of Primary Health Care
School of Medicine
Flinders University of South Australia
Bedford Park SA 5042

Dear Dr. Stocks,

H/37/89 A Population Based Prevalence Survey of Visual Impairment in the Rural Aboriginal Population of South Australia

Thank you for your letter of 13 September 1989.

I am pleased to inform you that the Chairman on behalf of the Committee for the Ethics of Human Experimentation has approved the above project.

Please note that any change to the project which may affect its ethical aspects will invalidate the project's approval. In such cases an amended protocol must be submitted to the Committee for further approval.

Where possible, subjects taking part in the study should be given a copy of the Information Sheet and the signed Consent Form to retain.

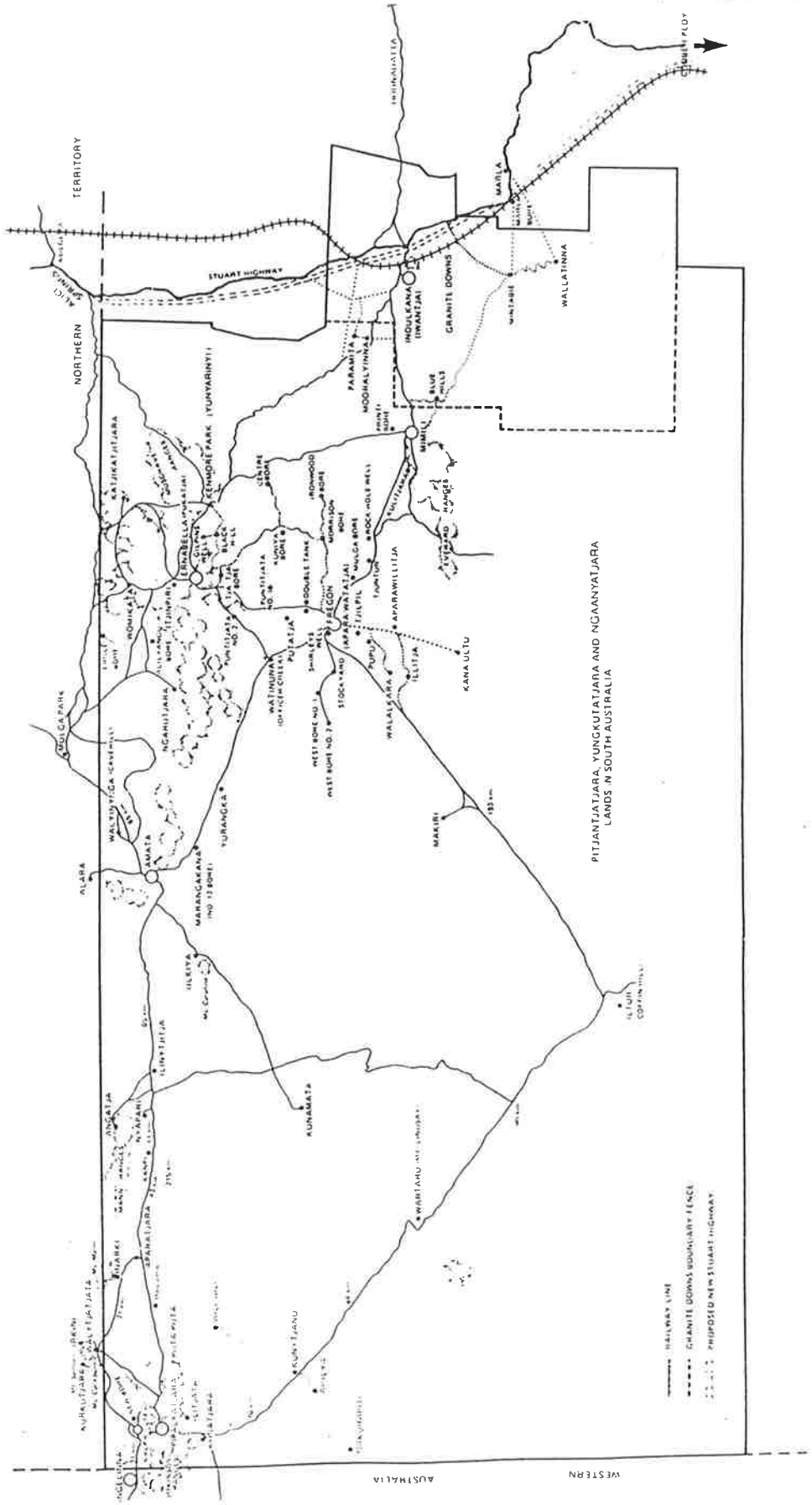
Project approvals are current for one year. The expiry date for your project will be 30 September 1990. Applications for renewal must be accompanied by a brief report on the project's progress and any ethical issues which may have arisen. If the project is completed before that time, a brief report on its outcome and the ethical considerations should be made to the Committee.

I take this opportunity to wish you well in your research.

Yours sincerely,

F.J. O'NEILL
Registrar

Telephone: (08) 228 5333 FAX: (08) 224 0464 Telex: UNIVADAA


TERRITORY
NORTHERN
STUART HIGHWAY
INDULKANA (WANTAJA)
GRANITE DOWNS
MARLA
WALLATINNA
MINGILI
KANA ULTU
MAKIRI
PITJANTJATJARA, YUNGKUTATJARA AND NGAANYATJARA LANDS IN SOUTH AUSTRALIA
AUSTRALIA
WESTERN
RAILWAY LINE
GRANITE DOWNS BOUNDARY FENCE
PROPOSED NEW STUART HIGHWAY

Trachoma hurts your eyes.

It is a germ spread by flies and dust.

Alot of people here have trachoma.

It can make you blind after a long time because it turns the lashes in on the eye ball.

There is medicine.

Nº 1 Wash your face and the kids faces every day.

To prevent Trachoma.

Tjana warkaringi kurungka, wati Minyma tjutungka munu tjitjinka. Munnya kulangka nyanangi. Anangu kutjupa tjuta Amatalanguru pitjanya--ngka. Ka minyma, wati, kutjupa tjuta kuru putu nyakupai. Kutjupa tjuta kuru glassku mukuringanyi.

Nganampa pitjangu Adelaide languru munnya Kanpiku, Nyapariku anangu nyakuntjitjitja anu.

Munya malaku pitjangu Pipalyatjaraku. Tjitji tjuta nyakuntjitjitja kulanka. Munnya nyakula wiyaringkula anu Wingelinalakutu. Munula Wingelinala anangu tjuta nyanangi. Ka kutjupa tjuta kuru pataringu. Kutjupa tjuta kuru palya. Doctor paluru tjana ini David Mornya munu Nigel Stokes munu kunga kutju educator, Marianya Camino, munu kutjupa co ordinator paluru ini Debbie Reid.

Ngayulu helpamilangi ranangku ngayulu palunya tjananya parakatiringangi.

ngayulu ini
Ron Watson