Trachoma in Australia: an evaluation of the SAFE strategy
and the barriers to its implementation

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of the degree of Doctor of Philosophy

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DEDICATION

This work is firstly dedicated to my beautiful wife, Kelly, without her understanding, support, encouragement, and love it would not have been possible.

It is secondly dedicated to my grandfather, Frank Meldrum, who obtained his PhD 70 years ago and is a source of great inspiration to me.
Trachoma is known to be a significant cause of blindness in Australia. It was brought into the public spotlight 30 years ago by Fred Hollows. Unfortunately public interest has waned and so have efforts to combat this terrible and painful blinding disease. The World Health Organization has set the goal of eliminating the disease by 2020. Unless momentum is soon gained in Australia, there is a very real risk that Australia will be the last country on earth where blinding trachoma remains. The importance of trachoma in the overall context of Indigenous health is constantly debated. We set out to evaluate the SAFE strategy, including the impact of a swimming pool. However the project soon changed course. This thesis shows that trachoma is still a major public health concern and a cause of significant visual morbidity. This thesis demonstrates that the A and F components of the SAFE strategy can be an effective intervention. This thesis reports on some of the barriers that are impeding the widespread implementation of SAFE within the Northern Territory of Australia.

A total of 434 children were examined during two visits that made up the baseline findings. 16.7% of children living in the coastal region had trachoma, 54.8% of children living in the desert region had trachoma. Living in a desert community, having poor facial hygiene and increased attendance at school were predictors of trachoma. There was no association between trachoma and the other common infectious diseases of childhood. Mass antibiotic distribution and promotion of facial cleanliness was undertaken in the desert community. At 6 month follow up no children had very unclean faces and the prevalence of trachoma was significantly reduced. A survey of older adults demonstrated that the prevalence of severe visual impairment and blindness was 24 times greater than seen in Urban Australia. Trachoma was a significant contributor.

The SAFE strategy has not been widely implemented in Australia; those with a role in delivering the trachoma control program were interviewed to identify the barriers to its implementation in the Northern Territory. Several critical success factors emerged that must be addressed before a SAFE based trachoma control program can be implemented.
DECLARATION:

This is to certify that

(i) the thesis comprises only my original work towards the PhD
(ii) due acknowledgement has been made in the text to all other material used, 
(iii) the thesis is less than 100,000 words in length, exclusive of tables, maps, 
biographies and appendices.

____________________________________
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Paper: Trachoma in Australian Aborigines. RANZCO Victorian Branch meeting, Melbourne 2006.

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CHAPTER 1

1 Trachoma
Trachoma is the leading cause of infectious blindness worldwide. An estimated 85 million people have active trachoma, 7.6 million have trachomatous trichiasis and more than 1 million are blind.\textsuperscript{1,2} It is a disease of poor hygiene affecting those living in the poorest conditions that has disappeared from most developed countries.

Primary ocular infection with the obligate intracellular bacteria \textit{Chlamydia trachomatis} results in a self-limiting inflammatory response. However; repeated or persistent episodes of chlamydial infection result in the clinical syndrome of trachoma. Trachoma progresses from inflammation to scarring of the upper tarsal conjunctiva; eventually distortion of the eyelid causes trichiasis and subsequent loss of vision secondary to corneal opacity and scarring. In most settings where trachoma is endemic trachomatous blindness is essentially irreversible. The cycle of infection, re-infection, conjunctival scarring and trichiasis can be broken at various stages before the development of corneal opacities and visual impairment; and to achieve this The World Health Organization (WHO) has developed the SAFE strategy.\textsuperscript{3} Four related components should be delivered at the community level: Surgery for trichiasis, Antibiotics for active infection, Facial cleanliness and Environmental improvements.

Led by the WHO there is an international commitment to eliminate blinding trachoma from the world by the year 2020; this project has been named Global Elimination of Trachoma by 2020 (GET 2020).\textsuperscript{4} The mainstay of GET 2020 is the SAFE strategy which is effective in reducing the burden of blinding trachoma.\textsuperscript{5} However; simple, reliable and cost-effective systems are needed to identify populations at risk of the blinding complications of trachoma and to assess the effectiveness of trachoma intervention programs. Population based prevalence surveys are the gold standard for estimating the prevalence of active trachoma and trachomatous trichiasis within a community; and have been the mainstay of targeting and monitoring trachoma intervention.\textsuperscript{3} However, population based surveys are expensive, time consuming and may utilise resources that could be better spent on intervention programs. Therefore, WHO has developed guidelines on how to efficiently prioritise communities for intervention.\textsuperscript{6}

Once a method for surveying the population has been determined a reliable and reproducible method to identify individuals with trachoma or chlamydial infection must be used. Historically, clinical examination has formed the cornerstone of this
work, and laboratory tests have been largely confined to research. For the last several decades the simplified WHO grading system has been successfully learned.\textsuperscript{7} The simplified WHO system has proven to be easily learnt by local health workers and has demonstrated a high level of reproducibility.\textsuperscript{8} Traditionally laboratory tests used to identify \textit{C. trachomatis} lacked sensitivity, were time consuming and expensive, and often required skilled technicians or specialised equipment that was not readily available in trachoma endemic areas. However, nucleic acid testing techniques that have been developed over the last two decades offer new precision in diagnosing chlamydial infection, and a new point of care test may be suitable for use in the developing world, where trachoma predominantly thrives.

\section*{1.1 Brief history of trachoma}

Trachoma established itself as an endemic disease in Europe at the start of the nineteenth century with the return of the British and Napoleonic troops from Egypt. The disease, Egyptian ophthalmia, was said to have infected ninety per cent of British troops returning from that campaign with one in every ten eyes blind.\textsuperscript{9} Trachoma soon spread from the overcrowded military barracks to the equally overcrowded and squalid urban slums of Dickensian London. During this outbreak of hyperendemic trachoma many of most famous eye hospitals were founded;\textsuperscript{10} including in 1805 the establishment of the Central London Ophthalmic Hospital; now Moorfields Eye Hospital.

Despite its surge towards prominence in the early part of the nineteenth century the history of trachoma stretches back as far as recorded history. The oldest known records of medicine, written around 1550 BC describe the disease (Figure 1.1).\textsuperscript{11} The origin of the disease is unknown some argue it spread out from the Middle East, particularly Egypt; others claim it originated in Mongolia and spread east into China with the conquering armies of Genghis Kahn and from there to the lands around the Mediterranean.\textsuperscript{12} Records of Trachoma include: writings in China from the first millennium BC, records from Mesopotamia and Samaria pre the first millennium BC and from the Ebers Papyrus; a collection of 700 prescriptions written by Egyptian physicians between the 15\textsuperscript{th} and 19\textsuperscript{th} centuries BC.\textsuperscript{13}
The Ebers papyrus is the oldest known document that describes trachoma. It is dated from about 3000 BC and describes both active and cicatricial disease. The Ebers papyrus describes trachoma as a mucopurulent discharge and details the inverted eyelashes. Epilation forceps and medications such as zinc oxide used for the treatment of trachoma have been discovered in Egyptian tombs. The Corpus Hippocraticum; authored by the father of modern medicine in the 5th century BC, includes works on trachoma and trichiasis and in fact may provide the origin of the word trachoma from the Greek *trachus* meaning roughness. Celsus a famous Roman physician who lived during the time of the Emperor Nero wrote in his *Treatises on the Sacred Disease* that trachoma was caused by rheum flowing down from the head. He describes a surgical procedure involving the making of linear incisions in the forehead and applying red hot cautery to prominent vessels, this presumably had the effect of blocking the flow of rheum from the head.

There was little progress in the management of trachoma from the time of Celsus until the 8th century when Middle Eastern learning rose to prominence. For six centuries Arabia was the dominant centre of learning and many Arab ophthalmologists have left writings on ophthalmology in general and pertaining to trachoma in particular. Following the decline of Arabian science at the end of the fourteenth century there was little written about trachoma until it burst on to the scene once again in the early eighteen hundreds; at which time modern pathology was becoming a well characterised discipline. Lymphoid follicles; not granules, were recognised to be the...
cause of the typical roughened appearance of the conjunctiva. The natural history of the disease; progressing from inflammation to scarring of the upper tarsal conjunctiva, distortion and subsequent corneal opacity, was determined. Corneal vascularisation and Herbit’s pits were identified as hallmarks of the disease. During the 18th and 19th century Trachoma was common, often severe and treatment often ineffective; it was thought to be an infectious disease but no pathogen had been identified. Many medical and surgical treatments were attempted including: opium solution with a blistering fluid on the eyelid, zinc chloride in glycerine drops, scrapings and juice of bryonica nigra, nitric oxide of mercury, bisulphate of guanine powder, sulphur ointment and even the application of leeches to the eyes.9

It was not until the beginning of the twentieth century that two Austrians, Halberstaedter and von Prowazek, used Giemsa stain and light microscopy to demonstrate chlamydial inclusion. The so-called Halberstaedter-Prowazek (HP) bodies were found in the conjunctival scrapings of patients with trachoma and from orang-utans inoculated with infected material.14 However, the role of HP bodies was not definitively proven until 1957 when T’ang isolated chlamydia in the yolk sac of an egg.15,16

Around the start of the 20th century living conditions began to improve in the major cities of Western Europe, North America and Australia. Improvements in hygiene and reduced overcrowding quickly eliminated the conditions required for trachoma to survive and it was eradicated from these cities. By 1900 there was no active trachoma in Melbourne and cases had to be sourced from the nearby Goulbourn and La Trobe valleys to teach students.10 Trachoma continued to disappear as Australians, Europeans and Americans moved into better housing with separate rooms and beds, running water and adequate waste disposal systems. In Australia trachoma had even disappeared from non-Indigenous rural areas by the late 1930’s and in the United States the last trachoma hospital was closed soon after the end of the Second World War.
1.2 Epidemiology

Trachoma has been described as a disease of the crèche and a disease of poverty. In reality it is probably a disease of poor personal and community hygiene. Trachoma has disappeared from Western Europe and North America with the improvements in living standards and hygiene however it is still endemic in 53 countries throughout much of Africa, the Middle East, Central and South-East Asia, Latin America as well as pockets of disease in Australia and the Pacific islands (Figure 1.2).17

![Figure 1.2: Worldwide Distribution of Trachoma](image)

World map showing the distribution of trachoma, this map has been provided with permission by Dr S. Pollack.18

Trachoma tends to be localised to dry and dusty areas that are often economically disadvantaged and have inadequate access to medical services19. Migrants emigrating from endemic areas to developed countries in which trachoma has been eliminated do not seem to act as a reservoir of disease suggesting that ocular transmission of \textit{C. trachomatis} does not take place under the improved living conditions of industrialised countries.13 Trachoma will disappear with the economic development of the
impoverished regions of the world that suffer from hyperendemic levels; however it is clear that the world cannot sit around and wait for this to occur while people continue to go blind from what is an easily prevented disease.

1.2.1 The global Burden of Blindness

The number of blind in the world has stabilised over recent times; however blindness is disproportionately represented amongst the peoples of the developing world. There are 37 million blind people in the world according to a 2004 estimate, an additional 124 million people have low vision. This estimate is nearly one million lower than the 1995 estimate and substantially less than the prediction of 54 million blind by the year 2020. Over the same time period the worlds population has increased by a billion people and there as been a steady ageing of the population; this is of particular significance as 80% of blindness occurs in people over 50 years of age. The stabilisation of the overall level of blindness is a credit to the numerous ongoing programs particularly those that have been implemented in developing regions of the world; many of which are under the umbrella of Vision 2020 ‘the right to sight’ an IAPB initiative to eliminate avoidable blindness.

In 1995 the burden of blindness was found to be primarily due to Cataract (41.8%), trachoma (15.5%) and glaucoma (13.5%); however, age-related macular degeneration (AMD) and diabetic retinopathy were not included due to a paucity of data. The most recent estimate of global blindness, published in 2004, places cataract as the leading cause of blindness (47.8%); glaucoma (12.3%) has replaced trachoma as the second leading cause and AMD (8.7%) not analysed previously was third (Figure 1.3).
There has been a dramatic decrease in the levels of trachomatous blindness over the last decade. In the 1995 analysis trachoma was seen to be largely absent from developed countries but accounted for 19.4% of blindness in Sub-Saharan Africa and for 23.6% in parts of Asia. In 1995 there were an estimated 5.9 million people blind from trachoma. A review of the data in 2003 supported this estimate and suggested that about 84 million people suffered from active trachoma and 7.6 million from trachomatous trichiasis.\(^1\) The most recent estimate made in 2004 suggested that the number of people blind from trachoma had fallen to about 1.3 million.\(^2\) Nevertheless, trachomatous blindness is still disproportionately high amongst developing nations where it accounts for about 8% of blindness and is still an important population health priority.\(^20\) Blindness is not only associated with significant disability but in the developing world leads to a significantly increased risk of mortality.\(^21\) In Africa and the Western Pacific trachoma is the fourth major cause of blindness behind: cataract, glaucoma and other corneal opacities in Africa; and cataract, glaucoma and AMD in the Western Pacific region.\(^2\)
1.2.2 The Epidemiology of Trachoma

Many epidemiologic factors have been associated with *C. trachomatis* infection and the development of active or cicatricial trachoma; demographic, environmental, socioeconomic and biologic risk factors have all shown to be important. Trachoma is a disease of poor personal and community hygiene (Figure 1.4).

![Figure 1.4: The Vicious Cycle of Infection](image)

The facile transmission of *C. trachomatis* leads to repeated infection amongst children; severe inflammation ensues and is a major risk factor for the development of cicatricial trachoma and blinding complication later in life. With permission from Prof. Hugh R Taylor.

Trachoma is a focal disease that clusters to certain households within certain communities. Active trachoma is mostly seen in young children and the prevalence steadily decreases with age. The prevalence of cicatrical disease and trachomatous blindness steadily increases with age. Trachoma has been described as “a disease of the crèche” predominantly effecting young children. Hygiene factors such as the lack of a household latrine and overcrowded living conditions promote the facile transmission of trachoma between family members; this leads to repeated episodes of re-infection, which are known to be necessary for maintenance of active trachoma.
In many regions women have 2 to 6 times the rate of trichiasis that is seen in men. The higher rates of trachoma seen amongst women may be due to their role in child rearing and their continued exposure to *C. trachomatis.* Flies have long been suspected to be an important vector in the epidemiology of trachoma; and household fly density is an important and potentially amenable risk factor for trachoma. Much circumstantial evidence that flies are an important vector in the transmission of trachoma was confirmed with the discovery in a trachoma endemic area that the eye seeking fly *Musca sorbens* carries *C. trachomatis.*

Children with clean faces are less likely to have trachoma than children with unclean faces. Children with poor access to water and those living with domestic animals are also more likely to have active trachoma. Having a sibling with trachoma or having had previous episodes of active trachoma are other strong predictors of disease. Individuals tend to have a distinctive response to chlamydial infection. Longitudinal studies in several areas have demonstrated that children with moderate to severe disease were more likely to have moderate to severe disease on follow up than those with mild or no trachoma at baseline. Similarly Tunisian children were found to have a relatively stable intensity of trachoma over time. It is not entirely clear if this individualised response is due to genetic or environmental factors; however, the severity of active trachoma is strongly associated with the chance of progression to cicatricial disease.

### 1.3 Aetiology

Ocular infection with serovars A, B, Ba and C of the obligate intracellular gram negative bacterium *C. trachomatis* normally causes a relatively mild self-limiting disease; inclusion conjunctivitis. However, repeated episodes of infection produce the prolonged and intense inflammation of the conjunctiva that leads to scarring and is typical of trachoma. The infective inflammatory form of the disease or active trachoma generally occurs in young children. While infection may occur amongst adults living in trachoma endemic areas, clinical signs of active trachoma are not often present. Repeated re-infection of children leads to inflammation that progresses to scarring in later life and eventually the scarring becomes significant enough to distort the architecture of the upper eyelid. This causes the eyelid margin to roll in and the eyelashes begin to rub on the cornea. The constant abrasion on the cornea is
painful and leads to edema and possibly secondary bacterial infection. Eventually the cornea may become opaque causing an essentially irreversible loss of vision.

**Epidemiology of Trachoma**

![Epidemiology Graph]

**Figure 1.5: The natural history of trachoma**

Trachoma generally progresses from infection and active disease in children through scarring to trichiasis and blindness in adult life. With permission from Prof. Hugh R Taylor.

### 1.3.1 Biology of Chlamydia Trachomatis

*C. trachomatis* is a gram negative bacteria belonging to the genus Chlamydia. Chlamydiae are obligate intracellular bacteria that have evolved to deal with the particular difficulties associated with an intracellular lifecycle; these specific adaptations are likely to impact on the host pathogen interaction. All chlamydiae share a unique morphology and development cycle, an abundant major outer membrane protein (MOMP) which determines serologic classification, a cell wall that lacks muramic acid, a small genome and a limited capacity to synthesise macromolecules.

The chlamydial developmental cycle consists of an elementary body (EB) and a reticulate body (RB) (Figure 1.6). The metabolically inactive EB is adapted to life outside the cell. It electrostatically binds to host cells; generally mucosal, and is
internalized by endocytosis. Within the host cell cytoplasm the EB remains within a membrane bound vacuole. Normally lysosomes would fuse with such a vacuole and pour hydrolyses into it destroying its contents. However, Chlamydia are able to circumvent this defense mechanism; by an unknown mechanism and replicate within the host cell, but separated from the cytoplasm. The EB reorganizes itself within its membrane bound vacuole into an RB which multiples by binary fission. Over a replication period of 36-48 hours the RB will produce some 500-1000 daughter RB particles; during which time host cell function is minimally disrupted. The newly formed RBs consolidate to form new EBs that can be released from the cell by either cytolysis, which destroys the host cell, or by exocytosis which does not damage host cells. However, this evidence is from culture experiments with quite disabled cells and may not be a completely accurate picture of what occurs naturally.
Chlamydiae are unable to synthesize the full range of macromolecules required for multiplication. The ability to utilize host cell macromolecules rather than manufacturing their own provides a fitness advantage in the adaptation to intracellular life; allowing them to possess one of the smallest genomes of any non-viral microorganism. However, chlamydiae do need to synthesize some macromolecules and this makes them susceptible to certain antibiotics and cytokines. Of most significance is their susceptibility to azithromycin, an azalide antibiotic that inhibits RNA-dependent protein synthesis via its binding to the 50S rRNA subunit. Azithromycin is the first choice antibiotic for the treatment of ocular and genital *C. trachomatis* infections primarily because it is effective as a single dose.
1.4 Pathology

In an extensive review of the pathogenic potential of the genus Chlamydia Moulder proposed three questions.44 First; how do hosts destroy infecting Chlamydia? Second; how do Chlamydia injure their hosts; is it a consequence of intracellular growth or is it related to an inappropriate host immune response? Third; do the host and infecting organism reach a balance that facilitates the phenomenon of persistent, latent or chronic infection and if so how? The answers to these three questions are still unclear; however by addressing each we can gain some understanding of the complex pathophysiology of trachoma.

1.4.1 Host defense

Chlamydia trachomatis is an intracellular bacterium and has many of the pathologic features of a virus. One would expect that an effective host defense would be dominated by the cellular arm of the immune system.45,46 The pathogenesis of trachoma is not fully understood; however, both humoral and cell mediated immunity are induced by ocular infection with C. trachomatis.47 The immune response does provided partial protection against subsequent infection, but is also primarily responsible for the inflammation and tissue destruction that leads to blinding complications.48,49

Chlamydiae have evolved several mechanisms to evade the host immune response. Their intracellular location largely protects chlamydia from antibody and complement attack. Down-regulation of host MHC class 1 molecules by infected chlamydiae cells limits the ability of cytotoxic T cells to bind to and kill their host cells. Finally, intracellular chlamydiae are able to avoid fusion with host lysosomes. The detailed immunopathology of trachoma is not fully understood. Animal models of trachoma have suggested that a delayed type hypersensitivity reaction induced by repeated episodes of infection may be the cause of long term inflammation of the conjunctiva.50-52 Episodes of infection in children appear to be less severe and of a shorter duration as they get older.53 Some have posited that this reflects the progressive development of immunity; others have questioned whether it reflects decreased exposure to episodes of reinfection. Experimental primary infections in humans and in animals do induce some partial immunity to subsequent challenge
following recovery but this partial immunity is easily overcome. Immunity to Chlamydia is predominantly cellular, however, humoral immunity may play a limited role.

The pathological hallmark of trachomatous inflammation is the formation of lymphoid follicles that have a germinal centre and a parafollicular region dominated by lymphocytes. A diffuse inflammatory infiltrate exists between follicles and contains B and T cells, plasma cells, dendritic cells, macrophages and polymorphonuclear leucocytes.

It is probable that a successful host immune response relies on rapid activation of the Th1 cellular immune response followed by swift diminution of the inflammatory response to prevent excess tissue destruction. Any imbalance between pro-inflammatory and anti-inflammatory cytokines may result in either failure to clear infection rapidly or drawn out inflammation. Both cases result in tissue destruction and fibrosis the result of which is scarring, trichiasis and eventual corneal opacification. Children with ocular chlamydial infection rapidly upregulate the pro-inflammatory cytokines interleukin (IL) 1β, interferon γ (IFN-γ) and IL-12p40 and the regulatory cytokine IL-10. IL-1β, IFN-γ, matrix metalloproteinase 9 (MMP-9) and perforin are up-regulated in children with clinical signs and infection. Those children with clinical signs but who have cleared the chlamydial infection have increased levels of tumour necrosis factor-α (TNF-α). IFN-γ, a marker of Th1 activity, appears to be the dominant response to chlamydial infection. IFN-γ induces indoleamine 2,3-dioxygenase (IDO) which catabolises tryptophan a macromolecule required for the normal development of chlamydia. However it is possible that IFN-γ and IDO can induce persistent chlamydial infection characterized by aberrant reticulate bodies. These aberrant chlamydia may have pathological significance and have been shown to be more sensitive to azithromycin than tetracycline. IL-12p40 has a role in induction of IFN-γ and the Th1 response. IL-1β has been shown to be found in higher levels amongst those with trachoma and may be important in scar formation. IL-1β and TNF-α may stimulate extracellular matrix proteolysis via the production of MMP-9 primarily from macrophages. This reaction presumably facilitates the migration of leukocytes, macrophages and fibroblasts into the inflamed tissues that is characteristic of trachoma. Macrophages are thought to induce
conjunctival scarring via local production of connective tissue growth factor, basic fibroblast growth factor and vascular endothelial growth factor as well as IL-1β and TNF-α.\textsuperscript{65}

As soon as infection has been cleared the inflammatory reaction must be dampened to prevent excess tissue destruction. IL-10 appears to be the most important regulatory cytokine. However the impact of aberrant IL-10 production is unclear because excess production may inhibition the initial Th1 response and decreases the ability to clear infection but will also facilitate the rapid decrease of the inflammatory reaction.\textsuperscript{66} Regulatory (T_R) cells may also be important and are thought to have a role in the production of IL-10.\textsuperscript{67}

The intracellular nature of chlamydiae protects them from antibodies and complement. However, studies in humans and monkeys have repeatedly demonstrated the importance of Chlamydial heat shock protein 60 (cHSP60) in the immunopathogenesis of trachoma.\textsuperscript{51,52,68,69} Anti-cHSP60 antibodies were found to be associated with scarring when taken from the tears of Nepalese patients.\textsuperscript{56} Aberrant reticulate bodies that can persist after exposure to IFN-γ continue to produce cHSP60 and this may be an important cause of chronic tissue destruction and fibrosis.\textsuperscript{70,71} Antibodies against the outer membrane protein of chlamydia provide incomplete protection by inhibiting the elementary body from binding to and being internalized by the host cells.\textsuperscript{72}

Increasing scar tissue formation results in loss of the mucous secreting glands, degeneration of the tarsal plate and formation of subepithelial scar tissue.\textsuperscript{73} Symptoms of dry eye may develop and further inhibit the natural defense mechanism of the ocular surface, leaving the host susceptible to further infection. Alternatively fibrosis of the nasolacrimal duct may lead to a watery eye and chronic bacterial conjunctivitis. Avascular fibrous tissue appears clinically as scars and the vertical collagen fibres contract driving the formation of trichiasis.\textsuperscript{74} Both the extent of scarring and the other factors such as degeneration of the tarsal plate and weakening of the orbicularis oculi muscle help determine progression of disease.\textsuperscript{75}
1.4.2 Clinical Features of disease

The clinical features of trachoma can be divided into two distinct categories. Active trachoma results from inflammation caused by repeated infection with \textit{C. trachomatis}. Cicatrical disease develops in individuals who have had active trachoma in the past. The hallmarks of cicatricial disease are: conjunctival scarring, entropion, trichiasis and corneal pannus and opacity. Active trachoma may induce an ocular mucopurulent discharge; however, the entire spectrum of trachoma may be asymptomatic until the end-stage when eyelashes rub on the cornea and cause pain.

![Figure 1.7: Trachomatous inflammation follicular](image)

\textbf{Figure 1.7: Trachomatous inflammation follicular}

Picture demonstrating the follicle the hallmark of active trachoma.

The major sign of active trachoma is the characteristic follicle (Figure 1.7). Present on the superior tarsal conjunctiva, follicles are large white or pale yellow spots that can be slightly elevated. Follicles have a diameter of at least 0.5 mm and may be up to 2 mm. Papillae may appear alongside follicles and initially emerge as pinpoint red dots but may become much larger. They can coalesce and the conjunctiva will take on a thickened and edematous appearance (Figure 1.8). However, papillae are not specific for trachoma. The intensity of the papillary response tends to increase with the severity of disease and the conjunctiva can take on a velvety red appearance. The
 conjunctiva can become so thickened and edematous that it obscures the underlying deep tarsal vessels from view. Older people who develop ocular \textit{C. trachomatis} infection often do not display a follicular response but may still develop a papillary reaction, particularly if there is secondary bacterial infection. Although red, their scarred tarsal conjunctiva usually will not have a fully developed papillary response.

\textbf{Figure 1.8: Trachomatous inflammation intense}

Intense inflammation results in an oedematous conjunctiva with a thickened velvety appearance. Over time fine scars appear on the superior tarsal conjunctiva (Figure 1.9a). Initially small stellate figures they gradually coalesce to form a dense basket-weave pattern. A thick band often forms near the lid margin and is termed Arlt’s line (Figure 1.9b). Once significant scarring has occurred it can be difficult to detect follicles amongst the scarring. The scar tissue disrupts the mucous secretion of the conjunctiva and can lead to symptoms of dry eye.
Figure 1.9: Trachomatous scarring
Initially fine scars develop a) over time they will coalesce to form a more dense pattern b) that can alter the architecture of the eyelid.
Scar tissue contracts and eventually it can distort the lid margin causing it to rotate inwards, entropion. The lashes will be pulled towards the globe and may rub on the cornea, trichiasis (Figure 1.10).

**Figure 1.10: Trachomatous Trichiasis**

If scarring alters the architecture of the eyelid sufficiently the lid margin rotates in and the lashes will contact the globe.

Corneal oedema, ulceration and scarring secondary to the abrasion of the lashes on the cornea lead to opacity and essentially irreversible blindness (Figure 1.11). The hallmarks of trachoma are pannus the inflammatory vascular tissue that extends across the cornea from the limbus; and the pathognomonic Herbert’s pits. Pannus and Herbert’s pits do not directly cause vision loss; rather they are signs that have been used to aid in diagnosis of trachoma. However, neither sign is specifically looked for in the currently used simplified WHO grading system.
1.4.3 Animal Models of Trachoma

Much of the evidence regarding the pathogenesis of trachoma has been gleaned from animal models; these models can also help to establish the kinetics of trachoma. Models of trachoma have been developed in the cynomolgus, owl, rhesus and pig-tailed monkeys, and the guinea pig.\textsuperscript{50,52,54,76-79} Experiments fall into three broad categories. Primary infection involves inoculating animals that have had no previous exposure to trachoma. Secondary infection examines the response to rechallenge with infectious agent in animals that have recovered from a previous infection. However, only repeated infection, in which animals are inoculated with infectious agent at regular intervals, leads to a clinical picture comparable to human trachoma.

Primary infection

Primary inoculation of cynomolgus monkeys with \textit{C. trachomatis} leads to an acute, self-limiting conjunctivitis. An acute mucopurulent discharge develops on the third day, follicles develop slowly over the first three weeks and spontaneous resolution
begins after four weeks with complete resolution by about ten weeks after infection (Figure 1.12). This picture is very similar to acute infection in humans. In the monkey model C. trachomatis can be isolated experimentally by cell culture on the third day after inoculation, prior to the development of follicles. It is possible to isolate organism for about 4 weeks after inoculation, but the clinical signs remain for a further 6 weeks in the absence of identifiable organism. A similar picture is seen in guinea pigs inoculated with guinea pig inclusion conjunctivitis agent (GPIC). This produces an acute conjunctivitis without follicles that resolves in 4-6 weeks.\textsuperscript{82} Conjunctival scrapings of guinea pigs showed similar kinetics to the monkeys with GPIC inclusions seen from about day 3 to 3 weeks.
Wright HR. Trachoma.

Figure 1.12: Primary infection in Cynomolgus monkeys
A single inoculation in naïve monkeys leads to a self limiting conjunctivitis.83

Secondary infection
Inoculation of cynomolgus monkeys that have recovered from previous infection or that have been vaccinated elicits an attenuated clinical response (Figure 1.13).83 The less severe response and shorter duration of clinical signs is evidence for a level of resistance in the animals.54 Evidence of moderate levels of immunity is seen even when higher titres of inoculum are used in subsequent challenges, and this finding has be repeated in owl monkeys78 and amongst human volunteers.81,84
Evidence of partial immunity comes from the attenuated clinical response seen in monkeys that have had previous exposure to *C. trachomatis*.\(^{54}\)

### Repeat infection

Repeated inoculation of cynomolgus monkeys with chlamydia leads to the development of a chronic follicular conjunctivitis closely resembling human trachoma (Figure 1.14).\(^{52,54,79,83}\) With weekly re-inoculation, follicles appear after one week and become more pronounced over 2 months. Thereafter, the inflammatory response wanes somewhat but persists for as long as inoculations are continued. The follicular and inflammatory response resolves over about 3 months once the weekly inoculations are stopped.\(^{54}\)
A pattern similar to human trachoma is only seen when animals are subjected to repeated inoculations.\textsuperscript{83}

A similar response is seen in Guinea Pigs that are subjected to repeated inoculations with (GPIC), at various intervals ranging from 30 to 112 days. A chronic inflammatory response is seen, characterised by the development of progressively larger follicles after each reinfection.\textsuperscript{50} The duration of inflammation increased after each successive inoculation culminating in an inflammatory response that persisted for over a year. In the cynomolgus monkey model chlamydia can be detected by Giemsa cytology, culture or DFA within one week of starting inoculation as is seen after primary inoculation. However, despite the continuation of weekly inoculations chlamydia cannot be isolated after a period of time depending on the sensitivity of the test; about 4 weeks for Giemsa cytology, 6 weeks for culture and 10 weeks for DFA (Figure 1.15).\textsuperscript{85,86}
Laboratory tests fail to identify organism after a certain period of time despite continued inoculation.86

1.4.4 Kinetics of Trachoma

The kinetics of trachoma is a controversial topic and is still not well understood. However, an understanding of this topic is imperative to the optimal design of a trachoma intervention program because it may govern the optimal timing for monitoring and re-treatment. A simplistic model (Figure 1.16) describes a prodrome period during which C. trachomatis infection is present but clinical signs have not yet appeared. This is followed by a period of ‘frank disease’ during which infection and clinical signs co-exist. Once the immune system clears the infection there is a period of time, recovery phase, during which clinical signs persist in the absence of identifiable infectious organism. This model is complicated by repeated re-infection and possibly by persistent infection.
Figure 1.16: The kinetics of trachoma

There is a prodrome prior to the development of clinical disease. Once infectious agent has been cleared there is a recovery period.\cite{87}

Trachoma is complicated by the notion that it is sustained by repeated episodes of reinfection that maintain the pathological immune response that is clinically recognised as ‘active trachoma’. The time frame for each of these stages, that govern the relationship between chlamydial infection and clinical trachoma, has been studied in both animal models\cite{50,52,54,76-79,82,88,89} and humans.\cite{23,40,80,81,84,90} However, human studies are complicated by the inability to measure or control the exposure to infection and the occurrence, or timing, of repeated episodes of reinfection. One hundred members of 9 Tanzanian families were examined for trachoma and had DFA swabs collected every three months for a year.\cite{23} Twenty of the 53 children had clinically active trachoma on each visit; these persistently infected children were antigen positive by DFA 85% of the time. Over the year 14% of children developed active trachoma; and in 26% active trachoma resolved. Most of the children who developed active trachoma during the study had demonstrable chlamydial antigen when they were first seen with active disease. One child who was antigen positive but clinically normal on one visit had developed active trachoma at the next visit. Antigen was always undetectable in children at the visit prior to the resolution of active trachoma. The lag period between the last demonstration of infection and resolution ranged from 3 months (the next visit) to 9 months. Also of interest was the finding of 3 children who had chlamydia in their conjunctiva who did not develop active trachoma.
The duration of each phase of the disease is not known with certainty. From animal models we can estimate that the prodromal phase is short lasting for several days to no more than a week. The duration of ‘frank disease’ may persist for as long as re-infection continues to occur. However, in the absence of re-infection animal models suggest it may last for about three or 4 weeks.

Insight into the duration of the recovery phase may be gained from longitudinal studies. Clinical signs can persist in humans with trachoma for a period of 3 months or more. Individuals in the Gambia were examined on three occasions over a 20-month period. The majority of active trachoma was found in the under 15 year old group. On each visit those who had moderate to severe trachoma on a previous survey were more likely to currently have moderate or severe trachoma than those who had previously had mild or no trachoma. A finding that could be taken as support for the theory that certain individuals have a susceptibility to severe disease and the subsequent risk of developing scarring and visually disabling lesions. The length of time that clinical signs persist after organism has been eradicated might be quite variable, a study in Nepal found a greater decline in the prevalence of infection than of clinical signs after mass antibiotic treatment the persistence of follicles was provided as one possible explanation for this. The above findings are consistent with those described in the monkey model and suggest that there is a lengthy lag period during which clinical signs of trachoma persist and infectious agent can not be identified.

1.5 Grading and Diagnosis

There have been three major grading systems used in the clinical assessment of trachoma. In 1908 MacCallan first proposed four stages of the disease and published a grading system based on these stages in 1931. However, this system represented a simplistic view of trachoma that was not entirely correct. The standard WHO system codified by Dawson, Jones and Darougar in 1976 rectified the inconsistencies in MacCallan’s system. This new system was added to over a number of years and ultimately become to complicated and cumbersome to be of practical use in the field setting. The simplified WHO system was published in 1987. It discarded many of the clinical features used by the previous systems, and focused on five key clinical signs that were each graded as present or absent.
1.5.1 MacCallan

The four stages of trachoma proposed by MacCallan (Table 1.1) represented a great advance at the time because it recognized the progressive nature of the disease. However, the MacCallan classification lacked the ability to differentiate between varying degrees of inflammation and did not provide data on visually disabling lesions. It also incorrectly assumed the disease always progressed from stage I to IV and did not allow for the possibility of active disease co-existing with cicatricial disease. Between 1950 and 1975 a series of WHO Expert Groups met in an effort to address the above concerns with the grading system. Multiple additions and sub-classifications were added over the years as the system developed and expanded. However, it eventually became very complex and ultimately unworkable.

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage I:</td>
<td>Incipient trachoma: immature follicles in superior tarsal conjunctiva and early corneal changes.</td>
</tr>
<tr>
<td>Stage IIa:</td>
<td>Follicular hypertrophy: mature superior tarsal follicles with possible limbal follicles, superior pannus and subepithelial infiltrates.</td>
</tr>
<tr>
<td>Stage IIb:</td>
<td>Papillary hypertrophy: follicles become obscured by conjunctival inflammation.</td>
</tr>
<tr>
<td>Stage III:</td>
<td>Cicatization: characterized by scarring and early lid deformities in addition to the presence of follicles.</td>
</tr>
<tr>
<td>Stage IV:</td>
<td>Inactive trachoma: inflammation and follicles are absent however scarring remains and has led to lid deformities: cicatrical entropion, trichiasis and tear insufficiency.</td>
</tr>
</tbody>
</table>

Table 1.1: MacCallan classification

1.5.2 WHO System

In 1975 a new codified WHO System was developed by Dawson, Jones and Darougar that graded seven features independently. The WHO system introduced increased complexity, but rectified the deficiencies of the MacCallan system. Varying degrees of inflammation were distinguished using four tier scale that independently assessed lymphoid follicles (Table 1.2) and papillary hypertrophy (Table 1.3). Follicles and hypertrophy are scored according to their presence within three zones of the upper tarsus. Zone one includes the entire upper tarsal border; zone two occupies an intermediate area between zone one and three. Zone three includes the tarsal...
conjunctiva adjacent to the central half of the lid margin. Figure 1.17 demonstrates the grading zones used in the WHO system and the simplified WHO system.

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>F0</td>
<td>No follicles present</td>
</tr>
<tr>
<td>F1</td>
<td>Follicles but less than 5 in zones 2 and 3 together.</td>
</tr>
<tr>
<td>F2</td>
<td>More follicles than F1 but less than 5 in zone 3.</td>
</tr>
<tr>
<td>F3</td>
<td>Five or more in each of the 3 zones.</td>
</tr>
</tbody>
</table>

Table 1.2: Lymphoid follicular score

<table>
<thead>
<tr>
<th>Score</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>Normal deep subconjunctival vessels.</td>
</tr>
<tr>
<td>P2</td>
<td>Vessels appear hazy.</td>
</tr>
<tr>
<td>P3</td>
<td>Normal vessels obscured by thickened conjunctiva.</td>
</tr>
</tbody>
</table>

Table 1.3: Upper tarsal hypertrophy score

Conjunctival scarring, trichiasis/entropion, corneal pannus and Herbit’s Pits were also scored. Scores were then collated to give an overall disease severity (Table 1.4). Even this system proved to be complicated. Inter- and intra-observer reliability proved to be relatively poor even when used by experienced ophthalmologists. Much of the data collected was useful for standardized research projects; however, was not of much
practical benefit for planning or monitoring trachoma intervention programs. It was also impractical for use by local health workers, the mainstay of trachoma control program monitoring.

<table>
<thead>
<tr>
<th>Intensity</th>
<th>Follicle Score (F)</th>
<th>Papillary Hypertrophy (P)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inactive/ insignificant</td>
<td>F0 or F1</td>
<td>P1 or P2</td>
</tr>
<tr>
<td>Mild</td>
<td>F2(F3 if follicles &lt;0.5mm)</td>
<td>P1 or P2</td>
</tr>
<tr>
<td>Moderate</td>
<td>F3</td>
<td>P2</td>
</tr>
<tr>
<td>Severe</td>
<td>F1, F2 or F3</td>
<td>P3</td>
</tr>
</tbody>
</table>

Table 1.4: WHO standard system

1.5.3 Simplified WHO system

In 1987 the Simplified WHO Trachoma Grading System was introduced, it reduced the number of independent signs to five and graded each as present or absent (Table 1.5)\(^7\). It has been widely used over the last couple of decades and has proven to be easily learned by local health workers. It is highly reproducible; with good inter and intra observer reliability\(^8\).

<table>
<thead>
<tr>
<th>Grade</th>
<th>Clinical signs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trachomatous inflammation follicular (TF)</td>
<td>Five or more follicles of &gt; 0.5 mm on upper tarsal conjunctiva.</td>
</tr>
<tr>
<td>Trachomatous inflammation intense (TI)</td>
<td>Inflammatory thickening obscuring &gt; half the normal deep tarsal vessels.</td>
</tr>
<tr>
<td>Trachomatous conjunctival scarring (TS)</td>
<td>The presence of easily visible scars in the tarsal conjunctiva.</td>
</tr>
<tr>
<td>Trachomatous trichiasis (TT)</td>
<td>At least one eyelash rubbing on the eyeball.</td>
</tr>
<tr>
<td>Corneal opacity (CO)</td>
<td>Corneal opacity blurring part of pupil margin.</td>
</tr>
</tbody>
</table>

Table 1.5: Simplified WHO grading system

The simplified WHO system may be an oversimplification. It is undoubtedly of great practical value for field work, yet it may fail to collect data that are desirable in controlled research studies. If an individual has four follicles and only 30% of their deep tarsal vessels are obscured by edema then they are judged to be normal. This is of no-importance in a programmatic sense; however, it may create anomalous data if for instance PCR findings are compared to clinical signs. In the following section much of the published field work has been analyzed. Various grading system were used by the different studies and it was necessary to compare between the different
grading systems. No active trachoma, active trachoma, severe active trachoma and cicatricial trachoma were defined according to Table 1.6 for each of the three major grading systems.

<table>
<thead>
<tr>
<th></th>
<th>MacCallan</th>
<th>WHO-1976</th>
<th>Simplified WHO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active Trachoma</td>
<td>Stage I</td>
<td>Mild</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Stage IIa</td>
<td>Moderate</td>
<td>TF</td>
</tr>
<tr>
<td>Severe Active Trachoma</td>
<td>Stage IIb</td>
<td>Severe</td>
<td>TI +/- TF</td>
</tr>
<tr>
<td>Cicatricial Trachoma</td>
<td>Stage III</td>
<td>Mild or Moderate</td>
<td>TS +/- TF/TI ()</td>
</tr>
<tr>
<td></td>
<td>Stage IV</td>
<td>C1-3, T/E 1-3</td>
<td>TS +/- TT</td>
</tr>
</tbody>
</table>

Table 1.6: Comparison of the Major grading systems

### 1.6 Laboratory Diagnosis

There has been a historical evolution in the methods used to detect *C. trachomatis*. Identification techniques are classified into four broad categories.

- The cytological finding of intra-cytoplasmic inclusions within the patient’s epithelial cells either by Giemsa stain¹⁴ or by fluorescent labelled monoclonal antibodies (DFA)⁹⁶. DFA cytology can identify free elementary bodies in addition to those within the cytoplasm of host epithelial cells.

- The culture of chlamydiae in a suitable medium, initially egg yolk¹⁵,¹⁶ and then in a number of cell culture systems⁹⁷,⁹⁸.

- Nucleic acid detection is the newest and most sensitive test and relies on identification of unique chlamydial DNA or RNA sequences via probing or amplification techniques.

- Serology testing measures anti-chlamydial antibodies in host serum or secretions and has been used in the diagnosis of sexually transmitted chlamydial infection and chlamydial pneumonia but has not proved of practical use in the diagnosis of trachoma. Serological techniques have been widely used in epidemiologic studies to distinguish between specific serovars of *C. trachomatis*.

Much field work has been conducted over the last three decades examining the relationship between clinical signs and laboratory evidence of *C. trachomatis*. There
is no doubt that repeated infection with *C. trachomatis* is necessary for the development of the clinical syndrome of trachoma. However, this relationship has not always been easy to demonstrate. Four laboratory tests have been used and each is briefly described below.

### 1.6.1 Laboratory tests

**Giemsa**

The intra-cytoplasmic inclusions typical of chlamydial infection were first identified by Halberstaedter and Von Prowazek in 1907 using Giemsa stain and light microscopy to examine conjunctival scrapings of patients with trachoma. Giemsa is a relatively cheap however; it is time consuming and requires considerable expertise to identify the inclusion bodies. In much of the early work using this technique only a small percentage of clinical infected individuals had laboratory evidence of infections. This was thought to be due deficiencies in the test.

**DFA**

DFA can be considered an upgraded form of cytology in which labeled monoclonal-antibodies are used instead of a stain. Labeled antibodies bind to a target and can then be imaged using various techniques. Researchers at the Harvard school of Public Health first demonstrated the increased sensitivity of DFA by using fluorescent antibodies in 1963. DFA rapidly resulted in improved sensitivity. Sensitivity here and throughout this work refers to the proportion of individuals with clinical trachoma who are found to have laboratory evidence of infection. However, there were still a large number of people who had clinical signs but did not have laboratory evidence of chlamydial infection.

**Culture**

*C. trachomatis* is an obligate intracellular bacterium. Therefore it can not be simply cultured on a plate like many other pathogens. Rather a method was developed that mimicked the intracellular environment and thus allowed the bacteria to grow. The yolk sac method had long been used to isolate chlamydial species; however, T’ang and co-workers were the first to utilize this method to isolate chlamydia from patients with trachoma in 1957. This was really the definitive proof that *C. trachomatis* was
the causative agent for trachoma. Culture of chlamydia was difficult and proved to have a low sensitivity. Improved techniques led to better sensitivity. Gordon and Quan utilized irradiated McCoy cells in 1965 and Kuo and colleagues used DEAE-treated HeLa cells in 1972; however, the sensitivity rarely exceeded that of DFA.

Nucleic Acid Tests (NATs)

The development of polymerase chain reaction (PCR) and other nucleic acid amplification tests has revolutionized laboratory research. In this work these tests are discussed together under the heading nucleic acid tests (NATs). NATs have added a new magnitude of sensitivity to the older methods and in many areas of research have achieved sensitivity approaching 100% with a high specificity. Unlike the other tests NATs do not require great expertise and they can be rapidly performed. However, they are still expensive and require a well maintained laboratory. The highly sensitive NATs correlate relatively poorly with clinical grading particularly in areas with a low prevalence of trachoma\textsuperscript{99-101}; a finding that has prompted some to suggest that NATs could replace clinical grading as the tool for diagnosing trachoma\textsuperscript{5,102-106}. It is argued that because TF is poorly predictive of infection it should not be used as the basis for initiating an antibiotic based intervention.

1.6.2 The relationship between clinical and laboratory diagnosis

Data were identified by a search of Medline and by hand searching references from relevant articles. Search terms were ‘trachoma’ and ‘chlamydial infection’. Only English language papers were reviewed. Data were included from studies that reported the results of laboratory tests on individuals who had undergone clinical assessment for trachoma. Much field work has been undertaken over the last several decades and data from the following studies were analysed\textsuperscript{23,39,41,43,90,92,99,101,102,104,105,107-129}. The increasing accuracy of laboratory tests is reflected in their ability to identify \textit{C. Trachomatis} in individuals with clinical signs of active trachoma. In areas hyperendemic for trachoma (≥ 20% prevalence) swabs taken from children with active trachoma were positive 30% of the time for Giemsa, 35% for culture, just fewer than 60% for DFA and 64% of the time for PCR (Figure 1.18). Laboratory tests tended to become more accurate at detecting infection in
children with clinical disease as the prevalence of trachoma increased. PCR was only positive in 17% of children who had clinical signs of active trachoma in hypoendemic areas (< 10% prevalence); however, this rose to 27% in endemic areas (10-19% prevalence) and 64% in hyperendemic regions (Figure 1.18).

Figure 1.18: Laboratory tests for diagnosing C. trachomatis infection.87
The references in figures 1.18, 1.19 and 1.20 are from a previously pub

The severity of clinical disease was also an important predictor for the sensitivity of laboratory tests (Figure 1.19). Children with intense inflammation (TI) are more likely to have organism identified from a swab than those who have active trachoma but do not have the TI sign. Quantitative PCR has confirmed this finding by demonstrating higher levels of organism in those with TI with or without TF than those with TF alone.130
Chlamydia was often identified in people who did not have current signs of active trachoma (Figure 1.20). Organism was identified more frequently in those with trachomatous scarring than those without scarring. This may be because they continue to live in ‘trachoma families’ with poor hygiene and are in close proximity to children with active trachoma. Alternatively a low grade, persistent infection may contribute to the pathological process of scarring\textsuperscript{60,131}. The high proportion of people without active trachoma who were positive by PCR in hyperendemic areas has not been adequately explained. Adequate precautions against possible specimen contamination in the field were not always undertaken, especially in the early studies, and this finding must be viewed circumspectly. Alternatively the widespread use of the simplified WHO system may mean that individuals in the early stages of ‘frank disease’ (see Figure 1.16) may be classified as normal when they have some signs of trachoma but not sufficient to meet the criteria for TF. However, it may represent a genuine phenomenon and there may be a subset of individuals who carry \textit{C. trachomatis} but do not develop clinical trachoma. Work undertaken as part of this thesis has suggested and validated the use of a more detailed grading system for research. The grading system is based on photographs. Field work can continue to be performed by health workers and will be only minimally disrupted. However, researchers should then grade photos to further classify the severity of active trachoma.

\textbf{Figure 1.19: Laboratory tests according to disease severity.}

The presence of \textit{C. trachomatis} in people who do not have current signs of active trachoma (Figure 1.20) suggests that organisms may persist in these individuals, contributing to the pathological process of scarring. The high proportion of people without active trachoma who were positive by PCR in hyperendemic areas has not been adequately explained.
The clinical signs and laboratory tests used to diagnose trachoma correlate relatively poorly, particularly in low prevalence settings. This seems to be largely due to the kinetics of infection and clinical signs rather than problems inherent in either detection system. Trachoma has an incubation period with infection in the absence of clinical signs; this is followed by frank disease with both infection and clinical signs. Finally there is a recovery phase after the organism has been cleared during which clinical signs slowly resolve. The relative proportion of people in each phase will vary with intensity of infection and the frequency of re-infection. There is evidence for this prodromal phase from volunteer studies.80

**1.7 Survey Methods**

Simple, reliable and cost-effective systems are needed to identify populations at risk of the blinding complications of trachoma and to assess the effectiveness of trachoma intervention programs. Prevalence surveys have proved the mainstay of targeting and monitoring trachoma intervention, generally using a 2 stage cluster sampling technique published by the WHO.3 However, prevalence surveys tend to be expensive and time consuming, possibly utilising resources that could be better spent on trachoma intervention programs. Trachoma Rapid Assessment (TRA) developed by the WHO6 attempts to quickly, cheaply and efficiently obtain the information needed to identify and prioritize areas for intervention programs. Unfortunately some authors
have used data from TRA surveys to give prevalence estimates. It was explicitly
designed not to yield prevalence data as it selects an ‘optimally biased’ sample in
order to detect trachoma if present. A third method, Lot Quality Assurance Sampling
(LQAS), has been also been trialled in an effort to rapidly and efficiently categorise
regions with blinding trachoma by prevalence bands.132 When used in the setting of
trachoma intervention programs it has been called Acceptance Sampling Trachoma
Rapid Assessment (ASTRA). Due to the uncertainty regarding survey techniques in
the literature a short review was prepared and published as part of the work for this
thesis.133

1.7.1 Field trials of TRA and ASTRA

Results of several TRA field tests have been published some of which have compared
TRA with prevalence survey results.134-137 They suggest that TRA is reasonably
accurate in prioritising communities with higher levels of active trachoma. However,
TRA did less well ranking communities with a low prevalence, although this is
relatively less important as these communities were almost always assigned a low
priority ranking. All studies reported that TRA was quicker and cheaper than a
prevalence study. Two studies134,136 reported that there was an overemphasis on risk
factor scores and this may need to be addressed. There was one report of the
effectiveness of LQAS in trachoma assessment.132 The threshold was set at 14 and a
maximum of 50 children aged 2-5 were identified for examination. They were able to
accurately identify a community with a prevalence of \( \leq 20\% \) with a sensitivity of 94%
and a prevalence of \( \geq 40\% \) with 95% sensitivity.

1.7.2 Which method is most appropriate?

According to WHO guidelines a community should receive mass antibiotic treatment
when the prevalence of TF is greater than 10% amongst 1-9 year old children.
Treatment should continue for three years before the village is reassessed; after which
mass treatment should continue until the prevalence drops below 5%. The three
survey methods discussed above all have different strengths and weaknesses and any
decision about which to use must take into account local factors and the aim of the
survey.
When deciding on which survey technique to use it is important to consider what the aim of the survey is. TRA may be useful for rapidly prioritising communities for intervention. However once a community has been identified for intervention a prevalence survey, or possibly ASTRA should be undertaken to allow program monitoring. Finally in order to certify that a region is clear of trachoma TRA is probably the most efficient method. The role of ASTRA needs to be further defined and more research is needed particularly examining the effect of using different cut-off points.
1.8 The Safe Strategy

Trachomatous blindness is virtually untreatable but it is eminently possible to disrupt the cycle of infection and re-infection that prelude the development of active trachoma and cicatricial disease. It is even possible to operatively correct end-stage disease and prevent or reduce the progression to blindness. However, once the cornea is opaque there is no effective management that is suitable in the regions of the world where trachoma is endemic.

Figure 1.21: The SAFE strategy
Cartoon demonstrating the four interrelated components of the SAFE strategy. With permission from Victoria Francis.

The WHO has set the admirable goal of eliminating trachoma has a cause of blindness by the year 2020; Global elimination of Trachoma by 2020 (GET 2020). Non-governmental organizations, UN agencies, governments and health ministries are working towards this goal through promotion of the SAFE strategy. All components of the SAFE strategy should be implemented wherever trachoma is endemic: surgery to treat end stage disease, antibiotics to help reduce the reservoir of infection within
communities, facial cleanliness and environmental improvements to reduce the transmission of disease (Figure 1.21). However the SAFE strategy is more than just these four components it is about instigating community involvement through education and disease awareness promotion, knowledge about possible solutions and supporting individual, household and community level action\(^5\). Sustainable trachoma control requires that the community and individuals commit to certain behavioural changes and these will only occur with a strong involved and educated community.

### 1.8.1 Surgery

Corneal opacity may develop in a third of individuals with untreated trichiasis over a year.\(^{138}\) Trichiasis itself is a cause of significant disability and reduced quality of life.\(^{139,140}\) If active trachoma were to be eliminated today there will still be a generation at risk of trichiasis and unnecessary blindness. For them surgical intervention is currently the only effective management and more research is required for the optimal delivery of surgical programs. WHO recommends the bilamellar tarsal rotation (BTR) procedure\(^{141}\) for the treatment of trichiasis on the basis of an RCT conducted in Oman.\(^{142}\) The procedure was first described by Wies in 1955\(^{143}\) and refined by Ballen in 1964.\(^{144}\) Surgical intervention programs have been widely implemented, but are thwarted by high recurrence rates and poor acceptance of surgery.

Trichiasis surgery has an acceptable complication profile but recurrence has been a major concern.\(^{145}\) Reacher reported a 2 year recurrence rate of 18% for major trichiasis;\(^{142}\) and a recent surgical program in Ethiopia reported a one year recurrence rate of just 8%.\(^{146}\) Both studies undertook meticulous surgery and represent a benchmark recurrence rate that surgical programs should aim for. Reported recurrence rates after two or 3 years vary greatly, from 20% to 60%,\(^{147-152}\) and this may represent less attentive surgery. However, recurrence is often defined as a single lash touching any part of the globe and so may still represent a significant improvement. Furthermore, due to the progressive natural history of trachoma some level of recurrence may be inevitable. Individuals followed for 17 years after surgery had recurrent trichiasis in 47% of operated eyes compared to new trichiasis in 55% of unoperated eyes.\(^{153}\) Risk factors for recurrence include: concurrent chlamydial infection,\(^{154}\) inflammation,\(^{155}\) the type and number of sutures used,\(^{156}\) and minor
variations in surgical technique.\textsuperscript{157} Recurrence rates do vary between surgeons and with disease severity\textsuperscript{158} reiterating the importance of high quality surgery combined with ongoing surgical audit and suggesting that early intervention may be warranted.

Azithromycin may reduce post-operative recurrence and has been assessed in three trials. The first RCT found no benefit for adjuvant azithromycin; however, the rate of chlamydial infection was low (5\%) and recurrence rates were very high.\textsuperscript{158} Another RCT in an area with a higher prevalence of infection (19\%) found a 33\% reduction in the risk of recurrence for patients given azithromycin.\textsuperscript{146} Further support for adjuvant azithromycin comes from a controlled study in Nepal.\textsuperscript{159} It is unclear whether the reduced recurrence is due to a specific reduction in chlamydia or a more general reduction in Gram positive ocular pathogens.

In Tanzania as few as 1 in 5 women with major trichiasis presented for surgery within 2 years of diagnosis.\textsuperscript{160,161} Barriers to acceptance of surgery and predictors of attendance for surgery have been identified (Table 1.7).\textsuperscript{160-165} The major barriers to surgery appear to be ignorance of surgery, fear of surgery, the perceived direct and indirect costs and transport difficulties. If surgical programs are to be successful they must identify important local barriers and address these as well as those identified above. With proper training and attention to detail surgery provided by ophthalmic nurses is as good as surgery provided by ophthalmologists\textsuperscript{166} and village-based surgery is safe and effective.\textsuperscript{147} The provision of local surgery by trained ophthalmic nurses should reduce the costs and transport difficulties associated with accessing surgery and may be more acceptable than health centre-based programs.\textsuperscript{167} High recurrence rates may contribute to poor acceptance of surgical programs. The provision of high quality surgery needs to be augmented by annual follow up and rigorous surgical audit to monitor recurrence rates.
Predictors of Acceptance of Surgery | Predictors of not attending for Surgery
---|---
Other household member with income$^{164}$ | Ignorance of the availability of surgery$^{161,164,165}$
Symptoms that interfere with work$^{164}$ | Cost$^{160,161,163-165}$
Previous ignorance of the availability of surgery$^{164}$ | Being too busy$^{160,164,165}$
Bilateral trichiasis$^{162}$ | Fear$^{164,165}$
Being a widow$^{162}$ | Transportation difficulties$^{30,51,165}$
Living near the main road$^{162}$ | No support person to accompany them$^{160,164,165}$
Low socioeconomic status$^{162}$ | Having to leave children at home$^{160}$
Knowing someone who has had surgery$^{162}$ | Symptoms not that bad$^{164}$
Knowing someone who has had surgery$^{162}$ | Previous bad experience with surgery$^{164}$
Epilation (or other treatment) fine$^{164}$ | Heard radio broadcast$^{164}$
Illiteracy$^{165}$ | 

Table 1.7: Barriers to the acceptance of surgery

There are numerous reasons why people accept or do not accept the provision of surgery as summarised in this table. It may be possible to address some of these barriers and increase the uptake of surgical intervention programs. (Wright, Turner and Taylor. Seminar: Trachoma. Lancet. Submitted)

Trichiasis surgery is not sight restoring, unlike cataract surgery, and the challenge is to develop surgical programs that provide rapid, acceptable surgery with a low recurrence rate. Modelling suggests that if surgery could be provided to 80% of patients with trichiasis it would avert 11 million disability-adjusted life years (DALYs) annually at a cost of between US$13- US$78 (international dollars) per DALY averted.$^{168}$ In the Gambia providing local surgery costs about one-tenth of the estimated cost due to lost productivity secondary to trachomatous visual impairment.$^{169}$ Surgical intervention is not the only treatment option for trachomatous trichiasis. Epilation has presumably been used to treat trichiasis since the beginning of history.$^{142}$ However, its efficacy is limited and it is associated with a high risk of corneal scarring.$^{170}$ Permanent eyelash removal using electrolysis, cryotherapy and laser have not proven effective in the treatment of trichiasis, nor are such technologies generally availability in trachoma endemic areas.$^{171}$
1.8.2 Antibiotics

Chlamydia trachomatis is amenable to eradication; it is susceptible to both topical and oral antibiotics and has no known animal reservoir. But mass, community based treatment is needed. Providing antibiotic treatment to individuals with active trachoma who live in an endemic area is a futile gesture. The facile transmission of *C. trachomatis* and the overcrowded conditions that are typical in trachoma endemic areas mean that individuals will be rapidly re-infected. The reservoir of infection within a community must be reduced in order to minimise the transmission of trachoma and the chance of re-infection, and this requires mass community-wide treatment. The antibiotic distribution arm of the SAFE strategy calls for annual community-wide antibiotic treatment when the prevalence of active trachoma is greater than 10% in children aged 1-9. Treatment should continue for at least 3 years and then the prevalence should be reassessed; treatment should continue until the prevalence drops below 5%.1

The medical management of trachoma dates back to the use of copper salts as recorded on the Ebers papyrus 3500 years ago. The use of copper salts was a treatment that may have done more harm than good, and they were still routinely used to treat active trachoma in the United States until Loe demonstrated the efficacy of topical and oral sulphonamides in 1938.172 In the following years reports of high cure rates abounded. Thygeson reported a cure rate of 96%, in Morocco Reinhards demonstrated a cure rate of around 90% and Schultz reported a cure rate of greater than 80% for various regimens of topical tetracycline and oral sulphonamide.173 However, despite the apparent high cure rates no long term decrease in trachoma prevalence could be attributed to antibiotic treatment programs. Three year follow up after mass treatment with combined topical tetracycline and oral sulphonamide to Indian children on an Arizona reservation demonstrated that the prevalence was unchanged despite an initial 90% cure rate.173 Results of the first randomised controlled trial were published by Foster in 1966. Three hundred and twenty five children with active disease were randomised to receive oral sulphonamide, topical tetracycline or no treatment.173 Foster reported no difference in cure rate between the treatment groups and the control group at 3 or 12 month follow up. The disappointment of treating individuals with antibiotics was further highlighted when
Woolridge failed to demonstrate a significant cure rate with topical tetracycline on its own or in conjunction with systemic sulphonamides in three separate field studies.\textsuperscript{174} Despite the early setbacks many authors were still in support of systemic treatment for individuals with active trachoma, particularly with the advent of a new class of long acting sulphonamides.\textsuperscript{175} However, the cost and side effect profile of systemic antibiotics led to a push towards topical antibiotics in many trachoma programs. Tetracycline and rifampicin proved to be more effective than Boric acid or topical spiramycin\textsuperscript{176,177} and no difference in effectiveness was found between topical tetracycline and oral doxycycline; furthermore, each was found to be more effective than placebo.\textsuperscript{178} Rifampicin eventually lost favour, possibly due to the emergence of resistant strains of \textit{C. trachomatis} in vitro and the current WHO recommendations are either topical tetracycline (6 week course) or oral azithromycin (single dose of 20 mg/Kg).

Azithromycin is expensive and its availability limited in many of the countries that need it.\textsuperscript{179} It is therefore most often used as part of an international donation program set up by Pfizer and the International Trachoma Initiative (ITI).\textsuperscript{180} In 1974 an Editorial in Investigative Ophthalmology lamented the fact that despite 25 years experience with antibiotic treatments for trachoma there was still considerable confusion about the effectiveness of various regimens.\textsuperscript{181} Despite mass antibiotic treatment being the cornerstone of the SAFE strategy this considerable confusion largely remains.

The role and even the need for mass antibiotic treatment has been debated at length, some view it as a panacea, whereas others argue that only socioeconomic development will end trachoma. Undoubtedly socioeconomic development is the definitive solution; however, the world can not sit back and wait while millions needlessly go blind. The Cochrane database of systemic reviews identifies 15 randomised controlled trials that assess the effectiveness of antibiotics against trachoma.\textsuperscript{182} These data are consistent with antibiotics having no effect and suggest that oral antibiotics are neither more nor less effective than topical antibiotics. However, the review includes papers that do not adequately follow the WHO guidelines (Table 1.8). Ten of the 13 reviewed papers assessed treatment of individuals, not mass community-wide treatment, and three papers assessed
antibiotics that are no longer used. Only two of the included studies examined community-wide antibiotic distribution, that used currently recommended antibiotics. These studies were randomised at the community level; however, in the two studies a total of only 6 village pairs were randomised to receive mass treatment with azithromycin or tetracycline. The number of clusters randomised was therefore very small leading to large confidence intervals, despite this both papers supported the use of azithromycin over tetracycline.
<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Treatment</th>
<th>Results summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foster(^{173})</td>
<td>1966</td>
<td>Individual</td>
<td>No significant difference between treatment (1% tetracycline eye ointment) and control group.</td>
</tr>
<tr>
<td>Shukla(^{185})</td>
<td>1966</td>
<td>Individual</td>
<td>Didn’t assess antibiotics recommended by WHO (oral sulphadimethoxine and topical sulphafurazole). However, antibiotics were found to give a greater ‘cure rate’ than control.</td>
</tr>
<tr>
<td>Woolridge(^{174})</td>
<td>1967</td>
<td>Individual</td>
<td>Topical tetracycline failed to decrease the prevalence of active trachoma.</td>
</tr>
<tr>
<td>Dawson(^{186})</td>
<td>1969</td>
<td>Individual</td>
<td>Didn't assess antibiotics recommended by WHO (oral trisulfapyrimidines). However, the group receiving antibiotics had a higher ‘cure rate’ than those receiving placebo.</td>
</tr>
<tr>
<td>Attiah(^{187})</td>
<td>1973</td>
<td>Individual</td>
<td>No significant difference between treatment (1% tetracycline eye ointment) and control group.</td>
</tr>
<tr>
<td>Hoshiwara(^{188})</td>
<td>1973</td>
<td>Individual</td>
<td>Did not assess antibiotics recommended by WHO (oral doxycycline). However, antibiotics were found to give a greater ‘cure rate’ than control.</td>
</tr>
<tr>
<td>Darougar(^{178})</td>
<td>1980</td>
<td>Family based</td>
<td>Decreased prevalence of trachoma in groups treated with topical tetracycline ointment compared to those receiving placebo.</td>
</tr>
<tr>
<td>Peach(^{189})</td>
<td>1986</td>
<td>Individual</td>
<td>Not published in a peer reviewed journal. Topical antibiotics were found to be marginally more effective than eye washing and control.</td>
</tr>
<tr>
<td>Tabbara(^{190})</td>
<td>1996</td>
<td>Individual</td>
<td>No difference between individuals treated with azithromycin or tetracycline.</td>
</tr>
<tr>
<td>Dawson(^{191})</td>
<td>1997</td>
<td>Individual</td>
<td>No difference between topical tetracycline and oral azithromycin.</td>
</tr>
<tr>
<td>Schachter(^{183})</td>
<td>1999</td>
<td>Community based</td>
<td>Greater decrease in the prevalence of trachoma in villages that received mass azithromycin treatment than in villages that received mass treatment with topical tetracycline.</td>
</tr>
<tr>
<td>Bowman(^{192})</td>
<td>2000</td>
<td>Individual</td>
<td>Children given azithromycin were significantly less likely to have disease than those given topical tetracycline at 10 week and 6 month follow. However, the cure rate was high in both groups.</td>
</tr>
<tr>
<td>Fraser-Hurt(^{184})</td>
<td>2001</td>
<td>Community Based</td>
<td>The group receiving oral azithromycin had a significantly lower prevalence of trachoma at 6 and 12 month follow up than the group receiving topical tetracycline.</td>
</tr>
</tbody>
</table>

Table 1.8: Studies included in the Cochrane review of antibiotics for trachoma
The randomised controlled trials that were included in the Cochrane review are summarised, included is the first author, publication year and a summary of the findings.
In 1999 the results of the first randomised controlled trial (RCT) that randomised at the community level were published and supported community wide treatment with oral Azithromycin as being superior to community wide treatment with topical tetracycline. Since then at least four large cohort studies performed in Tanzania, Ethiopia and the Gambia have demonstrated reduced prevalence of chlamydial infection and/or clinical signs of active trachoma following community wide treatment with oral azithromycin. The results of a single mass treatment in a trachoma hyper-endemic village in the Kongwa district, Tanzania, demonstrated a reduction in the prevalence of chlamydial infection from 57% to 12% two months after treatment. Similarly, in the trachoma endemic Rombo district, Tanzania, a sustained reduction in the prevalence of chlamydial infection was achieved after a single mass distribution of azithromycin; although, in Rombo all children with active disease at 6, 12 and 18 months were offered topical tetracycline treatment. Both studies also reported significant reductions in the prevalence of clinical disease. In Ethiopia children in 24 randomly selected villages were monitored for chlamydial infection following community-wide mass oral treatment with Azithromycin. The prevalence of infection dropped from over 50% at baseline to less than 10% at two months. However, in this hyperendemic community the prevalence of infection rapidly increased after treatment suggesting a need for bi-annual treatment to eliminate disease in hyperendemic areas. In a region of the Gambia with hypoendemic trachoma a sustained reduction in the prevalence of chlamydial infection was achieved in 12 of 14 villages that received mass antibiotic treatment with oral azithromycin.

The evidence from cohort studies clearly demonstrates the effectiveness of mass azithromycin distribution programs and emphasizes the need for further research to determine the optimal interval between mass treatments; single, annual or bi-annual. Further support for the efficacy of mass antibiotic treatment comes from a recent RCT in Ethiopia. Intervention and control villages were randomly selected prior to assigning treatment and control villages were not assessed at baseline, because it was considered unethical to examine control villages and not provide treatment. Control villages were assessed during 12 month follow-up after which treatment was provided. The importance of antibiotics in the race towards the Global Elimination of Trachoma by 2020 should not be underestimated.
Mathematical modelling suggests that trachoma can be eliminated by progressively reducing the size of the reservoir of infection. A single mass treatment will only eliminate trachoma if the pre-existing conditions have changed; if there has been no environmental or behavioural change then the re-introduction of only a few infected individuals will eventually result in a return to the baseline prevalence. The speed at which the prevalence of infection increases after treatment determines the need for biannual or annual treatment. Theoretically biannual treatment will be required in areas with a prevalence of over 50% whereas annual treatment will be sufficient in areas with a prevalence of less 35%.

The optimal mode of delivery has not been established. It is generally accepted that treatment of individuals is of limited value. However, there is not a clear consensus as to whether mass community wide treatment, treatment of children only or treatment of effected children and their contacts is the best approach. Children carry the majority of the chlamydial load but 10% of individuals with high chlamydial loads may be asymptomatic adults. This group may be missed by treating cases and contacts and will be missed if only children are treated. Moreover, treating cases and their contacts generally accounts for the majority of the population anyway and has been shown not to be cost effective; although it does address the ethical concern of treating individuals who do not have disease. The effectiveness of different treatment strategies was examined after a regional survey in The Gambia. Limiting treatment to those with clinical disease covered only 25% of infected individuals. Extending treatment to include those with whom they share a bedroom would cover 50% of infected individuals. If everyone in the household of an individual with clinical disease was treated 95% of infected individuals would be covered but this would require the treatment of nearly 10 people per infected individual. Treating all people in a village were the rate of active trachoma was 15% or more in children aged less than 10 would cover 90% of infected individuals and would require the treatment of only 5 people per infected case. However, another study undertaken in Tanzania found that treating children less than 10 (37.7% of the population) would account for 97.2% of the community’s chlamydial burden. Mass treatment of all children aged 1-9 and targeted treatment of clinically active children and their contact’s has been compared in a trachoma endemic region of Nepal. There was no significant difference between the two treatment methods in terms of clinically active trachoma...
rates at 6 months. In terms of antibiotic usage the targeted method used fewer antibiotics if the prevalence was less than 10%; if the prevalence was greater than 10% it actually used more antibiotic than was used to treat all children. Due to the lack of any clear evidence supporting a particular targeted delivery method, mass treatment as recommended by WHO should be considered the gold standard.

The development of resistance in either the target pathogen or in another pathogen is a major concern with any mass antibiotic treatment program. Azithromycin resistant strains of *Neisseria gonorrhoeae* have been identified,\(^201,202\) and *in vitro* resistance to azithromycin has been demonstrated in *Hemophilus influenza*\(^203\) and *Streptococcus pneumoniae*.\(^204,205\) However, chlamydial resistance to azithromycin has not been documented, but it is possible that this may be due to difficulties associated with culturing the bacterium. Azithromycin resistant *S. pneumoniae* was first demonstrated after mass azithromycin treatment in a remote aboriginal community of Australia\(^206\) and subsequently in Nepal.\(^207\) However, no resistant microbes were able to be identified a year after treatment suggesting that resistance may not be an issue with annual mass treatment campaigns.\(^208\) However, resistance must be monitored in any mass anti-microbial distribution program.

Antibiotic treatment has not been shown to be as cost effective as surgical intervention. Results from a 30 year follow of trachoma control in Burma found that antibiotic distribution programs cost $193 per case of prevented vision loss and surgery cost $47 for each case prevented.\(^209\) A more recent study considered mass antibiotic programs to be cost effective only when azithromycin is donated free of charge or available at a reduced price.\(^210\) Furthermore, the establishment of a cost recovery component to the program may have a negative impact with one-third of households surveyed stating that they would not pay for future treatment.\(^210\) Moreover, those households that were unwilling to pay for treatment had the greatest risk factors for trachoma.

### 1.8.3 Facial cleanliness

The components of community and personal hygiene are aimed at disrupting the milieu that promotes the facile transmission of *C. trachomatis*. We know that trachoma disappeared from the developed world when improvements in infrastructure
reduced overcrowding, improved waste disposal and provided easy access to water for cleaning. Despite the apparent success of antibiotic distribution strategies, it is doubtful that they represent a sustainable mechanism to control active trachoma if the underlying causes of trachoma, poverty and overcrowding, remain. The F and E components of the SAFE strategy are therefore vital components of any trachoma control program.

Children with dirty faces are 2 or 3 times more likely to have trachoma than children with clean faces. Unclean faces can be a source of \textit{C. trachomatis} and this provides a reservoir of bacteria for transmission between individuals, but is also an important cause of ocular autoinfection. Proving the effectiveness of facial cleanliness campaigns is difficult due to intrinsic problems in study design. In Vietnam the S and A components of SAFE were initiated in two villages and one of the villages was randomly selected to also receive the F and E interventions. The village in which the entire SAFE strategy was undertaken had a lower prevalence of active disease at 2 years hinting at the importance of the F and E components of the SAFE strategy. The facile transmission of trachoma is possibly sustained by unclean faces; they may be the final common pathway for the modifiable behavioural and environmental risk factors for trachoma. One can speculate that children with clean faces are less likely to have their faces wiped with the same cloth as their siblings, are less likely to be targets for flies, and do not provide a ready source of ocular secretions to share with their siblings. However, a causal relationship between unclean faces and trachoma has not been definitively established.

Observational studies have suggested a benefit related to facial cleanliness campaigns. In the only published RCT that examined the effect of facial cleanliness three village pairs were randomised to receive antibiotic treatment or antibiotic treatment plus face washing promotion. At one year the villages that received face washing promotion there was a higher percentage of children with clean faces and children with clean faces had significantly less TI and tended to have less TF. A recent evaluation of three years of SAFE in the Sudan found the greatest decrease in trachoma was in areas were there had been good uptake of antibiotics and health education programs together with an increase in the number of children with clean faces.
1.8.4 Environmental improvement

The environmental change attempts to address those factors that promote trachoma. Potentially modifiable risk factors include water supply, faecal and refuse disposal, the presence of animal pens within human households and fly density. Various interventions have been directed at these and other risk factors with varying success. A Cochrane review identified three RCT that assessed the ‘E’ component. The first did not find a benefit for health education when combined with antibiotic treatment. Another two examined fly control and demonstrated a small reduction in the prevalence of trachoma related to fly control measures. However, fly control with insecticide spraying was subsequently found to give no additional benefit when used in conjunction with mass antibiotic treatment. It is probable that environmental improvements are best directed to facilitating facial cleanliness programs by ensuring appropriate access to water with which children can clean their faces.

The definitive solution to trachoma undoubtedly is the gradual increase in the standard of living and the ensuing environmental improvements that come with this. Trachoma has been eliminated from all the developed cities in the world without a specific population health campaign. Improved access to safe drinking water, adequate waste disposal and better housing are constructive objectives that provide a direct link between GET 2020 and the Millennium Development Goals.

1.8.5 Cost Effectiveness of SAFE

Eye care programs are often promoted as being highly cost effective. The Gambian eye care program was recently estimated to be delivering as much as a 20% internal rate of return. However, this analysis was primarily based on cataract surgical programs. Trachoma control is highly cost effective in its own right; the most comprehensive evidence comes from Burma. In 1964 a trachoma control program (TCP) was established the cost effectiveness of this program was reviewed 30 years after it inception. In 1964 the incidence of trachomatous blindness in females was 0.7/1000/year; by 1993 the incidence had decreased more than 10 fold. The analysis assumed that all of this reduction was due to TCP and this may bias the study and exaggerate the cost effectiveness. However, the TCP was highly cost effective costing
US$ 54 for every case of visual impairment prevented. This consisted of US$ 47 for non-surgical and US$ 193 for surgical interventions. Due to the difficulties in comparing the cost effectiveness of different interventions the authors suggest that order of magnitude dollar comparisons are needed. Therefore, they are reluctant to suggest that either surgical or non-surgical interventions are more effective.209

The cost effectiveness of eye-care programs can perhaps be more easily understood by analysing the cost per Disability or Handicap Adjusted Life Years (DALY or HALY) averted. In Burma TCP cost only US$ 4 per HALY averted consisting of US$ 3 for non-surgical interventions and US $10 for surgical interventions. Another, more recent study, estimated the cost of surgical programs to be similar at between International dollars (I$) 13-78168. However, antibiotic distribution was found to be cost effective only when Azithromycin was provided free of charge or at markedly reduced prices. Furthermore, tetracycline treatment and targeted Azithromycin treatment were shown not to be cost effective; a finding that is consistent with previous work showing that mass treatment is at least as cost effective as targeted treatment.220 The cost effectiveness of non-surgical techniques in the Burmese study may derive from the design of the program. In Burma an initial attack phase was undertaken to control hyperendemic trachoma, this was followed by maintenance of the disease. Maintenance was much cheaper than the initial phase. For much of the history of TCP in Burma they have been reaping the benefit of their early success in controlling the reservoir of infection. It has been argued that because of the long term changes in trachoma it is difficult to assess the cost effectiveness of a few doses of antibiotics.221 The study in Burma was conducted over a long duration, therefore is sensitive to the slow natural history of trachoma. It is reasonable to accept that it is a good indicator of the long term cost-benefit of trachoma control.

1.9 Trachoma in Australia

It will never be known for sure if Trachoma in Australia pre-dated European arrival. There were sketchy reports of ocular infection from early settlers; however, the first definitive description of trachoma came from Father Frank Flynn around 1944.222 Ida Mann carried out more extensive surveys in the fifties.223 It was in 1975 that trachoma came to prominence as a blinding disease with the National Trachoma and eye Health Program led by Professor Fred Hollows.
The most comprehensive eye health survey of Aborigines living in remote areas was the NTEHP. The team examined and treated over 100,000 people during the 1970s. The grading system used in that survey was different to the WHO simplified system that was used in this project. Follicular trachoma was said to be present in the NTEHP if one or more of the following signs were observed: obviously present follicles, 4 or more limbal follicles, any follicles with papillae, or any follicles with 4 or more Herbert’s Pits. This is a less conservative grading system than the WHO simplified system. For example if four follicles were obviously present then they eye would be graded follicular trachoma using the NTEHP system (obviously present follicles), however, it would be graded as a normal eye using the WHO simplified system (five or more follicles of greater than 0.5 mm diameter). The NTEHP can therefore be expected to provide an overestimate of what would have been found using the current grading system.

Since the NTEHP there has been only sporadic reporting of trachoma prevalence data. The most complete summary was provided by Rosanne Muller in an unpublished historical review of the prevalence of trachoma from 1983-2003. Dr Muller attempted to identify unpublished and published data including data from screening programs. She concluded that there was insufficient data to establish a trend in the prevalence of trachoma. There have been a number of publications that are directly relevant to the prevalence of trachoma in the two areas where our study communities were located. In 2003 Ewald reported that the prevalence of trachoma in a desert study community was 40% amongst children under 13 years of age (The community in this study is the same community that is referred to as Community D in this thesis). Lamming reported a prevalence of 42% amongst schoolchildren in a semi-desert community in 2000. Mak reported regional trachoma prevalence data from 1997-2004. The prevalence of trachoma was 40% in 1998 and 35% in 1999 in the central desert region. Stocks suggested that trachoma was improving secondary to socioeconomic improvements in several communities located in the ‘Red Centre’. The prevalence of trachoma in primary school children (5-9 years of age) was reported to be 56% in 1976, 46% in 1985, and 25% in 1990. However, in 2001 the prevalence of trachoma in several of the same communities was reported to be 79%, suggesting that Stocks et al. may have been premature in their conclusion.
Far less data are available regarding communities in the ‘Top-End’ or coastal north of the NT. Mak reported trachoma prevalence of: 3% in 1998, 0% in 2001, and 20% in 2002. Muller identified 108 individual community surveys from 8 different communities. A total of 3045 children were examined of whom 491 had trachoma (16%).

1.10 Ear health and skin infections

Otitis media is more common in Aboriginal children than it is in the broader Australian Community. Chronic suppurative otitis media is a massive public health problem and undoubtedly leads to hearing loss in children. Hearing loss impacts on education and subsequent employment opportunities. Otitis media is related to poverty, infection in early childhood, overcrowding, poor nutritional status, bottle feeding and passive smoking. Ear infection may occur in between 10- 54% of Aboriginal children, perforated tympanic membranes in 9- 36% and significant hearing loss may occur as many as half of Indigenous children. Otitis media has a prevalence of about 3% in non-Aboriginal children. Aboriginal children can expect to experience ear infections for a total of two years by the time they reach 14 years of age this is 8 times longer than that experienced by non-Aboriginal children.

Pyoderma or skin infection is strongly associated with poor hygiene and overcrowding. So much so that American armed forces recruits are still treated prophylactically with penicillin to prevent skin infections during boot camp. Pyoderma is often secondary to scabies and scabies control programs have had reasonable short to medium term success in reducing the prevalence of pyoderma. Several studies have reported a pyoderma prevalence in Indigenous communities ranging from 35- 70%. Skin infections are not notifiable and rarely directly cause death or admission to hospital. However, the dominant bacterial pathogen is thought to be group A streptococci (GAS), which is related to post-streptococcal glomerulonephritis (PSGNP) and rheumatic heart disease.
Wright HR. Trachoma.
CHAPTER 2

2 Methodology
The Centre for Eye Research Australia was invited to undertake an evaluation of the health impact of swimming pools in remote Indigenous communities; a study that was to form the basis for this thesis. However, the swimming pools were not constructed. Therefore, it was not possible to evaluate the impact that swimming pools, the ‘E’ component of the SAFE strategy, had on the prevalence of trachoma. Baseline data were collected and the impact of the ‘A’ and ‘F’ components of the SAFE strategy were evaluated in one of the two study communities as initially planned.

The delay in the construction of the swimming pools was mirrored by difficulties in implementing the SAFE strategy. In one of the two study communities mass antibiotic treatment was not undertaken despite having a prevalence of trachoma that warranted a population health intervention based on the SAFE strategy. The project evolved from an evaluation of the ‘AFE’ components of the SAFE strategy to an evaluation of the ‘A’ and ‘F’ components of SAFE. The difficulties in implementing the SAFE strategy led us to attempt to identify the impediments or barriers to establishing Trachoma Control Programs (TCP) in Australia (Figure 2.1).
The thesis is presented as 4 separate but related projects. The first project (black) examines the prevalence and risk factors for infectious diseases of childhood. The second (blue) looks at visual impairment and cicatricial trachoma in the 40+ population. The third (red) evaluates the impact of ‘A’ and ‘F’ in Community D and the fourth (green) project examines the barriers to the implementation of Trachoma control programs in the NT of Australia.

The thesis is reported as four closely related projects. Baseline data presents the prevalence of trachoma amongst children and the need for ‘AFE’ interventions in both communities. Risk factors for trachoma and other childhood infectious diseases were examined as were the associations between these diseases.

The natural history of trachoma is one of infection and inflammation in childhood that leads to blinding cicatricial disease later in life. We surveyed all adults aged 40 and older to establish the prevalence of cicatricial disease and the burden of blindness and visual impairment secondary to trachoma.

Prevalence surveys of children and adults aged over forty confirmed the high prevalence of both active trachoma and cicatricial trachoma. According to Australian
guidelines\cite{23} based largely on WHO recommendations\cite{1} a public health intervention based on the SAFE strategy was indicated in each community. The SAFE strategy was not initially implemented in either community in response to these data. However, after a delay of nearly a year and a change in staff at the local clinic we initiated and evaluated a program incorporating the ‘A’ and ‘F’ components of SAFE in Community D. This program was evaluated and forms the third part of this thesis.

There was a general opposition to implementing mass antibiotic campaigns and in one of the study communities mass antibiotic distribution was not undertaken. Local health staff at the community clinic did not feel they had time to deal with trachoma and there were reservations expressed by visiting health staff and a number of regional health officials. The fourth part of this thesis assessed the barriers to implementation of the SAFE strategy in the NT of Australia. We developed a qualitative research methodology based on semi-structured interviews to identify critical success factors for the implementation of TCP and to identify barriers that have prevented TCP from being successfully implemented.

### 2.1 Locations

The study was conducted in the two communities that were awarded contracts to construct swimming pools. The Pools in Remote Areas Committee (PIRA) determined the communities that would receive contracts. This committee consisted of representatives from the Federal and Territory Governments as well as Indigenous groups, community groups and representatives from industry. A tendering process was initiated in October 2004 and all remote Indigenous communities within the Northern Territory (NT) were invited to submit an application. Communities were expected to form a Pool Committee that could develop a detailed business plan. Communities had to contribute one-third of the capital required to build the swimming pool. In addition they had to demonstrate that they could manage and maintain the pool. Over a dozen applications were received by PIRA and two communities were awarded contracts to build swimming pools.

The two communities were from diverse geographical regions and provided an excellent opportunity to examine regional differences in patterns of disease (Figure 2.2). A large coastal community in the tropical northern portion of the NT (top-end)
and a large community in the southern desert region of the NT (the centre) were selected. The coastal community hereafter called Community C was a large and diverse community with an estimated population of between two and four thousand people. It had fourteen distinct language groups and a large number of the population lived in smaller outlying settlements and only periodically resided in the main community. During the tropical wet season the population swelled dramatically because many of the smaller outlying settlements were cut off by seasonal flooding. The community was divided into four separate regions or camps, each of which was dominated by a different language group or groups. Baseline surveys were undertaken in May and August of 2005. The desert community henceforth called Community D had a population of between five and eight hundred. It was dominated by a single language group.
Figure 2.2: Map of the Northern Territory.
Map of the Northern Territory demonstrating the approximate location of the two communities involved in the study. Map adapted from http://r2r.lgant.nt.gov.au/map/map.htm.
PIRA was only charged with determining the communities that would be awarded contracts for swimming pools. Funding and management of the swimming pool project was then handed over to regional authorities. Contracts were signed in December 2004 and by the end of 2005 plans for construction had not been finalised in either community. Delays were compounded in Community D due to the bankruptcy of the community council and by a category 5 cyclone in Community C early in 2006.

### 2.2 Ethics approval

The study was approved by the ethics committees of the Royal Victorian Eye and Ear Hospital, Melbourne, Australia (RVEEH HREC); the Central Australian Human Research Ethics Committee, Alice Springs (CAHREC); and the Human Research Ethics Committee of the NT Department of Health and Community Services and Menzies School of Health Research, Darwin (MHREC). Research was conducted in accordance with the National Health and Medical Research Council (NHMRC) national statement on Ethical Conduct in Research Involving Humans, 1999\(^2\)\(^3\)\(^2\), the NHMRC Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research, 2003\(^2\)\(^3\)\(^3\) and the Declaration of Helsinki.

There were a number of ethical considerations that needed to be addressed for this research. The study participants were in a dependent relationship because the research was conducted in consort with the existing Healthy School Aged Kids (HSAK) program. It was important to make it clear to participants that refusal to participate in the study would not impact on their involvement in existing health programs or their opportunity to use the pool. The infectious diseases being considered in this study occurred almost exclusively in children and thus the target population was children. The study design was appropriate for children and did not subject them to any physical, emotional or psychological harm. Consent was obtained from the parent, guardian or carer before any child was enrolled into the study. Consent was obtained with the aid of a local community member who acted as interpreter. The research project provided a possible benefit to participants because it augmented existing programs.
Indigenous communities can be considered a group of people who share a common identity with common customs and have a group of designated leaders who represent their interests in dealing with outsiders. The NHMRC uses the term ‘a collectivity’ to describe such groups. It is for this reason that it was critical that the project be approved by the community as a whole. Community consent or approval is a difficult concept that is hard to define and may be different in every community. However, a process of consultation and discussion was undertaken with each community and approval to undertake the project was provided by community elders some of whom held elected positions with the community council or the community health board. The project complied with the six values identified in the NHMRC ‘Values and ethics: guidelines for ethical conduct in Aboriginal and Torres Strait islander health research’ (Table 2.1).

<table>
<thead>
<tr>
<th>Value</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reciprocity Mutuo obligation</td>
<td>Benefit through the establishment or enhancement of capacities, opportunities or outcomes.</td>
</tr>
<tr>
<td>Respect</td>
<td>Acknowledgement of individual and collective contribution, interests and aspirations. Acknowledgement and affirmation of the rights to have different values, norms and aspirations.</td>
</tr>
<tr>
<td>Equality</td>
<td>Acknowledgement that all partners are equal, regardless that they may be different; the distribution of benefit; the value of collective memory and shared experience as a resource and inheritance.</td>
</tr>
<tr>
<td>Responsibility</td>
<td>To do no harm to individuals or communities, or to those things that they value; establishment of processes to ensure researcher accountability to individuals and communities, particularly with respect to cultural and social dimensions of community life.</td>
</tr>
<tr>
<td>Survival &amp; Protection</td>
<td>Protection against assimilation, integration and/or subjugation of values; respect for social cohesion; involvement that does not diminish the right to assertion or enjoyment of cultural distinctiveness.</td>
</tr>
<tr>
<td>Spirit &amp; Integrity</td>
<td>Demonstration of credibility in intent and process; an approach that does not impede upon the richness and integrity of cultural inheritance.</td>
</tr>
</tbody>
</table>

Table 2.1: Values in Aboriginal and Torres Strait Islander (ATSI) health research

The six values identified by ATSI people as important for research that is conducted into ATSI people.

Maintaining the privacy of individuals was important and all data were de-identified prior to statistical analysis. Children who required treatment were referred to the local clinic and their carer or a responsible family member was provided with a referral.
Ethics applications were submitted to Royal Victorian Eye and Ear Human Research and Ethics Committee (RVEEH HREC), Central Australian Human Research and Ethics Committee (CAHREC) and the Menzies School of Health Research Human Research and Ethics Committee (MHREC) in September 2004 but were rejected on the grounds that the communities to be studied had not been identified and therefore had not provided support for the project. Once communities were identified and letters of support obtained, ethics applications were re-submitted in December 2004. The application was approved by RVEEH HREC; however, the two Northern Territory ethics committees repeatedly rejected the applications. Comments were addressed and eventually ethics approval was obtained in May 2005. The NT ethics committees initially rejected the application because there was no Aboriginal researcher on the application and there were also some minor concerns with the consent form. These concerns were addressed and an Aboriginal researcher was invited to join the team.

2.3 Infectious diseases of childhood

2.3.1 Recruitment

This project aimed to determine the prevalence of specific infectious diseases that occur primarily in young children. The Healthy School Aged Kids (HSAK) program operates in the Northern Territory and endeavours to examine all children annually. The project investigated infectious diseases that were assessed by HSAK and we attempted to work in tandem with that project. This prevented duplication of examinations and alleviated the workload placed on the already overburdened health clinics because we assisted with the existing HSAK program. HSAK examines all school aged children; however, because the infectious diseases that we were interested in occur more frequently in younger children\textsuperscript{108,230} we limited our study population to primary school children. Primary school children were predominantly aged between five and ten however there were a number of children as young as three and as old as twelve attending primary school classes. Younger children may have had a higher burden of disease but they are not routinely examined as part of existing health
programs and this made it difficult to justify including them in the study population. The following outcome measures were assessed.

The prevalence of:

- Trachoma
- Pyoderma
- Otitis media and tympanic membrane perforations

Secondary Outcome measures were:

- School attendance
- Facial cleanliness
- Nasal discharge

We estimated that there were between three and four hundred primary school children in Community C and about seventy primary school children in Community D. The size of each community made a complete census possible and eliminated the need for a sampling technique with its concomitant problems. There were two additional reasons to conduct a census. Firstly and of ethical concern was that the use of a sampling method might have excluded some children from receiving medical care. The study was designed to work in tandem with HSAK and thus assist in the provision of medical services to each community. Indigenous children are often not brought to medical facilities unless they are extremely sick and HSAK provides an opportunity for many children to be diagnosed and receive treatment for conditions that might otherwise go unnoticed. Secondly a practical concern, the lack of reliable population data and the high population mobility within and between communities made it difficult to obtain an acceptable random sample.

A list of primary school children was obtained from each school. Schools in the Northern Territory have both current and former rolls. The current role includes all children who have attended school within the previous month. If children do not attend school for a month they are taken off the current role and placed on the former role. If children who are on the former role attend school they are placed back on the current role. Written informed consent was obtained from an adult family member or
guardian of each child on both the current and former rolls. Schools were visited on a daily basis over a period of up to three weeks. All children present were examined. In order to recruit children not attending school home-visits were conducted. A community member was employed to assist with home visits. A record was kept of children known to be out of town, ‘out-bush’ or involved in cultural activities that prevented them from being examined. This allowed us to make a good estimate of the coverage achieved during each survey. Children visiting the community were recruited if written informed consent was obtained from a responsible adult; they were recorded as visitors and the duration of time that they had been in the community was documented.

Children who were identified as having a medical problem that required treatment were referred to the local health clinic. In addition their guardian or an adult family member was informed of the diagnosis and need for treatment and was provided with a referral card. In line with Australian guidelines based on WHO recommendations, the SAFE strategy was recommended if the prevalence of trachoma was greater than 10% in primary school children. The need for mass antibiotic distribution was explained to the local clinic and regional health officials. Education and promotional material regarding the importance of facial cleanliness was provided to each community during the first survey and was reinforced at each subsequent visit (Figure 2.3).
Figure 2.3: Poster promoting the importance of clean faces

Posters were produced and provided to each community in an attempt to promote facial cleanliness.
Field trips were planned to occur during the ‘dry season’ in order to minimise the possible effects of seasonal variation and to facilitate travel. The dry season runs approximately from March to November. Two baseline surveys were conducted three months apart in 2005. There is a high level of population mobility within Indigenous communities and we undertook two baseline surveys to maximise coverage of the study population. Visits were scheduled at least three months apart because clinical signs of trachoma may persist for up to 12 weeks and we wanted to be able to assess the effect of treatment. Flexibility in the scheduling of visits was important to avoid conflict with cultural and social events within the community or special clinic activities. Community clinics are busy, particularly when specialist clinics or health promotion campaigns are occurring. Similarly schools undertake frequent bush trips during which a large number of primary school children are out of the community. These factors needed to be taken into account when scheduling visits. Even then visits might need to be cancelled at short notice. The initial survey of community D was planned for April of 2005 but was cancelled with one weeks notice due to ‘community issues’ and was rescheduled for June. Repeat screening was undertaken approximately 3 months after the initial visit. In Community C visits were undertaken in May and September of 2005. In Community D visits were undertaken in June and September of 2005.
Figure 2.4: Timeline of visits to the two study communities
Baseline visits were undertaken in 2005. Mass treatment was implemented in Community D only in 2006. The impact of ‘A’ and ‘F’ was evaluated during visits undertaken in 2006.

2.3.2 Grading and data collection

Basic demographic information was obtained about each child. Data were obtained from a member of the community and cross checked with the school roll. Children were asked to report how often they attended school on a scale of: most days, 2-3 days per week, 1 day per week, less than once a week or never. Primary outcome measures were recorded according to the schemes outlined in Table 2.2.
<table>
<thead>
<tr>
<th><strong>Trachoma:</strong> Simplified WHO System. Each sign is graded as present or absent.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Trachomatous inflammation follicular (TF)</strong></td>
</tr>
<tr>
<td><strong>Trachomatous inflammation intense (TI)</strong></td>
</tr>
<tr>
<td><strong>Trachomatous conjunctival scarring (TS)</strong></td>
</tr>
<tr>
<td><strong>Trachomatous trichiasis (TT)</strong></td>
</tr>
<tr>
<td><strong>Corneal opacity (CO)</strong></td>
</tr>
</tbody>
</table>

**Pyoderma:** Calculation of ‘Skin Sore Score’
The number and type of sores present in each body region is used to calculate a score.

<table>
<thead>
<tr>
<th>The total number of sores in each body region (upper limbs and lower limbs) and the types of sores present is recorded:</th>
<th>Number of Sores</th>
<th>Type of Sores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>&lt; 5</td>
<td>Flat/Dry</td>
</tr>
<tr>
<td>Moderate</td>
<td>6- 20</td>
<td>Crusted</td>
</tr>
<tr>
<td>Severe</td>
<td>&gt;20</td>
<td>Purulent</td>
</tr>
</tbody>
</table>

**Otitis Media and Tympanic Membrane Perforations:**
Each sign is graded as present or absent.

<table>
<thead>
<tr>
<th>Acute Otitis Media</th>
<th>Obviously bulging tympanic membrane or clearly evident pus in the middle ear.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tympanic Membrane Perforation</td>
<td>Clearly visible perforation in the tympanic membrane.</td>
</tr>
<tr>
<td>Purulent Discharge</td>
<td>The presence of free pus in the ear canal.</td>
</tr>
<tr>
<td>Otitis externa</td>
<td>Swollen erythematous external ear canal</td>
</tr>
<tr>
<td>Foreign body</td>
<td>The presence and type is recorded.</td>
</tr>
</tbody>
</table>

**Table 2.2: Primary outcomes**
The grading scheme used to assess each of the primary outcomes is summarised.
The everted eyelid was examined for clinical signs of trachoma with 2.5x loupes and the aid of a good light source. Trachoma was graded according to the WHO simplified grading scheme (Figure 2.5). This system has proven to be easily learnt and generally shows good reliability. A photograph of the left eye of each child was examined by a second observer to validate the reliability of grading using kappa statistics. Photographs had been shown to be an acceptable method for determining the reliability of trachoma grading. However, work published during the course of this thesis has questioned the reliability of grading photographs.

Figure 2.5: Active trachoma
Photographs demonstrating the clinical appearance of trachomatous inflammation follicular (TF) and trachomatous inflammation intense (TI). a) normal eyelid; b) TF; c) TI; and d) TF + TI.

The skin of the arms and legs was examined. Pyoderma was graded using the ‘Skin Sore Score’ that was developed by Dr Jonathan Carapetis and colleagues at the Menzies School of Health Research, Darwin, and later refined by Dr Carapetis and colleagues at the Centre for International Child Health, University of Melbourne. A score is calculated based on the number of skin sores and the severity of lesions (Table 2.2). A score of 1 to 3 is given for the number of sores present: 1 for mild, 2
for moderate and 3 for severe (Figure 2.6). This is then added to a score of 0 to 3 that is given for the type of sores present. If only flat dry lesions are seen a score of 0 is given, 1 is given for crusted sores, 2 for purulent sores and 3 if both crusted and purulent sores are present. A score is calculated for the number and type of lesions on the upper limbs and again for the number and type of lesion on the lower limbs. The maximum score for each body region is 6 and the maximum score for each child is 12. The ‘sore score’ method of grading Pyoderma has been validated in a remote Indigenous community.\(^{238}\) Results are presented using either the raw sore-score or in categories of mild (sore-score= 1- 2), moderate (sore-score= 3- 4) and severe pyoderma (sore-score= 5+).

Figure 2.6: Pyoderma

A photograph of pyoderma on the upper limb showing purulent and crusted lesions.
Each ear was examined in turn using a Welch Allyn otoscope. No effort was made to remove debris or wax that was obstructing the view. Ear pathology was assessed using a grading scale based on the Jirnani Ear Health Awareness Program. The program was developed at the Menzies School of Health Research for use by Aboriginal health workers, and is a simple method for collecting data on ear pathology. The presence or absence of 5 signs was recorded for each ear. Signs were only recorded if they were obviously present, i.e. if the presence of the sign was in doubt it was recorded as absent (Figure 2.7).

Figure 2.7: Ear infections
This photograph shows purulent discharge from the ear of a young Indigenous child.

Secondary outcomes were recorded during each examination. Facial cleanliness was graded subjectively as clean, unclean or very unclean and this was done prior to
assessment of trachoma to minimise observer bias. A face was considered unclean if there were any signs of dirt at all this included ocular discharge but not nasal discharge which was graded separately, a face was only considered very unclean if it was extremely dirty. The presence of nasal discharge was noted and recorded as mild, moderate or profuse. Discharge was recorded as clear, opaque or yellow/green and the presence or absence of excoriation noted. Facial cleanliness and nasal discharge were considered independently and nasal discharge was not considered when determining if a child had a clean, unclean of very unclean face. A combined score was then created to represent overall facial hygiene. Nasal discharge was considered severe if there was profuse discharge or if there was moderate discharge of a yellow/green colour or in the presence of excoriation. Any other discharge was considered mild. An overall facial hygiene score was created using both facial cleanliness and nasal discharge. Having either a very unclean face or severe nasal discharge was considered very poor facial hygiene. Having an unclean face or mild nasal discharge or both was poor facial hygiene and only a clean face without nasal discharge was considered good facial hygiene. Multivariate logistic regression was used to determine the relative importance of facial cleanliness, nasal discharge and overall facial hygiene as a risk factor for infectious disease.

<table>
<thead>
<tr>
<th>Facial cleanliness</th>
<th>Definition</th>
<th>Overall Facial Hygiene</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clean Face</td>
<td>No dirt observed on face</td>
<td>Good Facial Hygiene</td>
</tr>
<tr>
<td>Unclean Face</td>
<td>Dirt present but &lt;50%</td>
<td>Poor Facial Hygiene</td>
</tr>
<tr>
<td>Very unclean Face</td>
<td>Dirt on more than 50%</td>
<td>Very Poor Facial Hygiene</td>
</tr>
<tr>
<td>Severity of nasal discharge</td>
<td>Colour of Nasal discharge</td>
<td>Overall Facial Hygiene</td>
</tr>
<tr>
<td>No nasal discharge</td>
<td>No nasal discharge observed</td>
<td>Good Facial Hygiene</td>
</tr>
<tr>
<td>Mild nasal discharge</td>
<td>Discharge just visible</td>
<td>Poor Facial Hygiene</td>
</tr>
<tr>
<td>Moderate nasal discharge</td>
<td>Clear/opaque no excoriation</td>
<td>Poor Facial Hygiene</td>
</tr>
<tr>
<td>Moderate nasal discharge</td>
<td>Yellow/green or excoriation</td>
<td>Very Poor Facial Hygiene</td>
</tr>
<tr>
<td>Severe nasal discharge</td>
<td>Any</td>
<td>Very Poor Facial Hygiene</td>
</tr>
</tbody>
</table>

Table 2.3: Facial cleanliness, nasal discharge and facial hygiene.

Facial hygiene was determined using both facial cleanliness and nasal discharge according to the following table.

School attendance data were collected. The number of half days that each child attended school over the two months prior to each visit was counted. The number of days that made up the denominator varied and depended on school and public
Wright HR. Trachoma.

holidays and camps. The denominator ranged from 28 to 43 school days. The number of days attended was converted into percentage attendance.

All examinations in the field were carried out by a single observer, HRW, eliminating inter-observer bias. It was not possible to mask the grader. The reliability of trachoma grading was determined using photographs. Photographs were taken with a Canon EOS 20D digital camera fitted with a Sigma 105 mm macro lens and a Canon Speedlite 430EX flash with a light diffuser. The macro lens was set to 1:2 and focus was achieved manually. The shutter speed was set at 1/200th of a second and the F stop was set at 32, providing adequate depth of focus and good exposure. All photographs were taken by HRW while holding the everted lid. All baseline photographs were re-graded by HRW to assess the reliability of field grading. Photographs were also assessed by a second observer, Professor Hugh Taylor (HRT). A comparison of the grading of the photos between the two graders was undertaken to further confirm the reliability of HRW as a trachoma grader. Results were entered into SPSS version 12 and reliability was measured using kappa statistics for each sign. A kappa of greater than 0.6 was considered adequate and greater than 0.8 was considered excellent.

Grading of facial cleanliness was undertaken and recorded prior to everting eyelids and examining for trachoma. This effectively masks the relationship between facial cleanliness and trachoma. Photographs were examined in a masked fashion; however, both observers were aware of the approximate prevalence but not which visit the photographs were from.

2.4 Evaluation of the ‘A’ and ‘F’ component of SAFE

Mass antibiotic treatment was undertaken in Community D based on the prevalence of trachoma and in line with Australian guidelines based on WHO recommendations. A longitudinal cohort study was performed to evaluate the ‘A’ and ‘F’ components of the SAFE strategy. Extensive community liaison was undertaken in order to obtain community consent. Public information meetings, posters, an interview on the local radio station (Figure 2.8), and addressing a community meeting were all undertaken to raise community awareness of trachoma and the treatment program.
Figure 2.8: Interview on Walpiri community radio
HRW being interviewed at the Walpiri community radio station. The interview was aimed at providing the community with information about trachoma and the mass treatment program. The interview was translated into Walpiri and replayed.

Antibiotic distribution was undertaken in Community D during early April 2006. It was estimated that about five or six hundred individuals were residing in the community at the time. All members of the community were offered a single dose of azithromycin either one gram orally or 20 mg/Kg of bodyweight. Children weighing less than six kilograms were not offered treatment nor were pregnant women as per Northern Territory Health guidelines. Population lists were obtained from the medical records held at the community health clinic and were used as a guide to the community’s population. After each morning and afternoon treatment session the different teams met to collate the list of treated individuals. Names were either crossed off the population list or added to a list of extras. People who were identified as being out of town or who had left the community were also recorded. All refusals were recorded.

The treatment plan consisted of two arms. The first arm consisted of one team and treated all the children at school. Children who took their medication were provided with orange juice as a reward. This team was responsible for obtaining written
informed consent for each child on the school roll prior to the treatment program. The second arm consisted of two teams. Each team was provided with a population list and either visited households or set up tables in prominent areas of the community. A combination of door-to-door house visits and centralised treatment stations (Figure 2.9) was felt to be the most effective way to provide treatment to the entire community. Individuals who were out of town or who were not given antibiotic during the treatment week were requested to attend the clinic for treatment during an additional two week follow up period. Visitors to the community during the treatment week were all offered the antibiotic.

Figure 2.9: Antibiotic distribution station

Centralised treatment stations were set up outside the post office and the community store, they proved to be very popular. Many community members returned with their family members to make sure they received the treatment.

The facial cleanliness program consisted of education sessions at the school for the teachers and assisting them to implement a facial cleanliness program at the school. Posters were provided to the school for promotion of the program. All members of the community who received antibiotics were also educated about the importance of children having clean faces. Posters were positioned in prominent areas of the community to re-enforce the facial cleanliness message. No specific ‘S’ intervention
was undertaken at this stage, however, a screening program was conducted in both communities and is described in detail later. Facial cleanliness of children was the primary endpoint for the success of the campaign.

Three and six months after mass antibiotic treatment all primary school aged children were examined as described previously. Data was handled as previously described. The prevalence of trachoma at 3 and 6 months was compared to baseline and differences in prevalence were assessed using cross-tabs and gamma statistics. Facial hygiene measures were analysed in cross-tabs and differences were assessed using gamma statistics.

### 2.5 The prevalence of Cicatricial disease

A cross sectional survey was conducted to determine the prevalence of the blinding sequelae of trachoma amongst Aborigines 40 years and older. We surveyed older people because the blinding complications of trachoma predominantly occur in that age group. Written informed consent was obtained from or on behalf of all participants.

Primary outcome measures:

- Visual acuity
- Presence of TS, TT and CO
- Presence of other ocular pathology

Other Outcome measures:

- Possession of and need for distance glasses
- Possession of and need for reading glasses
- Medical co-morbidities including diabetes

Indigenous communities are typically under serviced and we were not only undertaking a research project but delivering an eye health service. For this reason we offered pin-hole refraction and reading glasses to all participants and made referrals or recommended glasses when appropriate.
2.5.1 Recruitment

We invited all Indigenous residents of each community aged 40 or over to participate. There were no formal exclusion criteria. It was not possible to accurately predict who would be present within each community at the time of the survey due to a lack of reliable population data and high population mobility. For this reason and for ethical reasons related to the service aspect of the research we did not use a sampling technique but conducted a census. The relatively small size of the two study communities made a complete population survey (census) possible. After community consultation, the decision to undertake a door-to-door survey of every household was made. Residents of each house were asked to identify all of the people aged forty and older who currently resided at that house. The names of all the occupants of each household were recorded. Each individual was invited to participate in the study. Arrangements were made to return at a later time to examine people who were not currently home or available for examination. We returned to each house until all occupants had been examined or had refused to participate. Refusals were recorded as were the names of any people who were thought to be in-town but could not be found. This enabled us to estimate the coverage that was achieved. After completing the survey and estimating coverage the list of names was destroyed to ensure that there was no breach of confidentiality.

2.5.2 Grading and data collection

Basic demographic information was recorded. Many people did not know their age or date-of-birth. If they were unable to find identification to confirm their date-of-birth other family or friends were asked and an approximate age was determined. Where there was uncertainty about the age of an individual the community health clinic records were checked. All residents were asked if they grew up in a desert or a coastal community because it is the region in which people spent their childhood that probably determines an individual’s risk of developing cicatricial trachoma. A brief medical history was obtained to determine the prevalence of non-ocular comorbidities. Diabetes was of particular interest because it provided us with an opportunity to provide people with diabetes information about the need for regular eye examinations. It was emphasised that this study did not replace their regular diabetic eye examination. Everyone was asked if they normally wore glasses for
distance or reading. Anyone identified as having ocular pathology was referred to the visiting ophthalmologist and those needing glasses were referred to the visiting optometrist.

Visual acuity was measured at four meters with a log-MAR ‘directional E’ chart (Figure 2.10). All visual acuity data are presented in the more familiar Snellen 6 metre format. Any individual who had a presenting visual acuity of less than 6/12 underwent pin-hole refraction to screen for refractive error. If pin-hole refraction improved the visual acuity then it was considered to be the best corrected acuity for the purpose of this study despite the fact that for those with higher refractive errors pin-hole acuity does not equal the acuity achieved by a full refractive correction. Visual acuity was analysed in the same categories that were reported in the Melbourne Visual Impairment Project (Melbourne VIP). Good visual acuity was either 6/6 or better or <6/6 to ≥6/12, mild visual impairment was <6/12 to ≥6/18, moderate visual impairment was an acuity of <6/18 to ≥6/60, profound visual impairment or legal blindness (Australian definition) was <6/60 to ≥3/60 and those with a visual acuity <3/60 were considered to be blind.

Near vision was assessed using a near ‘directional E’ chart held by the subject at their preferred working distance. Individuals who were unable to determine the direction of the E or who reported that the letters appeared blurry were offered glasses. Participants were asked to choose between the different reading glasses offered (+2.0D, +2.5D or +3.0D) and were asked to select the pair that provided the clearest image. The examiner assisted participants to select the most suitable reading glasses by ensuring that the subject tested the glasses at an appropriate working distance.

Each eye was examined for signs of trachoma with the aid of 2.5x loupes and a pen-torch. Eyes were first assessed for trachomatous trichiasis (TT) and corneal opacities (CO); the eyelid was then everted and examined for signs of trachomatous scarring (TS). Each sign was graded according to the simplified WHO system (Table 2.2). Eyes were also examined for the presence of cataract and any obvious external ocular pathology. A photograph of the left eye was taken to validate the grading of TS. All photographs were taken by HRW using the same camera and settings previously described.
Figure 2.10: Testing for visual acuity using the directional E chart
A directional E chart was held at a distance of four meters and study participants were asked to point in the direction that the E was facing.

2.6 Barriers to the implementation of the SAFE strategy

The SAFE strategy has been widely implemented in many of the poorest countries in the world where it has contributed to the dramatic reduction in the prevalence of trachoma over the last decade. However, implementation of the SAFE strategy in Australia has been patchy and poorly sustained. We used qualitative research methodology based on semi-structured interviews to identify critical success factors that form a pre-requisite for the implementation of a successful and sustained trachoma control program (TCP).

2.6.1 Participants

Health care professionals with a role in the TCP work at three different levels: Territory, regional or community. Individuals who work at the territory level were predominantly involved in policy development. People at the regional level primarily supported and assisted the health professionals working at the community level. Interviews were conducted predominantly with people who worked at the regional
level but key health care providers in community D were also interviewed to obtain a community perspective. Interviewees in Darwin worked predominantly with coastal communities and those in Alice Springs worked with desert communities.

Only individuals who had a direct role in the delivery of TCP were approached. Potential subjects were initially contacted by phone or e-mail and appointments were made over a two week period in September 2006. Participants were advised that interviews would take about 25 minutes, that ethics approval had been obtained and that we wanted to hear their opinions regarding the implementation of trachoma control programs. This enabled participants to have some time to consider their own positions prior to the interview.

Those approached for an interview had a broad variety of roles in TCP. Individuals were asked to identify their role in TCP using a generic title that would protect their identity. At the territory level were Public Health Physicians and a community paediatrician who were responsible for developing TCP policy. At the regional level were public health physicians, nurses and managers who were responsible for monitoring the results of screening and supervising the response. Also at the regional level were public health nurses and remote service providers who travelled to a variety of remote communities to assist local staff. Community level staff included remote area nurses who were responsible for the day to day running of the local clinic, the provision of emergency and after hours care and the implementation of population health interventions such as SAFE. A number of people in unique positions were also interviewed because of their importance in the implementation of programs such as an ophthalmologist and the principal of the community school in Community D.

2.6.2 Interviews

Participants were read a short formal statement outlining the purpose of the research (Quote 1). Participants were asked to agree on a title that both protected their identity and allowed responses to be meaningfully analysed. Permission to record the interview was requested and signed informed consent was obtained. Each participant was provided with an information sheet further outlining the research and summarising the situation regarding trachoma control activities.
I am going to read you a short formal introduction before we start.

Thank you for taking the time to talk to me today. My name is Heathcote Wright and I am currently undertaking a research project to try and identify factors that could help with the successful implementation of trachoma control programmes in Australia. [Insert name] is assisting me and will be taking notes. I will ask you about trachoma programs in Australia. We want to know what you think has worked well and what you think has not worked well.

I want to stress that there are no right or wrong answers but rather different points of view. We value your opinion and want to hear what you think. You will not offend me by speaking your mind. This is strictly a research project and there is no personal judgement involved.

It is important to us that we maintain your anonymity when we present our results. We would therefore like to agree upon a title that both protects your identity and allows your responses to be meaningfully analysed and presented.

What title would be suitable?

I would like to record the session because I don’t want to miss out on any of your comments. We will be on first name basis during our discussion but in the report there will not be any names attached to the comments only the title that you have agreed to. You may be assured of complete confidentiality.

Is it OK for me to record the interview?

Would you sign this form acknowledging your consent to be involved in this research?

Quote 1: Formal statement read to participants

Providing that permission to do so was granted, a digital recording of each interview was obtained. In addition notes were taken by an independent observer who recorded responses on a data sheet according to a pre-existing strategic management framework (Table 2.4). Interviews commenced with a series of standard questions and then moved on to free discussion (Quote 2). Interviewees described their role in TCP and were asked to specify how long they had been in that position and how much of their
working time was devoted to trachoma. Respondents were asked to identify which aspects of TCP they were involved with and to identify what inputs were required for these aspects to be successful.

*What is your role in the delivery of trachoma control programs? How long have you been in that role?*

*What percentage of your workload is devoted to trachoma and trachoma control activities?*

*The SAFE strategy stands for Surgery, Antibiotics, Facial cleanliness and Environmental improvements. What aspects of trachoma screening or the SAFE strategy are you involved with? What level of input is required to implement those components of SAFE?*

*Standard Questions:*

*Please answer the following questions using a scale of 1 (poor) to 10 (excellent):*

*How important is it to eliminate trachoma?*

*How would you rate your knowledge of trachoma?*

*How would you rate your knowledge of the SAFE strategy?*

*Given that the SAFE strategy was developed by the WHO for developing nations how relevant do you think it is to Australian conditions?*

*How well has SAFE been implemented in the Northern Territory?*

*Can you tell us about some aspects of trachoma programs that you think work well, are not working well or that do not work and why?*

*Quote 2: Standard interview questions*

Each interview commenced with a series of standard questions the last of which was designed to stimulate discussion.
The standard questions were rated on a scale of 1-10 with one being poor or least and ten being excellent or most. Responses were compared between people from the desert and coastal regions and between people in different roles without the use of formal statistical analysis. The amount of time people spent working on trachoma related activities and the duration that they had been dealing with trachoma was similarly analysed. Free discussion was encouraged and followed the direction set by the interviewee. The interviewer used neutral prompts to stimulate discourse and directed the interviewer to possible critical success factors that had not been covered. For example if the interviewee had not discussed the impact of having a well or poorly trained workforce the interviewer might stimulate discussion with the lead in, ‘is there any aspect of the people delivering TCP that you would like to comment on?’ Responses were initially categorised according to a strategic management framework adapted from that developed by Herring. Responses that did not fit into an existing category were coded as a new category. Responses were considered primary if they were brought up by the interviewee or secondary if they were agreed to by the interviewee in response to a prompt or lead in. The relative importance of each category was estimated by the crude number of primary and secondary responses. However, qualitative analysis of responses was important to identify vital points that

<table>
<thead>
<tr>
<th>Objective</th>
<th>Critical success factor</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Governance</strong></td>
<td>Effective Policy</td>
</tr>
<tr>
<td></td>
<td>Communication/Information</td>
</tr>
<tr>
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<td>Government support</td>
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<td></td>
<td>Outside support</td>
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<td><strong>Customer</strong></td>
<td>Affordability</td>
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<td>Quality</td>
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<tr>
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<tr>
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<td>Community support</td>
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<td></td>
<td>Regional awareness</td>
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<td><strong>Management</strong></td>
<td>Finance/resources</td>
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<td>Leadership/structure</td>
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<td><strong>People</strong></td>
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</tr>
<tr>
<td></td>
<td>Satisfied workforce</td>
</tr>
</tbody>
</table>

Table 2.4: Adapted strategic management framework

A strategic management framework specific to trachoma control programs was adapted from the work of Herring. The standard questions were rated on a scale of 1-10 with one being poor or least and ten being excellent or most. Responses were compared between people from the desert and coastal regions and between people in different roles without the use of formal statistical analysis. The amount of time people spent working on trachoma related activities and the duration that they had been dealing with trachoma was similarly analysed. Free discussion was encouraged and followed the direction set by the interviewee. The interviewer used neutral prompts to stimulate discourse and directed the interviewer to possible critical success factors that had not been covered. For example if the interviewee had not discussed the impact of having a well or poorly trained workforce the interviewer might stimulate discussion with the lead in, ‘is there any aspect of the people delivering TCP that you would like to comment on?’ Responses were initially categorised according to a strategic management framework adapted from that developed by Herring. Responses that did not fit into an existing category were coded as a new category. Responses were considered primary if they were brought up by the interviewee or secondary if they were agreed to by the interviewee in response to a prompt or lead in. The relative importance of each category was estimated by the crude number of primary and secondary responses. However, qualitative analysis of responses was important to identify vital points that
were expressed by these key individuals. Responses were coded by an independent observer during the interview and again by the researcher from the digital recording. Where there was initial disagreement in coding both observer and researcher re-assessed the recording and a consensus was reached.

### 2.7 Statistical analysis

All results were double entered into a Microsoft Access database. Any errors were checked against the original records. Data were de-identified and transferred to SPSS version 12.0.

The evaluation of ‘AFE’ study had adequate power to detect the expected to change in prevalence of trachoma. In the smaller desert community an initial prevalence of 50% was expected. In order to detect a reduction to 25% prevalence with a power of 80% then 58 participants would be required. If prevalence was reduced to 5%, the target prevalence recommended by WHO then only 15 participants were required to give the study 80% power. The estimated population that would be seen on each visit to Community D was 70 primary school aged children. In the larger Community C a lower initial prevalence of 15% was anticipated. In order to detect a reduction in prevalence to 5% or less with a power of 90% a population of 184 was required. The estimated primary school population in the coastal community was between 300 and 400 children. However, it is clear that these data can only apply to the two communities examined and that any wider speculation must be made with a high degree of caution.

The null hypothesis was that the implementation of the SAFE strategy incorporating a swimming pool as the ‘E’ component would have no effect on the prevalence of the primary outcomes. The prevalence of each primary outcome measure before implementation of SAFE was compared to the prevalence three and six months after SAFE. Cross tabs and Pearson’s chi square test were used to identify a significant difference between baseline results and those after implementation of SAFE. A significant difference would allow us to reject of the null hypothesis.

The study of cicatricial disease was only able to establish the presence of blinding trachoma. The sample size was not large enough to confirm the absence of blinding

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trachoma. The WHO considers that a TT prevalence of 0.1% is a public health concern requiring urgent attention.\textsuperscript{1} In the event that we found zero cases of trichiasis we would need to have examined approximately 3000 people for the upper bound of the 95\% confidence interval to be less than 0.1\%. Assuming a more conservative prevalence of less than 1\% as an indicator that trichiasis is not a public health problem, it was necessary to examine 300 individuals before the upper bound of the 95\% confidence interval would be below 1\% for a finding of zero cases. It was difficult to estimate the number of Indigenous adults aged 40 or over in each community. However, we estimated that we would see about 300 in Community C and 100 in Community D. Age was analysed in decades and due to the small number of individuals over seventy the oldest people were all considered in the 60 and over age bracket (60+) for some analysis.

Baseline data were analysed for the prevalence of each disease and for associations between primary outcomes. Assessment of association was made using cross tabs; Pearson’s chi square was used unless specified in the results section. Gamma statistics were used for ordered outcomes such as clean, unclean and very unclean. Differences were considered significant if the 2-sided p-value was less than 0.05. Age and attendance at school were analysed using independent samples t-test against a binary outcome such as trachoma or using a one-way ANOVA test against an ordered categorical outcome such as facial cleanliness. Due to high mobility not all children were able to be examined on both baseline visits. Data from children examined twice were analysed to determine change in disease status.

Risk factors for infectious disease were assessed for significance using univariate binary logistic regression or univariate ordinal logistic regression. The significance of risk factors, in the presence of other risk factors, was then confirmed using a multivariate binary logistic regression model with backwards elimination of non-significant variables. Risk factors that were assessed: community, gender, age, school attendance, facial cleanliness, nasal discharge, facial hygiene, other infectious diseases of childhood and scabies.

Clustering is an important phenomenon in trachoma. However, it was not possible to assess clustering because data regarding where children lived could not be collected. Furthermore Aboriginal children tend to live in a number of different households
during any given week. Children tend to move between households, staying with
different relatives, and may rarely spend more than a couple of consecutive nights at
the same dwelling.
CHAPTER 3

3 Results
3.1 Infectious diseases of childhood:

3.1.1 Demographics:

Study population:
Each community was visited twice in 2005 and a total of 434 children were examined, 40% of whom were examined on both visits. In community C 345 different children were examined and 89 different children were examined in community D. There was a similar age and gender distribution across the two communities. The mean age of children in the study population was 6.9 years (range 3-12). The mean age of children in Community D was older than that of children in Community C (7.4 vs. 6.7, p=0.03). There was equal representation of both sexes with 50% of the study population being female. There was a higher proportion of males in Community D (55%) than in Community C (49%), but this difference was not significant (p=0.31). There was considerable variation in the number of children seen across the age range. However, the gender ratio remained relatively consistent across most ages (Figure 3.1).
Coverage:

In Community C an estimated 73% of the children present in the community were seen on each visit. It was difficult to accurately estimate the coverage in Community C because of the absence of reliable population data. There were 386 names on the school roll during the first visit to Community C. We identified and examined 233 children and 67 (17%) were known to be absent from the community or unavailable for cultural reasons (Table 3.1). The proportion of children thought to be in the community who were examined (coverage) was estimated at 73% (233 out of 319). Twenty children who were not on the school roll were identified and examined during home visits making a total of 253 children seen on the first visit. On the second visit to Community C 229 children were examined, 15 of whom were not on the school roll, again representing coverage of about 73% (229 out of 314) of the available population. Table 3.1 provides the reasons why children were not available for
participation in the study. Town refers to Darwin for Community C and Alice Springs for Community D. Out-bush refers to children who were camping or visiting small nearby outstations. The category of other refers to any larger or more distant communities and children who had left the community permanently were classified as having moved. Being out of town for cultural reasons refers to children that had been taken out bush by elders to learn about traditional customs and law or those who were involved in ceremonial activity and for whom examination would not have been appropriate at that time.

<table>
<thead>
<tr>
<th>Community</th>
<th>Town</th>
<th>Outbush</th>
<th>Other</th>
<th>Cultural</th>
<th>Moved</th>
<th>Refused</th>
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<td>20</td>
<td>0</td>
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<td>45</td>
</tr>
</tbody>
</table>

Table 3.1: Reasons why children could not be examined

The various reasons why children could not be examined are provided in the table. Figures are given for each visit and for each community.

In Community D a high proportion of the children who were in the community were seen but on each visit many children were unavailable for examination. During the first visit 95 names were on the school roll and 58 of these children were identified and examined and the remaining 37 (39%) were not in the community during the visit. Thus, we estimate that all of the children in the community were examined.

Moreover, seven children were identified and examined in the community who were not on the school roll meaning that a total of 65 children were examined on the first visit. On the second visit a total of 61 children were examined. Twelve children not on the school roll were identified and examined. Of the 46 children on the school roll who were not examined 45 (47%) were known to be unavailable for examination and only a single child was in town but could not be enrolled into the study. Therefore a coverage rate of 98% was achieved. Table 3.1 summarises the reasons why children were not available for examination.
At each community a different sample of children were seen at each visit. In Community C a total of 345 different children were examined over the two visits. On the first visit 253 children were examined compared to 229 children on the second visit. Of the children examined on the second visit only 60% had previously been seen on the first visit. In Community D a total of 89 children were examined during both visits. On the first visit 65 children were enrolled in the study. On the second visit 61 children were examined but only 61% of these children were also seen at the first visit. Only 40% of the study population were examined twice; 40% in Community C and 42% in Community D. Figure 3.2 demonstrates that the youngest and oldest children were less likely to be examined multiple times with children aged five to ten being the most likely to undergo two examinations.

Figure 3.2: Number of children screened
Bars represent the number of children of each age group seen either on the first visit, the second visit or who were seen at both visits.

In Community D almost all the children who were in the community were included in the study. However, a relatively low proportion of children on the school roll 61% (58 of 95) were in the community on the first visit. On the second visit the proportion of children in the community was even lower (51%, 49 of 95). The low proportion of the
study population that was in the community during the study periods is a direct result of the high mobility of families and children. Several children were known to have permanently left the community but their names had not been removed from the list, these children were excluded from any further analysis. In Community D most of the children unavailable for participation in the survey were in Alice Springs (48%, 35 of 73), the nearest regional centre, or were visiting another remote community (38%, 28 of 73). During the first visit six children (21%) were unavailable for examination due to cultural responsibilities.

In Community C a lower coverage was achieved than in community D but a smaller proportion of children on the school role were unavailable to participate in the study. On the first visit 13% (50 of 386) and on the second visit 21% (82 of 396) of children were unavailable. The main reasons why children were unavailable for examination: visiting Darwin, the nearest regional centre (31%), cultural responsibilities (27%), visiting another community (24%) or they were out-bush (17%). In Community C a smaller coverage was achieved but a larger proportion of children were in the community compared with Community D. The approximate total coverage is estimated by including children who were known to be unavailable, but not children who had left the community permanently, in the denominator as shown in Table 3.2.

<table>
<thead>
<tr>
<th>Community and visit</th>
<th>Coverage (%)</th>
<th>Exclude unavailable children</th>
<th>Include unavailable children</th>
</tr>
</thead>
<tbody>
<tr>
<td>C visit 1</td>
<td>233 of 319 (73%)</td>
<td>233 of 369 (63%)</td>
<td></td>
</tr>
<tr>
<td>C visit 2</td>
<td>228 of 314 (73%)</td>
<td>228 of 388 (59%)</td>
<td></td>
</tr>
<tr>
<td>Community C total coverage</td>
<td>320 of 388 (83%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>D visit 1</td>
<td>58 of 58 (100%)</td>
<td>58 of 87 (67%)</td>
<td></td>
</tr>
<tr>
<td>D visit 2</td>
<td>49 of 50 (98%)</td>
<td>49 of 94 (52%)</td>
<td></td>
</tr>
<tr>
<td>Community D total coverage</td>
<td>81 of 94 (86%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 3.2: Estimated coverage

The estimated coverage in each community on each visit is provided depending on whether unavailable children are included or excluded from the denominator.

The low proportion of children examined is a potential bias if those children not examined were different from the children examined. To estimate the likelihood that children who were out of the community differed from those who were in the community we assessed the prevalence of trachoma among children seen twice (stable group) and children only seen once (mobile group). If the two groups had
significantly different disease prevalence then one could surmise that mobile children are different to stable children. Such a finding would suggest that the children who were unavailable for the study were not the same as those who participated in the study. Table 3.3 shows that there was no statistical difference in disease prevalence between stable and mobile children.

<table>
<thead>
<tr>
<th>Population (n)</th>
<th>TF (%)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community C Stable (268)</td>
<td>40 (15)</td>
<td>0.38</td>
</tr>
<tr>
<td>Community C Mobile (189)</td>
<td>34 (18)</td>
<td></td>
</tr>
<tr>
<td>Community D Stable (71)</td>
<td>39 (55)</td>
<td>0.84</td>
</tr>
<tr>
<td>Community D Mobile (49)</td>
<td>26 (53)</td>
<td></td>
</tr>
</tbody>
</table>

Table 3.3: Prevalence of trachoma amongst stable and mobile children

The prevalence of trachoma was not statistically different between children who were examined twice (stable) of children who were examined a single time (mobile).

However, this does not demonstrate that our sample is without bias. To determine the possible extent of any selection bias the minimum and maximum prevalence of trachoma was calculated. If all the children who were not examined had active disease the reported prevalence would be an underestimate this value was the maximum prevalence. If none of the children who were not examined had trachoma then the reported prevalence would be an overestimate of the actual prevalence, this is the minimum prevalence. In Community C there were 388 children on the school roll at the second visit 87 of whom were not enrolled in the study. If we exclude visitors there were 50 children with TF out of 301 examined (17%). The minimum prevalence was 13% (50 of 388) and the maximum prevalence was 35% (137 of 388). In Community D there were 94 children on the school roll at the time of the second visit. If we exclude visitors 77 children were examined of whom 45 (58%) had active disease leaving only 17 children who were not examined on either visit. The minimum prevalence was 48% (45 of 94) and the maximum prevalence was 66% (62 of 94). The prevalence range in each community is reasonably narrow, but most importantly the minimum prevalence in each community is above the recommended threshold for implementation of SAFE.

Despite seeing only a moderate proportion of all children on each visit by undertaking two visits a much higher proportion of children were seen. In Community C 77% (301 of 388) of children were seen and in Community D 82% (77 of 94) of children were
seen. Despite being able to examine only 52%-67% of the available population on each visit, approximately 80% of the study population were examined by undertaking multiple visits. Less than half of the study population were examined twice, 40% in Community C and 42% in Community D. High population mobility explains the heterogeneity of the of the population at each survey despite visits being undertaken only three months apart.

**Refusals and exclusions:**

All Indigenous children of primary school age (4-10 years old) living in the community at the time of the visit were included. Children aged three, eleven or twelve who attended primary school were also invited to participate in the study. Non-Indigenous children were excluded. Consent to participate was given from all parents or guardians who were invited to enrol their child in the study. During the second visit to Community C consent was withdrawn for one child that had been examined on the first visit to that community. The child had severe spina-bifida and had found the initial examination distressing. Her parents felt that a repeat examination was unnecessary; however, they were keen for the results of her initial examination to be used in the study.

Twenty seven children (6%) refused to have their eyes examined for signs of trachoma a further 2 children refused to have their left eye examined after having their right eye examined.

Of the 434 children enrolled all provided demographic information, 433 had their faces assessed and 429 had their skin examined. Eleven (3%) children refused to have their ears examined. All of the eleven children who refused to have their ears examined also refused to have their eyes examined. All refusals occurred in children aged less than six. All of the refusals occurred because the child became upset during the examination and it was not considered appropriate to continue. If examinations were not performed data were coded as missing. There was no difference in the refusal rate between the genders (p=0.44) or between the two communities (p=1.0). There was a strong relationship between the rate of refusal and age (p=<0.001) with 93% of refusals occurring in children aged 3-5.
3.1.2 Primary outcomes

Trachoma

Children were considered to have active trachoma if they had either TF or TI or both in either eye. The prevalence of trachoma was 17% (54/323) in Community C and 55% (46/84) in community D. There was one child who had TI in Community C (0.3%) and four children had TI in Community D (5%). There were no children with TS in Community C but in Community D three children (4%) had TS. All children who had TI also had TF. Table 3.4 demonstrates the difference in prevalence between the two communities. The difference in prevalence between the two communities was highly statistically significant ($p<0.001$). Age was not associated with active trachoma (Independent t-test, $p=0.21$) (Figure 3.3), nor was gender with females no more likely to have active disease than males ($p=0.82$).

<table>
<thead>
<tr>
<th>Community</th>
<th>Active trachoma</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Community C</td>
<td>54 (17)</td>
<td>269 (83)</td>
</tr>
<tr>
<td>Community D</td>
<td>46 (55)</td>
<td>38 (45)</td>
</tr>
<tr>
<td>Total</td>
<td>100 (25)</td>
<td>307 (75)</td>
</tr>
</tbody>
</table>

Table 3.4: Active trachoma prevalence by community

The prevalence of active trachoma in each community is shown. The difference between communities is highly statistically significant $p<0.001$. 

Figure 3.3: Active trachoma prevalence by age and community

The bars represent the percentage of children of each age group who have active trachoma in at least one eye. Results are divided by community and demonstrate the difference in prevalence between the coastal and desert community. Error bars show the 95% CI around the estimate.

The trachoma status of most children who were examined twice did not change. Of the 174 children who were seen on two occasions 167 (96%) underwent ocular examination on both occasions. Nineteen percent of children had active trachoma on both occasions and 73% did not have active disease on either visit. Only eight children (5%) had active disease on the first visit which had resolved by the second visit and 5 (3%) of children developed active trachoma between the first and second visits (Table 3.1). Children who had trachoma on the first visit had a significantly higher chance of having trachoma on the second visit than children who were initially disease free (OR 97.6; 95% CI 29.9-318.7; p=<0.001). It was not possible to mask the examiner as to the trachoma status of the child on the previous visit because all examinations were conducted by the same observer. The examiner was aware of a previous positive finding of trachoma for several children.
Digital photographs of the everted left eye were re-assessed to assess the validity of field grading. A photograph was taken of 97% (395/407) of children who underwent ocular examination for trachoma. Photographs were considered ungradable if more than a third of the grading area was out of focus or obscured by shadow or light reflex. Only 273 photographs (69%) were considered gradable. The disappointing percentage of gradable photographs and the general poor quality of photographs indicates the difficulty of photographing a curved, glistening surface at a very short focal length. The percentage of ungradable photographs we had was similar to that reported by Emerson in the Lancet, in what is to date the largest study that uses photographs for grading reliability. Photographs were re-examined by the author (HRW) to estimate the reliability of field grading. Professor Hugh Taylor (HRT) also assessed the photographs and this was compared to HRW grading of those photographs to ensure the reliability of HRW as a grader of trachoma.

HRW graded photographs similarly to the way he graded children in the field (kappa = 0.85) suggesting that the field grading was valid and not a source of systematic bias. The overall prevalence of TF was 25% according to field grading and 26% according to HRW photo-grading further confirmation that grading in the field was an accurate representation of the true prevalence of TF. Inter-observer agreement when grading the photographs was less reliable (kappa = 0.67). HRW consistently graded in a more conservative manner than did HRT. According to HRT the prevalence of TF amongst the photos was 33% compared to 26% found by HRW. There was disagreement about TF regarding thirty-six of the 273 photos. Twenty-eight were graded as TF by HRT and normal by HRW and only 8 were graded as TF by HRW and normal by HRT.

<table>
<thead>
<tr>
<th>Status of Active Disease</th>
<th>Community Name</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Community C</td>
<td>Community D</td>
</tr>
<tr>
<td>Active disease visit 1 only</td>
<td>3 (2)</td>
<td>5 (15)</td>
</tr>
<tr>
<td>Active disease visit 2 only</td>
<td>3 (2)</td>
<td>2 (6)</td>
</tr>
<tr>
<td>Active disease both visits</td>
<td>17 (13)</td>
<td>15 (44)</td>
</tr>
<tr>
<td>No active disease</td>
<td>110 (83)</td>
<td>12 (35)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>133</strong></td>
<td><strong>34</strong></td>
</tr>
</tbody>
</table>

Table 3.5: Change in active disease between visits.
The number (%) of children who had active disease on both visits, on only one visit or did not have signs of trachoma is shown.
Grading of TI was even less reliable. HRW photo grading only compared adequately with the field grading (kappa= 0.61) while HRW and HRT had poor agreement on the grading of TI on the photos (kappa= 0.33). The prevalence of TI varied dramatically with different observers, HRT graded 19 (9%) photos as TI while HRW considered that only 4 (2%) had TI on field grading and that 9 (4%) individuals had TI on photo-grading. All photos that were graded as TI in the field were considered to have TI by both photo-graders and there was only one photo graded by HRW as having TI that was not considered to have TI by HRT. Due to the poor reliability of TI grading it was not further analysed. All subsequent analysis in this thesis uses the field grading by the author unless otherwise specified.
Pyoderma

Nearly half (49%) of all children had pyoderma more than half of whom (28%) had mild disease. Of the 430 children examined 15% had moderate disease and 6% had severe disease. There was no difference in the overall prevalence between the communities (p=0.49) and the severity of disease was similar between communities (Figure 3.4). Data for pyoderma were therefore analysed on the entire sample unless specified.

Figure 3.4: Sore score prevalence for each community.

The bars represent the percentage of children who had that ‘sore score’. Results are by community to demonstrate the homogeneity of the sample. Error bars show the 95% CI around the estimate.

Figure 3.5 demonstrates that the risk of having pyoderma was not associated with age (one-way ANOVA p=0.67). Males did have significantly worse pyoderma than females (gamma, p=<0.01).
Figure 3.5: The severity of pyoderma by age.
Bars represent the percentage of children of each age according to disease severity. Error bars show the 95% CI around the estimate.

More than half (59%) of the 174 children who were examined twice changed their status with respect to pyoderma (Table 3.6). Fifty six children (32%) had no signs of pyoderma on either visit and only 16 children (9%) had the same category of disease at each visit. The severity of disease was significantly worse on the second visit (p=0.003) and this was particularly marked for severe pyoderma, 4% (7 of 174) of children on the first visit had severe disease and this increased to 14% (24 of 174) on the second visit. From the first visit to the second visit 36% of children got worse by at least one category with 12 (7%) children going from no pyoderma to severe disease. On the other hand 40 children (23%) improved, but only one child improved from having severe disease to having no signs of pyoderma. Moreover, 70% of children who improved did so by only one category, whereas 42% of children who deteriorated did so by two or 3 categories. The pattern of change was similar in both communities.
Table 3.6: Pyoderma prevalence at baseline visit 1 and visit 2

The percentage of children in each category of pyoderma is shown for the first and second visits. Only children seen on both visits were analysed. The prevalence of disease was significantly different on the second visit despite many of the children receiving treatment.

Scabies was a common finding with 35% (149 of 430) children having clinical evidence of scabies. Infected scabies was diagnosed in 29 (7%) of individuals. Scabies was associated with pyoderma (gamma, p=0.03). This association was largely due to the impact of infected scabies (Table 3.7). Children without scabies had roughly the same prevalence of pyoderma as children with non-infected scabies (p=0.87). However, the prevalence of pyoderma was 72% amongst children with infected scabies whereas it was only 47% amongst children who did not have infected scabies. The odds ratio of a child with infected scabies having any pyoderma compared to a child without infected scabies was 2.9 (95% CI 1.3- 6.7; p=0.01).

Table 3.7: Scabies and Pyoderma.
The severity of pyoderma is shown for individuals with no scabies, scabies or infected-scabies. Percentages are provided in parenthesis.

<table>
<thead>
<tr>
<th>Scabies</th>
<th>Pyoderma</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>None %</td>
</tr>
<tr>
<td>No Scabies n= 281</td>
<td>53</td>
</tr>
<tr>
<td>Non-infected Scabies n= 120</td>
<td>52</td>
</tr>
<tr>
<td>Infected Scabies n= 29</td>
<td>27</td>
</tr>
<tr>
<td><strong>Total (%)</strong></td>
<td><strong>51</strong></td>
</tr>
</tbody>
</table>

Ear pathology

98% of the 434 children examined had their ears examined, of whom 30 (7%) had wax obstructing the view in both ears. Children with obstructed views were considered to have normal ears. 19% of the population had ear infection and 26% had a perforated ear drum. Children with wax obstructing the view bilaterally were
assumed not to have ear pathology. If they were excluded from analysis the prevalence of infection increased to 21% and the prevalence of perforation increased to 28%.

There was no difference in the prevalence of ear infections between the communities (Community C 19%; Community D 20.5%; \( p = 0.73 \)) or the genders (female 22%; male 17%; \( p = 0.17 \)). There was no difference in the prevalence of perforated tympanic membranes between the communities (Community C 25%; Community D 32%; \( p = 0.18 \)); however females were more likely to have a perforation than males (female 31%; male 22%; \( p = 0.03 \)). The prevalence of ear infections (independent samples t-test \( p = <0.001 \)) and perforations (independent samples t-test \( p = <0.001 \)) were strongly age dependent. Figure 3.6 shows that infections were more common in younger children and the prevalence steadily decreased with age while the prevalence of perforations steadily increased with age.

![Ear pathology by age](image)

**Figure 3.6: Ear pathology by age**

The prevalence of ear infections and ear perforations is provided by age. Error bars show the 95% CI around the estimate.
3.1.3 Secondary outcomes

Facial cleanliness

All but one child had their faces assessed for cleanliness; that child ran away while demographic information and consent was obtained from their parents and could not be subsequently found. A clean face consists of two components, the amount of dirt on the face; this was called facial cleanliness, and the presence and severity of nasal discharge. Each component was assessed independently and combined to give an overall rating of the cleanliness of each child’s face, called facial hygiene.

Facial cleanliness did not differ between the communities (p=0.32) or between the genders (p=0.51). However, as shown in Figure 3.7 age was strongly associated with having an unclean face. The mean age of children with a clean face was 7.8, the mean age of children with unclean faces was 5.8 and the mean age of children with very unclean faces was 4.6 (one-way ANOVA, p<0.001). This pattern was similar in both communities.
Figure 3.7: Facial cleanliness by age

The bars represent the prevalence of unclean and very unclean faces amongst children of each age. Error bars show the 95% CI around the estimate.

There was no significant difference between the communities for the severity of nasal discharge although there was a tendency for less discharge amongst children in Community C (p= 0.18). Males tended to have more profuse nasal discharge than females (gamma, p= 0.04). Again the presence of nasal discharge was strongly associated with age (p=<0.001).
Table 3.8: Predictors of having an unclean or very unclean face

The table shows the results of a multivariate binary logistic regression model with backwards stepwise elimination of non-significant variable. Age is presented as the odds ratio of a child one year younger (age x-1) than another child (age x) of having an unclean face.

As was expected there was a very strong correlation between facial cleanliness and nasal discharge. Children with nasal discharge had a much greater likelihood of having an unclean or very unclean face than did children who did not have any nasal discharge (Table 3.8). However, there was significant overlap between nasal discharge and facial cleanliness and children would be missed if either sign was used in isolation. Thirty children had a very unclean face and 38 children who did not have a very unclean face had copious nasal discharge making a total of 68 children with very poor facial hygiene (Table 3.9).

Table 3.9: Facial cleanliness and nasal discharge

The number of children in each category is shown, percentages are provided in parenthesis.

The facial hygiene of children was significantly improved when they were screened for a second time (gamma, p= <0.001) (Table 3.10); although it was not possible to mask the observer has to the fact that a visit was pre- or post- facial hygiene campaign. 174 children had their face assessed at both visits. On the first visit only 59% had a clean face and this improved to 76% on the second visit (Figure 3.8).

Similarly the number of children with a very unclean faces halved from six (3%) to 3
(2%). Interestingly there was no change in the severity of nasal discharge (gamma, p=0.293) with similar percentages of children having no discharge (70% vs. 74%) or mild discharge (19% vs. 20%). However, the number of children with copious discharge reduced from twenty (12%) to eleven (6%). A similar pattern was seen in both communities.

<table>
<thead>
<tr>
<th>Facial Cleanliness</th>
<th>Visit 1 n=174</th>
<th>Visit 2 n=174</th>
<th>Total n=174</th>
</tr>
</thead>
<tbody>
<tr>
<td>% Clean</td>
<td>59</td>
<td>76</td>
<td>68</td>
</tr>
<tr>
<td>% Unclean</td>
<td>38</td>
<td>22</td>
<td>30</td>
</tr>
<tr>
<td>% Very Unclean</td>
<td>3</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 3.10: Facial cleanliness on visit 1 and visit 2

The percentage of children with a clean, an unclean or a very unclean face is shown for the first and second visits. Only children who were seen on both visits were analysed.

Most children (88%) who had a clean face on the first visit had a clean face on the second visit with only one child having a very unclean face on the second visit. Of the 66 children who had an unclean face on the first visit 46 (70%) improved, 19 (29%) stayed the same and only one child got worse. Five of the 6 children with a very unclean face on the first visit had either a clean or unclean face on the second visit. The majority of children (70%) had the same category of nasal discharge.
Facial cleanliness by Visit

The line shows the age-specific prevalence of unclean and very unclean faces on the first and second visits. Error bars have not been provided.

School attendance

Of the 434 children 33 were identified as visitors and were thus excluded from analysis of school attendance. Attendance was recorded as the percentage of days attended over a period of approximately two months prior to each visit (attendance period). More than a quarter of children did not attend school during the attendance period. The mean attendance of all children was 38% of days.

Amongst children who did not attend school there was no gender difference ($p=0.714$). However, significantly more children did not attend school in Community C (29%) than in Community D (14%) ($p=0.005$). The mean age of children attending school was older than the mean age of children that did not attend school (7.1 vs. 6.4, $p=0.001$).
Limiting analysis to children who did attend school gave the data a normal distribution (Figure 3.9a). Better attendance was not associated with gender (independent t-test, p=0.73) or age (Figure 3.9b) (Pearson correlation= 0.08). Children in Community D attended school on a mean of 57% of days and children in Community C attended school significantly less, a mean of 49% of the time (difference 7.8; 95% CI of difference, 1.1-14.5, p=0.02).

Figure 3.9: Percentage attendance at school
7a) Histogram demonstrating the percentage of school attendance. 7b) Scatter plot showing that percentage attendance did not vary with age.

It was not possible to analyse school attendance data by quartiles or quintiles because there were too many children with zero attendance, and ‘the zeroes’ would spill into the second quartile or quintile. Therefore attendance was analysed in categories of <20% attendance, 20%-<40%, 40%-<60%, 60%-<80% and >80%. Analysis in categories confirmed the significantly better attendance at Community D (gamma, p<0.001). However, better attendance was associated with age (one-way ANOVA p<0.01), but, this was largely related to the number of younger children who did not attend school at all. There was no difference in attendance between the genders difference (gamma, p=0.57).
3.1.4 Risk factors for trachoma

Living in Community D was the most significant predictor of having trachoma (OR 6.0; 95% CI 3.6- 10.1; p=<0.001). Younger age was not a predictor of trachoma (OR 1.06; 95% CI 0.99- 1.16; p=0.21) nor was being female (OR 1.1; 95% CI 0.7- 1.7; p=0.8).

Facial cleanliness and trachoma

Having an unclean face is a well established risk factor for trachoma. However, the specific component or components of facial hygiene that best predicted trachoma are less well described. Nasal discharge may be more important than dirt on the face (facial cleanliness) in predicting trachoma.243

The prevalence of trachoma increased for children with clean, unclean and very unclean faces (Table 3.11) this was significant according to Pearson Chi-square (<p=0.01); however, if we assume that from clean to unclean to very unclean is an ordered category then the results are not significant (gamma, p= 0.09). Table 3.11 shows that there is little difference in the prevalence of trachoma between children with clean faces and children with unclean but not very unclean faces (p= 0.95). Children with an unclean or a very unclean face were at no higher risk of trachoma than children with a clean face (p= 0.25). It was only children who had a very unclean face that had an increased risk of trachoma. More than half (54%) of children with a very unclean face had trachoma compared to 23% of children who did not have a very unclean face (p= <0.001).

<table>
<thead>
<tr>
<th>Facial Cleanliness</th>
<th>Active trachoma %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clean n= 236</td>
<td>23</td>
</tr>
<tr>
<td>Unclean n= 145</td>
<td>23</td>
</tr>
<tr>
<td>Very Unclean n= 26</td>
<td>54</td>
</tr>
<tr>
<td>Total n= 407</td>
<td>25</td>
</tr>
</tbody>
</table>

Table 3.11: Facial cleanliness and trachoma

The prevalence of active trachoma according to facial cleanliness.

There was a trend for children with greater nasal discharge to have more trachoma (Table 3.12); however, this was not significant (gamma, p= 0.06). The association between severe nasal discharge and trachoma was significant (p= 0.02) but was not as strong as the association between very unclean faces and trachoma. There was a trend
for children with mild nasal discharge to have more trachoma (25%) than children without nasal discharge (22%) but this was not significant (p= 0.1).

<table>
<thead>
<tr>
<th>Nasal discharge</th>
<th>Active trachoma %</th>
</tr>
</thead>
<tbody>
<tr>
<td>None n= 260</td>
<td>22</td>
</tr>
<tr>
<td>Mild n= 94</td>
<td>25</td>
</tr>
<tr>
<td>Copious n= 53</td>
<td>38</td>
</tr>
<tr>
<td><strong>Total n= 407</strong></td>
<td><strong>25</strong></td>
</tr>
</tbody>
</table>

Table 3.12: Nasal discharge and trachoma

The prevalence of active trachoma according to nasal discharge.

The two signs were combined together to give an overall picture of ‘facial hygiene’ that incorporated both facial cleanliness and nasal discharge. Facial hygiene had a stronger association with trachoma than either facial cleanliness or nasal discharge in isolation (gamma, p=<0.01). In addition, as shown in Table 3.13 there was an associated increase in the prevalence of trachoma with worsening facial hygiene. Having a very unhygienic face was strongly associated with having trachoma (p=<0.01). There was also a significant association between having an unhygienic face and trachoma (p=0.03).

<table>
<thead>
<tr>
<th>Facial Hygiene</th>
<th>Active trachoma %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hygienic n=194</td>
<td>20</td>
</tr>
<tr>
<td>Unhygienic n= 152</td>
<td>25</td>
</tr>
<tr>
<td>Very unhygienic n= 61</td>
<td>39</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>25</strong></td>
</tr>
</tbody>
</table>

Table 3.13: Overall facial hygiene and trachoma

The prevalence of active trachoma according to facial hygiene.

Univariate binary logistic regression demonstrated that having a very unclean face, copious nasal discharge or very poor facial hygiene was predictive of trachoma. However, having an unclean face, moderate nasal discharge or poor facial hygiene did not (Table 3.14). Facial cleanliness seemed to be the best predictor but there was a large degree of overlap in the 95% confidence intervals.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Baseline</th>
<th>Level</th>
<th>OR</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facial</td>
<td>Clean</td>
<td>Unclean</td>
<td>1.0</td>
<td>0.6-1.7</td>
<td>0.95</td>
</tr>
<tr>
<td>cleanliness</td>
<td>Clean</td>
<td>V. Unclean</td>
<td>4.0</td>
<td>1.8-9.3</td>
<td>0.001</td>
</tr>
<tr>
<td>Nasal Discharge</td>
<td>None</td>
<td>Moderate</td>
<td>1.2</td>
<td>0.7-2.0</td>
<td>0.61</td>
</tr>
<tr>
<td></td>
<td>None</td>
<td>Copious</td>
<td>2.2</td>
<td>1.2-4.0</td>
<td>0.02</td>
</tr>
<tr>
<td>Facial</td>
<td>Good</td>
<td>Poor</td>
<td>1.4</td>
<td>0.8-2.3</td>
<td>0.23</td>
</tr>
<tr>
<td>Hygiene</td>
<td>Good</td>
<td>V. Poor</td>
<td>2.7</td>
<td>1.4-5.0</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

Table 3.14: Facial hygiene and trachoma

Univariate binary logistic regression demonstrates the ability of facial cleanliness, nasal discharge and overall facial hygiene to predict trachoma.

The percentage of children with a clean face was similar in each community (p=0.69). However, in Community D a significantly greater proportion of children who did not have a clean face had a very unclean face (p=<0.001). More children in Community D (45%) had nasal discharge than did children in Community C (36%) but this difference was not significant (gamma, p=0.1). The relative importance of facial hygiene in each community was analysed with univariate logistic regression (Table 3.15).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Baseline</th>
<th>Level</th>
<th>OR</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community C</td>
<td>Clean</td>
<td>Unclean</td>
<td>0.8</td>
<td>0.4-1.5</td>
<td>0.53</td>
</tr>
<tr>
<td>Facial</td>
<td>Clean</td>
<td>V. Unclean</td>
<td>3.8</td>
<td>1.2-11.6</td>
<td>0.02</td>
</tr>
<tr>
<td>cleanliness</td>
<td>None</td>
<td>Moderate</td>
<td>1.0</td>
<td>0.5-2.1</td>
<td>0.95</td>
</tr>
<tr>
<td>Nasal Discharge</td>
<td>None</td>
<td>Copious</td>
<td>1.2</td>
<td>0.5-2.9</td>
<td>0.70</td>
</tr>
<tr>
<td>Facial</td>
<td>Good</td>
<td>Poor</td>
<td>1.2</td>
<td>0.6-2.3</td>
<td>0.54</td>
</tr>
<tr>
<td>Hygiene</td>
<td>Good</td>
<td>V. Poor</td>
<td>1.6</td>
<td>0.7-3.8</td>
<td>0.27</td>
</tr>
<tr>
<td>Community D</td>
<td>Clean</td>
<td>Unclean</td>
<td>2.8</td>
<td>1.0-8.0</td>
<td>0.06</td>
</tr>
<tr>
<td>Facial</td>
<td>Clean</td>
<td>V. Unclean</td>
<td>2.5</td>
<td>0.7-9.3</td>
<td>0.18</td>
</tr>
<tr>
<td>cleanliness</td>
<td>None</td>
<td>Moderate</td>
<td>1.1</td>
<td>0.4-3.0</td>
<td>0.87</td>
</tr>
<tr>
<td>Nasal Discharge</td>
<td>None</td>
<td>Copious</td>
<td>4.7</td>
<td>1.2-18.9</td>
<td>0.03</td>
</tr>
<tr>
<td>Facial</td>
<td>Good</td>
<td>Poor</td>
<td>2.5</td>
<td>0.9-6.8</td>
<td>0.09</td>
</tr>
<tr>
<td>Hygiene</td>
<td>Good</td>
<td>V. Poor</td>
<td>4.6</td>
<td>1.4-15.4</td>
<td>0.01</td>
</tr>
</tbody>
</table>

Table 3.15: Facial hygiene and trachoma by community

Univariate binary logistic regression demonstrates the ability of facial cleanliness, nasal discharge and overall facial hygiene to predict trachoma in each of the study communities.
Both facial cleanliness (gamma, p=<0.01) and nasal discharge (gamma, p=0.05) were associated with trachoma in Community D. In Community C the prevalence of active trachoma was not associated with the presence of nasal discharge. The prevalence of trachoma was 16.4%, 16.7% and 18.9% for children with no nasal discharge, mild nasal discharge and copious nasal discharge respectively (gamma, p=0.8). Facial cleanliness was not associated with trachoma (gamma, p=0.3). However, children with a very unclean face had a prevalence of trachoma of 43% compared to a prevalence of 15.5% for children who did not have a very unclean face (p=<0.01). This raises the intriguing possibility that in a lower prevalence community a very unclean face is required to transmit infection whereas in a higher prevalence community an unclean face will suffice. Facial cleanliness, nasal discharge and facial hygiene were not associated with other infectious diseases of childhood (facial hygiene: pyoderma p=0.43; scabies p=0.27).

The relationship between the different childhood infectious diseases

Children with pyoderma were just as likely to have trachoma as children without pyoderma (OR 1.2; 95% CI 0.7-1.8; p=0.51). Children with scabies were no more likely to have trachoma than children without scabies (OR 1.2; 95% CI 0.7-1.9; p=0.57). Table 3.16 shows the raw numbers and a lack of association can clearly be seen. There was no association between trachoma and the other infectious diseases of childhood when each community was analysed in isolation (Community C: pyoderma OR 1.5; 95% CI 0.9-2.8; p=0.15; scabies OR 1.2; 95% CI 0.7-2.1; p=0.57; Community D: pyoderma OR 1.2; 95% CI 0.5-2.9; p=0.66; scabies OR 1.5; 95% CI 0.5-4.9; p=0.50).
Table 3.16: Trachoma and skin infections

Children with pyoderma or scabies were no more likely to have trachoma than children without skin pathology. P-values were calculated using gamma statistics.

Children with ear infections were no more likely to have trachoma than children without ear infections in either community (Table 3.17) (Community C: infection OR 1.4; 95% CI 0.6-3.0; p=0.39; perforation OR 0.8; 95% CI 0.4-1.7; p=0.52; Community D: infection OR 0.7; 95% CI 0.2-2.5; p=0.62; perforation OR 0.5; 95% CI 0.2-1.5; p=0.25).

Table 3.17: Association between ear pathology and trachoma

Children with ear pathology were no more likely to have trachoma than children without ear pathology. P-values were calculated using Pearson’s chi square test.
Table 3.18 shows the risk factors for ear pathology as determined by a multivariate binary logistic regression model.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Baseline-level</th>
<th>OR</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ear infection</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perforation</td>
<td>None-perforated</td>
<td>5.9</td>
<td>3.1-11.1</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Age</td>
<td>Age x-age x-1</td>
<td>1.2</td>
<td>1.1-1.4</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Facial Hygiene</td>
<td>Good-Very poor</td>
<td>2.3</td>
<td>0.9-5.6</td>
<td>0.07</td>
</tr>
<tr>
<td>Ear perforation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infection</td>
<td>None-infected</td>
<td>5.6</td>
<td>3.0-10.4</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Age</td>
<td>Age x-age x-1</td>
<td>0.8</td>
<td>0.7-0.9</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Gender</td>
<td>Male-female</td>
<td>1.9</td>
<td>1.1-3.1</td>
<td>0.02</td>
</tr>
<tr>
<td>Scabies</td>
<td>None-Infected</td>
<td>4.0</td>
<td>1.0-16.7</td>
<td>0.06</td>
</tr>
</tbody>
</table>

Table 3.18: Predictors of ear pathology

The predictors of ear pathology were determined in a multi-variate binary logistic regression model. All variables that had a p-value of <0.1 are shown. Variables included in the model: community, gender, age, school attendance, trachoma, facial hygiene, pyoderma, scabies and ear pathology.

**School attendance and disease**

Children who did not go to school tended to have less trachoma (21%) than children who did go to school (27%) but the difference was not significant (p=0.24). Children with trachoma had a higher percentage attendance at school than children who did not have trachoma (43% vs. 35%; independent samples t-test p=0.03). Figure 3.10 shows that children who attended school more often had a higher prevalence of trachoma (gamma, p= <0.05). This pattern was only seen amongst children who did not have a clean face (unclean faces gamma, p= 0.02; clean faces gamma, p= 0.60). The odds of having trachoma increased by about 1% for every 1% increase in school attendance (for x% x+1%, OR 1.01; 95% CI 1.00- 1.02; p=0.03).
Trachoma, school attendance and clean faces

Figure 3.10: Trachoma and school attendance
The bars represent the prevalence (%) of children who have trachoma according to attendance at school. The prevalence of trachoma increases with increasing attendance at school but this is only true for children with unclean faces. Error bars show the 95% CI around the estimate.

Multivariate model of risk factors for trachoma

Living in a desert community, attending school and poor facial hygiene were independent predictors of trachoma. A multivariate binary logistic regression model with backwards stepwise elimination of non-significant variables was created to confirm that these risk factors were still significant in the presence of other variables. Two models were created one included facial cleanliness and nasal discharge and the other included the combined effect of those factors, facial hygiene. Age, gender and the other infectious diseases of childhood were included in the model; only factors that remained in the model were reported. The significance was assigned at 0.05 and factors were removed if they had a p-value of greater than 0.1.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Baseline</th>
<th>Level</th>
<th>OR</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total data set including facial cleanliness and nasal discharge</td>
<td>Community</td>
<td>Comm. C</td>
<td>Comm. D</td>
<td>5.3</td>
<td>3.1-9.0</td>
</tr>
<tr>
<td></td>
<td>Face Clean</td>
<td>Clean</td>
<td>V. unclean</td>
<td>3.4</td>
<td>1.4-8.5</td>
</tr>
<tr>
<td>Total data set including facial hygiene</td>
<td>Community</td>
<td>Comm. C</td>
<td>Comm. D</td>
<td>5.9</td>
<td>3.5-10.0</td>
</tr>
<tr>
<td></td>
<td>Face Hyg</td>
<td>good</td>
<td>V. poor</td>
<td>2.3</td>
<td>1.2-4.6</td>
</tr>
<tr>
<td>Community C including facial cleanliness and nasal discharge</td>
<td>Face Clean</td>
<td>Clean</td>
<td>V. unclean</td>
<td>3.8</td>
<td>1.2-11.6</td>
</tr>
<tr>
<td>Community C including facial hygiene</td>
<td>There were no significant variables in this model</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community D including facial cleanliness and nasal discharge</td>
<td>Nasal Dis.</td>
<td>None</td>
<td>Copious</td>
<td>6.5</td>
<td>1.5-28.6</td>
</tr>
<tr>
<td></td>
<td>% attend</td>
<td>x%</td>
<td>x+ 10%</td>
<td>1.19</td>
<td>1.03-1.36</td>
</tr>
<tr>
<td>Community D including facial hygiene</td>
<td>Face Hyg.</td>
<td>Good</td>
<td>V. poor</td>
<td>5.6</td>
<td>1.6-20.1</td>
</tr>
<tr>
<td></td>
<td>% attend</td>
<td>x%</td>
<td>x+ 10%</td>
<td>1.17</td>
<td>1.01-1.33</td>
</tr>
</tbody>
</table>

Table 3.19: Multivarite Binary Logistic Regression Models

The significance of variables that were independently considered predictors of trachoma was confirmed in a multivariate model. Age, Gender, Community, %attendance, other infectious diseases of childhood and either facial hygiene or the individual components of facial hygiene (facial cleanliness and nasal discharge) were included in the model. Variables were considered on the entire population and on each community individually. Percentage school attendance data provides the odds ratio that a child who attends school more often (attendance = x+ 10%) has trachoma compared to a child who attends school less frequently (attendance = x%).
3.2 Evaluation of ‘A’ and ‘F’

3.2.1 Treatment coverage

Treatment was undertaken over a single week. 500 individuals were provided with antibiotics and only twelve individuals were unable to be treated, 2 because they did not wish to participate and in ten individuals treatment was contraindicated. 112 individuals were out of town during the treatment week and another 100 individuals whose name appeared on the list could not be found for treatment but were not known to be out of town.

<table>
<thead>
<tr>
<th>Age range (n)</th>
<th>% Treated</th>
<th>% Not treated</th>
<th>% Out</th>
<th>% Unable</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4 (89)</td>
<td>52</td>
<td>17</td>
<td>23</td>
<td>11</td>
</tr>
<tr>
<td>5-15 (144)</td>
<td>69</td>
<td>23</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>16-49 (383)</td>
<td>70</td>
<td>14</td>
<td>16</td>
<td>0.3</td>
</tr>
<tr>
<td>50+ (108)</td>
<td>79</td>
<td>0</td>
<td>20</td>
<td>1</td>
</tr>
<tr>
<td>Total (724)</td>
<td>69</td>
<td>14</td>
<td>16</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 3.20: Treatment in Community

The percentage of individuals who received treatment (treated), were not able to be found (not treated), where out of town (out) or who refused/excluded from treatment (unable) is given.

3.2.2 Study population

The baseline results with a sample size of 89 were compared to follow up surveys conducted at three and six months after the mass azithromycin distribution. There were no significant differences in the demographics of each population. Figure 3.11 shows that there were similar numbers of children seen at baseline and at the two follow up points and that the gender mix did not differ markedly (p= 0.97). The mean age of children in each survey was not statistically different (one-way ANOVA, p= 0.28) (Table 3.21).
Figure 3.11: Number of children examined and gender mix
The number of children examined in each survey is shown by the height of the bar (n). The proportion of males and females is shown.

<table>
<thead>
<tr>
<th>Survey</th>
<th>Age</th>
<th>Gender</th>
<th>Trachoma</th>
<th>Facial Cleanliness (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (95% CI)</td>
<td>% male</td>
<td>% TF</td>
<td>Clean</td>
</tr>
<tr>
<td>Baseline</td>
<td>7.4 (6.8- 8.0)</td>
<td>55</td>
<td>55</td>
<td>58</td>
</tr>
<tr>
<td>3 month</td>
<td>8.0 (7.3- 8.6)</td>
<td>56</td>
<td>47</td>
<td>58</td>
</tr>
<tr>
<td>6 month</td>
<td>7.9 (7.4- 8.4)</td>
<td>54</td>
<td>22</td>
<td>58</td>
</tr>
<tr>
<td>p-value</td>
<td>0.28</td>
<td>0.97</td>
<td>&lt;0.001</td>
<td>0.88</td>
</tr>
</tbody>
</table>

Table 3.21: Results of baseline survey, three month and six month follow up surveys
The p-value indicates whether any difference between the surveys was significant. The mean age, gender mix, prevalence of active trachoma and facial cleanliness are provided. Clean face is provided because this was shown to be the most important predictor of trachoma in the multivariate model. P-values are calculated using Pearson’s chi square test.

### 3.2.3 Prevalence of active trachoma and facial hygiene

In evaluating the ‘A’ and ‘F’ components of SAFE it was important to monitor the prevalence of trachoma and the facial hygiene of children (Figure 3.12). The prevalence of trachoma dropped significantly over the six month period after the mass distribution of azithromycin. The prevalence of trachoma was not significantly
different from the baseline prevalence at the three month survey (p= 0.30). The prevalence at the six month survey was significantly lower than both the baseline prevalence (p= <0.001) and the three month prevalence (p= 0.001).

Figure 3.12: Prevalence of trachoma and unclean faces
The age specific prevalence of trachoma, unclean faces and very unclean faces are provided for baseline and six month follow up. Error bars show the 95% CI around the estimate.

There was not a statistical improvement in facial cleanliness (one-way ANOVA, p= 0.37) but there was a dramatic reduction in the number of children with very unclean faces (gamma, p= <0.001). Children with very unclean faces improved to have an unclean face but not a clean face. This resulted in a significant increase in the number of children with unclean faces (gamma, p= 0.02) and for this reason there was not a significant overall improvement in facial cleanliness.

The amount of nasal discharge did improve overall (one-way ANOVA, p= 0.05). In contrast to the pattern seen with facial cleanliness there was no change in the proportion of children with copious nasal discharge (gamma, p= 0.52). A significant number of children improved from having a moderate nasal discharge to having no nasal discharge. The overall facial hygiene of children was not statistically different.
(one-way ANOVA \( p = 0.39 \)). However, there was a significant decrease in the number of children with very poor facial hygiene (gamma, \( p = 0.04 \)). The number of children with good hygiene did not improve (gamma, \( p = 0.88 \)). Children tended to move from the very poor category to the poor category and there was a non-significant increase in the number of children with poor facial hygiene (gamma, \( p = 0.28 \)).

### 3.3 Visual impairment and cicatricial trachoma

#### 3.3.1 Demographics

Community C was visited in November 2005 and Community D in June 2006 to examine Indigenous adults aged 40 and older. In total 260 individuals consented to participate in the study. We identified 186 individuals aged 40 and over in Community C and 157 individuals consented to participate in the study (84%). In Community D we identified 105 adults aged 40 or older of whom 103 (98%) consented to participate in the study. Three individuals living in community D grew up in a coastal region and six individuals from community C grew up in a desert community. Therefore 154 individuals grew up in a coastal region and 106 grew up in a desert area. Analysis of cicatricial trachoma uses the community that an individual grew up in.

Females accounted for 56% of the total study population. The average age was 51.7 (range, 40-85). More elderly people were seen in Community D where 38% of the over 40 population was 60+, whereas in Community C only 10% of over 40s were in the 60+ age category (\( p = 0.001 \)). There was a higher proportion of females in Community D (62%) than in Community C (51%) but this difference was not statistically significant (\( p = 0.09 \)). Results were analysed by decade with 60+ being the oldest category. Only 22 people (9%) were aged 70 or older and 19 (86%) of them were from community D. In both communities the higher proportion of females was more pronounced in the over sixty age bracket.

No Indigenous people were excluded from the study. A number of individuals who consented to participate elected not to partake in one or more components of the study. There was only one individual whose eyes could not be everted. There was no difference between the communities in the percentage of refusals for any aspect of the
Eight individuals (3%) refused or were unable to have their visual acuity measured. Thirteen individuals (5%) refused or were unable to have their near acuity measured; this included a number of blind individuals for whom assessment was not possible. No individuals refused to have their eyes examined, however, as mentioned it was not possible to evert the eyelids of one individual and TS could not be assessed. An acceptable photograph could not be taken in 14 (5%) of individuals. In the case of refusals data were coded as missing and excluded from analysis.

Over half of the study population (51%) reported having co-morbidities. Diabetes was reported by 29% of individuals followed by heart disease (20%), respiratory problems (15%), hearing problems (7%), renal disease (7%) and mobility concerns were expressed by 6% of the population. Three people reported having had a stroke, one person had epilepsy, one had dementia and one person had terminal cancer. The presence of co-morbidities was strongly associated with increasing age (gamma, p= <0.001). One-in-five people in their forties reported having diabetes and this increased to 38% of the population over 50. The association with age remained true for all co-morbidities except hearing and ‘other’ for which a trend was seen but was not statistically significant, possibly due to the small numbers.

### 3.3.2 Visual acuity

Visual acuity was excellent during the 5th decade of life. However, visual acuity began to deteriorate between 50 and 59 and less than half (34%) of the adults aged 60 or older had good vision (Table 3.22).

<table>
<thead>
<tr>
<th>Age</th>
<th>Good Vision</th>
<th>Visual impairment</th>
<th>Blind</th>
<th>Total n</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>≥6/6</td>
<td>&lt;6/6-6/12</td>
<td>mild</td>
<td>moderate</td>
</tr>
<tr>
<td>40-49</td>
<td>105 (86)</td>
<td>15 (12)</td>
<td>1 (1)</td>
<td>1 (1)</td>
</tr>
<tr>
<td>50-59</td>
<td>35 (45)</td>
<td>32 (41)</td>
<td>5 (6)</td>
<td>5 (6)</td>
</tr>
<tr>
<td>60-69</td>
<td>6 (18)</td>
<td>8 (24)</td>
<td>4 (12)</td>
<td>12 (36)</td>
</tr>
<tr>
<td>70-79</td>
<td>0</td>
<td>9 (53)</td>
<td>2 (12)</td>
<td>6 (35)</td>
</tr>
<tr>
<td>80+</td>
<td>0</td>
<td>0</td>
<td>1 (50)</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>146 (58)</td>
<td>64 (25)</td>
<td>13 (5)</td>
<td>24 (10)</td>
</tr>
</tbody>
</table>

| Age adjusted prevalence | 9% | 17% | 1% | 4% |

Table 3.22: Visual Acuity

Raw visual acuity data are presented by decade of age.
The prevalence of visual impairment for each age group is shown. The Black dotted line provides the age adjusted prevalence of visual impairment for the total population. The population was compared to an urban Australian population. Error bars have not been provided.

Visual acuity deteriorated with increasing age (One-way ANOVA, p = <0.001). In a univariate analysis being female (gamma, p = <0.01) and living in Community D (gamma, p = <0.01) were both associated with significantly worse visual acuity. However females were older as was the average age in Community D and when corrected for age neither gender (p = 0.27) nor community (p = 0.38) remained statistically significant predictors of poor visual acuity. A multivariate ordinal regression model was developed and identified that the predictors of moderate or worse visual function (VA <6/18) were age (for each decade, OR 11.5; 95% CI 4.4-30.3; p = <0.001) and having trachomatous trichiasis (OR 8.7; 95% CI 1.7-43.5; p = 0.009). Having TS was a predictor of moderate visual loss in the univariate model but was eliminated from the multivariate model due to the strong effect of the related TT.
Table 3.23: Causes of visual impairment

The number of individuals with mild moderate and severe visual impairment is shown, along with the cause of vision loss. One individual had vision loss from cataract in one eye and trachomatous opacification in the other eye and thus 0.5 is contributed to each condition in the table. The prevalence of diabetes amongst those with no cause for their visual impairment is provided. The prevalence of diabetes in the total population was 27%.

Table 3.23 shows that a total of 42 people (17%) had a best corrected visual acuity of less than 6/12. A cause for vision loss was identified in half of these individuals. The age adjusted prevalence of blindness (<3/60) was 4%. Five people had a visual acuity of less than 6/60; two were blind from trachoma both of whom had a visual acuity of less than 3/60. No cause could be identified on external exam in the other three cases. The age adjusted prevalence of severe visual impairment was 1%.

The age adjusted prevalence of moderate visual impairment was 17%. Twenty-four people had moderate visual impairment (<6/18-≥6/60) half of whom had bilateral cataracts, one had bilateral corneal opacities from trachoma, another had bilateral traumatic eye injuries and one had a cataract in the right eye and trachomatous opacities in the left eye. No cause was identified among the remaining nine people with moderate visual impairment. The age adjusted prevalence of mild visual impairment was 9%. Four of the 13 people with a visual acuity of <6/12 and ≥6/18 had bilateral cataracts, no cause was identified in nine people.

The age adjusted prevalence of visually significant bilateral cataracts was 9% in people aged 40 and older. The age adjusted prevalence of monocular blindness, defined as a VA of <3/60 in at least one eye, was 12%.
3.3.3 Diabetes and visual acuity

There were 21 individuals with visual impairment in whom a cause could not be identified. Diabetic retinopathy was unable to be directly assessed and it was a probable cause for much of the undiagnosed visual impairment. Table 3.23 provides the causes of visual impairment and the prevalence of diabetes amongst individuals with undiagnosed visual impairment. In the general population the prevalence of diabetes was 27%; whereas, 52% of those with visual impairment of unknown aetiology had diabetes (p= 0.02). Diabetes was most strongly associated with mild visual impairment, 78% of individuals with mild visual impairment of unknown aetiology were diabetic (p= 0.001).

![Diabetes and visual acuity](image)

**Figure 3.14: Diabetes and visual acuity**

The percentage of diabetics and non-diabetics in each visual acuity category is shown. Error bars have not been provided. Error bars show the 95% CI around the estimate.
Diabetes was associated with poorer visual acuity gamma p= 0.03 (Figure 3.14). Individuals with mild visual impairment (<6/12- ≥6/18) were significantly more likely to have diabetes than those with a VA of 6/6 or better (age adjusted OR 4.2; 95% CI 1.1- 16.4; p= 0.04). Those with other categories of visual impairment were no more likely to have diabetes than individuals with good visual acuity.

### 3.3.4 Cicatricial trachoma

The prevalence of scarring was much higher in people who grew up in a desert area than those who grew up in a coastal region (78% vs. 26%; p= <0.001) (Table 3.24, Figure 3.15). Age was strongly associated with TS (gamma, p= <0.001), gender was also associated with the presence of trachomatous scarring (p= 0.02). No other co-morbidities were independent predictors of scarring. A multivariate binary regression model was created to confirm the significance of age, gender and location of childhood as predictors of TS. For every decade increase in age the odds ratio of having TS increased by 3.9 (95% CI 2.5- 6.0; p=<0.001). Growing up in a desert community was a strong predictor of having TS (OR 7.0; 95% CI 3.6- 13.3; p=<0.001). Female gender was not a significant predictor of trachomatous scarring in the model (p= 0.3).

<table>
<thead>
<tr>
<th>Age in decades (n)</th>
<th>Prevalence of TS (%)</th>
<th>p-value Desert vs. Coastal</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total n= 259</td>
<td>Desert n= 105</td>
</tr>
<tr>
<td>40- 49 (122)</td>
<td>24</td>
<td>57</td>
</tr>
<tr>
<td>50- 59 (82)</td>
<td>52</td>
<td>74</td>
</tr>
<tr>
<td>60- 69 (34)</td>
<td>85</td>
<td>90</td>
</tr>
<tr>
<td>70- 79 (18)</td>
<td>83</td>
<td>88</td>
</tr>
<tr>
<td>80+ (3)</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Age adjusted total</td>
<td>61</td>
<td>77</td>
</tr>
</tbody>
</table>

Table 3.24: Prevalence of TS.

The prevalence of TS in the total sample and amongst individuals who grew up in either a desert or a coastal community is given. The size of each age group is provided. Pearson’s chi-square assessed for a difference in TS prevalence between coastal and desert people.
Figure 3.15: Cicatricial trachoma
The bars represent the prevalence of cicatricial disease by age according to the area that individuals grew up in. Error bars show the 95% CI around the estimate.

The age adjusted prevalence of trichiasis in Community D was 14% all individuals with TT were aged over 60. There were no cases of trichiasis in Community C. There was a non-significant trend for females to have more TT (p = 0.08). The age adjusted prevalence of CO in Community D was 6%, all cases occurred in individuals aged over 60. There were no cases of CO in Community C. Older age and growing up in a desert community were strongly associated with both TT (age p = <0.001, growing up in desert p = <0.01) and CO (age p = <0.001, growing up in desert area p = <0.01). Odds ratios could not be calculated because there were no cases of TT or CO amongst individuals who grew up in a coastal area; and there were no cases of TT or CO amongst individuals aged less than 60. One individual was diagnosed with TT on the basis of having had previous surgery. There were no individuals with evidence of epilation.
3.3.5 Refractive error

Refractive error was an important contributor to visual impairment. Only five people (2%) reported using distance glasses; two were in their 40s two in their 50s and one was aged 61. Twenty-one individuals (8%) had an improvement in their better eye with pinhole. Forty-three people (17%) improved their visual acuity by at least one line in at least one eye with pin-hole refraction.

<table>
<thead>
<tr>
<th>Age</th>
<th>Has reader (%)</th>
<th>Power of preferred reader</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>None (%)</td>
<td>+2.0D (%)</td>
<td>+2.5D (%)</td>
</tr>
<tr>
<td>40-49</td>
<td>8</td>
<td>15</td>
<td>50</td>
</tr>
<tr>
<td>50-59</td>
<td>15</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>60+</td>
<td>2</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>9</td>
<td>10</td>
<td>31</td>
</tr>
</tbody>
</table>

Table 3.25: Preferred reading power by age
The percentage of people who had reading glasses is provided. The percentage of people who preferred each reading power is provided by age.

A total of 247 individuals had their near vision examined, only 22 (9%) of whom reported having reading glasses. Thirteen people (5%) refused to have their near vision examined or were unable to be examined. Refusals were more common amongst older people. One individual in their forties did not have their near vision assessed 7% of people in their fifties and 11% of people over sixty did not have their near vision tested. A larger proportion of people aged in their fifties (15%) had reading glasses compared to people in their forties (8%). Only one person aged over sixty reported having reading glasses. Males tended to have reading glasses more than females but this trend was not significant (p= 0.13). There was no difference in the number of people who owned reading glasses between the two communities (p= 0.51). The power of reading glasses preferred correlated strongly with age (gamma, p= <0.001) (Table 3.25). The median reading power for those in their forties was 2.0D, 2.5D for people aged in their fifties and 3.0D for those aged over sixty.
3.4 Barriers to the implementation of the SAFE strategy

3.4.1 Participants

Fourteen interviews were conducted over a two week period, and 13 were recorded. Interviews lasted from 13 minutes to 47 minutes (the mean duration was 24 minutes). Signed informed consent was obtained from each interviewee. Four people who were contacted about interviews were not able to arrange a time. One was too busy and the other three where away over the two week interview period. Due to confidentiality issues it is not appropriate to identify those who did not participate but all were based in the desert region and they came from a variety of different positions.

Five respondents described themselves as public health physicians, one as a public health co-ordinator and another as a public health nurse; they are grouped as public health workers (PHW). Four respondents described themselves as remote service providers (RSP). A principal, a remote area doctor, a paediatrician and an ophthalmologist were interviewed. All respondents are identified only using the title that they agreed could be used to describe their role or position. Nine were from the central desert region and 5 were from the coastal area of the Top-End. One participant estimated spending 15-20% of their time on trachoma control activities, three reported spending 5% and nine spent less than 5% of their time dealing with trachoma. One interviewee was unable to provide an estimate of the amount of time that was spent dealing with trachoma. The length of time that participants had spent working in their current role is shown in Table 3.26.

Public health workers predominantly reported having a supervisory role with the A, F and E components of SAFE. They also had a role in overseeing the screening program but none had a direct hands-on role in the TCP. Furthermore, one PHW was only involved in trachoma surveillance and another was purely involved at the policy level. Remote service providers reported having a more hands-on role and assisted communities with the planning and execution of screening programs. They reported various involvements with TCP but all reported an involvement in the promotion of face washing programs. The ophthalmologist and the remote area doctor were
primarily involved in the delivery of surgical services. The remote area doctor was
involved in opportunistic screening as part of the primary health care service and the
ophthalmologist provided access to surgery via the visiting specialist program. The
remote area principal was involved with implementing a facial cleanliness program at
the school. The paediatrician was the chair of the trachoma working group and was a
strong driver for a TCP throughout the territory and he was actively involved in
aspects of screening, surveillance and the implementation of the ‘AFE’ components of
SAFE.

3.4.2 Interviews

Responses varied widely in the perceived importance of trachoma. Five respondents
rated the importance of trachoma as a disease within the context of Indigenous health
as being a nine or ten out 10. At the other end of the spectrum five respondents rated
the importance of trachoma as three or less. There was not obvious pattern although
the three RSP from the desert region all rated trachoma as being very important and
the RSP from the coastal area did not feel the disease was of great importance. Most
people rated their knowledge of trachoma and the SAFE strategy as being adequate
with only the remote principal and the remote doctor rating their knowledge as being
below five. Everyone felt that the SAFE strategy was relevant to Australian
conditions. Most felt that it had been implemented poorly with the highest score being
5 and six respondents rating the implementation of SAFE to date as a 1 or a 2.
<p>| Region       | Position               | Time in position | % of time on trachoma | *Importance of trachoma | *Knowledge of trachoma | *Knowledge of SAFE | *Relevance of SAFE | *Implement of SAFE | Aspects of TCP |
|-------------|------------------------|------------------|-----------------------|------------------------|------------------------|--------------------|-------------------|-------------------|----------------|----------------|
| Desert      | Public Health Physician| 2.5 years        | 5%                    | 2.5                    | 6                      | 6                  | 7                 | 2                 | Scr A          |
|             | Public Health Coordinator| 2 years         | &lt;5%                   | 3                      | 6                      | 6                  | 7                 | 1                 | A F E          |
|             | Public Health Nurse    | 8 months         | &lt;5%                   | 10                     | 6                      | 6                  | 9                 | 2                 | A F E          |
|             | Remote Service Provider| 7 months         | 5%                    | 8                      | 6                      | 6                  | 8                 | 4                 | Scr A F        |
|             | Remote Service provider| 5 months         | 15-20%                | 10                     | 5.5                    | 6                  | 8                 | 2                 | Scr F E        |
|             | Remote Service Provider| 7 months         | &lt;5%                   | 10                     | 7.5                    | 7.5                | 8                 | 3.5               | Scr F          |
|             | Remote Principal       | 14 weeks         | 1%                    | 10                     | 3                      | 1                  | ?                 | ?                 | F              |
|             | Remote Area Doctor     | 5 months         | &lt;1%                   | 3                      | 3                      | 6                  | 8                 | ?                 | S (scr)        |
|             | Ophthalmologist        | 6 years          | 5%                    | 5                      | 10                     | 10                 | 5                 | 2                 | S              |</p>
<table>
<thead>
<tr>
<th>Coastal</th>
<th>Public Health Physician</th>
<th>10 years</th>
<th>Unable to estimate</th>
<th>8.5</th>
<th>7.5</th>
<th>10</th>
<th>10</th>
<th>5</th>
<th>Scr A F</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Public Health Physician</td>
<td>13 years</td>
<td>1-2%</td>
<td>5</td>
<td>6</td>
<td>6</td>
<td>7.5</td>
<td>3</td>
<td>Policy</td>
</tr>
<tr>
<td></td>
<td>Public Health Physician</td>
<td>3 years</td>
<td>&lt;5%</td>
<td>9</td>
<td>6</td>
<td>7</td>
<td>9</td>
<td>3</td>
<td>Surveillance</td>
</tr>
<tr>
<td></td>
<td>Remote Service Provider</td>
<td>3 years</td>
<td>5%</td>
<td>2</td>
<td>6</td>
<td>7</td>
<td>?</td>
<td>2</td>
<td>Scr A F</td>
</tr>
<tr>
<td></td>
<td>Paediatrician</td>
<td>4 years</td>
<td>2%</td>
<td>3</td>
<td>9</td>
<td>9</td>
<td>6</td>
<td>3</td>
<td>A F E</td>
</tr>
</tbody>
</table>

**Table 3.26: Participants**

The table shows the titles agreed to by the participants and the area that they predominantly work in. In each column is: the number of years that they have been in their current position and dealing with trachoma, the percentage of their working time they spend on trachoma, the rating they gave to their knowledge of trachoma and the components of TCP that they are involved in (Scr = screening). *Self rated knowledge of trachoma.*
3.4.3 Requirements for the implementation of SAFE

For each component of trachoma control respondents described what input was required from Government, regional, local and community levels. Input from each level was essential for screening, surgical programs, mass antibiotic treatment and even for the optimal implementation of facial cleanliness programs. However, different levels of input were seen as being of more significance than others. Government input was seen as the critical factor for initiating environmental change. The majority of people interviewed worked at regional level and this highlighted the importance of a regional response to trachoma. For the purpose of this work local inputs were considered as the inputs of community organisation and the professionals that work at these institutions such as the health clinic and the remote area nurses who work there. Community input was considered as the input from members of the community at large. Local inputs can be considered as coming from service providers and the community was the recipient of the service but still a valuable and necessary source of input to a TCP.

<table>
<thead>
<tr>
<th>Component</th>
<th>Input level</th>
<th>Summary of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screening</td>
<td>Government</td>
<td>An acknowledgement of trachoma in policy and increased resources to employ and train staff.</td>
</tr>
<tr>
<td></td>
<td>Regional</td>
<td>Regional support was critical for a successful TCP and required improved training of regional staff.</td>
</tr>
<tr>
<td></td>
<td>Local</td>
<td>Local health workers can work with regional staff to undertake routine screening activities.</td>
</tr>
<tr>
<td></td>
<td>Community</td>
<td>Community acceptance of screening was high and this was seen as an opportunity to provide education.</td>
</tr>
<tr>
<td>Surgery</td>
<td>Government</td>
<td>Surgery was provided within the existing health care framework.</td>
</tr>
<tr>
<td></td>
<td>Regional</td>
<td>Tertiary surgical services are provided at a regional level through the specialist outreach program.</td>
</tr>
<tr>
<td></td>
<td>Local</td>
<td>Local staff have an important role in opportunistic screening for trichiasis.</td>
</tr>
<tr>
<td></td>
<td>Community</td>
<td>The uptake of surgery can be low and individuals may be more accepting of locally delivered surgery</td>
</tr>
<tr>
<td>Component</td>
<td>Government</td>
<td>Regional</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>Policy is in place but not yet backed by sufficient resources to implement mass treatment programs widely.</td>
<td>Regional centres need to direct and assist remote area workers.</td>
</tr>
<tr>
<td>Facial cleanliness</td>
<td>Direction from the education department that hygiene programs were core-business for remote schools.</td>
<td>Provision of education. Development of models and promotional materials for remote schools to use.</td>
</tr>
<tr>
<td>Environmental improvements</td>
<td>The only solution to what is said to be the underlying cause of many of the health problems in communities. However, this is not currently a policy priority for government and there are insufficient resources</td>
<td>It is seen as a problem that is too big to deal with and is a source of despair amongst staff.</td>
</tr>
</tbody>
</table>

Table 3.27: Input required at each level for effective trachoma control programs

Summarises the inputs required for successful trachoma control programs. For each component of trachoma control multiple inputs are required at the different levels from government to regional and to community level inputs. Each input is important to the success of a TCP some are more important than others.

Local input was essential for all aspects of a TCP. Without the support of local staff to drive TCP it was unlikely to eventuate. Local health workers were best placed to inform and liaise with the community. They were already in a position of trust within their communities and were best placed to obtain the necessary community support for a TCP. Local teams were vital in implementing policy; they had access to the best
population data, knew many members of the community and were able to best tailor an intervention that would be appropriate to their community. However, locally driven programs were unlikely to succeed without the policy and resources being in place and without support from regional teams.

Community input was seen as critical, and not just from the point of view of obtaining community consent for a TCP. The community must be an active partner in a TCP for it to have any chance of success. That involved engaging the community in the period leading up to TCP so that they would have an understanding of the reasons for the program and actively seek to participate in it. Allowing time to talk to people while delivering treatment and educating them about trachoma and the all the aspects of the TCP was a vital step in establishing a sustainable and acceptable program.

### 3.4.4 Description of Categories

Qualitative analysis of interviewee responses identified nineteen categories (Table 3.28). Twelve of the 14 categories from the existing strategic management framework were raised by participants. The cost of the program and the quality of the program were not raised as an issue by any respondent. Participation in a TCP is free for community members and as such the affordability of programs was not considered an issue. Similarly the quality of programs was not raised as an issue. Seven additional categories were raised by participants that were not in the SMF. A summary title of each category and whether it was from the existing SMF or an additional category is provided in Table 3.28. In that table categories are grouped according to their objective.

Categories are explained in greater detail following the summary and are presented in an approximate order of importance. The order of importance was estimated from the number of participants who raised that category during their interview. For example all interviewees discussed issues that fitted into the effective policy category so it was
assigned a high importance; however, antibiotic resistance was only discussed by a single participant and was assigned a lower priority.

<table>
<thead>
<tr>
<th>Objective</th>
<th>Categories from SMF</th>
<th>Additional categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Governance</td>
<td>Effective Policy</td>
<td>Priority of trachoma</td>
</tr>
<tr>
<td></td>
<td>Communication and Information</td>
<td>Screening</td>
</tr>
<tr>
<td></td>
<td>Government support</td>
<td>Resistance</td>
</tr>
<tr>
<td></td>
<td>Outside support</td>
<td></td>
</tr>
<tr>
<td>Customer</td>
<td>Acceptance of program</td>
<td>Mobility</td>
</tr>
<tr>
<td></td>
<td>Affordability of program</td>
<td>Not raised by any interviewee</td>
</tr>
<tr>
<td></td>
<td>Quality of program</td>
<td>Not raised by any interviewee</td>
</tr>
<tr>
<td>Awareness</td>
<td>Community awareness</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Community support</td>
<td></td>
</tr>
<tr>
<td>Management</td>
<td>Finance and resources</td>
<td>Database</td>
</tr>
<tr>
<td></td>
<td>Leadership and structure</td>
<td></td>
</tr>
<tr>
<td>People</td>
<td>Trained workforce</td>
<td>Time consuming</td>
</tr>
<tr>
<td></td>
<td>Satisfied workforce</td>
<td>Staff turnover</td>
</tr>
</tbody>
</table>

Table 3.28: Categories

The responses of participants were considered in 19 different categories. Categories were broadly grouped into five areas according to the objective of the category. Twelve of the 14 categories from the SMF were discussed by participants and seven new categories were created. Two categories included in the SMF were not raised by any interviewee.

Effective Policy

All respondents made comments that were included in the effective policy category. Comments were generally supportive of the current trachoma policy, which comes from the national guidelines. However, four people expressed concern over the policy of instituting mass treatment campaigns when the prevalence of trachoma was only 10% as they all felt that 20% was a more reasonable figure. Another individual who agreed with the 10% cut-off figure felt that it was causing so much concern that it was actually counterproductive. The policy of treating household contacts was felt to be an issue due to the difficulty in identifying households and the high mobility of children within communities.
*It is trying to balance simplicity versus common sense and not treating 90% of people who don’t have a problem for 10% that do.*

Quote 3: PHW, Coastal

Concerns were expressed about the ethics of conducting screening programs without having the necessary resources and infrastructure to respond to the results of screening programs.

*Should we even be screening for trachoma when we can’t even treat it?*

Quote 4: RSP, Centre

It was argued that while the policy was in place it was not backed by sufficient resources to implement that policy. It was felt that this was because much more trachoma was found by the screening programs than was expected.

*The policy was put in place but there are not the resources to back it up. I do not think they thought they would find this much trachoma and I think it has been a bit of a learning curve.*

Quote 5: RSP, Centre

Several people suggested that the current policy left treatment largely in the hands of the remote area nurses (RAN) and that this would inevitably lead to a patchy implementation of programs that was dependent on the personality of individuals within each community.

*I am dead against each place doing its own thing because it is a huge waste of resources... we need a central process*

Quote 6: Paediatrician, Coastal
This problem could be further compounded by high staff turnover with many of those interviewed having been in their current position for only a short time. Several treatment failures were described and it was felt by some that perhaps the policy may not be appropriate in the context of remote Aboriginal communities. A RSP expressed uncertainty about the role of laboratory tests, specifically PCR, in diagnosis and screening. A PHW suggested that PCR might have a role in investigating presumed treatment failures.

The idea of a macro-regional approach to mass treatment or a territory wide azithromycin treatment week was raised by many respondents. The paediatrician felt that non-health staff could be used to distribute azithromycin and argued that the policy should include directions regarding hand washing between ocular examinations. The remote principal felt that there was a lack of clear policy support from the education department with respect to implementing facial cleanliness campaigns in schools. He also felt that the role of health workers within the school had not been made clear to the school and that this initiative needed to have a clear policy framework particularly with respect to their role in hygiene programs.

**Leadership and Structure**

There was consensus of opinion that there was a failure of structure and a lack of anyone to drive trachoma programs. Eleven people stated that adequate structure was critical to respond to screening data with a successful TCP. There was one PHW and one RSP who felt that the existing structure was adequate but nine felt that the existing structure was unable to deliver a TCP in response to screening data. The three individuals who did not raise the issue of structure all agreed that it was a problem when questioned about it.

_You need an overall responsibility for trachoma and I don’t think anybody is truly doing that… there is not a big commitment, I don’t think, from anybody because everybody is busy with other things._
Quote 7: PHW, Coastal

Respondents felt that data were being collected but that it was not being adequately disseminated to the appropriate people. Most felt that this was because there was no clear description of who should be provided with data. Nor was there an individual who had overall responsibility for monitoring the transfer of data and ensuring that appropriate responses were initiated.

_I guess what is happening at the moment is that a whole lot of numbers are being collected and they don’t seem to be going on to the next step_

Quote 8: RSP, Centre

Surgical programs were struck by similar structural failings. The remote doctor reported that only about 50% of those patients who were sent for surgery actually received surgery. The ophthalmologist identified several structural failings that made it difficult for Indigenous patients to receive surgery.

_We need to be able to provide opportunistic care, so we need to be able to say to someone...you have got eyelashes scratching your eye I can do an operation for you today or tomorrow._

Quote 9: Ophthalmologist, Centre

Finance and Resources

Thirteen of the fourteen respondents identified a lack of money and or resources as being a direct barrier to establishing the TCP. There was a shortage of money at the regional level resulting in there being insufficient staff to implement a successful TCP. General resource constraints at the local level meant that community health clinics were not able to implement programs without regional support. Remote service providers stated that there were too many communities for them to assist them all with
screening and the implementation of a TCP. They added that individual communities
did not have the capacity to undertake these activities without regional support. A
large increase in resources would be required to deliver mass antibiotic treatment on a
macro-regional or Territory wide scale. Moreover, one PHW questioned if a TCP was
an appropriate allocation of resources given the relative priority of trachoma in the
broader context of Indigenous health.

*It is about money…money drives everything and you can do it well with lots
of money but it is how you use it*

Quote 10: PHW, Centre

There was an absence of appropriate teaching, educational and promotional resources
at the regional level. This made it difficult to maintain an educated workforce. It also
made it difficult for RSP to increase regional and community awareness of trachoma.
There was a lack of resources for the provision of surgery in the Centre. Theatre lists
were regularly cancelled due to lack of nursing staff, beds or anaesthetic staff. Long
waiting lists and uncertainty about the availability of theatre time resulted. The
uncertainty of surgery compounded difficulties in transporting patients into the
regional centre from remote communities.

**Priority**

The priority that trachoma has within the broader context of Indigenous health was
identified as an important category by eleven respondents. At the regional level there
was a consensus of opinion that trachoma had to take a low priority when compared
to some of the other health and social issues faced by remote Indigenous
communities. People working with trachoma all had responsibility for other disease
programs. Given a lack of time and resources other disease programs took priority at
the expense of trachoma. It was suggested that for the TCP to be successful it needed
to be implemented by staff that did not have competing interests. Having a low
priority was not a reason to dispense with the TCP and it was pointed out that there
was a genuine opportunity to eliminate trachoma using the SAFE strategy and that this made it worthwhile.

*Quite frankly it is not a priority for me...we have got kids dying of rheumatic heart disease and dying from TB...that's more important to me than someone who might be going blind in thirty years from trachoma.*

**Quote 11: PHW, Centre**

Trachoma was a low priority for communities and was considered not even to be on the ‘health radar’. Community support is integral to implementing and maintaining a successful program. Given the low status of trachoma, community awareness needed to be increased so that trachoma became a priority issue before community support would be obtained. One PHW questioned the morality of raising trachoma awareness within communities that are already overburdened by other more pressing health issues. On the other hand, several argued that it was morally inappropriate to use the lower priority of trachoma as an excuse because it was a problem that had a solution and that there was a moral obligation to deal with it. Trichiasis and its close temporal relationship to vision loss was felt to be a high priority and there was a high importance placed on the provision of surgery and specialist eye care.

*There is a bit of a fallacy that you have got to choose between do you want your diabetes treated or do you want your trachoma treated. I don’t think that is an ethical thing...I think if you have got something there that is treatable... there is an obligation.*

**Quote 12: PHW, Coastal**

Indigenous people living in remote communities give a low priority to their personal health. There was a reluctance of Indigenous people to take responsibility for their own health and this made it difficult to deliver appropriate public health programs especially those directed at personal hygiene. It also made the provision of surgical
services difficult because individuals rarely presented to the visiting specialist and were often reluctant to have surgery. Indigenous people would generally prioritise their surgery below any concurrent cultural events and this meant they sometimes did not attend appointments.

Community Support

Eleven people raised the importance of establishing community support. All were adamant that community support was critical to establishing and maintaining a good trachoma control program. Having broad community support did not necessarily equate to receiving community assistance because communities would often be overwhelmed with other responsibilities such as cultural events or sorry business. Community support also included the infrastructure within a community that was needed to support visiting teams. For instance some communities do not have adequate accommodation for regional support staff.

*You need to have community support otherwise it will fail anyway*

_Quote 13: PHW, Coastal_

Remote clinics that are run by a single RAN are not able to offer meaningful assistance because they have to maintain the day to day business of the clinic. Communities that had been appropriately informed about trachoma were supportive of mass antibiotic treatment programs and remote schools supported the need for screening and hygiene campaigns.

_One nurse clinics can not undertake a mass treatment on top of their existing workload, that’s ridiculous!_

_Quote 14: RSP, Centre_
Acceptance

Acceptance is related to community support but attempts to gauge the level of acceptance amongst individual community members. The remote principal reported that children were accepting of screening and school based hygiene programs. Parents were accepting of screening programs; no one could recall having had consent for screening refused. There was a general uneasiness about the link between acceptance of a program and the idea of informed consent; several wondered just how informed was the consent. Mass antibiotic treatment programs were well accepted by communities because the logic of taking a tablet to deal with a problem was simple and easy to comprehend.

*The idea of mass treatment- Aboriginal communities are familiar with that.*

Quote 15: PHW, Coastal

No one reported a community being unwilling to participate in a mass treatment program. The Remote Area Doctor (RAD) reported that there were no adverse outcomes after mass treatment in community D. One PHW argued that ready acceptance of mass treatment programs was a philosophical concern because it emphasised the growing desire to ‘medicalise’ social problems.

Trained Workforce

Ten respondents spoke of the lack of a well trained workforce inhibiting the ability to deliver the TCP. The level of knowledge about trachoma amongst health staff was low, even among those responsible for screening children for clinical signs. Several RSP commented that they lacked confidence in everting eyelids and being able to correctly identify the clinical signs of active trachoma.

*How well trained am I to actually find trachoma and how confident do I feel?. How confident are community people and if people are even confident to look for it, if they find high results they get questioned about their ability?*
The challenge of maintaining a trained work force is not unique to trachoma, however, it was more difficult because it is a neglected disease and many staff commence work with a very limited knowledge base. Currently orientation programs were not providing sufficient information about trachoma and there was no formal ongoing education about trachoma. The people overseeing mass antibiotic treatment programs often had little idea of what to expect. Information about the natural history of trachoma and of what to expect after a treatment program was urgently needed. The lack of an appropriately trained primary care workforce made opportunistic screening for trichiasis difficult.

_We expect sometimes that people will just flip eyelids and they know what they are looking at... and I wonder sometimes how accurate these figures are_

The development of a good standardised orientation program was felt to be important. Several people argued for a standardised trachoma training program that included accreditation. Any program needed to cover clinical examination techniques, diagnostic skills and information about implementing the SAFE strategy. High turnover of staff and high staff mobility were issues that compounded the difficulties of maintaining an educated workforce. A database of trained staff would assist to track workers with experience and expertise in trachoma.

**Community Awareness**

Community awareness was raised by nine people and a tenth person agreed that it was an important issue when brought up in discussion. There was a very low level of community awareness about trachoma and some suggested that this was in proportion to the low importance of the disease. Everyone agreed that community awareness needed to be raised prior to gaining community support, a prerequisite for a successful
program. The lack of community awareness flows directly from the low level of awareness amongst RAN and health workers at community clinics because they provide much of the health information to communities. Remote schools were also not aware of trachoma and the steps that they could take to reduce the burden of the disease. Schools were the logical place to initiate hygiene programs but in order to do this staff at the school needed to be educated about the reasons for such programs.

**Mobility**

Seven interviewees raised mobility as an issue and an additional three agreed that it was an important consideration during discussions. The speed and magnitude of mobility seen within Indigenous populations between communities was considered to be unique to Australia. Various people expressed a number of concerns relating to the high level of population mobility. Firstly, it was difficult to obtain an accurate population list during screening or mass antibiotic treatment and this made it difficult to estimate coverage. Secondly, mobility adversely impacted on the effectiveness of mass antibiotic treatment because infected individuals would re-enter the treated community creating a reservoir of infection.

*There was a treatment in a community that had a prevalence of 40%. One year later the community was screened again and only 30% of the population had been treated the previous year and the prevalence had increased to 65%.*

**Quote 18: PHW, Centre**

Thirdly, to counter mobility, the unit of mass antibiotic treatment would need to be macro-regional or territory wide and this would greatly increase the complexity and cost of the TCP. Finally, the high intra-community mobility meant that targeted household treatment was difficult and possibly not effective.
...yes we have all the environmental risk factors but we also have this huge population mobility which is not what you find anywhere else where the SAFE strategy works.

Quote 19: Ophthalmologist, Centre

Screening

Screening has been successful in both regions. It was seen as a core business activity that assessed multiple diseases within a single program, thus eliminating the priority issues that surround trachoma. Effective screening has been in place for a long time in the coastal region but has only recently been initiated in the desert region. Prior to this screening was haphazard and even when it did happen, screening for trachoma was sporadic.

This is the second year that central Australia has been doing screening so it has gone from nothing to actually doing it, so that is a big improvement

Quote 20: Paediatrician, Coastal

The quality of the data produced by the HSAK programs was questioned and this related back to having an inadequately trained workforce. Screening data were not systematically reviewed and analysed, nor was there consensus on who was responsible for ensuring that data were acted on. A surveillance unit was needed to collate and disseminate the data and someone needed to take ownership of screening results and ensure that appropriate action was promptly initiated. There was no consensus on the process by which screening should lead to the implementation of a TCP.

Government Support

Government support was seen as critical by the six people who discussed it. Historically support had been poor but that had changed in recent years with a
renewed interest in trachoma. Recent increases in resources, the new national policy guidelines, the creation of a new job dedicated to trachoma, the surveillance unit and a training unit were all mentioned as positive steps forward. Trachoma is a disease of poverty related to underlying socioeconomic disadvantage and it was felt that, unless the government addressed larger issues such as housing, any efforts were futile. However, the construction of swimming pools was mentioned as a positive initiative.

*I think that is the sadness because trachoma highlights the social situation for most Indigenous communities*

Quote 21: RSP, Centre

**Information, education and communication**

Five people commented on the lack of communication between the various stakeholders and the lack of appropriate information resources. There was poor communication between groups responsible for different programs. Better communication would allow the sharing of resources and lead to increased efficiencies. If program models were provided to communities and schools it would assist them with the timely and efficient implementation of programs. The remote principal explained that initiating a school based hygiene program was very time consuming and that once established it would be easier to maintain. He explained that any extra information regarding establishing a program could potentially save time and increase efficiency. Hygiene campaigns are not core business for the school and need to be undertaken in what little spare time teachers have.

*We are trying to organise a mass treatment in a community and there is not even a standard set of resources about education in the territory... you have to start most things from scratch*

Quote 22: RSP, Centre
Adequate communication with communities was critical to increasing awareness and obtaining support. There were few resources that could assist with the process. The development of posters, videos or a flip chart would be useful in the provision of information about trachoma to communities.

*The trachoma message is very simple and it is one of the fundamental public health messages*

Quote 23: PHW, Centre

**Regional awareness**

Five people discussed issues that were categorised as regional awareness. A dedicated trachoma PHW could facilitate training and increase the awareness of regional health staff. One respondent felt that the low level of awareness was related to the low significance trachoma had as a population health problem. Trachoma was not on the list of priority diseases. There was little information about the blinding complications of trachoma in the coastal region and better data were needed to adequately determine the public health importance of trachoma.

**Outside support**

Outside support would include the assistance provided by research institutes like the Centre for Eye Research Australia, non-government organizations like the Fred Hollows Foundation or other government departments. It was interesting that only two respondents mentioned the benefits of outside support. A PHW spoke of the need to strengthen relationships with the education department because the most appropriate avenue for the successful implementation of ‘F’ was through schools and that this required support from the education department. The ophthalmologist acknowledged the assistance he had received from collaborating with an NHMRC research project but this was not specifically linked to a TCP but rather was part of his existing practice which incorporates the ‘S’ intervention.
Time consuming

Trachoma programs are time consuming and while this may be argued to fall under resources, two specific comments were made that deserved attention in their own right. School based hygiene programs are not considered core business. They are time consuming because many children have little or no experience of good hygiene practices. Teachers are unable to devote sufficient time to hygiene programs because they already struggle to keep up with their core business. Travel to communities was time consuming, particularly road travel, and this impacted on the time available to deliver services within remote communities.

Database

The need for a centralised database was discussed by two PHW and the ophthalmologist. Both PHW felt that a database would need to include trachoma prevalence information and the type of treatment that was instituted. It would be critical to record the coverage of treatment because this would be necessary to monitor program success. It was acknowledged that data collection would be difficult and that work needed to be done to establish how to collect the required information. The ophthalmologist pointed out that databases need to be regionally co-ordinated to deal with the high population mobility. A patient may be seen in a different community on each visit and that without a centrally co-ordinated database it was impossible to track the patient’s history and provide good continuity of care.

Staff Turnover

There was a high level of staff turnover compounding the difficulties of maintaining a well trained workforce as previously discussed. The high staff turnover of RAN in remote clinics added to the haphazard implementation of programs. Currently programs were highly dependent on the personality of the local RAN. Staff often did not stay in one place for long and programs would often come and go with the staff that drove them. This added to the already patchy implementation of the TCP. A
combination of patchy implementation and high population mobility was thought to be a reason for the failure of the SAFE strategy to eliminate trachoma.

**Satisfied workforce**

The principal spoke of the low morale of teachers and the sense that any new initiative might fail. He said this was related to the entrenched social disadvantage as well as the failure to be able to ensure that the essentials of life were provided.

*Staff see the problems as being overwhelming and this leads to low morale and a sense that anything they try will fail*

**Quote 24: Remote principal**

He reported that one teacher went for two weeks without running water at her house. It was hard to try and get her interested in a hygiene campaign while she could not maintain her own hygiene. Amongst the RSP there was a similar sense of hopelessness that the problems were all too big to solve and that anything they did was a waste of time.

**Resistance**

One PHW was very concerned about the possible development of antibiotic resistant pathogens, an important consideration in any mass antibiotic campaign. It was argued that the haphazard manner in which mass antibiotic campaigns have been implemented was increasing the chance of resistant pathogens developing. Current programs were probably doing very little to treat trachoma but were adversely effecting our ability to treat other, often more serious, infectious diseases.

*I am constantly concerned about the level of antibiotic resistance and giving broad spectrum antibiotics to communities living in filth which has this effect on the level of antibiotic resistance and we know there are high rates of macrolide resistance of staphylococcal isolate...in the hospital...I am*
concerned that it is due to widespread use of azithromycin in the communities which is obviously doing very little for trachoma...however it is detrimental when we are dealing with the other organisms that it leads to resistance in.

Quote 25: RSP, Centre
CHAPTER 4

4 Discussion
4.1 **Summary of Findings**

4.1.1 **Infectious diseases of childhood**

A total of 434 children were examined during two visits that made up the baseline findings. The majority, 345 were from Community C and 89 were from community D. Over 80% of children residing in either community were examined. There was a high prevalence of infectious diseases. In Community C 17% had trachoma, 49% had pyoderma, 19% had ear infection and 25% had a perforated tympanic membrane; only 46% of children had a clean face. In Community D 55% of children had trachoma, 49% had pyoderma, 21% had ear infections and 32% had a perforated tympanic membrane; only 46% of children had a clean face. The prevalence of trachoma was significantly different between the two communities however the prevalence of pyoderma, ear pathology and clean faces was not different. Living in Community D, having poor facial hygiene and attendance at school in Community D were predictors of trachoma. There was no association between the different infectious diseases of childhood and trachoma. Trachoma was not associated with gender or age.

4.1.2 **Evaluation of ‘A’ and ‘F’**

An antibiotic distribution program was initiated in Community D and over 80% of the population received antibiotics. Only two individuals who were offered antibiotics refused. Repeat surveys were undertaken at 3 months and 6 months. The prevalence of trachoma fell significantly at the 6 month follow up but not at the 3 month follow up. The prevalence of children with very unclean faces dropped significantly at both the 3 and 6 month follow up visits.
4.1.3 Trachoma and visual impairment amongst Aboriginal adults

Aboriginal adults aged 40 and over were offered a basic eye examination. The prevalence of scarring increased with age and was more common in Community D than Community C. There were no cases of trichiasis or corneal opacity secondary to trachoma in Community C. In Community D the age adjusted prevalence of trachomatous trichiasis was 14% and 6% had corneal opacities. The prevalence of visual impairment was 24 times higher in the Aboriginal population than in an age matched urban population. The prevalence of blindness was forty fold higher in the Aboriginal population. Trachoma was the most common cause of blindness. Bilateral cataract accounted for about 50% of those with moderate or worse visual impairment.

4.1.4 Barriers to the implementation of the SAFE strategy

The SAFE strategy has not been widely implemented in Australia and we interviewed those with a role in delivering the trachoma control program to identify the reasons for the poor implementation of the SAFE strategy in the Northern Territory. Semi-structured interviews were undertaken and responses were coded as categories. There were several themes that emerged as being potential barriers to SAFE based trachoma control and it is possible that many of these barriers can be easily addressed. Critical success factors for a trachoma control program include: an acceptable policy that is backed by sufficient resources and funding, a centralised trachoma co-ordinator who can take ownership of the program and organise regional assistance to remote clinics, the development of a set of education, information and promotional resources; and the development of partnerships with communities as a prerequisite to implementing a mass treatment program.
4.2 Communities and Participants

4.2.1 Overview

In 2003 research conducted in two remote Indigenous communities in Western Australia demonstrated the improved health of Aboriginal children following construction of a community swimming pool. The prevalence of pyoderma and tympanic membrane perforations amongst children decreased. Partly as a result of this research the Federal and Territory Governments initiated a program to build swimming pools in remote communities of the Northern Territory. The Pools In Remote Areas (PIRA) committee was established to oversee the project. A meeting was held in August 2004 were the author (HRW) and Associate Professor Jill Keeffe (JEK) presented a proposal to evaluate the impact of the new swimming pools. The Centre for Eye Research Australia (CERA) was invited to undertake an evaluation of the health impact of swimming pools in remote communities. Funding was provided by a substantial grant from Christian Blind Mission International (CBMI) and the Vision CRC.

A study timeline was developed based on information provided by PIRA. Two communities were selected by PIRA to participate in the program in December 2004. Extensive consultation was undertaken and each community provided letters outlining their support of this research project. Construction of the pools was to be complete by the middle of 2005. A baseline survey was planned and undertaken prior to the estimated construction time. Follow up surveys were then to be undertaken after construction of the pool. Unfortunately the pools had not been constructed by the end of 2006. The community council in Community D was placed in receivership putting plans to construct the pool on indefinite hold. Construction was further delayed in Community C by a category 5 cyclone early in 2006. No other ‘E’ components were specifically implemented and it was not possible to include an evaluation of the ‘E’ component of SAFE. Furthermore, mass antibiotic treatment was not undertaken in
Community C nor was follow up in 2006 possible, largely due to the impact of the devastating cyclone. The impact of ‘A’ and ‘F’ components of SAFE were evaluated in Community D.

Trachoma is a public health concern because infection in children may cause vision loss in adult life. Thus it is important to assess the elderly population as well as monitor children. The ‘S’ component of the SAFE strategy involved a community based door-to-door survey of Aboriginal adults aged 40 and older. Individuals with trichiasis were referred for surgery through the existing health services. This survey was not only important because it was part of the holistic SAFE strategy but provided valuable information. There is a paucity of data on the late stages of trachoma particularly in the ‘Top-End’. Trachoma in children is of limited importance if it does not progress to blinding disease; therefore, it is important to know both the prevalence of active trachoma and cicatricial disease within a community. Many health professional in Australia do not believe that trachoma is still a public health concern. We have demonstrated, at least in Community D that trachoma is a public health concern and a major contributor to an alarmingly high prevalence of visual impairment amongst older people.

According to Australian guidelines²³¹ based on WHO recommendations¹ the prevalence of trachoma found in each community warranted a SAFE based trachoma intervention. A trachoma control program was not undertaken in Community C and the program in Community D was delayed for nearly a year and certainly would not have been undertaken without the participation of this research project. Trachoma programs have been rarely implemented in Australia and where they have been implemented they have not been sustained. Why is trachoma control not being systematically implemented in the Northern Territory of Australia? Semi-structured interviews were undertaken with those involved in trachoma control programs in an effort to determine critical success factors that must be achieved in order to implement a trachoma control program.
4.2.2 Communities

The study was undertaken in two remote Indigenous communities in the Northern Territory of Australia. Communities were selected because of their involvement in PIRA. The two communities were very different: geographically, culturally and politically. Community C was a large coastal community with diverse language and cultural groups. Community D was located in the dry, dusty central desert region of NT. Communities in the tropical coastal regions of NT have historically experienced a lower prevalence of trachoma than central desert communities. Having two such diverse communities provided a valuable opportunity for comparing the pattern of disease and data is presented by community unless stated. Community C had a population of about 3,000 and Community D a population of about 750. However, both populations were extremely mobile and there was large population variability within each community. The population was particularly effected by important regional or local cultural activities. The term cultural activities is a generic term that is used in this thesis to describe a wide range of important activities that include: the passing on of traditional law, regional meetings (corroboree’s), funerals (sorry business), secret men’s and women’s business (the passing on of law that only men or women can know), coming of age ceremonies (were boys become men and girls become women), and bush trips during which children are taught how to survive, hunt and gather food on their traditional land.

Both communities were extremely socioeconomically disadvantaged. Houses were small, generally between 100 and 200 square meters, and had an average of about 17 occupants (personal communication Peter Gamblin Director of CDEP program initially at Community D but subsequently at Community C). Each community had a community health centre (clinic) that provided basic health care, emergency care, provided on-call after hours care, dispensed medications, facilitated specialist medical care and was responsible for delivering population health interventions. Emergencies and acute medical conditions were evacuated to the nearest regional hospital.
Specialist medical services were generally provided on a fly-in fly-out basis. Population health measures, such as HSAK and trachoma control activities were delivered by clinic staff with the assistance of regional health care professionals.

**Clustering**

Aboriginal communities do not generally follow the typical model of a ‘western nuclear family’. An intricate set of family and inter-personal relationships persist that are largely based on ‘skin groups’. Many children have a number of adults who are responsible for various aspects of their upbringing. Grandparents are of particular importance in child rearing and often take on the role of the child’s primary carer. The traditional style of childrearing has an important aspect on the dynamics of trachoma and the effectiveness of any trachoma intervention. There is a high level of intra-community mobility of children; children will often have several houses at which they live. Furthermore each child may have a number of different names depending on who they are staying with. Trachoma is a disease known to cluster at the household level. It is important to account for clustering in analysis and it must be taken into account in treatment. It is also possible to utilise clustering in study design; for instance by randomising at the level of the household. However, due to the high mobility of children within both the study communities it was not possible to examine clustering.

**Community events**

Community visits were planned well in advance to facilitate coordination with the school, the clinic, regional child and maternal health nurses and to avoid conflicting with visiting medical specialists or other researchers. Health care, particularly preventative health care, takes a relatively low priority in community life. Community events, particularly important cultural ceremonies may last for days, weeks or in some cases months. They can occur with little notice such as ‘sorry business’. During such times a large portion of the community may re-locate to culturally significant land to
mourn for and remember the departed. Even if people did remain in town it was not appropriate to approach them regarding their participation in a health research project during such a difficult time. The scheduling of community visits also needed to consider more practical matters such as regional sporting carnivals, school holidays and the availability of accommodation within the community.

The first visit to Community D was cancelled with only a few days notice because about half the population had left town and were not likely to return until after the visit. The mine that exists on the people’s traditional land was paying royalties in a neighbouring community and many people had travelled to that community to ensure that they received their appropriate share of the royalties. In 2006 no surveys were conducted in Community C because a category 5 cyclone had struck the community and had severely damaged much of the infrastructure. It was not appropriate to place an extra burden on the community during an already difficult re-building phase.

4.2.3 Ethical consideration

Aboriginal people, particularly those living in remote areas, are marginalised and disadvantaged. Marginalisation, disempowerment, language barriers and the ‘cultural divide’ create a milieu in which ethical considerations must be carefully considered. Despite the health disparity between Aborigines and mainstream Australians there remains a paucity of good epidemiological data; particularly on the health of those living in remote communities.

Research involving Aborigines has not always been conducted with the best interests of Aborigines in mind. There are many unfortunate examples of ‘racist’ research that will not be further discussed. Not unexpectedly there is a level of mistrust towards research. This mistrust can be overcome only by working in a genuine partnership with communities.
The six values and ethical principles (Table 2.1) form an excellent framework for assisting with the development of an appropriate research methodology. A careful assessment of how this research related to each of the six ethical principles was undertaken.

**Reciprocity**

The two communities involved in the study actively sought part in the PIRA program; part of that program was an evaluation of the health impact of the pool. Communities took responsibility for the pool and were expected to operate and maintain the pool. Part of the reason communities entered into the PIRA program was for the possible health benefits and communities were keen to participate in the study to confirm this benefit.

**Respect**

The project methodology was determined in conjunction with each community individually. Survey techniques were designed in deference to local customs and traditional beliefs. An effort was made to ensure that each aspect of the study was consistent with such beliefs as determined in conjunction with community leaders. Local ‘guides’ were paid to assist in all field work. Guides translated and identified important local issues to ensure that the research team did not inadvertently act inappropriately.

**Equality**

All partners within the project were equal. We provided expertise in scientific methodology and medical knowledge the community representatives had knowledge of their community and the population without which the project could not have proceeded.
Responsibility
When working in a remote Indigenous community there are responsibilities above and beyond the fundamental tenant of doing no harm. Local Customs and beliefs that are often very different from our existing experiences must be appreciated. When communicating with people who come from a very different knowledge base and background it is important not to diminish things that are seen as important. It is important to provide information and appropriate education in an understandable and meaningful way and this may require the assistance of assistance with translation. Advice was always sought about the appropriateness of approaching people in their homes and regarding locations for undertaking examinations.

Survival and Protection
This is an ethical principle that ensures the protection of Indigenous people from attempts to assimilate, subjugate or integrate them. The project did none of those things. It was a project that assists in the evaluation of a novel public health intervention that the community has elected to undertake. Unfortunately that intervention was delayed.

Spirit and Integrity
The researchers established close relationships with a number of community members who advised them on how conduct themselves in a manner that was consistent with locally acceptable practices. No aspect of our project impeded or commented on the richness and integrity of Aboriginal cultural inheritance.

4.2.4 Consent
Community consent is required by ethics committees prior to undertaking research in Indigenous communities. We obtained a letters of support from traditional land owners, the health board, the director of the community clinic, and the CEO of the community council. However, does this truly represent the consent of the entire
community? The only way to truly ensure community consent is to speak to every member of a community; but this is neither possible nor appropriate. Obtaining community consent is likely to be different in every community. However, the principles may be similar and will generally involve talking to community leaders, providing them with the appropriate information and listening to their perspective. Aboriginal communities may be thought to operate as a ‘collectivity’. Responsibility may be placed with a group of respected leaders or elders who are charged with speaking for the entire community. It is the support of these leaders that may best be considered community consent.

We obtained written informed consent for every child enrolled in the study. An information sheet was provided. In no case was consent refused; there was a single situation where the parents of a disabled child felt repeat examination was unnecessary; however, they were adamant that the results of her first examination by used in the study. They stated that the study was important for the community and the health of children and they wanted to support it. In general parents were most interested in the fact that their children would receive a health check–up, they were interested in the story of trachoma and the idea that a swimming pool might improve the health of children. Few appeared to be interested in the finer details of confidentiality and the de-identification of data-sets.

4.2.5 Participants

A total of 434 children were examined over the course of two visits to each community in 2005. The age and gender distribution across the two communities was reasonably homogenous. Approximately equal numbers of children aged from four to ten were seen in both communities. There were smaller numbers of children at each end of the age range, aged three or aged eleven or twelve. This disparity occurred because our study group was children attending primary school and not all three year olds attended school, similarly many children aged eleven or twelve had moved to
high school or left school. We did not recruit children who were enrolled in senior classes or children less than five who were not enrolled at school.

Demographics were recorded for each child. Very few children were sure of their age and almost none knew their date-of-birth. Children often used a variety of different names; some would change the name they used depending on who they were living with. This made it difficult at times to reconcile a child with the list of students provided by the school and local knowledge was critical in this process. The age recorded on the school roll was used; if the school did not have an age then the clinic records were consulted. Initially an attempt to map the houses that children stayed in was made so that we could analyse the effects of clustering. However, children and teachers found it very difficult to describe their location. Children for instance would state that they lived in ‘green house’ and point. Neither community had named streets. Houses were identified by a number on a council map. No children and few adults were aware of the number of their house. Furthermore, many children were highly mobile within the community and stayed at a number of different houses during any given week. The inability to assess the effect of clustering is an important weakness of this study.

The absence of a reliable population list made it difficult to recruit children and even harder to estimate the coverage achieved. The school roll was the primary source of population information; however, in neither community was it an accurate representation of the current primary school aged population. Children who had not enrolled in school were not on the list; however, this number was likely to be small as most children attended school at least occasionally. In both communities senior community members would collect children from the community and take them to school. There were numerous duplications on the roll; either the same name was recorded twice with different ages or the same child was recorded two or more times with different names. The school was apparently unable to delete such duplications because NT policy stated that names could only be removed from the roll at the end of
each year. Much duplication was identified with the assistance of community members and teachers; however, it is improbable that all duplications were recognized. Another major source of inaccuracy in the population list was that children visiting the community who attended school were entered onto the roll; such children were not removed from the roll when they left the community. Many previous visitors were identified on the roll; however, again it is improbable that all such cases were identified. The number of children on the roll was therefore probably higher than the number of children who were actually in the community. Thus in Community C the estimated proportion of children examined is perhaps an underestimate of the actual coverage.

The population of children was highly mobile as evidenced by the low number (40%) of children whom were examined on both baseline visits. Further evidence for the high mobility of children comes from the large number of children that were confirmed as being out of the community during each visit. On the second visit to community nearly half (48.4%) of children on the school roll were confirmed as being away from the community. In the more remote Community C children tended to be less mobile with only 13 and 21% of children being away during each visit. In both communities the most common reason for children being away from the community was that they were visiting the nearest regional centre. A destination that was much easier to reach from Community D than Community C and the isolation of Community C is probably the best explanation for the lower mobility seen within that community.

In the large and diverse Community C only 73% of the children who were thought to be in the community were examined. In the smaller more homogenous Community D all the children thought to be in the community on the first visit were seen and only a single child who was thought to be in the community was not examined on the second visit. The lower coverage achieved in Community C combined with the lower proportion of children away from that community meant that the overall coverage was
approximately the same as in Community D where the high coverage was cancelled out by the high proportion of children who were out of the community. A total coverage of over 80% was achieved in each community over the course of the two baseline visits. The high mobility of Indigenous populations and the difficulty in obtaining good coverage rates particularly in larger more diverse communities highlights the need for multiple visits, if a good cross sectional sample is to be achieved. A point that has been previously documented. \(^{229}\) A number of children were not enrolled in the study because it was not possible to find an appropriate adult from whom consent could be obtained; consent was never refused if an appropriate person could be found. There were several instances when we obtained consent for a child but subsequently were unable to locate that child again.

Two hundred and sixty Indigenous adults aged forty or older participated in the survey of cicatricial trachoma and visual impairment. Similar to the survey of primary school children the large size and the more diverse nature of Community C made the survey more difficult within that population. It is impossible to accurately predict a denominator due to the lack of reliable census data. It is probable that people who did not want to participate in the study simply stayed inside and did not respond when the research team visited their home, such people are not accounted for in the denominator. Therefore, the denominator is probably an underestimate of the population and the coverage an over-estimate. This problem was more pronounced in Community C, in Community D the local health workers were able to identify those who were in town and the denominator is probably reasonably accurate. The uncertain coverage, particularly in Community C is an important potential bias. In Community C where there were 388 primary school children only 186 adults were invited to participate in the study. The 40+ population was therefore about half (0.48) the size of the primary school population. In Community D there were 94 primary school children and 105 adults making the 40+ population 1.11 times the size of the primary school population. This large difference in the proportion of the 40+ population to the
primary school population is further evidence that the coverage in Community C was inadequate.

There were a higher proportion of females in our adult population sample. This is expected due to the longer life expectancy of females. The mean age of participants in Community D was significantly older than participants in Community C (56.6 vs. 48.5). Community C is far more isolated than Community D and it may be more difficult for elderly people with multiple medical conditions to stay in the community. The movement of old and sick individuals out of the community to regional centres where they had better access to health care might result in a reduced number of elderly people in the population. Infectious disease particularly TB is more common in coastal areas and may impact on the life expectancy of people living in these regions. However, it seems improbable that such rationalization could explain the dramatically different age profiles. It must be concluded that one or both of the samples were not an accurate representations of the true population. Given the lower than expected coverage in Community C we must conclude that this sample was insufficient and that it may have selectively missed older individuals. Elderly Aboriginal people often live a more traditional lifestyle and may have less confidence with English. It is probable that they might have been more reluctant to participate in the study than younger community members. Visual impairment and the presence of cicatricial disease are strongly associated with age. Therefore, in Community C coverage was probably lowest amongst those with the poorest visual function and greatest risk of cicatricial disease.

Historical data demonstrate that trachoma is more prevalent in dry and dusty desert regions. Cicatricial trachoma is most likely to occur in people who suffered intense disease in childhood. Therefore data on cicatricial trachoma was analysed according to where people spent the majority of their childhood; in a coastal or a desert region. Three individuals living in Community D grew up in a coastal region and were analysed with the 151 individuals who lived and grew up in a coastal area. Six
individuals living in Community C grew up in a desert community and were grouped with the 100 people living in the desert who grew up in a desert area. None of these nine individuals had TT or CO. The decision to analyse based on region of childhood therefore had little bearing on the prevalence of cicatricial disease. Interestingly only one of the six adults who lived in Community C but who grew up in a desert region had TS, much lower than the overall prevalence of 77.8% for people who lived in Community D and grew up in a desert region. Despite the small numbers this difference was statistically significant (p= 0.001). However, five of the six individuals were in their forties and when corrected for by age the difference did not reach significance (p= 0.07). However, this finding does raise the possibility that ongoing exposure to either C. trachomatis or the dry and dusty conditions typical of desert regions may be important components in the ongoing pathogenesis of trachomatous scarring.

Thinking from my cultural perspective I would imagine that people with eye problems would desire a vision check to a greater extent than those with good vision. This would tend to bias the sample to generally older individuals with poorer vision. However, the view of health that many Indigenous people have is very different to the western view of health. It is probable that those with poor vision did not want to be examined, perhaps through fear that something might be done to them or that they might be sent away to hospital, a place where people go to die. One of the two ladies that was blind (VA < 3/60) as a result of trachomatous corneal opacification was sitting on her porch in Community D when we approached the household offering vision checks and asking people to consent to the study. Several younger household members consented and underwent examination. We asked if the old lady wanted to have her eyes checked and were informed that she did not need a check because she was already blind. When we explained that we still wanted to examine her eyes she and her family readily agreed to participate in the study.
4.2.6 Development of methodology

Research that directly impacts on a disempowered group within society, such as Aboriginal people living in remote communities, necessitates specific considerations. Such considerations may not be necessary for research amongst people in the mainstream of society (the dominant culture). The term disempowerment has been used to describe a group of people who do not have complete control over their own destiny. Disempowerment occurs to groups on the margins of society and has many causes including lack of education, language barriers and lack of representation. Within the context of the Australian Indigenous population it can be argued that disempowerment has lead to passivity. People can not see a way to improve their situation and this has lead to a cycle that includes anti-social behaviour, extreme poverty and social disadvantage. The debilitation caused by disempowerment is starting to be well understood and research involving and in partnership with disempowered groups must consider its effects.

The ideal is for individuals from disempowered groups to initiate, design and conduct research that is identified as important within that group. However, this may not always be possible. Disempowered groups may lack the education, resources and technical expertise to undertake quality scientific research. External researchers can provide the expertise and may have access to resources, but they must ensure that research is in partnership with and inclusive of the disempowered group that is the subject of the research.

The first step in the development of this thesis was an extended period of extensive consultation and collaboration with a wide range of community leaders, regional health professionals and bureaucrats. This process commenced in April of 2004, it become focused on the two communities involved in December 2004 when PIRA announced the swimming pool contracts. Consultation and collaboration continued up to and beyond the first survey conducted in April 2005. A year was spent in
establishing partnerships with the communities, developing the project, obtaining community consent and ethics approval. This process was made challenging by both the isolation of the communities, and the language and cultural differences between the researcher and community partners.

Selection of the study population was undertaken in consultation with each community. WHO recommendations are that children aged 1-9 be surveyed for active trachoma, because they have the greatest burden of disease. The Australian guidelines recommend that children aged 5-9 be surveyed and this primarily because they are at school and this makes them an easily accessible sample. A survey should include children aged 1-4 if there is community acceptance of this. It was clear from discussions with community representatives that the study should focus on school children (5-15) and not pre-school children (1-4). The school population is assessed annually by the existing HSAK program and clinic staff were keen to have assistance with that program. Including teenage children in the data set was not necessary, because the study was adequately powered without including older children. Therefore, it was agreed that the project would work in conjunction with HSAK and HRW would assist with the examination of all children participating in HSAK but that data would only be collected from children enrolled in primary school classes. Children enrolled in primarily school were predominantly aged 5-10 but there were also a number of younger children who had started school early and a number of older children still enrolled in primary classes. The impact of targeting our population by school class is demonstrated by the consistent number of children of aged 5-10 but smaller numbers of children at the extremes of the sample.

Both communities recommended a similar recruitment plan. Children at school were examined in conjunction with HSAK when possible; children not attending school were followed up in the community by home visits. However, the details were subtly different in each community. In Community C HRW attended each classroom in the morning and examined children at a table at the back of the class, teachers would
nominate each child in turn to be examined. Children who were present and did not have consent were noted and an attempt to obtain consent was made that afternoon so that the child could be examined the following day. Due to the sporadic attendance of children there were several cases where children could not be found after obtaining consent for enrolment in the study. In the afternoon a member of the community was employed to assist us with home visits. Some of the people employed had taboos or language barriers that prevented them from communicating with certain members or groups within the community; therefore, it was necessary to employ a variety of different people in order to maximise coverage. In Community C locals were employed to assist with home visits and there was limited direct involvement with the clinic. In Community D the school provided a small treatment room, assistant teachers would bring a group of about three children to the room where they were examined. In the afternoon one of a small number of Aboriginal Health Workers would assist us to find and examine children at their homes.

Possibly the most disappointing aspect of the project was the failure, despite all the effort and planning, to co-ordinate with the HSAK program. In Community C regional population health officers decided to trial a new method of undertaking HSAK. This decision was made despite them being actively engaged with us during the development phase and even planning dates for undertaking the survey. It was decided to undertake short visits one a month; this decision was made due to the poor coverage that had been achieved over the previous two years. The last two HSAK screenings had both seen less than 100 children aged 5-15. A significant amount of time had been spent liaising with the community and regional health officers attempting to arrange dates for the survey and HSAK before we became aware of the policy change. Baseline surveys in Community C were therefore undertaken on their own. In Community D the survey was scheduled to occur in conjunction with HSAK but when HRW arrived at the community there was an acute shortage of staff and HSAK had been cancelled. The survey was undertaken and results were provided to
the clinic and the data were used in lieu of formal 2005 HSAK data. Finally, on the third visit to Community D, the three month follow up visit, the survey and HSAK were conducted together.

Undertaking multiple visits to each community had a number of direct advantages. Firstly, multiple visits enabled us to increase our coverage. Secondly and more importantly, on each visit educational messages were reinforced. The importance of good facial hygiene was particularly stressed. Antibiotics may be able to lower the point prevalence of trachoma in a community; however, without a change in the milieu that promotes facile transmission and repeat infection trachoma is likely to reappear. The institution of good facial hygiene amongst children is a simple, cheap and potentially sustainable long term change that may be critical in eliminating trachoma. The importance of facial hygiene programs at the school were discussed with teachers. Parents were advised about the importance of keeping their children’s faces clean. Posters were provided to the clinic and the school to assist with the facial cleanliness message.

It was not possible to develop an appropriate methodology that incorporated a control group. The ideal project design was a cluster randomised controlled trial (RCT). Clustering would be at the level of the community and would involve a large number of communities and subsequent randomisation of those communities to receive ‘A’ or ‘F’ or ‘Both’. The two study communities would have been non-randomly assigned to receive ‘E’. The original project design was primarily examining the impact of swimming pools ‘E’ on the prevalence of trachoma. It was not considered appropriate to include communities in such a project that were not going to benefit from a swimming pool.

Clustering can also be undertaken at the level of the household. Trachoma is a disease of the crèche and transmission of disease has traditionally been thought to occur primarily within the household. However, such clustering is probably not of such
significance in Aboriginal communities for two reasons. Firstly, children tend to be highly mobile within the community, moving between various homes. Secondly, children attending school are in close contact with many other children and this is a potentially important mechanism in the transmission of disease. Finally, it was unethical to deny the intervention to control groups. SAFE is a well established intervention backed by a large body of scientific evidence. The implementation of SAFE should be considered the standard level of care for any trachoma endemic community in Australia.

We undertook a longitudinal cohort study. It was not possible to unequivocally state that any reduction in prevalence was due to any aspect of the intervention. In distinguishing between the ‘A’, ‘F’ and ‘E’ components of SAFE this is a mute concern. The three arms of the strategy are intertwined and should be implemented together and their impact evaluated as though a single intervention. Trachoma will disappear with socio-economic improvements and in many developing countries there is a secular trend for trachoma to disappear in the absence of specific programs. This trend was seen throughout developed cities worldwide over the last hundred years. It is not possible to exclude the possibility that the prevalence of trachoma just started to improve and that the intervention was not important; however, this must be considered extremely unlikely given the history of trachoma in Australia.

4.3 Infectious diseases of childhood

4.3.1 Trachoma

The results of this research do not indicated that the prevalence of active trachoma has changed significantly in the Northern Territory over the last 50 years. Trachoma has not disappeared from remote Indigenous communities as it did from urban Australian populations about 75 years ago. This is a stark reminder of the extreme disparity in Australia. Trachoma is a disease of poverty, overcrowding and above all things poor
personal and community hygiene. The fact that blinding trachoma persists in Australia is a national disgrace. It is unconscionable that Australia continue to sit back and observe another generation of Indigenous children go needlessly blind in the hope that socio-economic improvements will occur. We must implement specific and proven interventions now or today’s children will be tomorrow’s blind.

In the desert community over half of primary school aged children (55%) had active disease, a prevalence only found in the most severely affected areas of the world. In the coastal community where trachoma is not thought to be a public health concern 16.7% of primary school children had clinical signs of disease. Endemic disease is defined as prevalence greater than 10% and indicates the need for intervention. A population health intervention based on SAFE should have been implemented according to Australian guidelines based on WHO recommendations. Recommendations that are relevant to and undertaken in some of the poorest countries in the world; yet in Australia no action was taken.

**Comparison with existing data**

The NTEHP considered the region containing Community D the ‘Red Centre’ and the prevalence of follicular trachoma in children aged 1-9 was 50% (n= 2,934). Other prevalence data from Community D itself or from the region containing Community D are: 56% in 1976, 46% in 1985, 25% in 1990, 40% in 1998, 35% in 1999, 42% in 2000, 79% in 2001, and 40% in 2003. These data demonstrate that little has changed over the last 30 years in the central desert communities.

In the ‘Top-End NT’ a region that includes Community C the prevalence of follicular trachoma reported in the NTEHP was 21% (n= 2,517). Less data are available regarding the coastal regions than desert regions. Mak reported trachoma prevalence of: 3% in 1998, 0% in 2001, and 20% in 2002. Muller collated data from 3,045 children from 108 surveys and reported an overall prevalence of 16%. There were no
data from Community C; however, the prevalence in the region does not appear to have changed in the last 30 years.

**Sandy blight: a desert disease**

Trachoma has traditionally been thought of as a disease that predominates in dry and dusty regions and was called ‘sandy blight’ by the early pioneers. The stark difference in prevalence between Community C and Community D is consistent with historical Australian data and further supports the idea that trachoma flourishes in dry and dusty desert regions. The gender mix and age profile of children was similar in each community. There did not appear to be a major difference in social conditions or the level of overcrowding between the communities, however, environmental factors were not formally assessed. Overcrowding and poor hygiene are thought to be the factors that promote skin and ear infections and were not obviously different between the two communities. Why the striking difference in the prevalence of trachoma? Several mechanisms for this difference can be speculated upon:

- The most obvious explanation is that children in the ‘Top-End’ are living on the coast and therefore have access to the sea. The hypothesis being that swimming in the ocean would keep the children cleaner and reduce the transmission of disease. However one would expect to see a substantial difference in the number of children with clean faces if this was the case. However there was no significant difference in the proportion of children with clean faces between the two communities. Furthermore, while working in Community C I did not see many children swimming in the ocean. I did see children using plastic tubs full of water to escape the heat of the day (Figure 4.1) and a number of crocodiles (Figure 4.2). Crocodiles are common along the coast and rivers near Community C and limit the appeal of swimming in the ocean.

- Winter nights are very cold in the desert community and this may lead to a greater level of crowding. It is the effect of children with unclean faces living in close
quarters and passing eye secretions from one to another that enables the facile transmission of trachoma. This effect was not seen with ear and skin infections. It is possible that transmission of *C. trachomatis* requires close contact with others who are also unclean, while the development of pyoderma and ear infections simply requires poor hygiene. However, U.S. armed services recruits are still treated with prophylactic penicillin to prevent pyoderma during boot camp. The disease is thought to be common in trainees due to the high level of crowding.\(^{230}\)

➢ Dry air increases the rate at which the tear film protecting the ocular surface evaporates. Sand and dusty conditions may cause micro-abrasions to the dry ocular surface. This may limit the ability of the ocular epithelial cells to resist infection. Decreased resistance to infection will enhance the facile transmission of *C. trachomatis*. Children in dry and dusty conditions might suffer more episodes of infection from the same number of exposures, allowing the bacteria to establish a larger reservoir of infection, and further intensifying the cycle of repeat infection and facile transmission that is the hallmark of hyper-endemic trachoma.
Figure 4.1: Children using a tub full of water to escape the heat

Indigenous children in Community C escaping the heat of the day, in the background was the site for the proposed swimming pool.
Using photographs to assess grading reliability

Photographs confirmed that there was good internal validity of grading but external validity was uncertain because HRW consistently graded more conservatively than HRT. Grading reliability is unlikely to reach 100% for two reasons. Firstly, photographs are technically challenging and may provide a different view to that seen in the field. Follicles that were obvious in the field may not be seen on the photograph and conversely follicles that were difficult to appreciate in the field may be highlighted on the photograph. Photographs allow the observer to spend a longer time to consider if a sign is present. Secondly, the simplified grading scheme uses an arbitrary cut-off of five follicles greater than 0.5 mm diameter. This creates an area of uncertainty or a grey zone where judgement is used; experts may grade the same
photo differently on different days if it is in this grey zone. This is not generally a problem in trachoma programs because it is the community prevalence that is of interest not individual diagnosis and if trachoma is endemic there will always be sufficient examples of obvious disease to indicate the need for intervention. However, it can pose a problem in research because the undiagnosed cases of TF may have an impact on the risk factor analysis. Missed cases of TF or incorrectly diagnosed cases of TF could also impact on studies comparing laboratory diagnosis with clinical diagnosis and this may contribute to the poor correlation of clinical diagnosis with laboratory tests seen in some studies, particularly if cases were incorrectly included.

Grading TI appears to be more difficult than TF, and the sign has not always been graded well. The prevalence of TI is generally about 10-20% of the prevalence of TF. Several recent papers have reported a prevalence of TI that was greater than the prevalence of TF with one paper even reporting a prevalence of TI that was double the prevalence of TF. TI generally occurs in conjunction with TF and represents an intense or severe form of the disease. When the prevalence of TI is similar to or greater than the prevalence of TF the reliability of grading should be questioned or an alternate explanation for the high prevalence of the TI sign, such as acute viral conjunctivitis, should be considered. Given that the TI sign is possibly not well graded and that it adds little useful information to field programs its continued use in programmatic work could be re-assessed.

Photographs have been extensively used to assess the reliability of grading since validated by West and Taylor in 1990. However, the dependability of photographs as a test of grading reliability has been recently questioned. Solomon and colleagues identified studies that have used photographs to validate trachoma grading or have photographs as the sole means for grading trachoma. Table 4.1 shows the agreement (kappa statistics) reported between field and photo-grading from each study. Several of the above publications report results from the same data set, so only the first paper that reported the kappa scores
has been included. Most studies report a kappa statistic of approximately 0.6-0.7 and this suggests good to very good agreement. The study by Solomon in which photo-grading was re-evaluated reports the poorest agreement by a considerable margin. The largest study is that by Emerson et al. in which more than 3500 photographs were graded. Reliability was consistently good with kappa statistics ranging from 0.63-0.69.

<table>
<thead>
<tr>
<th>Study (number)</th>
<th>TF (%)</th>
<th>TI (%)</th>
<th>TF Kappa (n)</th>
<th>TI Kappa (n)</th>
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<td>N/A</td>
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<tr>
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<td>N/A</td>
<td>0.72* (100)</td>
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<tr>
<td>Baral 1999&lt;sup&gt;101&lt;/sup&gt; (726)</td>
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<td>0.50* (125)</td>
<td>N/A</td>
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<tr>
<td>Holm 2001&lt;sup&gt;29&lt;/sup&gt; (5262)</td>
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<td>0.9%</td>
<td>0.76 (130)</td>
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<td>&lt;1%</td>
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<td>Solomon 2006&lt;sup&gt;236&lt;/sup&gt; (948) all</td>
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<td>12%</td>
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<td>0.56, 0.38, 0.43</td>
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Table 4.1: Kappa statistics from studies that have used photo-grading

The major difference in methodology between the work of Solomon and Emerson was the way they dealt with ungradable photographs. Emerson et al. excluded ungradable photographs from the data set according to pre-determined criteria and only 63% of photographs were considered gradable. Solomon et al. considered ungradable photographs as disagreement. The graders determined if a photograph was gradable and considered very few to be ungradable. We eliminated photographs as ungradable if they met set criteria similar to the work of Emerson et al. and achieved similarly good reliability scores.
Assessing reliability using photographs is a valid and important tool in confirming the reliability of trachoma grading. Moreover, because it is often impossible to mask the examiner to the intervention grading reliability must be undertaken if results are to be accepted with confidence. A standard method of taking pictures is required and a standard method of dealing with the inevitable poor quality images must be agreed upon.

### 4.3.2 Other infectious diseases of childhood

It was initially decided to monitor the prevalence of several other infectious diseases of childhood (pyoderma and ear infection) because it was anticipated that these diseases would be impacted upon by the swimming pool. The swimming pool was not built and we did not examine children for pyoderma and ear infections at the follow up visits for ‘A’ and ‘F’. Furthermore, it was not possible to validate the grading of pyoderma and ear infections. A reliability study was planned with the community paediatrician in Darwin. It was anticipated that he would attend on one of the visits and undertake a reliability study on a sample of the population. Unfortunately, due to personal circumstances this did not eventuate. The prevalence of the other infectious diseases is reported primarily to highlight their association with trachoma. More detailed research has been undertaken examining both pyoderma and otitis media.

**Pyoderma**

Nearly half of the children examined had some evidence of pyoderma (49.1%), with an alarming 6% of children having severe disease. In contrast to trachoma there was no difference in the prevalence of disease between the coastal and the desert community. Trachoma and pyoderma are both thought to be strongly linked to poverty, overcrowding and poor hygiene; and it was anticipated that the two diseases would show a similar pattern. Pyoderma was less stable over time than trachoma. Amongst children that were seen twice many changed their pyoderma status whereas children who had trachoma on one visit tended to have trachoma on the subsequent
visit. The higher variability could be equally well explained by either a more rapid course of disease or a less reliable grading system.

Pyoderma is known to be related to scabies. Infestation with scabies makes the skin itch; children break the skin when they scratch their itch and this enables pathogenic bacteria to invade. Over a third of the children examined had scabies and it was correlated with pyoderma. This association was almost entirely due to the impact of infected scabies a finding that is consistent with the above aetiology.

**Ear infections**

About one in every 5 children had ear pathology. Younger children were far more likely to have ear infections while older children had perforated tympanic membranes. Perforation of the ear drum acts like a grommet and allows the pus to drain and helps clear up infection. It was not possible to undertake formal audiology studies but previous work has shown that profound hearing loss is common amongst Aboriginal children.  

Children with ear pathology were not more likely to have trachoma and this finding is similar to the lack of association between pyoderma and trachoma. Children with very unhygienic faces tended to be more likely to have ear infections than children with hygienic faces. This association was predominantly due to facial cleanliness (Clean-unclean, OR 2.1, 95% CI 1.1- 3.9, p= 0.03) but children with worsening nasal discharge also had higher rates of ear infection. There was no association between facial hygiene and ear perforations. This was expected because children with perforations are older and facial hygiene was generally good amongst older children.

**4.3.3 Associations between infectious diseases of childhood**

Trachoma, pyoderma and ear infections are all diseases strongly linked to socio-economic disadvantage, particularly poor hygiene and overcrowding. This is attested to by the dramatically different prevalence found in remote Indigenous communities.
and urban centres. It was anticipated that the burden of disease would be borne by a specific subgroup of children; those at greatest disadvantage. However, this was not the case. Children with pyoderma were no more likely than children without pyoderma to have trachoma. Children with ear-pathology were no more likely than children without ear pathology to have trachoma. There are two likely explanations for these data. Firstly, each disease may have different risk factors. Secondly, risk factors may be ubiquitous, or so prevalent, amongst the entire population that they do not select for a specific subset of the population. Whatever the explanation this finding is important for policy makers. If a subset of the population bore the burden of infectious disease then interventions could be efficiently targeted to those who need them most. However, our data suggest that this is not the case and screening of the entire population for each disease is the best approach.

Screening for a variety of infectious diseases as part of a single co-ordinated program targeted at children is the most efficient use of resources. Obtaining consent from parents and recruitment of children are the most time consuming aspects of the screening program. The examination is simple, quick and non-invasive. By undertaking a holistic screening program consent and recruitment is performed on a single occasion. Assistance for the program can be provided by regional centres. Maintaining an effective ongoing screening program is critical for guiding the implementation of interventions and for monitoring and evaluating the impact of existing programs. However, interventions may need to be directed at each infectious disease as a separate entity with its own aetiology.

### 4.3.4 Facial cleanliness and trachoma

Facial cleanliness probably the risk factor for active trachoma that is most amenable to intervention. West suggested that of the various components of an unclean face, nasal discharge may be the major contributor to trachoma. However, dirt on the face tended to be a better predictor of trachoma than nasal discharge in this study.
West and colleagues assessed 472 children for trachoma and assessed different signs of an unclean face: ‘sleep’ in the eyes, nasal discharge, food on the face, dust on the face and flies on the face. No sign was independently a statistically significant risk factor for trachoma (Table 4.2). However, children with nasal discharge and flies on their face were more likely to have active disease. West concluded that facial cleanliness campaigns should be targeted at nasal secretions and flies rather than wiping dust and food from faces.

<table>
<thead>
<tr>
<th>Facial Sign</th>
<th>Prevalence of Sign (%)</th>
<th>Odds ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep</td>
<td>60</td>
<td>1.1 (0.8-1.6)</td>
</tr>
<tr>
<td>Nasal discharge</td>
<td>70</td>
<td>1.3 (0.9-2.0)</td>
</tr>
<tr>
<td>Food on face</td>
<td>40</td>
<td>0.9 (0.6-1.3)</td>
</tr>
<tr>
<td>Dust on face</td>
<td>70</td>
<td>1.2 (0.8-1.8)</td>
</tr>
<tr>
<td>Flies on face</td>
<td>53</td>
<td>1.4 (0.9-2.0)</td>
</tr>
<tr>
<td>Nasal discharge and flies</td>
<td>54</td>
<td>1.7 (1.2-2.6)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Results from West et al.</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Unclean face</td>
<td>36.4</td>
<td>1.1 (0.7-1.9)</td>
</tr>
<tr>
<td>Very unclean face</td>
<td>6.9</td>
<td>3.4 (1.4-8.5)</td>
</tr>
<tr>
<td>Mild nasal discharge</td>
<td>24.2</td>
<td>1.0 (0.5-1.9)</td>
</tr>
<tr>
<td>Severe nasal discharge</td>
<td>13.6</td>
<td>1.3 (0.6-3.2)</td>
</tr>
</tbody>
</table>

Table 4.2: Components of a clean face as risk factors for trachoma

The importance of the various components of an unclean face are shown from our study and that of a previous survey undertaken by West et al. The importance of the various components of facial hygiene in the context of remote Indigenous communities was evaluated. The majority of assessments were undertaken inside at the school where there were few or no flies. Therefore, an assessment of the number of flies on the faces was of no practical use. We combined the categories of food on the face and dust on the face into a single category of facial cleanliness. This sign was graded independently of the presence of nasal discharge. Furthermore, rather than simply assessing the presence or absence of a sign we attempted to quantitatively assess each sign using a three tier scale of: not present or clean, present or unclean and severe or very unclean.
Encouraging children to have clean faces may be an important intervention for the long term control of trachoma, its effectiveness has been supported by a single randomised controlled trial. Each of the components of facial hygiene was a predictor of trachoma in a univariate binary logistic regression model. In contrast to the previous work of West these data suggest that facial cleanliness tended to be a better predictor of trachoma than nasal discharge. Nasal discharge was not a predictor of trachoma in the multivariate binary logistic regression model. Both components of facial hygiene are important and require attention if facial hygiene campaigns are to be effective. We are of the opinion that an unclean face must be washed with soap and water before being dried with a clean towel; while nasal discharge is removed by blowing the nose. Schools that are planning to implement facial cleanliness campaigns should ensure that adequate resources are available to wash faces and that tissues are available for children to blow their noses and clear away nasal secretions. Adequate time must be set aside for staff to supervise these activities. Even if poor facial cleanliness is a result of ocular discharge secondary to trachoma rather than a cause of the disease then keeping children’s faces as clean as possible could be expected to help reduce transmission.

There were some intriguing differences in the pattern of facial cleanliness and disease in each community. We only examined two communities and therefore no statistically significant conclusions can be made. However, several interesting possibilities can be raised that may be worthy of further investigation. In Community D the prevalence of active disease was high and having both an unclean face and nasal discharge were independently associated with trachoma. However, in the lower prevalence Community C only having a very unclean face was associated with trachoma. We have already argued that trachoma may be more prevalent in desert areas due to environmental factors unrelated to hygiene. The importance of hygiene as a risk factor for trachoma may depend on the prevalence of disease within a community. A child growing up in a modern urban city with a chronically unclean face would not develop...
trachoma because there is no reservoir of infectious agent. One can speculate that in a high prevalence community the reservoir of infectious agent is likely to be high and children are far more likely to be inoculated with infectious agent. In such an environment it is easy to see how having an unclean face increases the risk of active trachoma. However, the opposite argument also holds that if there is a high prevalence of infection then many of children will have ocular discharge and thus will have unclean faces.

In a lower prevalence community the reservoir of infectious agent is probably lower. Therefore children would be exposed to infectious agent less often. It is possible that only children with very unclean faces will receive sufficient inoculations of \( C. trachomatis \) to develop clinical signs of trachoma. Facial cleanliness campaigns may therefore have a higher yield in lower prevalence settings. This question may be worthy of further investigation because of the reluctance to administer mass antibiotic treatment in relatively lower prevalence settings in Australia. Opponents argue that too many people who don’t have disease receive antibiotics. It is possible that in lower prevalence settings effective facial cleanliness programs without mass antibiotics may be sufficient to eliminate disease. However this is speculation and needs to be scientifically investigated before any recommendation could be made.

There was no association between facial hygiene and ear and skin infections. This was a surprising finding and is further evidence for the different aetiology of these diseases. Ear infections are probably highly dependent on anatomical factors particularly the adequacy of drainage from the middle ear provided by the eustachian tube. Pyoderma is closely related to and perhaps secondary to scabies. Scabies may be more related to the cleanliness of clothes and bedding. Facial cleanliness programs may not necessarily have a direct impact on these diseases. This also brings into question the causal relationship between infectious disease and facial hygiene and supports the notion that children with trachoma develop unclean faces and not the other way around.
4.3.5 School attendance and trachoma

School attendance appears to be an important risk factor for the development of active trachoma. For every additional 10% of days that children in Community D attended school they had an extra 20% chance of having trachoma. However, children with clean faces were no more likely to have trachoma regardless of how often they attended school. It is probably the combination of having an unclean face and participating in the close social interaction with other children at school that facilitates the transmission of chlamydia. A recommendation that children not attend school to reduce the risk of trachoma is laughable. However, this important finding suggests that the education department have a duty to reduce the risk of children developing trachoma at school. This is best achieved by the widespread implementation of facial cleanliness programs at school.
Figure 4.3: Indigenous children in class

Children, many with unclean faces, are in close contact during class times and this may facilitate the transmission of *C. trachomatis*.

The school is the ideal environment to deliver facial hygiene programs. Currently in the Northern Territory the education department does not view maintaining facial cleanliness of students as a core business activity of community schools. Teachers that choose to take on the extra responsibility of running a facial hygiene program are expected to cram such activities into their already hectic schedule. Attending school may put students at risk of trachoma. Therefore, schools have an obligation to implement a simple program to ameliorate that risk. It is imperative that the education department ensures that schools are provided with the resources that enable them to implement and maintain facial hygiene campaigns. If hygienic behaviour can become
routine it may result in permanent behavioural change and this may be the best chance of achieving a sustainable reduction in the prevalence of trachoma in the short to medium term.

### 4.4 Evaluation of ‘A’ and ‘F’

The SAFE strategy has not been widely implemented within Australia. Two studies have evaluated the impact of different mass antibiotic distribution strategies. Neither study led to a sustained program; despite early reductions in the prevalence of disease the prevalence rapidly returned to historical levels. Lamming evaluated the impact of targeted treatment in a semi-desert community and reported a reduction in the prevalence of trachoma from 42% to 22% at 6 months (p= <0.001); however, there was no attempt to implement ‘F’ or ‘E’ and prevalence has subsequently returned to baseline (unpublished HSAK data). Ewald evaluated a more complete ‘AFE’ strategy in Community D; however, facial cleanliness was not measured and the program was not sustained. In Community D we have helped to implement what will hopefully be a sustained trachoma program. The program is largely delivered by local staff and community members with assistance from regional public health nurses and the author.

#### 4.4.1 Undertaking mass treatment

The most important part of the mass antibiotic distribution program occurred during the two months leading up to mass distribution. During this time extensive public education sessions and information nights were conducted. Posters were distributed throughout the community. In the week prior to the program HRW undertook a radio interview discussing the reason for the antibiotic distribution and encouraging the community to participate. The clinic manager and the community population health nurse were particularly involved in the project. The health team was divided into teams each of which was given a fully equipped box that contained all the items that
were needed. Teams were designed such one member of the team was always available to talk to people about trachoma and the reasons for the treatment program. In this way a large number of the community were engaged and provided with information about trachoma, facial cleanliness and the reason for distributing antibiotics. Interest in the program and trachoma was high amongst community members and the author spent the majority of the treatment week discussing trachoma. Many people remembered the work of Ewald undertaken 8 years previous and several remembered meeting Fred Hollows 30 years previously.

### 4.4.2 Facial cleanliness campaigns

The facial cleanliness campaign really began during the first survey. Particular attention was given to talking to primary school teachers about the health benefits of children having clean faces. The principal of the school was supportive and keen for the school to be actively involved in a facial cleanliness program. Discussions were held with the teachers at each visit. The school and clinic were provided with posters. The importance of facial cleanliness for children was stressed to everyone who received antibiotics. On each visit it was noted that the primary school staff, where the highest prevalence of unclean faces was, were making an effort to clean each child’s face at least twice a day. However, no objective measurement of face washing was undertaken.

### 4.4.3 Outcomes

The prevalence of trachoma and the facial cleanliness of children were assessed at 3 and 6 months after mass antibiotic distribution. There was not a significant reduction in the prevalence of trachoma at 3 months but after 6 months the prevalence was significantly reduced. A significant improvement in facial cleanliness was also observed at both follow up time-points. It is difficult to know why a reduction in the prevalence of trachoma was seen in this project and not observed by Ewald. Ewald used a targeted distribution strategy and we used a mass distribution strategy.
However, the high prevalence meant that Ewald and his team distributed antibiotic to about 70% of the community. The first two treatments were not observed and it is possible that a high proportion of people did not take their medication. Only during the third round was administration supervised. However, they did not review data following this third round of treatment and it is possible that an unobserved reduction in prevalence did occur. However, even if this was the case the prevalence of trachoma had returned to baseline by the time this study was undertaken 6 years later. There is little trachoma prevalence data during the intervening time so a complete picture can not be obtained.

The incorporation of a facial cleanliness program may have been an important component of the success of our intervention. However, there is no way to measure the impact of the individual components. Facial cleanliness is important because unless there is some sort of sustainable behaviour or socio-economic change then the prevalence of trachoma will inevitably return to baseline. Facial cleanliness programs should be able to be sustained over the long term. Mass antibiotic distribution programs are not sustainable. Furthermore, the success of the facial cleanliness program may have acted to curb the impact of mobility, cited as a probable reason for program failure by Ewald. Children who have a clean face are less likely to be inoculated by infected visitors entering the community. Infected children who return to the community and have their faces cleaned in the morning at school will be less likely to infect their schoolmates.

Closer examination of the pattern of facial hygiene seen at the follow up visits is interesting. Between the first and second surveys that made up the baseline data there was a difference in the number of children with unclean and very unclean faces. The teachers reported having made an effort to clean the children’s faces, particularly in the junior classes. There was not a corresponding decrease in trachoma, but because the visits were only three months apart it was probably too early for clinical signs of disease to have resolved.
Overall facial hygiene improved on each visit; however, nasal discharge improved more rapidly than did facial cleanliness. There was a dramatic reduction in the number of children with both copious and moderate nasal discharge with 75% of children having no nasal discharge at the 6 month follow up survey. Facial cleanliness improved but it was almost entirely due to the reduction in the prevalence of children with very unclean faces. In fact at the 6 month follow up there were no children with very unclean faces. Children with very unclean faces were those at the greatest risk of having trachoma. Therefore the absence of children with very unclean faces at the 6 month follow up visit was pleasing and probably had an impact on the prevalence of trachoma. However, it is possible that the treatment of ocular chlamydial infection had reduced ocular discharge and thus unclean faces.

A reliability study was not performed on the assessment of facial hygiene. Facial hygiene was always assessed before the eyelids were examined for signs of trachoma. Assessment of facial hygiene was highly subjective and susceptible to observer drift. It is possible that the increased number of children with unclean faces at the 3 and 6 month follow up visits were the result of observer drift. Children were generally cleaner at the subsequent visits and I suspect I became more critical about what constituted to be ‘any dirt on the face’. This was probably particularly important at the 6 month follow up visit when no children were considered to have a very unclean face but nearly half (43%) of children were considered to have an unclean face. This is an important weakness of the study and is a difficulty encountered with assessment of facial cleanliness in general. It is possible that some sort of photographic grading could be undertaken; however, unlike everted eyelids photographs are highly identifiable and the ethical considerations would have to be closely examined. A more objective assessment of facial hygiene needs to be developed before more rigorous studies on the impact of facial hygiene programs are undertaken. At the moment there is no definitive proof that poor facial cleanliness causes trachoma rather than being the result of ocular discharge secondary to trachoma.
4.5 Visual impairment and cicatricial trachoma

Trachomatous visual impairment is thought to be a public health concern amongst Indigenous Australians living in remote communities. However, there is little data on the prevalence of trachomatous scarring, trachomatous trichiasis, and trachomatous visual impairment secondary to corneal opacification to support this statement. Many health care professional who work with remote communities do not believe that trachoma is an important cause of visual impairment. The paucity of data regarding cicatricial trachoma has allowed this situation to occur. Indeed there is little data on the burden of visual impairment amongst Aboriginal people living in remote communities. The data that do exist suggest that the prevalence of visual impairment amongst remote Aboriginal populations is much higher than that found within urban Australian populations. Trachoma is probably a significant contributor to this disparity in visual function. In 1976 Edwardes et al. reported that 17.7% of Indigenous adult had a visual acuity of 6/9 or worse in the better eye.248 Taylor reported that the age specific prevalence of blindness amongst a cohort of 12, 500 Aboriginal people was: 1.1% in the fifth decade, 5.5% in the sixth decade, and 25.1% amongst those aged 60 and over.249 The prevalence of blindness in an Aboriginal population in South Australia was 1.5% across all ages; the major causes were trachoma, cataract and trauma.250

There are many major health issues facing Indigenous Australians; however, Aboriginal people perceive their visual health as a high priority.

Eye/sight problems were the most commonly reported conditions among Indigenous people (30%) followed by asthma (15%), various back problems (13%), heart and circulatory diseases (12%) and ear/hearing problems (12%).

Australian Bureau of Statistics, 4715.0, 2006
Vision is extremely important for Aboriginal people living in remote communities. Access to low vision services is essentially non-existent. Of all the people that were seen with low vision not one reported using any form of low vision aid. Traditional activities such as arts and craft, and hunting require good visual acuity. Vision loss can impact on the ability of elders to pass on traditional law and customs and this can impact on the ability to maintain a vibrant culture.

4.5.1 Visual impairment

Visual impairment was assessed using a Log-MAR directional E chart at 4 meters. Data is presented using the more recognisable 6-meter format. Data were compared to an urban Australian population as reported by the Melbourne Visual Impairment Project (Melbourne VIP). Data are presented in the categories that were used in the Melbourne VIP. Blindness was defined as <3/60. The prevalence of visual impairment was 24 times higher in Aboriginal people than an age matched urban Australian population (Table 4.3). The severity of visual impairment was also much greater amongst Aboriginal people, culminating in a prevalence of blindness 40 fold higher than seen in an urban Australian setting. It is also dramatically higher than non-Indigenous Australians living in rural areas (data not shown).
<table>
<thead>
<tr>
<th>Age</th>
<th>Pop</th>
<th>Good Vision</th>
<th>Visual impairment</th>
<th>Blind</th>
<th>Age adjusted (n)</th>
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<tr>
<td></td>
<td></td>
<td>≥6/6</td>
<td>&lt;6/6-6/12</td>
<td>&lt;6/12-6/18</td>
<td>&lt;6/18-6/60</td>
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<td>24</td>
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<td>36</td>
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<td>53</td>
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<td>49</td>
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<td>1</td>
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</tr>
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<td>20</td>
<td>65</td>
<td>8</td>
<td>4</td>
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</tbody>
</table>

Table 4.3: Comparison of visual acuity between an Indigenous and an urban population.

The age adjusted percentage of individuals within each visual acuity category is provided for each age group. The Indigenous population has been adjusted to fit the age profile of the larger urban population.

Young Aboriginal people have been reported to have excellent visual acuity, a low prevalence of ametropia, and a high proportion of individuals with unusually good visual acuity of 6/2 or better. In the fifth decade of life Aborigines had a low level of visual impairment similar to that seen in an urban Australian population. In the sixth decade there was a marked increase in visual impairment amongst the Indigenous population that was not seen in the urban population. This difference was statistically significant (gamma, p= <0.001). In the seventh decade the level of visual impairment seen in the urban population was similar to that seen in the Aboriginal population ten years younger. Visual function amongst older Aboriginal people was very poor with more than 40% having moderate or worse visual impairment. The
prevalence of people having moderate or worse visual function was 20-fold higher than that seen in the urban population.

4.5.2 Trachoma and other ocular pathology

People who grew up in a desert community had a significantly higher prevalence of scarring than did people who grew up in a coastal region. However, there was no significant difference between the communities in the prevalence of TS when those aged 60 and over were analysed in isolation. This may have been due to the small number of people aged 60 and over who grew up in a coastal region or that given sufficient time scarring develops in almost all individuals who were exposed to *C. trachomatis* infection during childhood; even those who had relatively less frequent and less severe episodes of active trachoma. Trichiasis was identified in eleven individuals; all aged over 60 and a desert region. All eleven individuals with trichiasis still lived in Community D. Of the eleven individuals who had TT five had CO. A prevalence of CO of about 50% amongst people with TT is consistent with the literature. Two individuals were bilaterally blind secondary to trachomatous CO. One individual was considered to have TT because he had undergone lid surgery to correct TT. There were no individuals identified who had signs of epilation.

No cases of TT or CO were found amongst individuals who grew up in a coastal area. Trichiasis predominantly occurs in the older age groups and only sixteen individuals in the 60 and over category grew up in coastal areas. The study was not adequately powered to exclude the possibility that TT is a public health concern in Community C. We can consider a prevalence of TT of 1% amongst people age 40 and over to be a public health problem; this is substantially lower than the prevalence of 0.1% that WHO uses to classify a public health problem.\(^1\) It would have been necessary to examine 300 individuals before the upper bound of the 95% confidence interval would be less than 1% for a finding of zero cases of trichiasis.
Trachoma is a disease that affects women more than men. Women are the primary carers of children and their closer relationship with children presumably increases their exposure to infectious agent. Alternatively males may be at lower risk because, in developing countries, they tend to leave the family home during their early teenage years to work on the land. This removes them their young siblings and presumably decreases their exposure to \textit{C. trachomatis}. We did not find a significant difference in the prevalence of TT between the genders. However, there were only a small number of cases identified and a possible difference may not have been identified.

Trachomatous scarring progress over time to TT; if women are at greater risk of TT it is reasonable to assume that there is also a higher prevalence of TS amongst females. There were a large numbers of individuals with TS but there was no significant difference in prevalence between the genders when adjusted for possible confounders in a multivariate binary linear regression model. Our data suggest that Indigenous women are not more likely to have TS than men; however, our data set is small, coverage incomplete and the age distribution uncertain. The possible lack of gender difference may be explained by social issues. Women were observed to have more interaction with young children than Indigenous men. If increased interaction with children is the reason that women are at greater risk of trichiasis then a difference should have been seen. However, if the reason that men develop trichiasis less than women in some countries is because they leave the home environment earlier to undertake manual labour then a difference would not have been seen. There is little employment in the two communities that were studied and neither boys nor girls tend to leave the overcrowded home environment to work during their early teens. Women may be at greater risk of trichiasis because they do not leave the home environment and have increased contact with children. This difference may not occur in Aboriginal communities where women and men appear to share a similar risk of cicatricial disease.
The eleven individuals with trachomatous trichiasis were provided with referral cards to consult the visiting ophthalmologist and the local clinic was provided with their names. Each was informed of their condition and the need for surgical intervention. The consequences of not having surgery were explained. Local Aboriginal Health Workers assisted with the process of explanation and all information was provided in English and reinforced by Aboriginal health workers in the local language. None of the eleven individuals reported that they would definitely travel to Alice Springs for treatment. They all appeared to comprehend the nature of their condition and the likelihood of vision loss. It is important that these individuals be followed up to determine how many present for surgery. Individuals who choose not to have surgery should be asked why they have elected not to have surgery.

Trachoma was the most common identifiable cause of blindness in the entire population. Three individuals were blind (< 3/60) two of whom had bilateral corneal opacification secondary to trachomatous trichiasis. There was no obvious cause of blindness in the other. Cataract was the most common cause of visual impairment, a pattern consistent with that seen in developing countries. Half of the twenty-four people who had moderate visual impairment had bilateral cataracts. Diabetes was reported by a higher proportion of those who had visual impairment without an obvious cause suggesting that diabetic retinopathy is a significant cause of visual morbidity.

The high number of people with unoperated cataracts suggests that the current eye-care service is not meeting the needs of the population. The current service may be either: culturally inappropriate and therefore not accessed, inadequately resourced to meet the needs of the population or the service may not be being adequately utilised by the population because they are unaware of it. The burden of cataract as an easily treatable cause of visual impairment in remote Aboriginal populations needs to be confirmed. Appropriate eye health delivery systems need to be developed to ensure that no Australians are visually disabled by cataracts.
4.5.3 Refractive error

Refractive error did not account for a significant number of people with visual impairment. Historical data suggests that Aboriginal people have low rates of refractive error. In our study 16.5% of the population had some improvement in vision with pin-hole refraction. Approximately half of these people achieved their best corrected visual acuity with pinhole. One individual improved from 3/60 to 6/30 in their right eye and from count fingers to 4/32 in their left eye. Another individual improved form 3/60 to 6/30 and another individual improved from 6/18 to 6/8. In each of these cases their pinhole acuity was superior to vision in their other eye and represented their best corrected vision.

Aboriginal adults required reading glasses at a younger age than would be expected in an urban Australian setting. A tendency towards hyperopia amongst Australian Aboriginals is not a new finding. Few people (8.9%) owned a pair of reading glasses of the population tested, but most of those tested stated that they would find reading glasses useful and wanted to purchase a pair. Readers are cheap and should be easy to provide. Education and information about the need for reading glasses as people get older must be provided and cheap glasses of appropriate power need to be readily available within communities.

4.6 Barriers to implementation of the SAFE strategy

4.6.1 Participants

There were a number of central themes raised by the majority of the wide range of people that were interviewed. Participants were predominantly from the regional level but I was able to interview a number of professionals who worked at the local level and who had recently participated in a highly successful TCP. People interviewed at regional level included those in senior managerial positions and population health nurses who had hands-on experience in screening and implementation of TCP. There
were no refusals to participate in the project; however, it was not possible to arrange
time to meet with a number of people who were approached for an interview.

There was diversity in the way individuals rated the importance of trachoma. There
was also a wide range in the way individuals rated their own knowledge of trachoma
and of the SAFE strategy. However, the two were not linked. Those that thought
trachoma was an important population health issue did not tend to rate their
knowledge as being better or worse than those who felt trachoma was not an
important population health issue. The majority respondents felt that the SAFE
strategy was relevant to Australian conditions and many commented that the new
Australian guidelines that are based on SAFE were appropriate. There was universal
opinion that SAFE had not been well implemented in the NT.

Interviews were only conducted with those who have a direct role in the delivery of
TCP in order to identify the factors felt to be important by the people actually doing
the work. It was important to hear what people wanted to say, not to get them to agree
with a set of pre-conceived themes that the research team had. Interviews largely
consisted of free discussion and structured questions were limited to those that were
reported in the methods. The interviewer made every effort not to ask participants
directly about the importance of any category, rather prompts were used that allowed
the respondent to discuss issues that they felt were important. There were 160
responses that were categorised; 122 (76%) of which were originally coded the same
by both observers. One participant did not consent to having their interview taped and
the interviewer coded responses immediately after the interview.

There is a potential bias in having the interview conducted by the researcher and by
having the researcher categorise responses. Interviewees were aware of the research
project being conducted and that the researcher had an interest in trachoma. It is
possible that participants were reluctant to speak their mind about trachoma and rather
provided responses that would not incite conflict. However, I do not feel that this was
the case. Interviewees seemed to be frank and comfortable and many spoke of the low priority of trachoma and the ethical concerns over treating well people with potentially harmful antibiotics. Responses were categorised by two people to minimise the effect of observer bias and there was a certain degree of difference in the way that certain responses were initially categorised. This is partly because the researcher had the luxury of listening for a second time and could play the tape repeatedly. The primary observer did not have this luxury. A consensus was reached regarding the coding of all responses.

4.6.2 Requirements for a successful TCP

A successful TCP program requires inputs from government, regional health networks, local health staff, and from the community itself. A failure at any level is likely to prevent any program from being successful. Government must develop and support a policy of targeting trachoma. This must include clear policy guidelines and the resources to implement those guidelines. Regional health networks are required to oversee the administration of policy, collect and collate data, ensure that screening results are appropriately acted upon, and to assist local staff with manpower, advice and resources. Local health staff are the key to a successful TCP. Local staff undertake much of the work, with regional assistance. Local teams are best placed to liaise with and educate the community about trachoma, SAFE and the need for TCP. The importance of community partnership in a successful TCP was paramount; this partnership was more than merely consent for the program but it required an understanding of, ownership and active participation with the program.

The exception to the above is ‘E’. Environmental improvement, the definitive solution to trachoma, is almost exclusively the realm of government. The community must play a significant role however; regional and local health professionals do not have a major influence on this component of SAFE. This had a negative impact on moral because it led to despondency; people thought that things would not change unless
circumstance outside their control changed and this reduced their willingness to become involved in the TCP.

4.6.3 Categories of response

The most important responses were categorised in what can be grouped together as governance and management areas. The categories of policy, leadership and structure, finance and resources, Government support and outside support are relevant to this area. Policy is perhaps the most important step for the widespread implementation of a successful TCP. Respondents were almost unanimous in their support of the new guidelines and their adoption as Territory-wide health policy. However, there were concerns. Perhaps the most important concern was the 10% cut-off for institution of mass antibiotic treatment. Several respondents asked why the cut-off was 10%. Several were unhappy with it suggesting that it resulted in an unreasonable number of ‘well’ people being treated. Another argued that it was counterproductive because of the amount of angst that it caused. The current situation is that TCP is not implemented in most communities that are hyperendemic (>20%), let alone those that are endemic (>10%–≤20%). It is likely that increasing the treatment cut-off to >20% would not decrease the number of communities that are treated. However, it may have the positive effect of removing this concern from the minds of those who are required to implement the program. Furthermore, the survey we conducted in Community C found no cases of trichiasis and there are no data that proves trachoma is currently a blinding population health problem in the coastal communities of the Top-End. This question needs to be answered as a matter of urgency.

Many respondents discussed the differentiation between mass treatment and targeted treatment. It is possible that by increasing the treatment cut-off to 20% you would almost obviate the need for targeted household treatment. The question about what to do if the prevalence is less than 20% remains. The current guidelines suggest treating children and their household contact if the prevalence of trachoma is <10%, this cut-
off could be raised to 20%. The resulting compromise would involve only two treatment options and a single screening target, i.e., the prevalence 20% or more.

It was generally agreed that while the policy was in place and was reasonable that the resources to back up the policy were not present. The major resource constraint on the TCP was the lack of leadership and structure. The majority of respondents devoted 5% or less of their time to trachoma, when combined with its perceived low priority the result was that trachoma control activities were often put off so that other activities could be undertaken. The lack of a specific structure that started with screening results and followed right through to implementation and evaluation of a TCP was a major problem. Most respondents were unsure exactly what happened to screening data and of the process that was required for the implementation of TCP. There was certainly no centralised data-base and data often did not reach those who required it or were supposed to receive it. Local staff felt overwhelmed by the responsibility of undertaking a TCP and regional staff were often unaware of the need for a TCP or were not sure how they could assist. A job has been recently created in Alice Springs to co-ordinate trachoma control activities and this should be able to address many of the above concerns. The person in that job should have a role in ensuring that screening occurs in a timely manner. They should ensure that screening data are disseminated to the appropriate people. That person could then identify communities that needed to implement TCP and advise them of policy. If required they should have an information pack that could be sent to communities. Regional staff would also need to be notified of the communities that should initiate a TCP so that they could contact those communities offer assistance and assist with planning.

Financial constraints were felt to be an important barrier and this goes back to Government support as well. However, the Federal Government has recently announced a large trachoma funding package that includes the position mentioned above. It is hoped that this money should be able to address many of the issues related to funding shortages, although it will not address the issue of staff shortages in the
communities. This is a chronic problem that is larger than any TCP. However, regional support to those communities that are short staffed could facilitate the implementation of a TCP. Furthermore, by providing communities with better information, assistance with planning and promotional material much of the work can be made easier. Outside support was a category that was rarely mentioned. The support of researchers, volunteers, and charities such as the Fred Hollows Foundation is an important resource that has so far been almost completely overlooked. It is almost certain that the program in Community D would not have proceeded without the involvement of this research project. It is probable that individuals working in trachoma have not been able to devote time to investing the possibility of utilising outside support, however, the new position will allow that time and this is a key area in getting the manpower required to implement programs.

The widespread success of the HSAK screening program was mentioned by many respondents. The inclusion of trachoma into this program has resulted in findings that may not have been anticipated, and resources and structure were not in place to deal with those findings. Despite the success of screening there were concerns raised about the quality of the data and what happened to the data. The training of staff who undertake screening for trachoma has been minimal and many commented that they were unsure of their reliability in correctly grading trachoma. Improved training is required and I and CERA have developed a compact disc based teaching resource (back sleeve) that may assist in recognising the signs of trachoma. Data need to be relayed to a central database were it is collated and steps can be undertaken to ensure that results are followed up. A National Trachoma Surveillance Unit has been recently established and is in place to assist with the results of the 2007 HSAK screening.

Active trachoma is a disease that may cause blindness decades into the future. For health professionals faced with the often overwhelming issues surrounding Indigenous health it takes a low priority. However, this is not to say it should not be appropriately resourced and addressed. It is not my intention to argue for the relative
importance of trachoma in the broader context of Indigenous health but to state that it will be swept to the side by already overburdened health professionals who devote about one or two hours to trachoma in a normal working week. The priority issue of trachoma is in a sense a red-herring. In a wealthy country such as Australia it should and must be addressed. To overcome the issue of priority it must be co-ordinated by an individual who does not have competing interests. A regional trachoma co-ordinator should undertake the majority of the work. This person would simultaneously deal with the issues around communication and information by being a centralised resource that could be contacted on any trachoma-related issue. They might be able to assist with raising regional awareness, overseeing the training of the workforce and perhaps ensuring that a component of staff orientation was devoted to raising awareness of trachoma and SAFE.

There are issues surrounding workforce satisfaction and the time consuming nature of TCP that a trachoma co-ordinator may be able to assist with. Travel to communities will always take time, however, the time taken to implement programs can be minimised by the development of flow charts and model programs to assist local health workers. The successful implementation of a TCP and observing a drop in the prevalence of trachoma may prove to be a success that lifts morale. In Community D the mass distribution, community reaction and subsequent decrease in trachoma prevalence was a tremendous source of pride to all who participated in the program. The issue of staff turnover is not going to change, however, by incorporating an introduction to trachoma in staff orientation packages and by developing a good set of resources that can be provided to health professionals, its effects can be minimised.

Population mobility was a major source of concern and was the reason given for the failure of past antibiotic distribution schemes. We have shown a reduction after ‘A’ and ‘F’ and argue that a good facial hygiene campaign can still be implemented where there is high population mobility. It is possible that a successful ‘F’ campaign could even mitigate the effects of high mobility because it reduces the likelihood of
transmission and infected individuals entering the community will be less likely to re-infected treated community members. Population mobility is not going to change, implementing a TCP at the macro-regional or territory level is a possible solution but it is probably never going to happen. To counter high population mobility increased emphasis must be placed on keeping all children’s faces clean. This is best achieved in the school environment. It requires a firm undertaking and acceptance of this responsibility from the education department who must allow teachers, particularly primary teachers, to devote a certain amount of time to hygiene programs.

Community awareness of trachoma is generally low and this follows on from the low level of knowledge that remote health care professionals generally have regarding trachoma. However, from the experience we have gained during this research project it is clear that community awareness can be raised over the relatively short period of several months. The story of trachoma can be told in a logical way and resounds with remote Aboriginal people who often have an awareness of the late cicatricial stages of the disease. Communities are generally accepting of screening programs as they have long played an important part in the delivery of health care to remote Aboriginal communities and screening for trachoma is generally already undertaken in most communities. Community acceptance of the idea of a SAFE based trachoma control program will only be obtained once awareness has been raised. The experience has been that when there has been an adequate period of consultation and the provision of appropriate information acceptance of and support for a trachoma control program has been forthcoming.

4.6.4 Critical success factors

The National guidelines based on the SAFE strategy were well accepted except for the treatment cut-off of 10%.

- If resources are not available to treat all communities prioritise those communities with the greatest prevalence of trachoma.
The appointment of a dedicated trachoma co-ordinator should address many of the concerns relating to lack of structure and leadership. This person should be responsible for:

- Ensuring that each community undertakes HSAK and that they screen primary school children (5-9) for trachoma.

- That each community is provided with educational material regarding the diagnosis of trachoma or that a regional health worker experienced with grading trachoma assists the local clinic staff with HSAK.

- Ensuring that they receive the results of trachoma screening. This should include the prevalence, the age range screened, and the estimated percentage of children in that age range who were screened. They should liaise with the Trachoma Surveillance Unit to ensure that all data are collected by that group.

- They should identify communities that require treatment and discuss this with both local clinic staff and regional health workers.

- Communities that are identified for a TCP should be provided with a detailed set of educational and promotional material, including a checklist that will help them deliver a successful program.

- The co-ordinator should arrange for trachoma to be included in staff orientation and should organise regular staff education sessions on the SAFE strategy and what to expect, grading and everting of eyelids, and strategies for successful undertaking of mass treatment.

- The co-ordinator should investigate the possibility of utilising increased outside support particularly from researchers, volunteers and charities.

Appropriate teaching, educational and promotional resources should be available A standardised set of resources should be provided to local clinic staff when they identify the need for a TCP. This should include:
Information about trachoma, SAFE and clinical grading.

Information and a checklist that assists with the implementation of a TCP.

Posters and promotional material that can be used within the community including: education about trachoma, mass treatment and facial hygiene posters.

A successful TCP requires partnership with the community. This will be different in every community and local health workers will be best placed to determine how to approach this issue. However, certain steps may be fundamental to any such approach.

- The provision of appropriate information over a reasonable period of time.
- Providing the community with access to talk to a senior regional health officer or trachoma researcher about the program.
- Developing an appropriate distribution strategy with the community.
- Arranging an appropriate date with the community.
- Delivering a quality service that allows those delivering the service plenty of time to explain what is happening and why people are being asked to take medication.

### 4.7 Strengths and weaknesses

This thesis is the result of a holistic project that investigated various aspects of trachoma and the population health management of trachoma. We have demonstrated that active trachoma is one of a number of infectious diseases that impact upon Indigenous children, that trachoma still causes blinding complications in older people, the effectiveness of a mass antibiotic distribution, that facial cleanliness promotion can reduce the number of children with very unclean faces, and we have identified barriers that have limited the implementation of trachoma control in the Northern Territory of Australia.
The two study communities were from different geographical positions and this allowed some interesting conjecture. For comparisons between communities the sample size was only two and therefore no solid conclusions can be made. However, we have further supported the well-known fact that trachoma is predominantly a desert disease. It is also possible that different degrees of facial hygiene are important with different degrees of endemicity.

Good coverage was achieved for the survey of children. The relatively large sample provided adequate power to assess the associations that we were interested in. A simple, quick and, non-invasive examination was performed that was well tolerated by the children. Three common and important infectious diseases of childhood were able to be assessed and children were able to receive treatment that they may not otherwise have received.

Through this project I was able to provide education about trachoma to a large number of different people from different aspects of life, ranging from health workers to Indigenous parents. I was also integral to implementing the ‘A’ and ‘F’ components of SAFE in Community D. However, the most rewarding aspect of this project has been the relationships that I have established with people living in the two communities. People that many Australians would never have the chance to meet, but whom can provide a very different perspective on life.

There were several limitations regarding the surveys of children and the assessment of the impact of SAFE. We were unable to assess the effects of clustering and we did not assess the impact of flies. Environmental risk factors were not assessed and the planned environmental intervention was not implemented. Finally we were not able to confirm the reliability of grading regarding pyoderma, ear infections, and facial hygiene.

The lack of any reliable population data made it impossible to accurately calculate the coverage that was achieved in either the survey of children or adults. The coverage of
people aged 40 and over in Community C was of particular concern. Results must be viewed with this in mind. Furthermore, we examined two individual communities and it is not clear to what extent results can be extrapolated to other Indigenous communities within the Northern Territory or indeed throughout Australia. However, this project indicates that there is a need to determine the extent of visual impairment amongst Indigenous Australians.

Best corrected acuity was assessed using pin-hole refraction not a full refraction. The directional E chart is a useful tool for populations were there is a high prevalence of illiteracy. However, it is possible that the test was difficult for some of the participants particularly the elderly and many people appeared unfamiliar with the test. The Melbourne VIP undertook a full refraction and used a letter chart with a literate population that was used to visual acuity tests. Thus the two populations are not directly comparable. The differences may tend to exaggerate the poorer visual function of the Indigenous population. Assessment of near function was not ideal. Only a small range of reading glasses was assessed and the working distance was not standardised. The examiner attempted to ensure that subjects used an appropriate working distance and tried to re-enforce that this distance should be similar to that which they undertook the majority of their activities. Artist who paint at a distance of about a meter were encouraged to use a similar working distance to determine their proffered glasses.

HRW had only the equipment and the expertise to undertake a basic eye examination. Cataracts were assessed with the aid of a pen torch and were not further classified. No fundus examination was undertaken and therefore no assessment of diabetic retinopathy was possible. There is a need for a more full scale assessment of the causes of visual impairment amongst Indigenous Australians. This needs to be undertaken at the community level and must include a full refraction and a fundus examination. Glaucoma is thought to be rare in Indigenous populations; however, a
complete eye health survey should include the measurement of pressure and an optic nerve head assessment.

4.8 Conclusion

Childhood infectious diseases were very common amongst Aboriginal children living in two remote communities. Childhood infectious diseases are all thought to be related to poverty, overcrowding, and poor personal hygiene. However, there was no association between the different diseases. The prevalence of trachoma indicated the need for a SAFE based trachoma control program. The ‘A’ and ‘F’ components were implemented in Community D; however, the ‘E’ component was not implemented. No specific trachoma control activities were undertaken in Community C. There was a significant reduction in the prevalence of trachoma and an improvement in the facial hygiene of children 6 months after mass treatment.

Aboriginal adults aged 40 and over had a high prevalence of scarring that increased with age and was more common in Community D than Community C. Trachoma was a major cause of visual impairment in Community D. Visual acuity was significantly worse amongst Aborigines particularly those aged 60 and over than it was in an age matched urban population. Bilateral cataract is an important and treatable cause of visual impairment.

The SAFE strategy has not been widely implemented in Australia and no trachoma control activities were undertaken in response to the prevalence reported in Community C. There are a number of barriers to implementation of the SAFE strategy that exist. Critical success factors for a trachoma control program include: an acceptable policy that is backed by sufficient resources and funding, a centralised trachoma co-ordinator who can take ownership of the program and co-ordinate regional assistance to remote clinics, the development of a set of education, information and promotional resources; and the development of partnerships with communities as a prerequisite to implementing a mass treatment program.
4.9 Recommendations

- Continue to screen for trachoma within the HSAK program.
- Improve training of health professionals who undertake trachoma screening.
- Prioritise interventions to those communities with the highest prevalence of disease.
- Undertake research to determine the pattern of infection (not disease) within a community to better guide the population that must be treated with antibiotics.
- Develop an appropriate job description for the trachoma co-ordinator based on the critical success factors identified above.
- Support an adequately resourced National Trachoma Surveillance Unit.
- Develop a trachoma information, education and promotion package for use by remote communities.
- Acknowledge the critical importance of community partnership in undertaking a successful community-based population health intervention such as a SAFE based TCP.
5 References

13. Schachter J. Human chlamydial infection, Ch. 4: Littleton; PSG Co., 1978.


44. Moulder JW. The relation of basic biology to pathogenic potential in the genus chlamydia. infection 1982; 10 supplement 1:s10-s18.


72. Steele LN, Balsara ZR, Starnbach MN. Hematopoietic cells are required to initiate a *Chlamydia trachomatis*-specific CD8+ T cell response. *The Journal of Immunology* 2004;173:6327-6337.


119. Javaloy J, Ferrer C, Vidal MT, Alio JL. Follicular conjunctivitis caused by
*Chlamydia trachomatis* in an infant Saharan population: molecular and

chlamydial infection in patients with trachoma: a clue to the pathogenesis of

121. Hardy D, Surman PG, Howarth WH. Cytological survey of conjunctival smears
from aboriginal school children at Yalata, South Australia. *British Journal of

122. Kumar VN, Sujata M, Satpathy G. Seroprevalence of Chlamydia trachomatis
types in children with clinical trachoma in New Delhi, India. *Revue
Internationale du Trachome et de Pathologie Oculaire Tropicale et

from a trachoma-endemic village in the Gambia by a nested polymerase chain
reaction: identification of strain variants. *Journal of Infectious Diseases.*

124. Darougar S, Jones BR. Conjunctival swabbing for the isolation of TRIC agent

of chlamydial inclusions in Giemsa-stained conjunctival smears in severe

126. Shokeir AA, al-Hussaini MK, Wasfy IA. Methyl green-pyronin stain for the

127. Surman PG, Hardy D, Howarth WH. The immunofluorescent staining technique
applied to trachomatous eye smears in aboriginal school children in South

128. Fan J, Zhang WH, Wu YY, Jing XY, Claas EC. Detection of infections of the
eye with Chlamydia trachomatis by the polymerase chain reaction.

evidence for persistent ocular Chlamydia trachomatis infection in Tanzanian

130. Mabey D, Solomon AW. Application of molecular tools in the control of
blinding trachoma. *American Journal of Tropical Medicine and Hygiene.*
2003;69(Supplement 5):11-17.

scarring in trachoma is associated with depressed cell-mediated immune
responses to chlamydial antigens. *Journal of Infectious Diseases.*

132. Myatt M, Limburg H, Minassian D, Katyola D. Field trial of lot quality
assurance sampling survey method for rapid assessment of prevalence of


Wright HR. Trachoma.


223. Mann I. Ophthalmic survey of the Kimberly Division of WA. Public Health Department. 1954.


6 Appendix 1:


