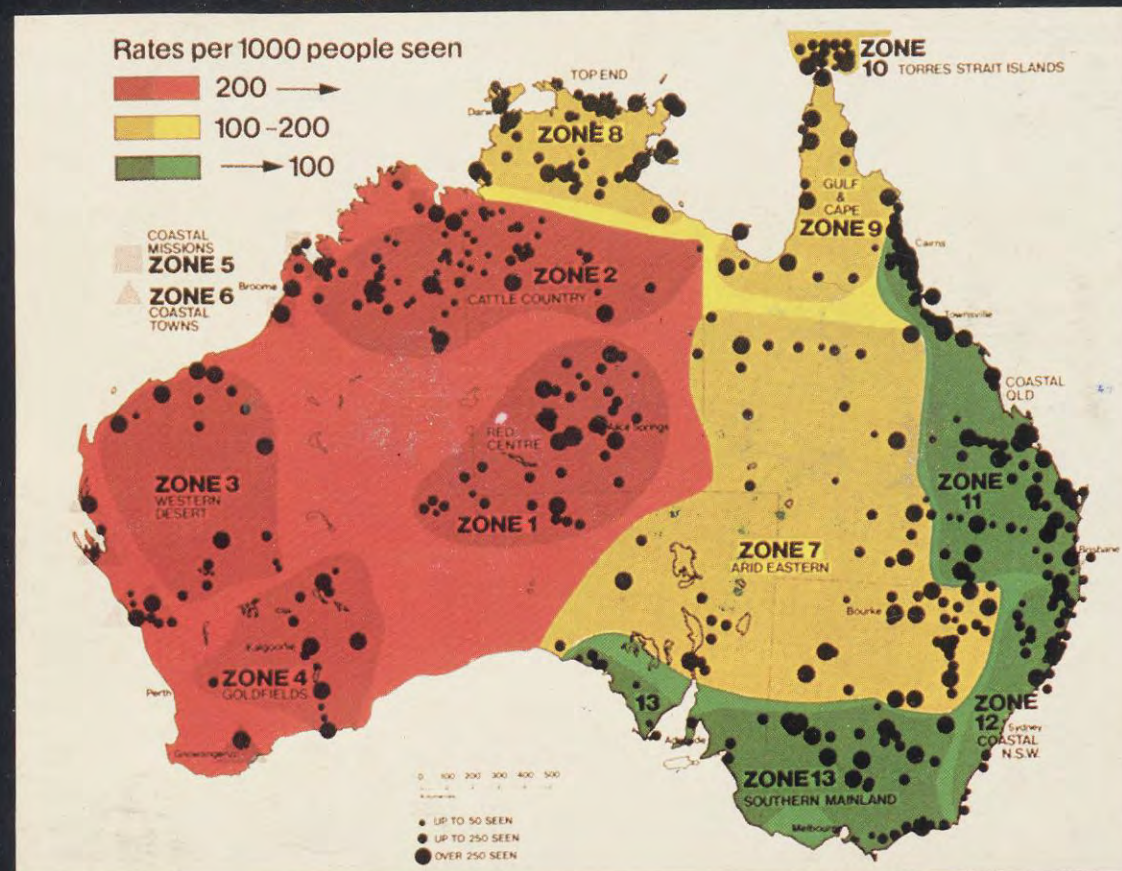
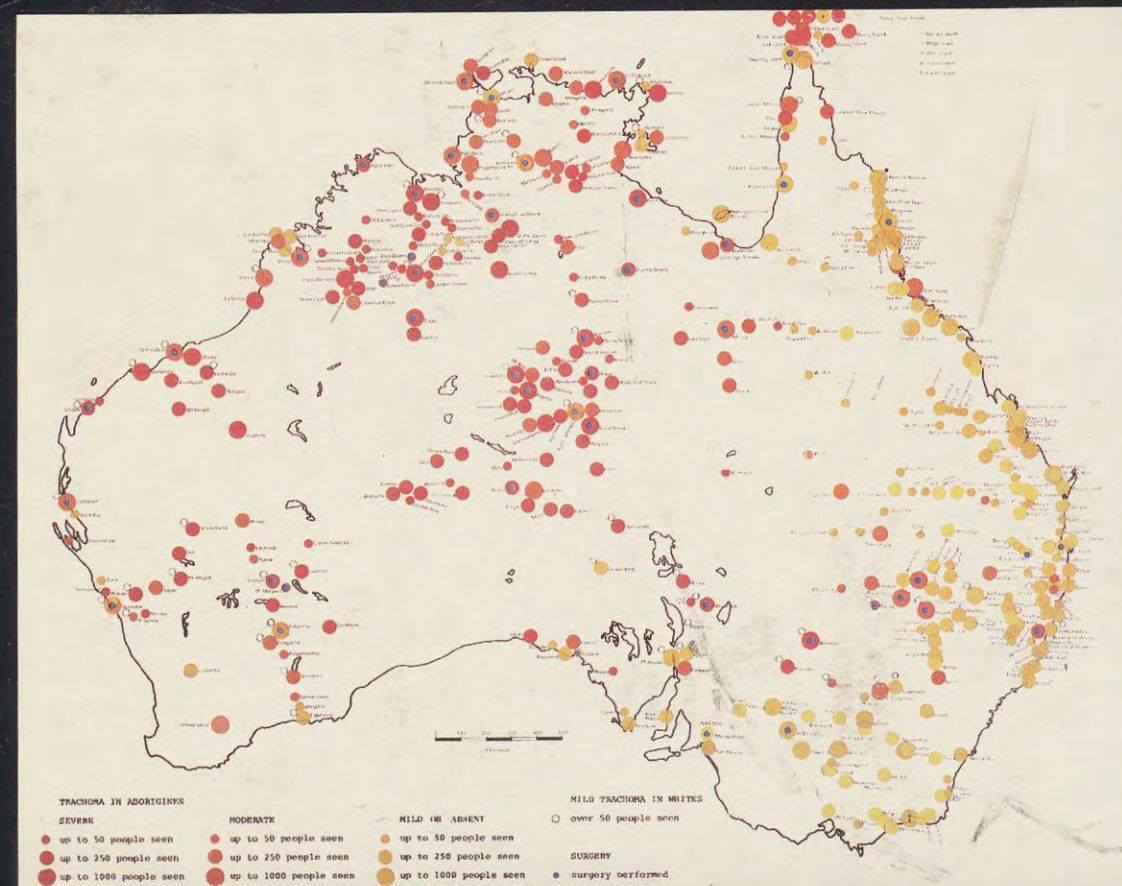




DISTRIBUTION OF BLINDNESS AMONGST ABORIGINES MORE THAN 60 YEARS OF AGE.

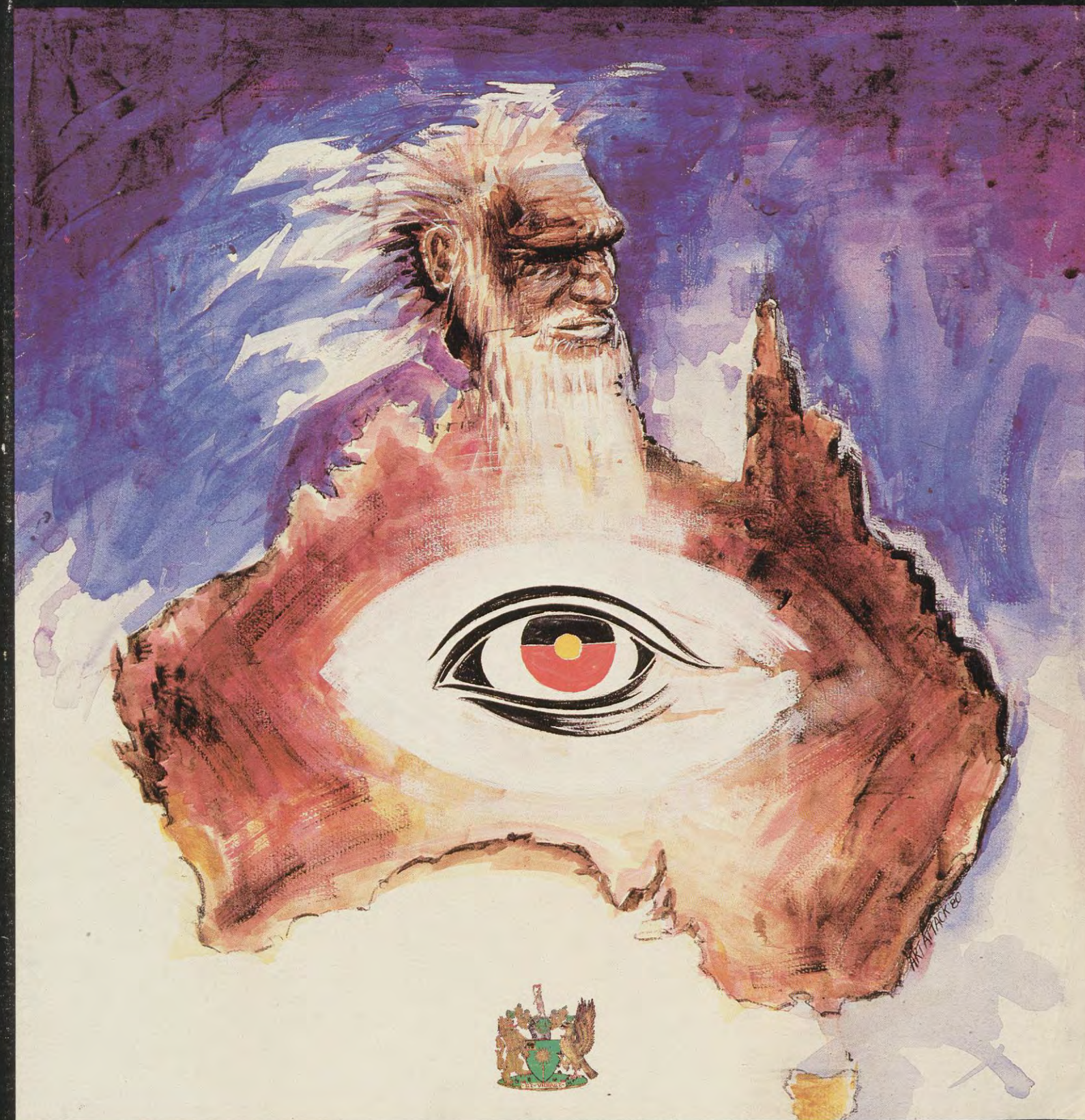


COVERAGE OF AUSTRALIA BY NATIONAL TRACHOMA AND EYE HEALTH PROGRAM FIELD TEAMS, 1976-1979.



THE REPORT OF THE NATIONAL TRACHOMA AND EYE HEALTH PROGRAM, 1980.

NATIONAL TRACHOMA & EYE HEALTH PROGRAM

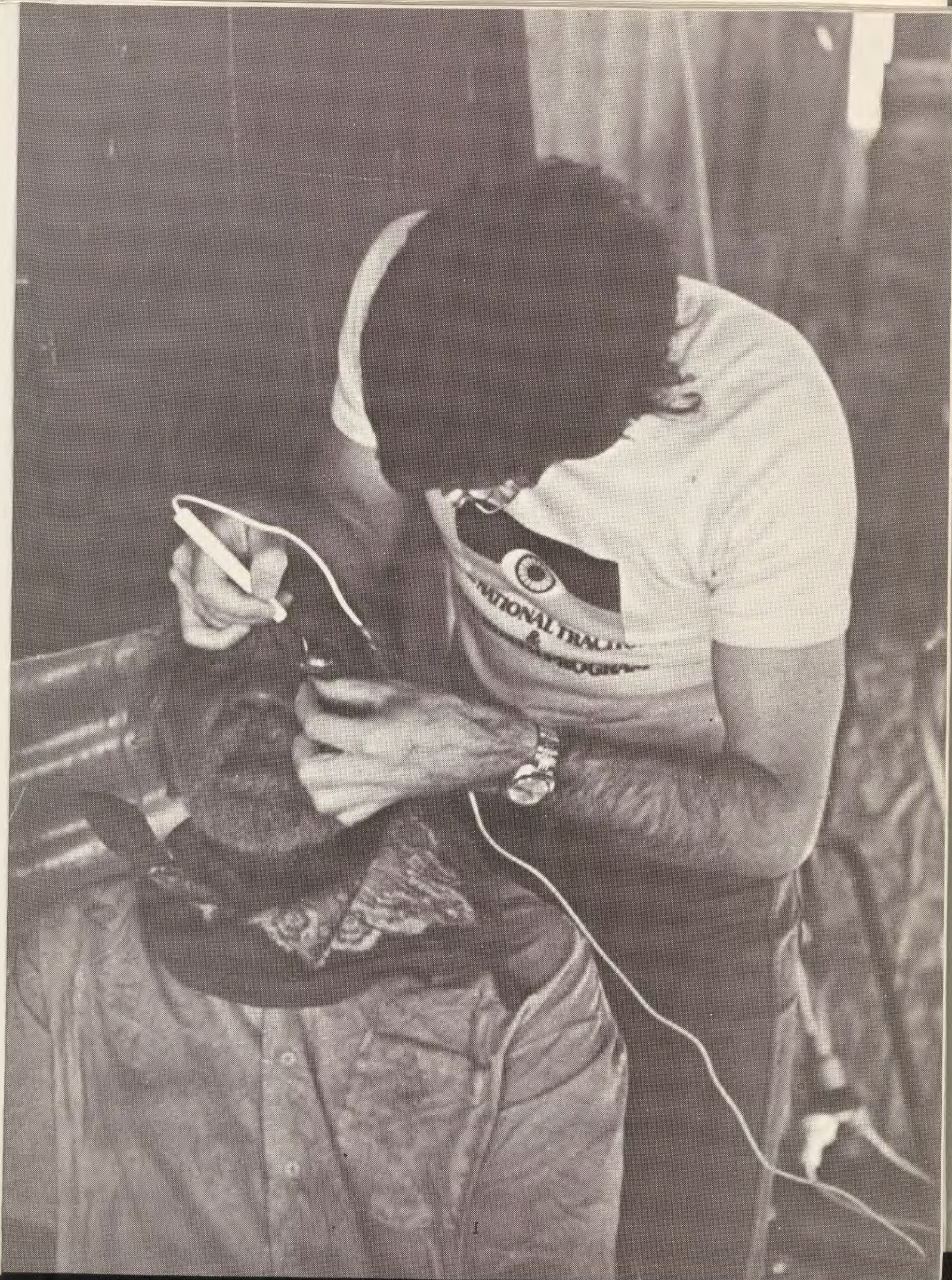


The Royal Australian College of Ophthalmologists.



**NATIONAL
TRACHOMA & EYE HEALTH
PROGRAM**

The Royal Australian College of Ophthalmologists.



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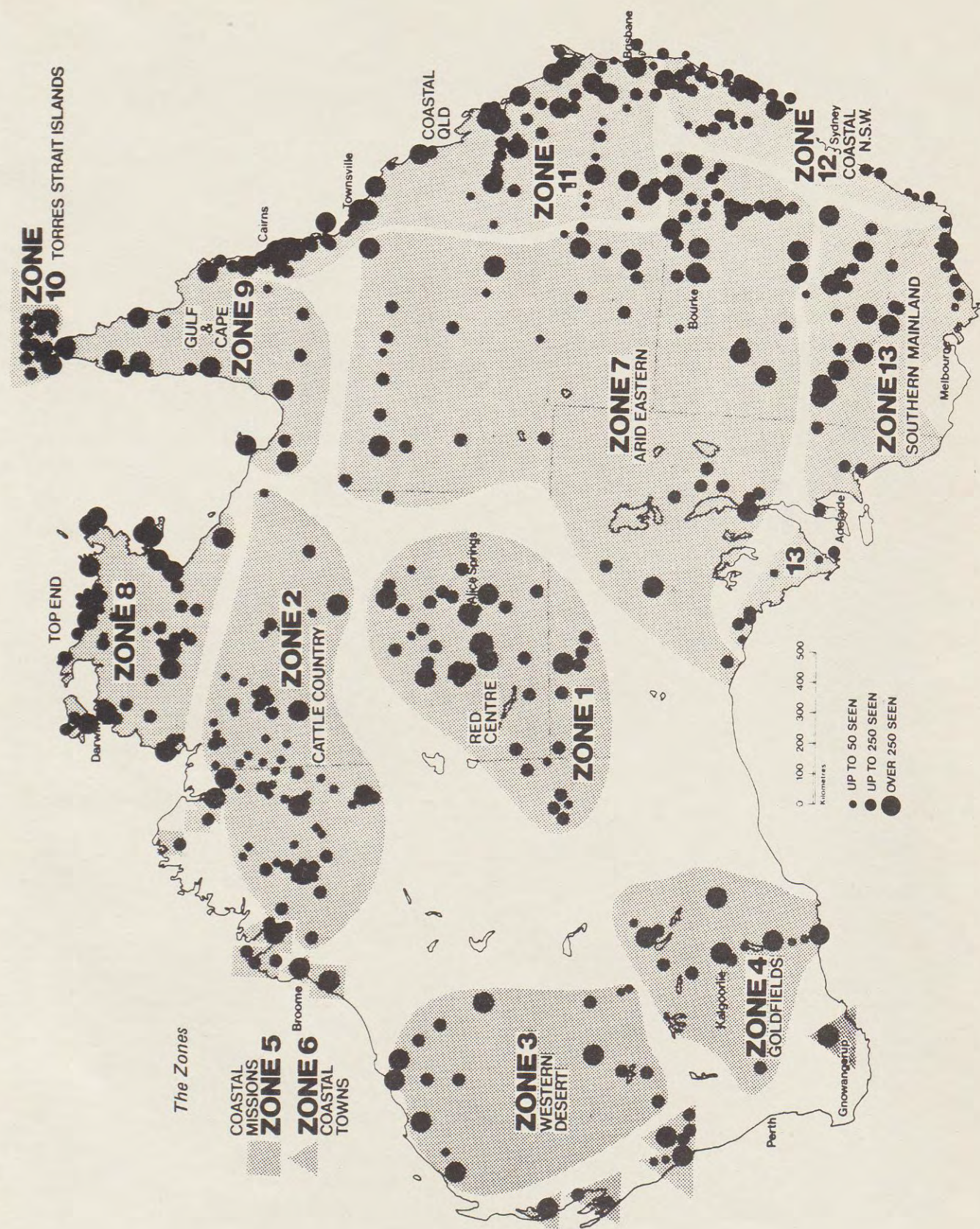
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THE NATIONAL TRACHOMA AND EYE HEALTH PROGRAM of the ROYAL AUSTRALIAN COLLEGE OF OPHTHALMOLOGISTS



Published by the
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Sydney, 1980



CONTENTS

Zone Map of Rural Australia	1
Title	iii
Contents	v
Preface	ix

Chapter 1	Trachoma in Australia, The Development of the National Trachoma and Eye Health Program	1
Chapter 2	On the Road	5
Chapter 3	Methodology	9
Chapter 4	A. Trachoma The Ocular Condition	24
	B. A Report on Microbiological Findings by Dr. D. M. Graham	29
Chapter 5	The Prevalence of Trachoma in Australia	37
Chapter 6	Vision in Rural Australia	54
Chapter 7	Trachoma and Vision	68
Chapter 8	Visual System Abnormalities in Rural Australia	82
Chapter 9	Some Infections in Rural Australia: Ear, Nasal, Respiratory and Skin Disease	101
Chapter 10	The Findings and The Environment	119
Chapter 11	Trachoma Treatment Programs	151
Chapter 12	The Provision of Surgery	161
Chapter 13	The Provision of Immediate Care and Spectacles	171
Chapter 14	On-Going Eye Health Care Programs	175
Chapter 15	Recommendations	180

CONTENTS

Appendix 1:	Aims of the National Trachoma and Eye Health Program	185
Appendix 2:	Communities Visited by the National Trachoma and Eye Health Program	186
Appendix 3:	A. N.T.E.H.P. Clinic Sheet	190
	B. Clinic Sheet Coding Guide	191
	C. N.T.E.H.P. Field Tally Sheet	193
	D. International Code of Eye Disease	194
	E. N.T.E.H.P. Action Card	195
	F. N.T.E.H.P. Surgery Card	196
	G. N.T.E.H.P. Community Interim Report	197
Appendix 4:	A. Tables ENV 41 - ENV 78	202
	B. Tables H7 - H60	205
	C. Tables C1 - C36	210
Appendix 5:	A. Trachoma Brochure	215
	B. Frog Poster	216
Index		217

The National Trachoma and Eye Health Program is sponsored by the Royal Australian College of Ophthalmologists and the Commonwealth Department of Health and is financed under the provisions of the Health Insurance Act.

ERRATA

- Page 15: Second column, fourth last line — "*integration*" should be "*interaction*".
 Page 17: Table SAM 1, 20-29 Age Group — "*894*" should be "*694*".
 Page 20: First column, last line — "*who*" should be inserted after "*those*".
 Second column, second last line of text — "*standard deviation*" should be "*standards of blindness*".
 Page 26: Caption headings —
 "*Figure 1*" should be "*Figure TOC 1*"
 "*Figure 2*" should be "*Figure TOC 2*"
 "*Figure 3*" should be "*Figure TOC 3*"
 "*Figure 4*" should be "*Figure TOC 4*"
 "*Figure 5*" should be "*Figure TOC 5*"
 "*Figure 6*" should be "*Figure TOC 6*"
 "*Figure 7*" should be "*Figure TOC 7*"
 Second column, first line — "*with trachoma follicles*" should be deleted.
 Page 99: Figure VSA 17 caption — "*Pterygia*" should be "*Pterygium*".
 Page 112: Figure 6 caption should read — "*Discharge from a case of chronic otitis media (wet perforation)*".

PREFACE

It now seems a long time since the Council of The Royal Australian College of Ophthalmologists resolved on 12 April 1975 "that Professor Hollows be asked to advise on the feasibility of the College organising a campaign to eliminate trachoma in Australia".

So many people have been examined in so many places, so many given medical and surgical treatment, so many spectacles prescribed, so much statistical data compiled, so much money spent . . . and now so many words written in this report.

With the fullest co-operation and financial support (now exceeding two million dollars) of the Commonwealth Government, the National Trachoma and Eye Health Program was established by the College with a three-fold purpose:—

- (i) the presentation to interested agencies of the state of ocular health of people living in rural Australia;
- (ii) the provision of immediate eye care to these people; and
- (iii) in the light of the experience gained in the above, consideration of the establishment of ongoing eye care programs and the training of medical, paramedical and interested lay persons in the skills necessary to provide eye care in rural Australia.

The following report more than adequately deals with the first two of these objectives and outlines the College's views on what should be done in respect of the third.

The findings of the Program published here reveal the extent and incidence of trachoma and other ocular health problems in the outback; they also highlight dramatic disparities between the general health situations of different groups in the Australian rural population. Recommendations are made to guide and promote the type of direct activities which could rectify these problems.

To conduct the NTEHP and compile this report has required an enormous effort by a great number of people. Foremost amongst these is a man of great humanity and unlimited enthusiasm — Frederick C. Hollows, Associate Professor of Ophthalmology, University of New South Wales. He has been remarkable for his untiring dedication to the task and his qualities have been an inspiration to all who have been associated with him in the Program.

Those involved in the Program are too numerous to name individually. They include the eighty or more ophthalmologists who went voluntarily to the outback to participate in the campaign; the orthoptists, nurses, optical dispensers, microbiologists and others who supported them; and then those who drove trucks, performed clerical duties or helped in other ways. On many occasions the field teams worked without time off for weeks on end and, in doing so, provided a coverage of rural Australia unmatched by any previous health exercise. The thanks of the College go to them all.

To the Commonwealth, State and Territory Health Officers who helped the Program in many different ways during the last three years, we also express our gratitude. Without their co-operation the Program could not have been fulfilled.

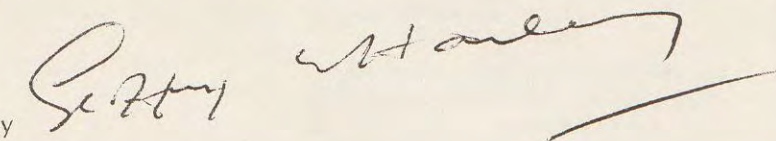
Of the Program's staff, special reference must be made to the efforts of Dr. David Moran, Misses Rosie Denholm, Susan Bennett, Reg and Rose Murray, Trevor Buzzacot, Sister Marjorie Baldwin, Penny Cook and Gabi O'Sullivan and Messrs Gordon Briscoe, Jack Waterford, and Dr. David Jones of the N.S.W. Health Commission. Though tempted to name more, the only Fellows of the College besides Professor Hollows to be publicly thanked are Dr. W.E. Gillies, the Chairman of the College's NTEHP Committee, and Dr. Hugh Taylor, who did so much of the field work.

From its inception, the work of the Program has been aided by the guidance and participation of the Aboriginal people whose advice was actively sought at every stage. The unique rapport the Program achieved with Aborigines was largely due to this input.

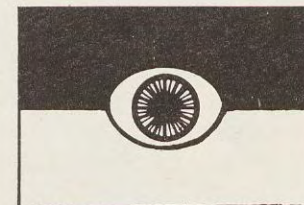
Finally, it should be stated, the College sincerely hopes that the various governments of Australia — Commonwealth, State and Territory — will give serious consideration to the recommendations made in this report. There is much to be done and we look forward to their continued co-operation. If we are to eliminate trachoma and other health problems associated with the outback in the foreseeable future, a concerted large-scale effort must be made.

In this regard, The Royal Australian College of Ophthalmologists is anxious and willing to do all it can to assist in this great national task.

Geoffrey Harley
 President
 The Royal Australian College of Ophthalmologists



November 1979



Chapter 1:

Trachoma in Australia

The Development of the NATIONAL TRACHOMA and EYE HEALTH PROGRAM

Trachoma has been endemic in Australia from at least the last part of the 18th century, originally affecting both whites and blacks.

Whether it was present in Aboriginal communities before the European settlement of Australia in 1788 is still a matter for debate, although there is some evidence to suggest that it might have been, perhaps introduced by earlier visitors to the north of Australia, such as the Chinese, Japanese, Macassans and Indonesians.

The first description of Aborigines by a European, William Dampier, in 1688, suggests that Aborigines in the Kimberleys region, on the north coast of Western Australia, may have had eye problems.

"They have great heads, round foreheads and great brows . . . their eyelids are always half-closed to keep the flies out of their eyes".¹

Among the early settlers, however, trachoma called "Sandy Blight" was endemic and frequently led to serious visual loss. There is little doubt that the early explorers, and the pastoralists and miners who followed them, had the disease. The pressures placed on Aboriginal communities by settlement, especially when large groups of them formed into settlement communities, probably caused the disease to flourish.

While trachoma, the frequently blinding "Sandy Blight", was well known to medical practitioners and ophthalmologists at the time, the transfer of the disease and its disastrous effects on Aborigines passed largely unnoticed.

As living conditions improved for Europeans, the disease gradually began to disappear. Increasingly, the only signs of trachoma encountered among Europeans were scarring among the

older people. The disease began to abate firstly in eastern Australia, the first area to be intensely settled by Europeans and the first to develop health amenities capable of warding off infectious diseases. In the less-settled parts of Australia, especially western NSW, Queensland, the Northern Territory and the arid and Kimberley regions of Western Australia, the disease persisted well into the 20th century.

Although trachoma had been occasionally noted among Aboriginal communities beforehand, there was very little understanding of its extent or effects until the early 1940's when Father Frank Flynn, an ophthalmologist who had had extensive experience with trachoma from his work at the Moorfields Hospital in London, was posted to an Australian Army hospital at Alice Springs.

In his first surveys into the extent of the disease, Father Flynn found that up to 90 per cent of the Aboriginal population of the Centre had some signs of the disease, many in severe form, with up to 7 per cent being blind in one or both eyes.

Father Flynn established a treatment program using sulphonamide drugs and eye ointments.

After the war he remained in the Northern Territory and continued his surveys, working with the Commonwealth Department of Health. Over the next 10 years, he surveyed the whole Territory, seeing about 10,000 Aborigines.

He found little difference in prevalence of trachoma between the Centre and Top End (some communities in the north having up to 84 per cent of their population with some trachoma signs), but striking differences in the course the disease took as one moved from the Alice Springs area to the Top End.

1. Abbie, A. : The Original Australians, extract from W. Dampier's log, Reed, page 21.



Father Frank Flynn fitting spectacles. Reproduced from, Flynn, F. & Willey, K: Northern Frontiers. Leonard, 1969.

In the dry and arid Centre, cicatricial stages of the disease were frequently severe causing visual loss; as one went further toward the more tropical north, a smaller percentage of severe cicatricial cases were found, with fewer being blinded or suffering substantial visual loss.

Father Flynn identified some of the factors associated with this trend as being the presence of secondary infection, aggravating the course of trachoma, and the climate, which led to irritation of the conjunctiva and cornea; particularly the drying effects of low humidity, heat, wind and dust.

In Western Australia, Professor Ida Mann was beginning her surveys of trachoma in that State, starting in the Kimberleys in 1953 and covering in the next few years the whole State, seeing more than 10,000 people, about half of whom were Aborigines.²

Her findings were met at first with shock and incredulity. More than 42 per cent of the people she saw in the Kimberleys, including 56 per cent of the Aboriginal population, showed some signs of trachoma, with 11.5 per cent of affected Aborigines blinded by it. In some communities, almost the whole Aboriginal population was affected by the disease.

In the Eastern Goldfields regions, about 58 per cent of the Aboriginal population seen had trachoma; almost 70 per cent of the children had follicular disease, while about 4.7 per cent of those affected were blinded by it.

Taking into account other eye conditions leading to blindness, more than 3 per cent of Aborigines and part-Aborigines she saw were blind in both eyes, with a similar proportion blind in one eye. The figures were much higher in the Kimberleys, but decreased in the south and south-west. The overall white blindness rate was about 0.2 per cent.

After the pioneering work of Professor Mann and Father Flynn, other ophthalmologists entered the field, including Dr. M. Moore, in South Australia, and Dr. Tom Boyd-Law in NSW, and gradual action was taken by the authorities. Programs were devised to identify and treat sufferers, particularly in schools; mobile trachoma nurses were appointed to travel in some of the endemic areas organising treatment and educational programs; some money was permitted for microbiological research into the trachoma organism.

In general, however, progress was very slow, with some workers feeling

that any improvement was more attributable to gradual improvements in living conditions than to medical-intervention programs. Public awareness of the problem, especially in the cities, was low, as was public and political willingness to commit funds to health programs and to further material improvement in living conditions of Aborigines.

Professor Mann had always argued strongly that the disease would only be eliminated after a substantial investment was made to improve living conditions for Aborigines. In an article reviewing the trachoma situation in Australia in 1972 she said:

"It has become increasingly clear that only by raising the standard of living of the Aborigines can the disease be controlled. This appears impossible at the moment for the following reasons: a lack of trained personnel; a lack of funds; a lack of understanding of the Aborigines' point of view and the fact that most Australians are town dwellers and are hardly aware of the problems of the Aborigines..."

The problem of trachoma control in Australia is only one facet of the complex native problem which is just beginning to worry everyone".³

By the beginning of this decade however, the political climate for change was beginning to emerge, and considerable attention was focussed on Aboriginal health issues.

One indication of this change was seen after a trip made by Professor Fred Hollows to Wattie Creek, in the cattle country of the Northern Territory, in 1972. There he found half the young children had trachoma, while more than half the adults had eye diseases, including trachoma, which were causing poor vision. A quarter of the older people needed surgery. The overall blindness rate was 4 per cent, perhaps 40 times the blindness rate among Europeans in NSW.

After the visit, the Australian College of Ophthalmologists arranged with the Federal Department of Health for ophthalmologists to visit the Northern Territory to assess the ocular status of Aborigines and to treat those with surgically correctable eye problems. Later that year, Professor Hollows made another trip to the Wave Hill and Hooker Creek area, where he confirmed the widespread existence of trachoma and operated on a number of people.

These visits, like the work of Professor Mann, Father Flynn and Dr. Moore, did much to spell out the theoretical framework of the N.T.E.H.P. program fully, demonstrating that it was possible to examine large numbers of people in their own communities and to organise local surgery in remote conditions. The visits led to calls for extensive surveys of trachoma with programs to treat and surgically relieve the disease, as well as improve the environment.

Professor Hollows was also conducting field work on trachoma at Enngonia in Western NSW, and, at the suggestion of Professors Max Kamien and Barrie Jones, undertaking treatment trials of Co-trimoxazole. These trials indicated a useful role for chemotherapy with improvements lasting some years.⁴

A number of other people and organisations were also working against the disease. In Queensland, the School Health Services had conducted a number of surveys in the 1950s, and had organised treatment. The disease was gradually disappearing, except in the far west and north, as living conditions for Aborigines in that State improved. In northern

and central NSW surveys had shown that the disease was on the wane.

After Professor Hollows' visit, the Federal Department of Health asked Dr. Doris Graham, a microbiologist at Melbourne University, to devise a trachoma-treatment model for the territory, based on the Wave Hill and Hooker Creek areas.

The Lions Club also organised a number of trips into remote Aboriginal settlements to help deal with the disease. In 1974, a team of eye surgeons, general practitioners and orthoptists, including Professor Hollows and Dr. John Slade, the chairman of Lions Save Sight Research Foundation (South Australia), travelled by light aircraft through the northern part of South Australia, western NSW and Queensland, and the Northern Territory, screening for eye disease. Of more than 1,000 children examined for signs of follicular trachoma, prevalence rates of up to 80 per cent were found.

The Development of the National Trachoma and Eye Health Program

In early 1975, the then executive secretary of the Australian College of Ophthalmologists, Mr. Jim Fair, had a discussion with Senator Peter Baume, a Liberal Senator active in health issues, in Canberra, during which Senator Baume said that private doctors should demonstrate their commitment to public health by action rather than words. He suggested that the college could involve itself in a project to tackle trachoma and trachomatous blindness among Aborigines.

Mr. Fair took the suggestion to the council of the college which responded positively, and asked Mr Fair to discuss its feasibility with Professor Hollows.

About that time, the then Minister for Health, Dr. Everingham, asked his department to prepare an analysis of trachoma in Australia and action which could be taken against it. This came after comments by a leading worker in Aboriginal health, Dr. Archie Kalokerinos, about the high levels of trachomatous blindness in the Northern Territory.

Dr S.J. (Pip) Ivil and Mr Gordon Briscoe, two officers of the Department of Health working in its Aboriginal health branch, sought Professor Hollows' advice. Together they and Mr Fair drafted a plan for a national survey of the ocular health of rural Australians, particularly Aborigines, involving screening, treatment (both chemotherapeutic and surgical), and eventual eradication of trachoma. It was quickly realised that the project should be organised through the college rather than an ophthalmology department of a university because it would then have access to voluntary help from ophthalmologists throughout the country.

By early September, 1975, a plan had been prepared for the project to begin early in 1976. The survey team, led by Professor Hollows, would both screen and treat for trachoma and other eye conditions, initially in the arid zones of all the States and then extending into the more temperate and coastal zones to ensure a nationwide cover.

The organisers decided to form a committee, to be composed also of Dr John Slade and Dr Doris Graham, to help draw up the final plans. The Department of Health representatives agreed to sound out each of the various State health authorities to ensure their full co-operation, while all agreed on the absolute importance of proper consultation and liaison with members of the Aboriginal communities to be visited.

Soon after, the plan was formally approved by the college, and an application for a health program grant, to "expand the current program directed towards the elimination of trachoma in Aborigines" by the "screening, diagnosing and treatment of all eye diseases" in rural Australia, was submitted. The college also decided that its members would help full-time program staff by sending volunteer ophthalmologists into the field for short periods, the volunteers having only their expenses covered.

A full-time organiser, Ms Rosie Denholm, was engaged by the college to co-ordinate planning for the establishment of the program.

The proposal was approved in principle by the Department of Health and its Minister, but formal approval for funding was seriously delayed by the constitutional and political crisis in Canberra. The De-

2. Mann, I.: Ophthalmic Survey of the Kimberley Division of Western Australia, Western Australian Public Health Reports, 1954-56.

3. Mann, I.: Australia, Israel Journal of Medical Sciences, 8: 8, page 1062, Aug-Sept. 1972.

4. Hollows F.C. Interim Report Enngonia Treatment Trial. Fed. Health Dept. 1975

partment of Health helped to ensure that the project was not delayed by arranging a short-term grant of \$25,000 through the Department of Aboriginal Affairs.

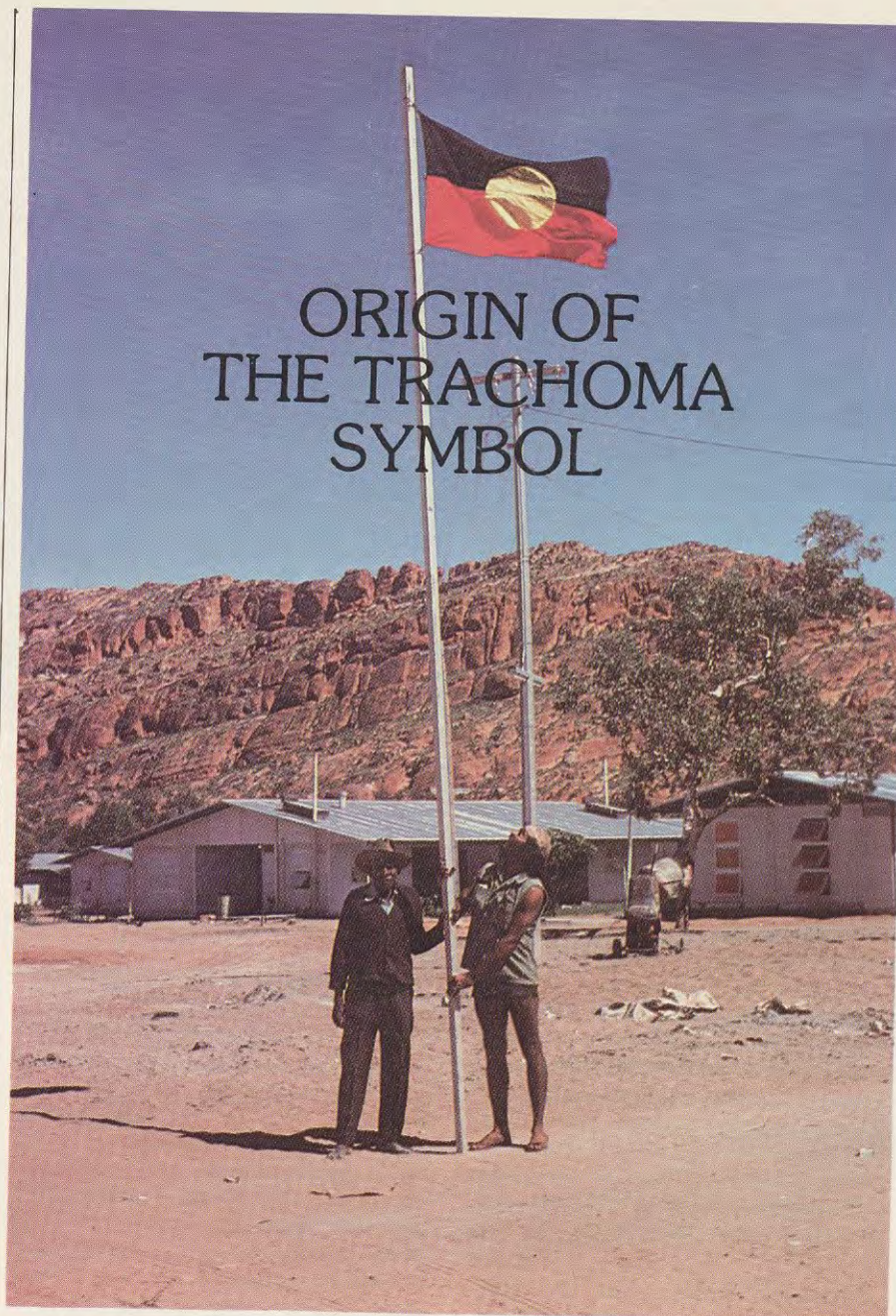
During December and January, program and Department of Health staff consulted various State health authorities, organised staff and equipment for the field work, and began preparing educational material and records systems.

Originally the team planned to start work in western NSW, the area with which program staff was most familiar, before moving to South Australia and the Northern Territory. These plans were dashed, however, by heavy flooding in central and western NSW early in 1976. In the event, the members of the team first worked at Walgett, NSW, where they surveyed the eye health of about 720 people during an exercise organised by the NSW Health Commission, but the visit to other NSW centres took place only after fieldwork in South Australia had been completed.

The program finally received formal approval from the new Minister for Health, Mr. Hunt, in February. Mr. Hunt, who had long taken a keen interest in Aboriginal health, gave strong support and encouragement to the program throughout its life, maintaining close contact with the team leader and college authorities.

The planning and organisation of the surveys was also helped by the advice and assistance of three men with long experience in Aboriginal and community-health matters: Father Frank Flynn, Dr. Archie Kalokerinos, and Professor Basil Hetzel, of Monash University, later to join the Commonwealth Scientific and Industrial Research Organisation as head of its new human nutrition branch. The support of the National Aboriginal Consultative Committee was also obtained.

The final title of the program — the National Trachoma and Eye Health Program — was suggested by the college council in March. The title was chosen to emphasise that the team was providing a total eye-care service, as well as looking for and treating trachoma.

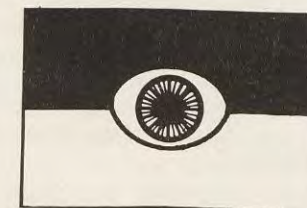


ORIGIN OF THE TRACHOMA SYMBOL

The Aboriginal flag represents the black people moving over the red sands of Australia, under a golden sun. It symbolizes for Aboriginal people their aspirations for national unity and improved status and health. The N.T.E.H.P. adopted the flag as its masthead, modifying the 'sun' into an eye, a symbol for



uwankuru palya ngalkulpai — better vision to all.



Chapter 2:

On the Road

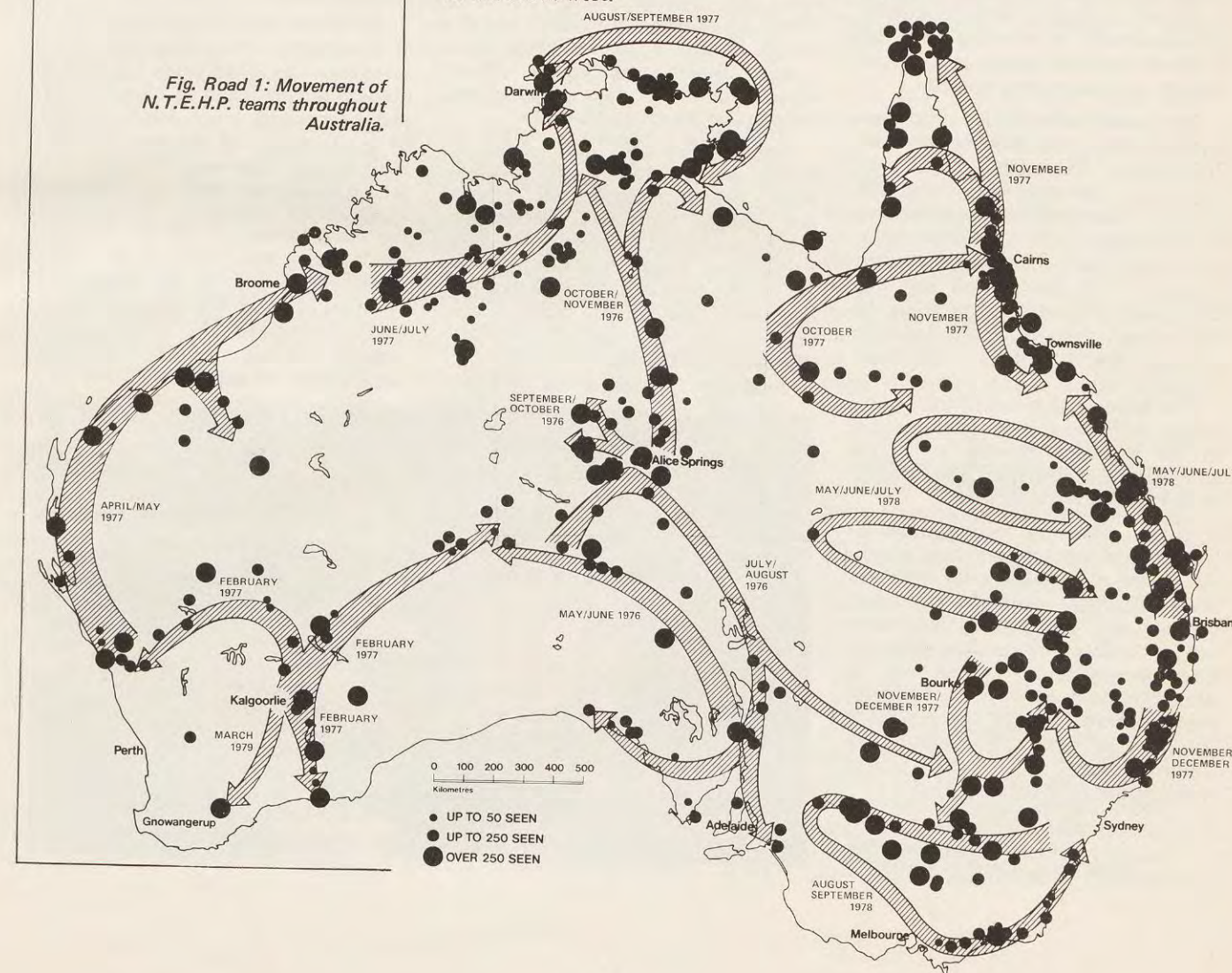
Planning for fieldwork began in January, 1976, with the understanding that the first clinics would be held in New South Wales in April. Equipment and supplies for field teams were ordered, and educational and publicity material prepared.

A short visit by program staff to Walgett in north-west NSW in March, with a NSW Health Commission team, helped set the pattern for future clinics and develop techniques for examining large numbers of people.

By then it was obvious that large-scale fieldwork in NSW would be impossible because of widespread flooding in the west of the State, and predictions of further flooding in the south west.

After consulting the South Australian Department of Health, the program decided to begin its fieldwork in South Australia, rather than wait for the flooding to ease in NSW. The assistant director of the program, Mr. Gordon Briscoe, and the program epidemiologist, Dr David Moran, went ahead of the team to liaise and consult leaders of the communities the program hoped to visit, and to employ liaison officers to inform people of the purpose of the program and how it would work. An itinerary was prepared, the team arrived in Adelaide on May 19, and after collecting vehicles from the Department of Administrative Services, arrived in Port Augusta on May 20.

Fig. Road 1: Movement of N.T.E.H.P. teams throughout Australia.



During the next 10 days, 1,143 people were seen at program clinics at Port Augusta and its environs, including the Aboriginal Social Club and Davenport Reserve. The stay at Port Augusta allowed time to organise equipment to help clinics run more smoothly and permit the easy packing and unpacking of clinics at different locations.

The team then drove to Indulkana in the North West Reserve of South Australia, where it held its first clinics among traditional people. From Indulkana, the team moved quickly to the north and west, visiting all the settlements and then moving, at the advice of its liaison officers, to various outstations and camps in the centre of the Pitjantjatjara Homelands.

It was in this area that the team began the practice of visiting small communities as well as major centres, as it was often in the small communities, usually the furthest from facilities and services, that the worst trachoma, the worst pathology and the highest levels of blindness and ear disease were found. The team rapidly developed a facility with equipment and a flexibility of planning which let it stop to examine groups at the roadside, or any place where needed.

The team then divided into two smaller teams, one remaining in the Pitjantjatjara Homelands and then moving up to areas within the Red Centre, while the other moved across to Oodnadatta and from there down the 'Ghan Track'. The teams rejoined briefly at Port Augusta on July 13, then separated again, one going to the western coast of South Australia and the other to Adelaide and Point Pearce.

The teams then returned to Sydney, having seen more than 5,000 people in 28 different centres in South Australia, and a further 2,300 people in and around Alice Springs.

Before fieldwork recommenced in late September, some members returned to the Centre to help with the program's first treatment campaign, carried out by Aboriginal health workers assisted by medical students, after arrangements worked out in discussions between Professor Hollows, the program's director, the program's liaison staff and the Pitjantjatjara Council. More than 2,000 people were treated in a 20-day period.

Fieldwork resumed in the Northern Territory in late September, with two teams working radially from Alice Springs where an office had been established to co-ordinate activities. After covering settlements, outstations and cattle properties in Central Australia, the teams moved north, holding clinics at Katherine, Pine Creek and southern Arnhem land, travelling as far eastwards as Borroloola, then working southwards back to Alice Springs.

In two-and-a-half months of fieldwork in the Northern Territory, the teams visited more than 50 communities and examined more than 6,500 people.

In November, again following close consultation with the Pitjantjatjara Council, an army surgical exercise was held at Amata, where some 41 Pitjantjatjara people had eye operations. The technique of bringing in the army to deliver surgical treatment in the area where people lived proved an outstanding success.

In early December, two field teams left Alice Springs for Sydney, travelling via Queensland and holding clinics in several far-western communities in that State, including Camooweal, Boulia and Dajarra. These clinics confirmed the presence of trachoma in these communities.

These teams also held clinics at Moree and Toomelah, in northern NSW, before returning to Sydney just before Christmas. Meanwhile, a third team had returned from Alice Springs via South Australia, reviewing on the way patients who had had operations, and holding clinics in several western NSW towns, Menindie, Wilcannia and Ivanhoe.

Fieldwork resumed in Western

Australia in the first week of February, 1977, and for the next two months the teams worked around the Western Goldfields and Murchison regions of that State, travelling as far north as Wiluna, and as far east as Wingellina.

A treatment program, involving more than 10,000 people in the Red Centre, began in mid-March and continued to the first week of April, with senior program staff returning for the orientation of medical students and others recruited to assist Aboriginal health workers in the dispensing of medications.

In early April, the teams moved north up the coast of Western Australia holding clinics in communities both on the coast and inland, including the Pilbara and communities at the edge of the western desert, before moving north to Broome and then east through the Kimberleys. Clinics were held at most cattle stations and at all settlements in the area, including Balgo Hills and Billiluna on the edge of the Great Sandy Desert.

On June 26, 1977, Miss Patricia O'Shaugnessy, the program's field secretary, was killed when the vehicle she was driving failed to take a corner and overturned on a sandy stretch of road about 20 kilometres from Halls Creek. She was 31 years old. She had always been an efficient, cheerful and tireless worker, even in the most adverse conditions, and her death was a great blow to the team. A rescreening visit to the Kimberleys 18 months after the tragedy found many Aborigines who affectionately remembered her and who were still saddened by her death.



"Patricia O'Shaugnessy, field secretary, at work in the field."

Almost 21,000 people, including 13,000 Aborigines, were seen by trachoma program screening teams in Western Australia between February and June, 1977. A total of 99 communities were visited.

The teams then moved into the cattle country of the Northern Territory, visiting cattle stations such as Wave Hill and Auvergne and Aboriginal settlements such as Lajamanu (Hooker Creek) and Daguaragu (Wattie Creek), before moving northwards to Darwin, which was used as a base for the completion of screening in the top end of the Territory. With poor road links between mainland communities, and screening carried out in such offshore communities as Bathurst Island, Elcho Island and Gove, extensive use was made of air transport, both commercial and charter, during this period.

Through much of this area, the program worked in three teams and during the three months until the end of September, the teams saw about 12,200 people in 99 communities. Concurrently, a surgery exercise was held at the Darwin hospital and also at Port Keats.

In August, a treatment campaign in the Eastern Goldfields and Murchison areas of Western Australia was carried out. A total of 4,500 people were treated, with 60 Aboriginal health workers and 30 university students being employed over the period.

Two teams left Darwin at the end of September, each working their way to Cairns, where a secretariat and base had been established.

The third team disbanded with the medical personnel flying to Alice Springs for a surgery exercise, afterwards conducting a review clinic in the Tennant Creek area before rejoining one of the screening teams at Mount Isa. One team travelled west to Borroloola (rescreening the children and reviewing the adults previously found to have eye problems), Doomadgee and towns centred around the bottom of the Gulf of Carpentaria: Burketown, Normanton and Croydon; the other through the Mount Isa and Cloncurry areas, travelling as far south as Boulia.

A third team was formed in Cairns, and three teams covered the remaining Gulf and Cape York country, the Torres Strait Islands and the communities in the tablelands surrounding

Cairns.

The teams then worked in communities as far south on the Eastern Coast as Townsville and Palm Island. In six weeks, 13,500 people in 57 communities were seen. This phase was until then the most efficient time for the program. This efficiency was due to three major elements. Firstly, the North Queensland Land Council (an Aboriginal body representative of all Aboriginal groups in the north and north-west) provided excellent local liaison. Secondly, Dr. P. Holt, superintendent of Thursday Island Hospital 'moved mountains' to see that as many as possible inhabited islands of the Torres Straits were visited, by organising transport using planes and boats of many types and sizes. (Unfortunately, due to inclement weather one team was unable to reach two islands). Thirdly, we had excellent co-operation from all State agencies.

An objection to the program's use of certain Aborigines for liaison work caused difficulties which threatened to slow the work. The imminent arrival of 'the wet' and the school holidays which limit field work efficiency made it wise to defer Queensland field work.

A liaison conference with NSW persons was quickly held in Townsville and field operations for NSW planned. In three days, all field teams travelled by road more than 1,200 miles into NSW, and field work started at three entry points: one coastal, one in the tablelands and one in the far west.

After a fortnight, the two east teams amalgamated and moved into the New England ranges, then travelling west to towns such as Wee Waa, Collarenebri and Lightning Ridge.

Before the teams returned to Sydney several days before Christmas, 1977, they had visited 55 coastal and western communities in the north and centre of the State and seen more than 11,500 people. Fieldwork in NSW proved as efficient as that in Queensland.

In the meantime, a mass-treatment campaign was being conducted in the Kimberleys and Pilbara areas of Western Australia, involving the treatment of some 7,000 people over 21 days.

In May, 1978, two teams were formed to complete screening in central and southern Queensland. One covered the western inland areas

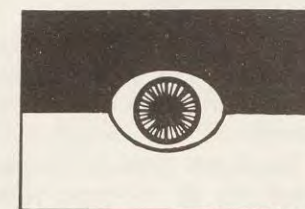
of the State, starting at St George and working as far west as Birdsville and as far east as Alpha, finally reaching Mount Isa in mid-June. The other team started in Brisbane and went northwards up the Queensland coast, travelling as far north as Babinda and rescreening Townsville in the process. The teams met in Cherbourg, holding joint clinics there. Then one team returned to NSW for a surgical exercise at Bourke, holding clinics in the Dubbo area before returning to Sydney. The other team travelled through the Darling Downs area holding clinics until early in July. At the end of the exercise, 75 communities had been visited, and nearly 18,000 people had been screened for trachoma and other eye conditions.

Before the second team had completed its coverage of Queensland, a small team had travelled to Central Australia, where, over eight days, eight communities had been visited and more than 1,000 people rescreened for the presence of trachoma. This rescreening indicated a heartening treatment effect, showing the level of follicular trachoma to have fallen.

In late July another team was formed to complete screening in southern NSW and Victoria. The team left Sydney on August 1, travelling to Wagga Wagga and then working its way west to Mildura and Gerard, in South Australia. The team also visited Griffith, Hay, Narrandera, Albury and Tumut, before travelling down to Melbourne and along the eastern coast and Gippsland country of Victoria and along the south coast of NSW. About 3,000 people were seen.

A small team then left for the Kimberleys to rescreen children treated almost a year before, and to review those found with eye problems. Over six weeks, about 3,000 people were seen; analysis of the findings showed, as in Central Australia that there had been a significant improvement in the level of follicular trachoma among children.

In March and April of 1979, a rescreening program was conducted in the Eastern Goldfields and Murchison area of Western Australia to reassess the level of follicular trachoma among the children, review surgery cases and other ocular pathology and prescribe glasses where necessary. Some 2,288 people were examined.



Chapter 3:

The program also took the opportunity during this trip to grade for the first time a community in the south-west corner of the State, the only rural area of Western Australia not previously covered by the program. Gnowangerup was chosen to be screened so as to provide comparison with other sections of the State and Australia.

A rescreening of the Pilbara region of Western Australia took place in May, 1979, and nine places were visited with a total of 1,688 people being examined in a fortnight.

In both the Pilbara and the Eastern Goldfields the prevalence rates for follicular trachoma were found to have improved significantly since the initial screenings and treatment campaigns had taken place.

SUMMARY

The above is a basic summary of the teams' progression around Australia and it must be borne in mind that many of the field activities were taking place concurrently, although independently.

Good liaison and program flexibility proved to be the key to smooth running and efficiency of the program's operations.

Good Liaison

In many communities where ophthalmic services had not previously been offered, a major investment in Aboriginal liaison was required both before, during and after screening to consolidate and further promote confidence and an understanding of the surgical and systemic treatment pro-

cedures employed by the program.

To ensure maximum co-operation with the States, team leaders at various stages during field operations were seconded to do advance liaison work at a high level between the different State departments and health agencies; this taking place before Aboriginal liaison officers started co-ordinating and appointing local liaison personnel (the latter being chosen as community representatives by the respective Aboriginal councils) in preparation for the arrival of the screening teams.

The pattern of travel was very much determined by feedback on advance liaison; whether a high proportion of the community would be there at the proposed time of visit or whether they would be 'out bush' or visiting another community; also climatic conditions often necessitated a 'last-minute' change of schedule.

Flexibility

According to medical requirements and availability of resources, systemic treatment campaigns and surgery exercises took place as shortly after the initial screening as could be arranged. This often necessitated the withdrawing of medical personnel from a field team, leaving one or perhaps two teams still operating, in order to provide immediate eye care services; (this being the third aim of the program). After completion of the exercise, the medical personnel then either rejoined the main screening body or formed a smaller grading team operating nearby.

To further facilitate team flex-

ibility, a central secretariat, co-ordinating and controlling alternate travel arrangements by air or sea, was usually established in regions where access to communities by road was not possible either physically or in terms of maximum use of time. Private charter was often the only method of transportation where normal routes were inappropriate for team requirements.

The teams carried a minimum amount of equipment but, at all times, whether travelling by road — the preferred mode — or by air and/or sea, were completely self-sufficient, to avoid having to draw upon the scanty and very often inadequate resources of the community.

In all, more than 84,000 kilometres were covered during the initial screening of rural Australia; this does not include distances travelled by air and sea to otherwise inaccessible communities.

Apart from local liaison staff, of whom more than 500 were employed during the course of the screening, and Aboriginal health workers, of whom more than 200 were employed during treatment programs, the program employed up to as many as 50 people concurrently at various stages during the screening exercise. These included ophthalmologists, orthoptists, optical dispensers, microbiologists, nurses, clerical staff and, of course, Aboriginal liaison officers. The program was assisted by 80 ophthalmologists who gave their time voluntarily in the field for periods of up to three weeks, receiving travelling expenses only.

Methodology

Screening Programs

The program's screening was based on the following principles:

1. The teams should be able to provide a range of ophthalmic diagnostic and therapeutic services to everyone, and these should be of the highest standard.
2. Services should be given immediately in order to minimise drop-out from medical care and surveillance, to encourage the use of future services, and to show that specialist care need not be complicated.
3. The services should be available and accessible to all.
4. The teams and their equipment should be mobile in order to provide the services in locations convenient to the target populations.
5. The teams should at all times work closely with the Aboriginal communities through liaison officers engaged from the communities for this purpose, to ensure that the service is suitable to the needs of the community, that the community is willing to use the service, and to advise teams on how to give the best possible service.
6. The team should use Aboriginal staff to the fullest: employing them in preference to similarly qualified Europeans; consolidating existing skills; helping them acquire new ones; lessening cultural barriers between teams and clients.
7. The teams should at all times encourage, inform, support and work with any person, group or agency as a move toward mobilising the community's interest in its own health.
8. The first contact with the communities should be the first step in establishing on-going eye care.

9. The team should note any factors within the community's environment which could be deleterious to the health of its members, and should advise the appropriate authorities, in consultation with the communities, on how to rectify them.

LIAISON

As later chapters in this report bear out, the program's success at reaching into and effectively delivering services to rural Australians depended on its liaison officers, all of whom were Aborigines.

The program's liaison was organised through Mr. Gordon Briscoe, a senior projects officer in the Department of Health who has been over the years a key figure in the expansion and development of medical services for Aborigines, particularly services in which Aborigines made a substantial input and were able to control. Since 1970, Mr. Briscoe has been associated with the development of the Redfern Aboriginal Medical Service, with the Central Australian Aboriginal Congress and other health services in Central Australia, and with the development of strong community-based medical services throughout Australia.

Under the guidance of Mr. Briscoe, the program employed many liaison officers in many parts of Australia: local Aborigines with the confidence and support of their own communities and with an extensive knowledge of the areas in which they were working. Additionally, the role of these personnel was supervised and co-ordinated by senior Aboriginal liaison officers.

Space, and the nature of this report, does not permit us to name all the liaison personnel who worked with the program, nor to thank them for their essential contribution to the program's success. Among those who do require special mention, however, are Mr. Trevor Buzzacott, the program's longest-serving senior liaison officer, who joined the program in South Australia and worked with it

through Western Australia, the Northern Territory and part of Queensland; Mr. Emmanuel Ebsworth, Mr. Greg Davis, Mr. Reg Murray and Mr. Michael Anderson in NSW; Mr. Mick Miller and Mr. Clarrie Grogan in Northern Queensland; and Mr. Michael Mace and Mr. Lindsay Black in southern and western Queensland; Mr. Lionel Turner and Mr. Don Ferguson around the Red Centre, and Mr. Allan Mallard and Mr. Kevin Cox in Western Australia. These and others were the program's key advisors in its activities, and played a most important role in its success.

The following report, from Mr. Trevor Buzzacott, shows the way in which the program's liaison staff worked, and gives his ideas about the role of liaison for outside resource personnel in future activities.

Liaison Report by Trevor Buzzacott

"Australian Aboriginal society has a structure — one with which most Australians are not familiar and will not become familiar in their lifetimes. The lack of familiarity with Aboriginal society, its history and its culture, has made it difficult for non-Aboriginal Australians to identify and help deal with the problems faced by Aboriginal communities.

The National Trachoma and Eye Health Program provided a successful service to rural and country-urban areas of Australia where the greatest proportion of Aborigines live. It identified areas of high trachoma prevalence, and high prevalences of

Fig.Meth 1: "Dr. David Moran, program epidemiologist, testing vision in the Pitjantjatjara country of South Australia."



other diseases; provided spectacles, treatment and surgery programs; and, in different locations, assisted local health agents to handle their communities' own health problems within their communities' structures. The program worked in a critical area where change had to occur.

The program's success in meeting its aims and objectives was due to a number of reasons, among which were:

1. The program's teams sought to identify and deal with the problems being faced by communities in the areas where the problems were: in hot, dusty climates with poor living conditions, often geographically remote and with irregular, if any, professional eye-care services being available.

Fig.Meth 2: "Discussing the fitting of spectacles with a tjilpi (elder) tribesman outside his dwelling."



2. The examinations were simple and easily understood by the communities, and involved participation by all field staff and the Aboriginal people.
3. There was considerable participation by Aboriginal people as liaison officers and field workers in all communities.
4. Consultations with communities, local people and different organisations were done by Aboriginal staff.
5. The program's advance fieldwork ensured that all Aboriginal communities were informed of the teams' visits well in advance, knew of the teams' aims and objectives, and ensured that informed permission was obtained from the community before the program began providing services.

6. The field teams identified with, and became very much part of, the communities they visited even when there were only short stays. Because of the program's independence for camping and cooking facilities, visits did not provide a burden on local facilities; a clinic was provided when one was not available; staff were prepared to work endlessly in providing a service to the people. Field team members also made a point of learning basic phrases in the local Aboriginal language such as 'hello', 'good morning', 'come closer', 'turn your head', 'look up', and so on, many of which were essential in providing a complete eye examination.

All these factors helped break down communication barriers, and enabled the program to examine persons who were relaxed, with only a few fears. Because of past experiences with medical services, including eye examinations, treatment and surgery, many Aboriginal people were afraid of being examined. In many cases they did not have the information from which they could decide about issues such as eye surgery, or treatment for follicular trachoma in children.

Consultation and communication was the most important factor in the program's success in reaching into Aboriginal communities. Through its liaison and consultation efforts, the program sought to involve people from the communities in its decision-making, and to show them its willingness to participate in movements for improved health, and its commitment to the communities among whom it was working. Unless the community was aware of and approved of what the program was doing, co-operation was not total, the best results would not be obtained, and the screening program would be regarded as merely another useless survey. The program thought it common courtesy to inform people of its aims and objectives: these concerned old people, children, their parents, their homes, their lands and their lives.

Each community the program visited had to be treated individually. Different groups spoke different languages; housing and lifestyle were frequently radically different; many communities were physically isolated from other centres. Within the communities there would be different authority structures, and differing input and control from outside agencies, including the Department of Aboriginal Affairs, other government departments, local non-Aboriginal resource personnel, and various religious institutions. All these factors had a strong bearing on how contact was made with each community. In some cases the hostility of some outside agencies meant that special efforts had to be made to reach the Aboriginal community itself.

On other occasions, the teams' movements were influenced by factors such as Aboriginal ceremonies, deaths within the community, link-ups with other surveys, and the movements of populations according to a number of factors. These have to be taken into account in planning screening or

follow-up visits.

Usually, initial contact would be made with communities a month or more before the arrival of field teams. This contact would be made by correspondence, enclosing information about the program and its objectives. An Aboriginal liaison officer would visit soon afterwards.

This first contact attempted to properly inform the local population of the aims and activities of the program. This included talking to senior persons in the authority structures of the communities, and such other people as community advisers, health and teaching staff and interested people working in the community.

Discussion and consultation was time-consuming. In most cases, Aboriginal people wanted to discuss issues among themselves and then return with answers and questions. It was necessary to clarify exactly what the eye-care service entailed, with a complete explanation of all aspects of the examination, and the likely follow-up with surgery and treatment if this was necessary.

Through such discussion and consultation, the program sought to involve the people from the communities, and to make them committed to its success. This ranged from obtaining the help of local people in the conduct of the screenings, the use of local interpreters and translators, and obtaining as wide a coverage of the community as possible. To achieve the latter, program teams were prepared to make camp visits and conduct clinics in different places. The nature of follow-up, including providing spectacles and making arrangements for surgery and treatment programs, would be explained where necessary so that the communities would know what to expect and would be able to have an input into continuing programs for eye health care in the communities.

After the initial contacts were made, information would be relayed to the field co-ordinator about the size and nature of the community, appropriate persons with whom to deal, the names of persons who would assist the field teams, the location of clinics and other facilities, and the community's wishes about the way in which the program should operate.

An itinerary would then be drawn up. The program, being independent

for facilities and carrying all the equipment for complete ophthalmological examinations, was flexible and operated according to often quickly changing conditions. This was in spite of enormous difficulties of time, distance, poor communications, and a lack of well-formed roads, with some communities being accessible only by air or sea. Despite these difficulties, with luggage and cargo kept to a minimum, and long and exhausting hours for field team members, the program kept to its schedules without reducing its service.

Once field teams were placed in Aboriginal communities, the same process of communication and consultation was necessary, using the contact and information obtained in earlier liaison work. Local people worked with field team members in achieving the program's objectives. The program's findings and their implications for the community would be discussed with the community; the program always left a complete set of its findings, and an interim report (see Appendix) summarising the picture in the whole community. Health workers and other interested people were instructed in the recognition and treatment of trachoma and other eye conditions.

Once a screening team had left an area, it was essential to maintain links with the community to ensure the necessary follow-up was achieved, and to assist the community in dealing with the problems seen by the program.

The success of the program's activities in one community would considerably assist in working with other communities in the same area: Aboriginal contacts were the key links in securing this.

The network of the Aboriginal people was the best avenue for liaison and communication. Aboriginal elders, wati ngunkaris (Aboriginal doctors), Aboriginal health workers, and Aborigines working with different agencies or departments within the community, were highly respected people and were able to secure the involvement and co-operation of people within the community.

It was within this network that the National Trachoma and Eye Health Program worked and this was appreciated and understood by the communities. The program's continued contact and empathy with this network

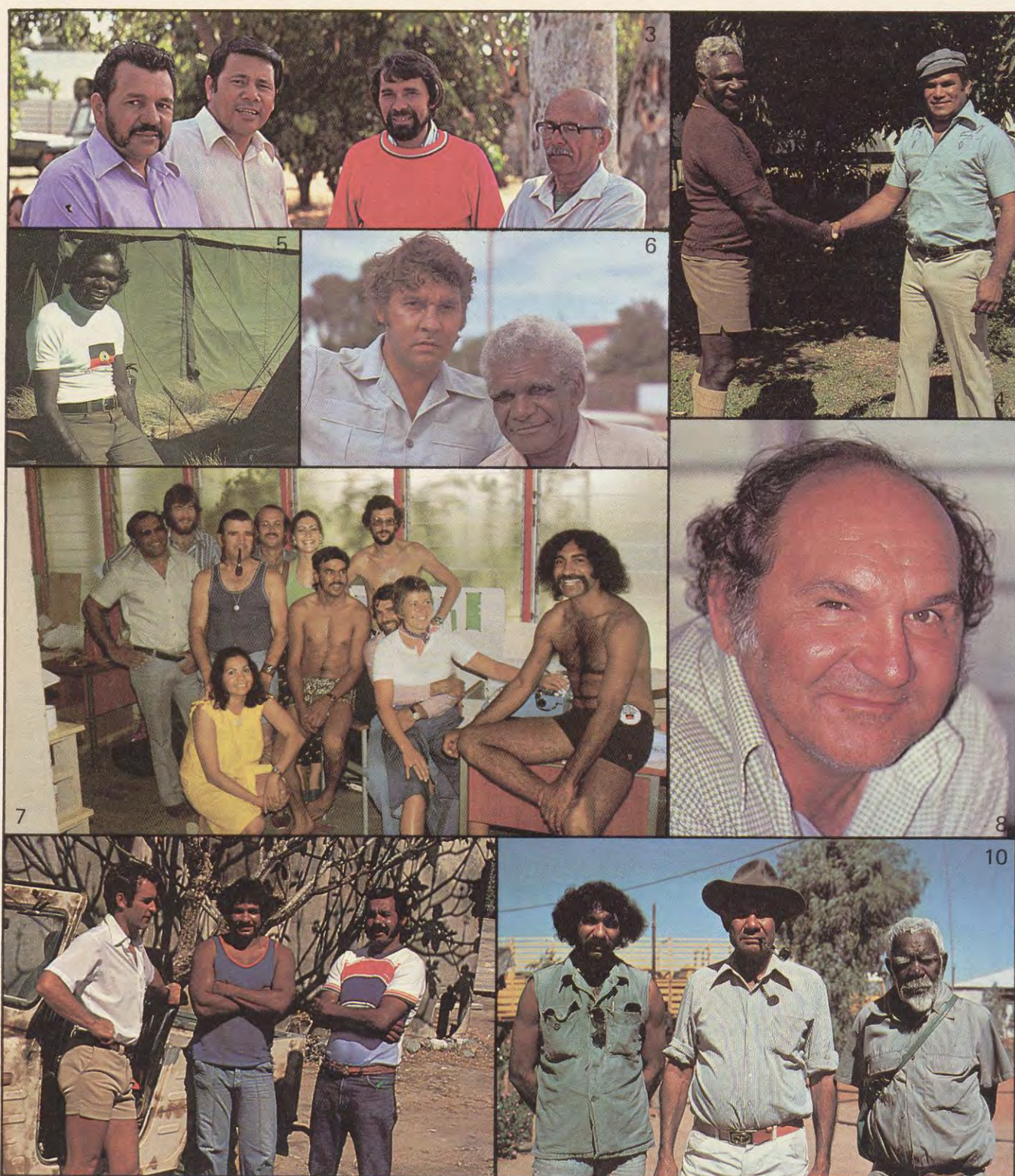


Fig. Meth 3: "Mr. Gordon Briscoe (2nd from right), the program's assistant director and senior liaison organiser in the Red Centre."

Fig. Meth 4: "Mr. Clarrie Grogan (r), liaison North Queensland, with Mr. Harry Daphne, liaison, Kowanyama."

Fig. Meth 5: "Mr. Don Ferguson, liaison, for the Pitjantjatjara nation."

Fig. Meth 6: "Mr. Allan Mallard (c) and Mr. Bill Wesley, liaison, Eastern Goldfields, Western Australia."

Fig. Meth 7: "A program field team, consisting of Aboriginal liaison personnel, trained eye specialists and secretarial staff, at Alice Springs, 1976."

Fig. Meth 8: "Mr. Lindsay Black, liaison, Central Queensland."

Fig. Meth 9: "Mr. Mick Miller (r), liaison officer for North Queensland, with Mr. John Budby (c) and Dr. Peter Holt, Medical Superintendent, Thursday Island Hospital."

Fig. Meth 10: Mr. Trevor Buzzacott (c), the program's senior liaison officer, with Mr. Peter Coffin and Old Dooley at Yandeyarra, Western Australia."

enabled it to be made aware of changes which had taken place, which meant that adjustments to schedules or ways of operating could take place without causing great difficulties. The 'grapevine' communication was able to get information very rapidly even to the most remote areas.

Working within this network meant that the program was able to leave some aspects of necessary follow-up with local or regional Aboriginal organisations, and to give these organisations support and assistance in meeting their own aims and objectives, almost invariably inherent in the program's own.

The empathy and support the program obtained from Aboriginal communities throughout Australia was not given without a price. It was secured on a clear understanding that the organisers of the program were genuine, and that the program's activities provided a starting point for improved health services in the future.

There is still an enormous need to consolidate the gains made by the program — and in dealing with trachoma and other eye diseases, in providing specialised eye health-care services to the largely neglected areas of rural Australia, and in outlining some of the changes necessary if Aboriginal health is to improve.

Aboriginal people who co-operated with, and supported the activities of the program, did so on the basis that this consolidation and follow-up would take place. If it does not the gains made by the program will prove short-term, and the empathy and support of Aboriginal communities will be lost.

The experience of the program was that the effectiveness of liaison and consultation was the single most important factor in the success of a screening visit to a community. Failure to properly consult or make adequate liaison arrangements almost invariably led to low turnouts and a degree of suspicion about the team; when the preliminary work was done well, few problems were encountered.

The Teams

Each team consisted of up to nine full-time staff:

- A trachoma grader, usually an ophthalmologist
- A senior Aboriginal field officer

An ophthalmologist, usually a volunteer from the Royal Australian College of Ophthalmologists spending several weeks with the team

- An orthoptist
- A trained nurse
- An optical dispenser
- A microbiologist
- A field secretary
- A mechanic and baggage master

Frequently teams would be smaller, with members of the permanent team able to do the duties of others. Overall, about half the staff were Aborigines, the proportion being greater at clinics where local people helped with clerical duties, liaison and interpreting, and transport.

Except in particularly remote areas in northern parts of Australia, the teams travelled by road, using four-wheel-drive vehicles — three or four to a team, able to carry all the staff and equipment. A team carried with it sufficient ophthalmic equipment to set up a normal clinic, and also drugs, camping gear, food and clothing.

Clinics

Once a team had arrived in a community and contacted the liaison staff, it would move to the clinic site and unload and prepare its equipment.

The site chosen was crucial to the team's success, particularly with those most in need of the services. The blind were often immobile, while those with visual impairment were often unable or unwilling to attend, whether because of diffidence or shame (especially if other conditions, such as leprosy or disfigurement, made them embarrassed) or because they had accepted their disability and were pessimistic about the prospects of improvement.

Effective liaison ensured that such people were known and, where necessary, the examination was taken to them. This might entail door-to-door visits, with vision testing and initial assessment of ocular status being conducted in or outside the tents or tents.

In many communities such visits were essential in gaining an accurate assessment of those who were blind, those with sight-threatening lesions, and those who could be helped by surgery.

Cases presented by local health agencies did not always accurately reflect the number of people in the community with such conditions, nor the extent of such problems.

Many cases of cataract and trichiasis urgently needing surgery have been identified and helped by the program but may never have received specialist attention had they been required to attend the clinic.

The program also found it worthwhile to stop and examine people while on the road. Once, a roadside examination of nine Aboriginal stockmen showed that four needed surgery for sight-threatening trachoma.

The largest number of people could be screened, however, at appropriately located and properly set up clinics, whether in the community's health centre, school, meeting hall or elsewhere.

A single experienced examiner with four or five well-trained staff could examine up to 500 children for trachoma signs during a school day, each child being tested for visual acuity and also examined for ear pathology. Clinics with substantial proportions of older people were considerably slower, with large numbers of people needing refractions for spectacles, examination for pathology and discussion about surgery or other appropriate treatment.

Overall, an average team would see more than 100 a day, taking no account of travelling time. During one two-month period in Queensland, where travelling conditions were substantially better than in most other areas, two teams saw more than 20,000 people in about 80 different towns, team vehicles travelling a total of more than 8,500 kilometres during the period.

The Examination

The subject's identifying particulars were recorded. Visual acuity was tested by orthoptists or other trained persons. The most appropriate method was to use the illiterate Snellen E chart, (see Chapter 6 page 54), with the subject standing six metres from the tester, covering one eye and indicating by a hand movement the direction in which the legs of the E pointed. The orthoptist would also note the presence of any strabismus.

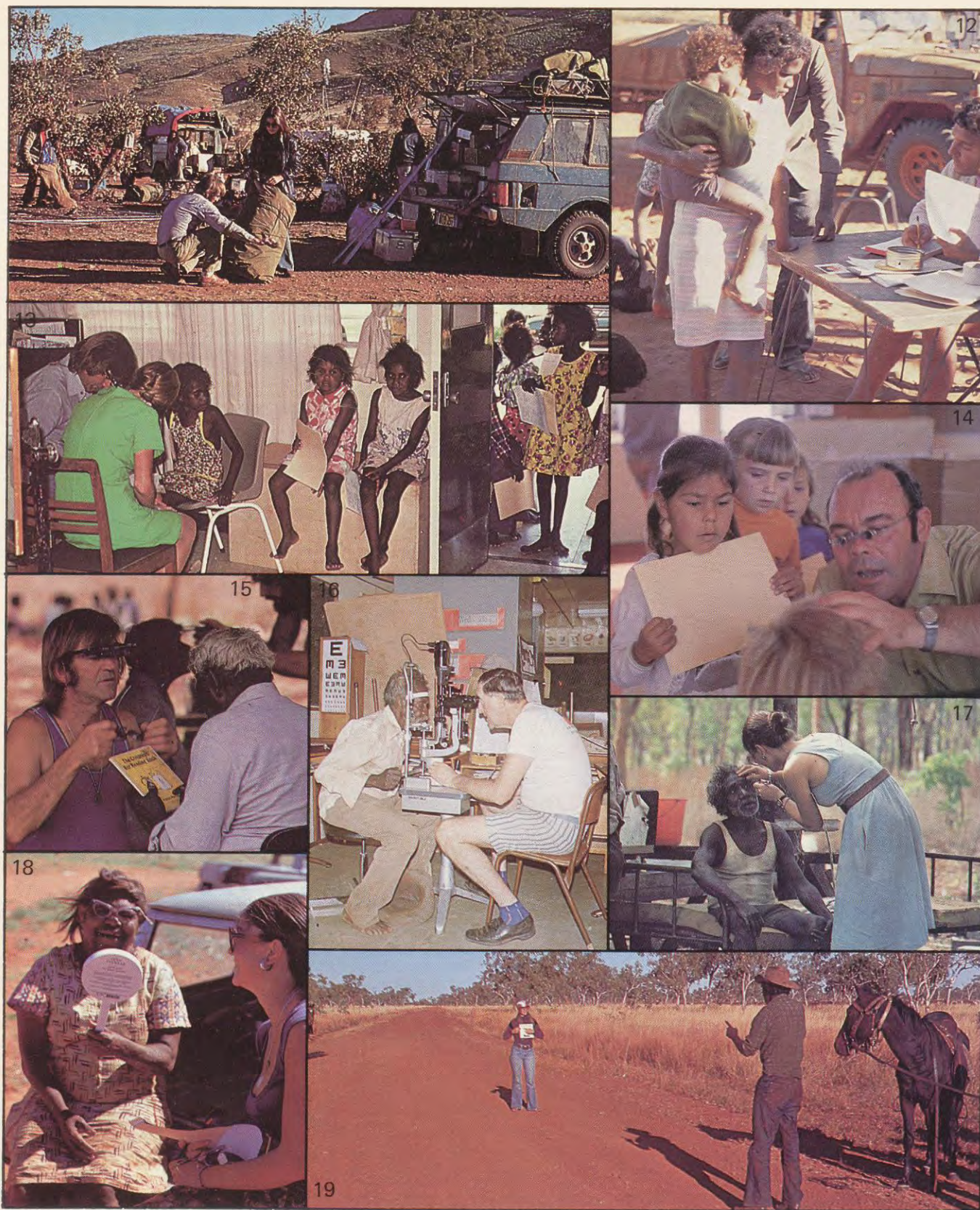


Fig. Meth 11: "Packing and unpacking becomes a ritual after visiting more than 600 communities around Australia."

Fig. Meth 12: "Personal details are recorded on a clinic card at the 'desk' before the examination."

Fig. Meth 13: "Children holding their clinic cards await examination. The program saw many children in their schools."

Fig. Meth 14: "Dr. John Ohlrich draws a young audience during a school clinic."

Fig. Meth 15: "Testing near vision in Arnhem Land."

Fig. Meth 16: "Teams carried full ophthalmological equipment. Here Dr. Ron Lowe uses a slit-lamp on an elder at Utopia Northern Territory."

Fig. Meth 17: "Orthoptist Gabrielle O'Sullivan examining eyes in an Arnhem Land outstation."

Fig. Meth 18: "Do they suit me?" More than 7,000 pairs of spectacles were dispensed by the program to people, many of whom had never had them before."

Fig. Meth 19: "A roadside eye-test. The stockman points the direction of the 'E' symbol on the chart."

The subject would then be seen by the trachoma grader, who would evert each eye lid to check for signs of follicular disease and note the presence of any other ocular pathology. The second ophthalmologist would perform any further examination or action as indicated. The trachoma grader would also make an auriscopic examination of each ear to note the presence or absence of otitis media and its sequelae, and make a quick visual examination for nasal discharge and skin infection, all results being noted on the clinic card.

Those who showed no signs of any eye pathology or visual problems could then leave. If closer examination was warranted, the person would be referred for a full ophthalmological examination.

Refractions, slit-lamp examinations, applanation tonometry, and direct and indirect ophthalmoscopy would be performed as in an ordinary ophthalmic clinic. Those who needed spectacles would have them prescribed and an optical dispenser would help in the selection of frames and would fit and measure them on the spot, making arrangements if the person could afford it, to have him pay for them. If a person could not afford them, under different arrangements made with each of the States, either the State authorities, the Federal Department of Health or the program would pay.

If surgery was indicated, the ophthalmologist would discuss the alternatives with the patient and relatives, perhaps helped by one of the field officers or liaison workers.

Running tallies would be kept by the field clerks of the race, age and sex groupings seen, so that if any group was under-represented deficiencies could be made good.

Liaison workers would also help arrange follow-up for patients needing treatment or surgery, make decisions about the appropriate place for surgery or treatment, or further examinations.

Once the clinics were completed, a report would be prepared for members of the community and their local health agents, perhaps a nurse, sometimes a doctor, and in some circumstances the teacher or station-owner's wife.

The report would set out the numbers of those seen, giving details of those identified as having ear,

skin or respiratory-tract infections, as well as summarising the pattern of follicular trachoma in the area. It would also list all those for whom spectacles had been prescribed, those found to be blind, or to have poor vision, and those needing surgery.

An original of each of the clinic cards would also be left with the local health agent, so that individual records could be incorporated in local health-record systems, and be available to any health practitioner who may visit the area.

Team members would also discuss with senior members of the community those features of the community's environment which it was felt contributed to any of the poor health found during the visit. When the community wanted it, the program lent weight to community applications for better water supplies, the provision of housing or the establishment of health-care systems. Some of the ways in which the program participated in community actions to try to improve living conditions are discussed in another chapter.

Discussions would also take place about the sort of follow-up appropriate to the community's needs. Where mass treatment programs were indicated, preliminary arrangements would be made, although final plans were not adopted until further, more extensive consultations and liaison were held; where there was surgery needed, the opinion of the community about the most appropriate way of doing it would be sought. Especially in more remote areas, the possibility of establishing a mobile Army hospital close to the communities would be discussed. In other cases, arrangements would be made for special surgical expeditions, operating in local facilities, and in some areas arrangements were made about referring the patients to ophthalmologists working in townships close to the communities.

Some recommendations for examining Aborigines

1. Aborigines place greater value on person-to-person encounters than do most other Australians. The clinical examination to them is seen as an integration with the examiner rather than a procedure. Aborigines have a heightened awareness of other

people's feelings, attitudes and demeanor and are especially sensitive to visual clues. There are in some situations personal avoidance regulations such as between a male examiner and an unmarried younger woman but these aside the examiner is well advised to use eye-to-eye contact and gestures rather than loud intonations in a vernacular that is not local, any local words such as 'nina kati' — sit down — (Western Desert) and a friendly manual indication towards the examination chair will be well responded to. Speak quietly and directly person-to-person.

2. To evert the upper eye in the often deep Aboriginal orbit, a glass rod is a useful aid.
3. Get used to using at least 3 x binocular loupes.
4. For subjective testing a mirror and E chart are essential in that they keep the bond between examiner and subject tight and enable the responses to be gauged.
5. Use a local person as 'head holder' and interpreter whenever possible.
6. Be wary of overdiagnosing cataract. With the small pupils usually found, and the high ambient light intensity, do not assume cataract present until confirmed by dilation of the pupil.
7. Use a lense rack for retinoscopy but remember the difficulties of keeping the small lenses clean in the Australian bush.
8. Pack all your lenses very carefully. A hundred kilometres of corrugated road can completely ruin the surfaces of plus lenses if they contact another hard surface.
9. For presbyopic subjects use the reduced E chart and remember plus lenses less than 2D are rarely indicated. You will need a fine point to indicate individual E's, a straightened out paper clip will do.
10. Keep your epilation forceps at the ready. Pull the lashes individually and do not break them.
11. Make sure that the patient understands for which distance glasses are prescribed. This is

best done by demonstration with the trial frame and lens on the patient. Improved distance vision with prescription is most effectively demonstrated to the patient by testing vision outside rather than at six metres.

The Sample

The program's findings were based on the screening of more than 100,000 people, some of whom were examined on two or more occasions. As such, a very large sample was involved. It is necessary, however, to know the characteristics of this sample before judgement can be made about how accurately the program's findings reflect the actual situation. This involves a consideration of the age, sex and geographical distribution of the people seen, and its comparison with the known characteristics of the general rural population of Australia.

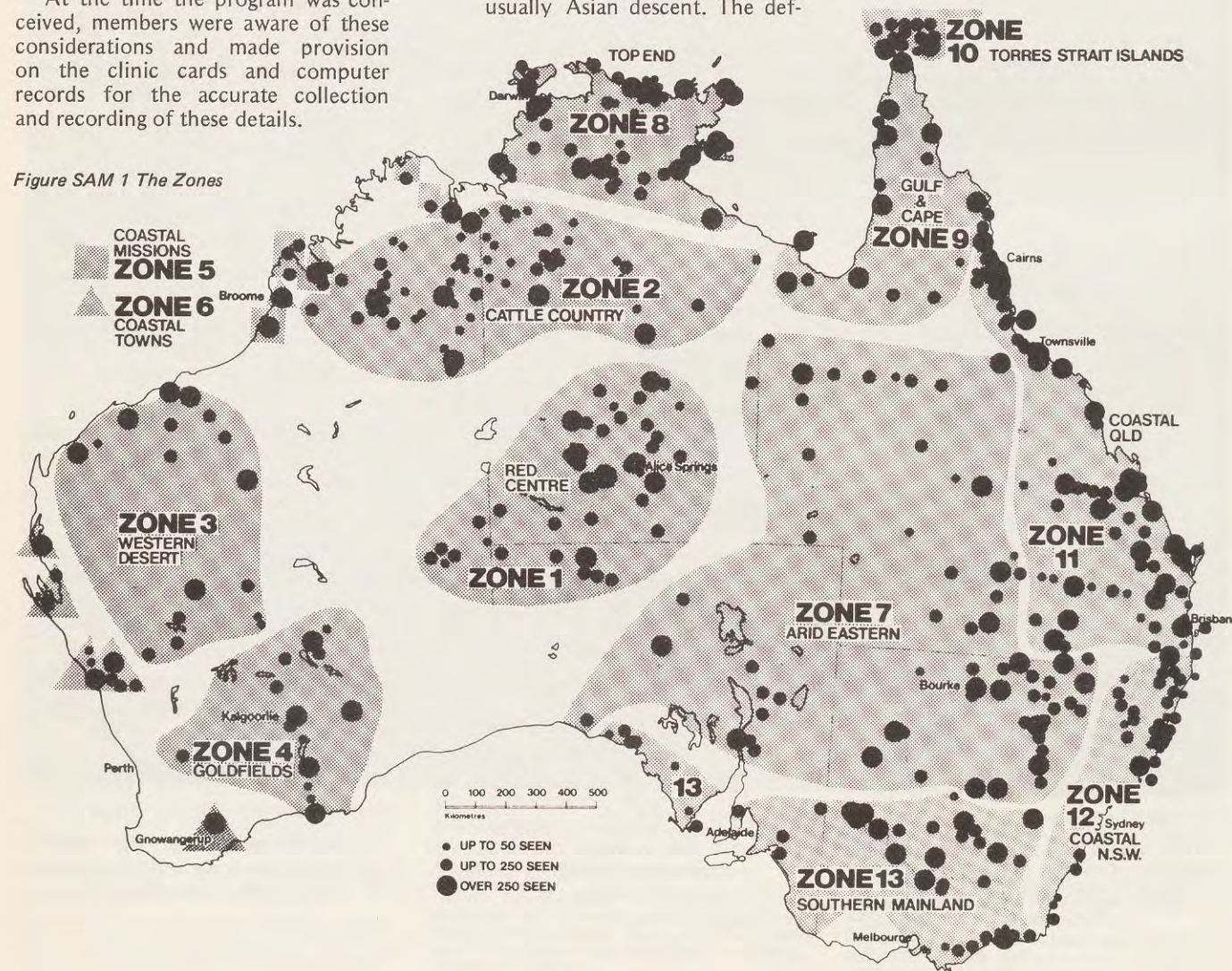
At the time the program was conceived, members were aware of these considerations and made provision on the clinic cards and computer records for the accurate collection and recording of these details.

Each clinic card contained an exclusive number, through which the record could later be pulled out and checked. Also recorded on the clinic card and punched on to the program's computer records, were:

1. Personal identifying details, including name, and where appropriate, tribal affiliation and subsection name; address; the identity of close relatives if this might be necessary in arranging follow-up.
2. The State and community at which the screening took place. Each community visited by the program had an exclusive number; in some cases where outstations clustered about a particular community, these outstations were given separate numbers.
3. The race of the person being examined. During screening, persons examined were coded as being Aboriginal, of primarily European descent, or of other, usually Asian descent. The def-

inition of Aboriginality used was the Commonwealth Government one — that a person is considered an Aboriginal if he identifies as one and is accepted as such by the community in which he or she lives — and caused no problems in practice; only small numbers of persons who were non-Aboriginal and not of European descent were seen, and during analysis these were grouped with those of European descent and classed as non-Aborigines.

4. The age of the persons being examined. Where this was not known, as was sometimes the case with elderly Aborigines, the person was asked whether he or she received a pension, in which case age was recorded as 60+, local health records were checked, or the advice of field officers was sought. In some cases, an estimate was made.



5. The sex of the person being examined.

Computer analysis of the program's findings was made on the basis of 13 zones of rural Australia, the zones having been chosen because of relative similarity in geographic, climatic, industrial and demographic conditions. Each community visited was placed in one of these zones. The zones are shown in Figure SAM 1 (the names of the various communities in each zone are listed in Appendix two at the rear of the report) and were given a name as follows, according to the main geographic feature of the zones:

- Zone 1 : **Red Centre**, covering Aboriginal communities in Central Australia, including the communities within the Pitjantjatjara Homelands in South Australia and Western Australia.
- Zone 2 : **Cattle Country**, covering the middle areas of the Northern Territory and communities within the Kimberleys of Western Australia based around the cattle industry.
- Zone 3 : **Western Desert**, covering inland regions of the Pilbara in Western Australia and also Murchison communities such as Wiluna and Meekatharra.
- Zone 4 : **Goldfields**, covering communities in the Eastern Goldfields region of Western Australia.

Zone 5 : **Coastal Missions WA**, primarily Aboriginal communities in north and north-western coastal regions of Western Australia.

Zone 6 : **Coastal Towns WA**, European settlements along the north and north-west coast of Western Australia in which Aborigines live, either on the fringes or integrated into the main townships.

Zone 7 : **Arid Eastern**, the dry far-western regions of NSW and Queensland together with arid rural regions of South Australia, other than the Pitjantjatjara homelands communities.

Zone 8 : **Top End NT**, including the islands, Darwin and Arnhem Land.

Zone 9 : **Gulf and Cape Country**, Queensland.

Zone 10 : **Torres Strait Islands**

Zone 11 : **Coastal Queensland**, most of the people in this zone actually lived very close to Australia's Eastern Coast. Also included in this zone, however, were those living in non-arid inner-western regions of the State.

Zone 12 : **Coastal NSW**

Zone 13 : **Southern Mainland**, including the Riverina areas of NSW, Victoria and non-arid regions of South Australia.

Although separate findings for each of the communities visited by the program will be published, and have already been made available in interim form to the communities, local health authorities and State and Federal health and welfare authorities, the findings presented in this report will be the general findings for each of these zones only.

This is not to suggest that the disease picture seen was necessarily uniform in the zones. Frequently it was not. There did, however, tend to be a similar pattern of disease throughout each zone, with variations frequently wholly attributable to differences in environmental facilities such as water, housing, and waste and sewage-disposal systems as well as climatic variations. These factors are considered elsewhere. For the purpose of outlining the general findings, however, the overall pattern within each zone will be described.

The Nature of the Sample

Tables SAM 1 and SAM 2 show the age and racial distribution of persons seen by the program. In all 100,732 people are considered in this report; of these 62,116 were Aborigines and 38,616 were non-Aborigines.

TABLE SAM 1

AGE AND DISTRIBUTION OF ABORIGINES SEEN BY THE NTEHP

	AGE GROUPS							
	0 - 9	10 - 19	20 - 29	30 - 39	40 - 49	50 - 59	60 +	TOTAL
ZONE 1	2,944	1,997	929	614	486	335	692	7,997
ZONE 2	1,793	1,085	894	445	397	302	710	5,426
ZONE 3	762	496	241	188	167	109	295	2,258
ZONE 4	642	440	225	143	114	74	107	1,745
ZONE 5	492	349	149	99	102	85	118	1,394
ZONE 6	1,335	1,122	298	217	182	111	240	3,505
ZONE 7	4,341	3,187	953	717	605	358	427	10,588
ZONE 8	2,564	1,954	1,043	638	496	321	385	7,401
ZONE 9	1,248	907	381	334	257	189	244	3,560
ZONE 10	804	791	248	138	162	178	153	2,474
ZONE 11	3,561	3,229	797	572	563	426	393	9,541
ZONE 12	1,106	940	250	196	165	107	91	2,855
ZONE 13	1,186	1,057	385	289	217	121	117	3,372
ALL ZONES	22,778	17,554	6,593	4,590	3,913	2,716	3,972	62,116

TABLE SAM 2
AGE AND DISTRIBUTION OF NON-ABORIGINES SEEN BY THE NTEHP

AGE GROUPS								TOTAL
	0-9	10-19	20-29	30-39	40-49	50-59	60+	
ZONE 1	273	135	222	128	42	44	22	866
ZONE 2	581	251	210	169	79	50	35	1,375
ZONE 3	220	88	87	59	28	27	18	527
ZONE 4	1,318	648	118	104	55	39	57	2,339
ZONE 5	287	144	48	35	19	21	10	564
ZONE 6	1,456	1,574	198	136	79	41	25	3,509
ZONE 7	4,631	4,600	486	391	314	205	239	10,866
ZONE 8	1,972	1,548	487	480	272	150	121	5,030
ZONE 9	478	358	130	89	43	33	38	1,169
ZONE 10	102	50	54	40	36	26	24	332
ZONE 11	3,331	4,399	229	228	203	157	240	8,787
ZONE 12	405	636	42	45	25	9	18	1,180
ZONE 13	980	754	89	73	54	65	57	2,072
ALL ZONES	16,034	15,185	2,400	1,977	1,249	867	904	38,616

The program's intention was to achieve a large coverage of at-risk groups and communities to obtain an accurate assessment of the prevalence of trachoma and other diseases and conditions, and also to see everyone in those communities who had eye problems requiring specialist care.

In the planning of the program, it was known that the bulk of the problems which would be encountered would be found among Aborigines. Because of this, the program's itinerary was devised so as to achieve maximum coverage of Aborigines, particularly in those areas where the problems were expected to be the worst. The young and the elderly of these were the main focus of the program's activities; the former because the highest prevalences of the follicular form of trachoma was likely to be found among them; the latter because they were the ones most likely to have sight-impairing problems as a result of trachoma or other disease.

The program also attempted to see enough people of Aboriginal descent in areas where facilities and access to specialist services were better to enable it to draw sound conclusions about the prevalence and pattern of eye disease in these communities. In practice this meant that the coverage in these areas was lower,

although there was still a relatively high coverage of the young and the elderly.

The program's services were open to all, whether Aboriginal or non-Aboriginal, and, in the course of the survey, large numbers of non-Aborigines, especially non-Aboriginal children and adolescents, were seen. The high coverage of children was related especially to the fact that the program saw all, or nearly all, school children, Aboriginal and non-Aboriginal, in communities where there was a substantial number of Aborigines. Although it was made known that the services were available to non-Aborigines beyond school age, it made little effort to obtain a full coverage of them. Non-Aborigines over the age of 16 thus tended to be strongly self-selected, and the program's findings for these must be considered with some caution: those who attended clinics were probably more likely to have had eye problems than those who did not.

Information of the size and distribution of the Aboriginal population is imperfect. At the time when this report was being prepared even 1976 census data was only available in limited form.

From this and other data, however, the program has estimated that about 127,000 Aborigines lived in areas screened by it, with

about 49,000 living in more-or-less traditional areas, (Zones 1, 2, 3, 4, 5, 6 and 8) and about 78,000 living in less traditional areas (Zones 7, 9, 10, 11, 12 and 13).

Table SAM 3 shows the program's estimates of its coverage in these two areas, with population figures for the region being projected from figures supplied by the Australian Bureau of Statistics.

It can be seen from the table that a high coverage was obtained in Zones 1, 2, 3, 4, 5, 6 and 8, especially of school children and the elderly. Although the sample was smaller for pre-schoolers and infants, it represented nonetheless almost half the Aboriginal population of these areas.

In Zones 7, 9, 10, 11, 12 and 13, the coverage was not as high, averaging about 42 per cent. The highest coverage was of school-age children with about 63 per cent seen, while 43 per cent of the estimated population of pre-school children were seen. The coverage of young adults was considerably lower, but improved with increasing age.

Overall, the program estimates that it saw about half the Aboriginal population of rural Australia, including more than two of every three Aborigines of school age and almost five of every eight persons aged 60 or more.

TABLE SAM 3 - ABORIGINAL POPULATION COVERAGE IN TRACHOMA SCREENING

AGE	TRADITIONAL AREAS*			LESS TRADITIONAL AREAS**			OVERALL		
	Estimated Population	Seen by NTEHP	Per-Cent Age	Estimated Population	Seen by NTEHP	Per-Cent Age	Estimated Population	Seen by NTEHP	Per-Cent Age
0-4	7,480	4,324	58	11,720	5,017	43	19,200	9,341	49
5-9	7,670	6,208	81	12,030	7,229	60	20,700	13,437	65
10-14	6,740	4,859	72	10,860	7,087	65	17,600	11,946	68
15-19	5,260	2,584	49	9,070	3,024	33	14,330	5,608	39
20-29	7,820	3,779	48	12,820	2,814	22	20,640	6,593	32
30-39	4,970	2,344	47	7,750	2,246	29	12,720	4,590	36
40-49	3,720	1,944	52	6,240	1,969	32	9,970	3,913	39
50-59	2,360	1,337	57	3,980	1,379	35	6,340	2,716	43
60+	2,950	2,547	87	3,510	1,425	40	6,460	3,972	61
ALL AGES	48,970	29,926	61	77,980	32,190	42	126,950	62,116	49

* Listed as traditional areas are Zones 1, 2, 3, 4, 5, 6 & 8.

** Listed as less-traditional areas are Zones 7, 9, 10, 11, 12 & 13.

Figure SAM 2 is a population pyramid that compares the program's sample of Aborigines with an estimate of the total rural Aboriginal population.

As later chapters will show, the highest prevalence of disease tended to be found in the zones labelled as being more traditional (Zones 1, 2, 3, 4, 5, 6 and 8). It was in these areas that the highest coverage was achieved. In general, it was possible to obtain very high coverages in small and remote communities, especially when adequate fieldwork had been carried out. The program saw the entire population of some outstations, cattle-station communities, and small settlements.

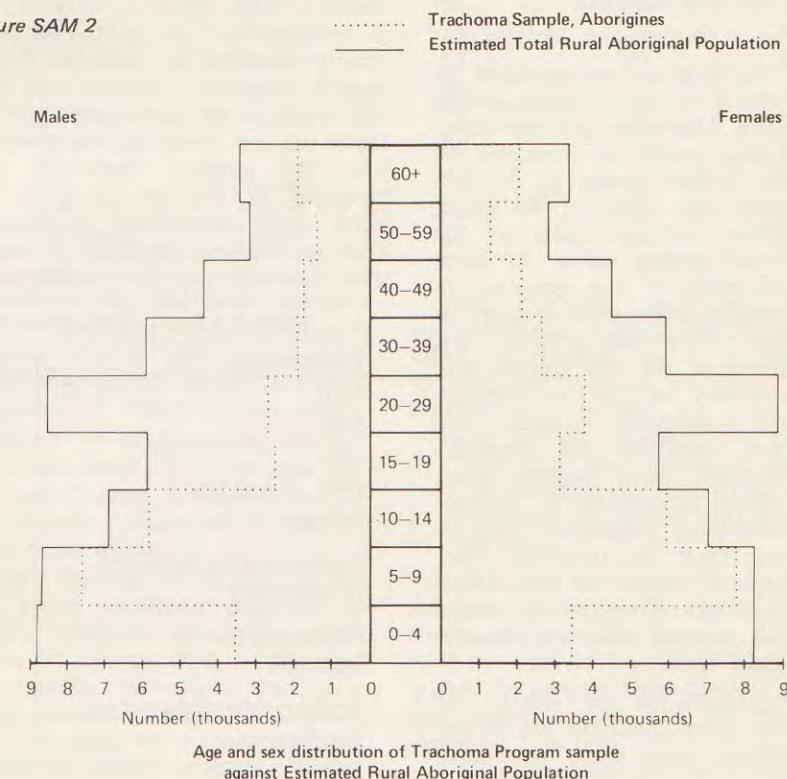
In general we feel that the Aboriginal population sample obtained in each area was an accurate reflection of conditions in that area. There may have been a tendency for more persons with visual disability to come forward, as the program believes was the case with its older non-Aboriginal sample, but the program's experience on rescanning suggests otherwise. On such occasions the program saw numbers of persons with visual disability who had not presented for first screening, of a proportion such as might have been expected had the sample been truly random.

Even assuming that the sample was random, caution must, however, be exercised in extrapolating dis-

ease rates on to the general population. This is because of differences between different zones. The average blindness rate among Aborigines aged 60 or more in Zones 1, 2, 3, 4, 5, 6 and 8, was for example, 237 per thousand, compared with a rate of 103 per thousand in the remaining zones. The overall rate was 189 per thousand. Be-

cause of the different coverages of the two areas, one could not safely use the overall rate to estimate that the number of elderly Aboriginal blind was 1,221. Instead, an analysis of the coverage would suggest that the number of elderly Aboriginal blind was about 846, within certain confidence limits.

Figure SAM 2



In all except the visual-systems abnormalities section of this report, the program's results have not been adjusted for age. For those who might wish to do so, however, the method of doing so is suggested by Table SAM 4.

Table SAM 4 shows the expected age distribution of non-Aboriginal Australians with, for comparison, the age distribution of the non-Aboriginal sample obtained by the program.

It is obtained, in a slightly modified form, from the Supplementary Report of the National Population Inquiry: Population and Australia (A.G.P.S. 1978).

Even assuming that the sample within any age group was representative, it is clear that the obtaining of any overall rates for non-Aborigines would have to be weighted to take into account the factors shown in Table SAM 4.

The program's consideration of its sampling methods had led it to conclude that its non-Aboriginal sample was representative of school-age children (5-14) but considerably less so of persons in other age groups. In each of the other age groups, the program believes it likely that its findings would considerably overstate the true prevalence of various ocular and other morbidity figures for rural Australia.

Some of the reasons for this are:

1. The program concentrated its efforts in regions where, among both Aborigines and non-Aborigines, health as measured by the indices chosen by the program was likely to be worst. These included some of the most remote areas of rural Australia. It was especially in smaller settlements in such areas where the program was likely to see the greatest proportions of the non-Aboriginal population; in more settled, and by the program's findings, more healthy areas, smaller proportions of the non-Aboriginal population were seen. Thus the program's findings in respect of non-Aborigines are likely to be weighted toward the less healthy areas.
2. Especially in the elderly, those who presented for examination were those considered

TABLE SAM 4 :

EXPECTED AGE DISTRIBUTION, NON-ABORIGINAL AUSTRALIANS		
Expected Distribution		Sample Obtained
Age	Number per 1000	Number per 1000
0-4	89	45
5-9	92	370
10-14	91	326
15-19	90	68
20-29	168	62
30-39	130	52
40-49	109	32
50-59	101	22
60+	130	23

they had eye problems, or believed they might, and who took the opportunity to obtain specialist opinion.

One instance of this is the number of elderly persons who took the opportunity to have prescriptions for spectacles checked; another involved the numbers of persons with visual handicaps, already diagnosed and under treatment, who sought second opinions on their conditions.

There is little epidemiological material available against which the program's conclusions about the representativeness of its sample can be checked. One which is available is an estimate¹ of the number of non-Aboriginal blind in Australia which suggests that the blindness rate among persons 60 years and over is about 10 per thousand. By comparison, the program found 46 per thousand in this age group to be blind. Even permitting some variation for standard deviation, it would seem apparent that considerable self-

selection in this age group occurred.

The program's findings have not, however, been adjusted to allow for any such selection. One purpose of the non-Aboriginal data was to set baselines against which Aboriginal morbidity could be measured: for this purpose, age specific rates which are compared have to be considered in the light of the likelihood that the baseline presented is higher than was probably the case.

Observer Variation

A person examined by program field staff for trachoma signs would have marked on his clinic card a number identifying the person who graded for the presence of the signs.

As Table SAM 5 shows, about 55 per cent of all seen were examined by one of three examiners: Professor Hollows, Dr. Moran or Dr. Taylor, each of whom spent extensive periods in the field with the screening teams.

TABLE SAM 5 : EXAMINERS FOR TRACHOMA EXAMINATION

EXAMINER	TOTAL PERSONS SEEN	PER CENT
FCH	34,316	35.0
DM	10,588	10.8
HRT	9,028	9.2
PRS, IF and GG	17,327	17.7
Others	26,661	27.2
Total coded for trachoma by examiners	97,920	100.0
Not coded for examiner	2,251	
TOTAL SCREENED FOR TRACHOMA	100,171	

Of the remainder, about 40 per cent were seen by one of three observers: Drs. Pararajasegaram, Francis and Gole, each of whom spent several months leading field screening teams. The rest were screened by visiting ophthalmologists who joined screening teams for several weeks at a time.

All observers were given considerable instruction in the recognition of the various trachoma signs and their degree, both by practical demonstration and by the preparation of slide presentations of typical trachoma pathology in different stages of the disease.

Frequent conferences were held between the trachoma graders in an effort to achieve standardisation of grading.

In spite of this, a certain amount of variation is to be expected within any group of observers who are examining subjects for any physical characteristics. Two sorts of variations are possible:

Differences between one observer and another (inter-observer variation), and

Differences between an observer on one occasion and the same observer on another occasion (intra-observer variation).

It is necessary to measure the extent of both variations in order to establish the confidence with which findings can be said to be comparable. This is, however, extremely difficult, especially in field conditions.

In an attempt to do this, a set of 135 slide transparencies showing normal eyes and a wide range of cases of trachoma was prepared. The slides were projected for each of the three major observers on two occasions (the slides randomly mixed before each test), with each of the observers grading five of the seven signs of trachoma, or those capable of being graded, for each slide. (On some slides, not every sign was able to be graded). Two of the signs, limbal follicles and trichiasis, were not graded during the test because the two-dimensional view displayed in a projected image does not permit an observer to make a grading with certainty. Obvious limbal follicles were graded in the same way as Herberts pits.

The results were then punched on to computer cards for analysis and comparison.

Intra-observer Variation

When each of the three major observers had viewed the slides on two occasions and the diagnostic criteria for follicular and cicatricial trachoma were applied, it was seen that no observer made exactly the same grading on any occasion. Tables SAM 6 and 7 show the pattern.

once that the signs permitted such a diagnosis and on the second occasion, that they did not.

This is when matched slides are compared. When, however, his overall findings for a community are examined, it is seen that some cancellation occurs; an equal number of "inconsistent" findings were made on each occasion so that his overall findings — that 25 of the 91 persons seen had follicular trachoma on each occasion — were the same.

TABLE SAM 6 :

INTRA-OBSERVER VARIATION : FOLLICULAR TRACHOMA			FIRST VIEWING		
			Present	Absent	Total
A: FCH	Present		20	5	25
	SECOND	Absent	5	61	66
	VIEWING	Total	25	66	91
B: DM	Present		15	2	17
	SECOND	Absent	5	69	74
	VIEWING	Total	20	71	91
C: HRT	Present		25	1	26
	SECOND	Absent	1	57	58
	VIEWING	Total	26	58	84

TABLE SAM 7 :

INTRA-OBSERVER VARIATION : CICATRICIAL TRACHOMA			FIRST VIEWING		
			Present	Absent	Total
A: FCH	Present		60	7	67
	SECOND	Absent	1	23	24
	VIEWING	Total	61	30	91
B: DM	Present		59	5	64
	SECOND	Absent	3	24	27
	VIEWING	Total	62	29	91
C: HRT	Present		66	3	69
	SECOND	Absent	1	13	14
	VIEWING	Total	67	16	83

None of the examiners actually found that follicular or cicatricial trachoma was or was not present. Instead they graded for the presence or absence of different signs which, considered in combination, according to the program's diagnostic criteria (see Chapter 4, pages 24 to 27 inc.), permit a diagnosis of whether the condition exists.

FCH's findings in respect of the signs which permit a diagnosis of follicular trachoma show that on 81 of the 91 slides when a diagnosis was possible, he made the same finding on each occasion. On 10 slides, or 11 per cent, he made a different finding on each occasion, finding

With cicatricial trachoma, FCH was consistent on 83 of the 91 slides, being inconsistent on 8 occasions, or nine per cent of the time. The cancelling-out effect was not as marked; on one occasion he found 67 persons to have cicatricial trachoma, on the other he found 61 to have, a difference in overall prevalence of 7 per cent.

DM made the same findings for follicular trachoma on 84 of 91 slides, being inconsistent on eight, or 9 per cent of the time. This, considered in overall terms, meant that the overall prevalences he found varied by 2 per cent.

HRT was consistent in 82 of 84

1. Australian Bureau of Statistics (1975) Chronic Illnesses, Injuries and Impairments, May 1974 Ref. Paper No. 17.16, Canberra.

slides he graded for follicular trachoma being inconsistent with two, or 2 per cent of the time. There was no difference with his overall findings; on each occasion he considered 26 of the 91 persons had follicular trachoma.

With cicatricial trachoma, HRT was consistent on 79 of 83 slides examined, being inconsistent with four, or 5 per cent of the time. In his overall findings about cicatricial trachoma prevalence, there was a 2 per cent difference.

In summary, considered individually each of these observers was consistent about nine times in every 10. There was, however, a cancelling-out effect when the results were considered on a community basis; the overall findings agreed about 19 times in every 20.

If these figures can be assumed to accurately reflect scoring patterns when persons are being graded in field conditions, it can be confidently expected that an observer's findings for a particular community are likely to be comparable with his findings in another community, within the confidence limits suggested.

Inter-observer Variation

Tables SAM 6 and 7 show a high degree of consistency between findings made by an observer on one occasion and on a second occasion. To what extent, however, do observers agree with each other, and how easily can the results of one observer be compared with findings made by another? To what extent does one observer's findings reflect the 'true' situation?

The grading of the slide transparencies permitted this comparison to be made. With follicular trachoma there were 84 slides graded twice by each examiner, and a further four graded once by each examiner. With cicatricial trachoma, there were 84 slides graded twice by each examiner and three graded once by each examiner.

A 'true' or consensus finding was considered to be one on which either all examiners agreed (with follicular trachoma this occurred 73 per cent of the time and with cicatricial trachoma 68 per cent of the time), or where two examiners agreed on a finding.

TABLE SAM 8 :
INTER-OBSERVER VARIATION : FOLLICULAR TRACHOMA

1 = Follicular trachoma present 0 = Follicular trachoma absent				
172 matched transparencies				
FCH	DM	HRT	Frequency	Per Cent
0	0	0	102	59.3
0	0	1	15	8.7
0	1	0	3	1.7
0	1	1	6	3.5
1	0	0	11	6.4
1	0	1	9	5.2
1	1	0	2	1.2
1	1	1	24	14.0
			172	100.0

The findings in respect of follicular trachoma are shown on Table SAM 8.

It can be seen that in almost three-quarters of the cases all three observers agreed. In two-thirds of the remaining cases, two examiners agreed that the presence of the trachoma signs was not such that a diagnosis could be made, while in a third of the cases two of them thought the diagnosis could be made.

Table SAM 9 shows how each observer's scoring pattern compared with the consensus scores. FCH agreed with the consensus on 155 of 172 occasions, considering follicular trachoma to be present 11 times when both other examiners considered

it to be absent, and considering it absent six times when the others considered it to be present.

FCH can thus be said to tend to overscore the presence of follicular trachoma slightly. This is balanced by the fact that he underscores about 3 per cent of the time.

If these findings can be presumed to be an accurate reflection of field conditions, it can be seen that FCH's findings for follicular trachoma are overstating the "true" situation by about 3 per cent, DM understates it by about 2 per cent and HRT overstates it by about 8 per cent.

In terms of community score, no observer is significantly different from the consensus (the highest

TABLE SAM 9 :

OBSERVERS AND COMMUNITY SCORE : FOLLICULAR TRACHOMA			
	Present	Absent	Difference from consensus
Consensus	41	131	
FCH	46	126	2.9% overscored
DM	35	137	1.7% underscored
HRT	54	118	7.6% overscored

TABLE SAM 10 :

INTER-OBSERVER VARIATION : CICATRICAL TRACHOMA				
1 = Cicatricial trachoma present 0 = Cicatricial trachoma absent				
171 matched transparencies				
FCH	DM	HRT	Frequency	Per Cent
0	0	0	16	9.4
0	0	1	25	14.6
0	1	0	2	1.2
0	1	1	7	4.1
1	0	0	3	1.8
1	0	1	7	4.1
1	1	0	11	6.4
1	1	1	100	58.5
			171	100.1

level of significance is with HRT for whom $p = 0.2$). The difference between DM and HRT is, however, significant ($p = 0.025$), though only just so.

With cicatricial trachoma there is less unanimity, although FCH and DM are in closer agreement than either is with HRT. Table SAM 10 shows the findings in respect of the slides by the three observers.

On 116 occasions all observers agreed about whether or not cicatricial trachoma was present. On a further 36 occasions FCH and DM agreed about a sign but HRT disagreed, while FCH and HRT agreed on nine occasions when DM disagreed, and HRT and DM agreed on 10 occasions when FCH disagreed.

As Table SAM 11 shows, FCH agreed with the consensus view on all but 10 occasions, on seven of which he thought the sign to be absent while on three he thought it to be present. If the consensus view is to be accepted, his findings slightly understate the situation.

DM, like FCH, tended more to call the slide as absent when it was present rather than vice versa. He agreed with the consensus view 95 per cent of the time.

HRT's findings agreed with the consensus view on 135 of 171 occasions, or 84 per cent of occasions.

TABLE SAM 11 : OBSERVERS AND "CONSENSUS" SCORE

CONSENSUS SCORE : CICATRICAL TRACHOMA				
		Present	Absent	
FCH	Present	118	3	Agrees with consensus 94% of time. Slight underscoring.
	Absent	7	43	
DM	Present	118	2	Agrees with consensus 95% of time. Slight underscoring.
	Absent	7	44	
HRT	Present	114	25	Agrees with consensus 84% of time. Overscoring
	Absent	11	21	

Unlike DM or FCH, he tended to call cicatricial trachoma as present more often when the consensus was that it was absent than he called it absent when the consensus was that it was present. He thus tended to overstate the cicatricial trachoma situation.

There was, however, some cancelling-out with each of the observers, as Table SAM 12 shows.

If the slide findings are to be regarded as comparable with field situations, it can be seen that on a community basis FCH varied from the consensus on about 2 per cent of occasions (tending to understate the "true" prevalence); DM to vary on about 3 per cent of occasions (again tending to understate) and HRT to vary from the consensus on about 8 per cent of occasions (his findings tending to overstate the "true" prevalence).

HRT's variance from the consensus view is not quite significant ($p = 0.1$) but varies significantly from DM's findings ($p = 0.025$) and FCH's ($p = 0.025$) but only just so. There was no significant difference between FCH's findings and the consensus view, or between DM's findings and the consensus view.

In conclusion, there was a high degree of relationship between the observers' scores and the true or consensus scores with no observer varying significantly from the consensus view with either follicular trachoma or cicatricial trachoma.

With each form of the disease, some observers tended to over score and some to underscore; sometimes the differences between observers

doing this were significant and these would have to be taken into account in a consideration of rescreening results or in comparing the results from one area with those of another. The way of doing so is shown from the observer and community score tables (Tables SAM 9 and 12).

No attempt has been made to assess the observer error of any of the other observers. In respect of Drs Parajasegaram, Francis and Gole, it would be expected that there would be little difference between what was found with the three major observers; with other observers the range could be expected to be wider, with more significant differences.

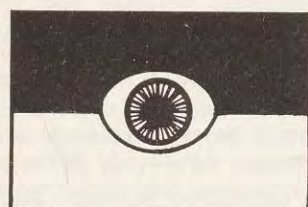
It is emphasised, however, that all other observers were working under the supervision of observers with considerable experience in grading trachoma, who not only spent time in demonstrating the various trachoma signs from which a diagnosis could be made, but who also made efforts to check and standardise grading by others with less experience with trachoma.

It is also emphasised that no field staff actually made a diagnosis of whether or not follicular or cicatricial trachoma was present; graders assessed the presence of each of the seven trachoma signs in the eyes of persons being examined according to the absence or their presence and degree. These were coded for computer analysis — the diagnosis of trachoma being made from the application of the program's diagnostic criteria.

The findings presented in this report are not adjusted for observer error.

TABLE SAM 12 :

OBSERVERS AND COMMUNITY SCORE : CICATRICAL TRACHOMA			
	Present	Absent	Difference from consensus
Consensus	125	46	
FCH	121	50	2.3% underscored
DM	120	51	2.9% underscored
HRT	139	32	8.2% overscored



Chapter 4: (A)

Trachoma — the Ocular Condition

Trachoma is an eye condition which at first affects only the conjunctiva (see Figure VSA 1, Chapter 8). The conjunctiva is the membrane which lines the inside of the eyelids and the front surface of the eyeball (except for the cornea). Trachoma is a form of conjunctivitis or inflammation of the conjunctiva associated with the presence of an organism called *Chlamydia Trachomatis*.

As a result of infection with this bacteria, usually in childhood, a chronic conjunctivitis develops, which progresses to scarring on the inside of the eyelid. This may directly or indirectly cause the cornea to be scarred and opaque, thus causing blindness.

Trachoma may be the most common, serious eye disease in the world, with about 700 million people affected by it. Some 20 million of these are blind. The disease is especially common and severe in countries with desert climates and poor living conditions.¹

Trachoma may be recognised by a number of clinical signs, some of which are peculiar to the disease and others which are also found associated with other forms of conjunctivitis. Some of these signs are most commonly seen in early forms of the disease; others at later stages. A system of grading these signs has been devised which enables an examiner to judge the stage the disease has reached and the severity of it.

Trachoma may be considered to consist of two stages of disease, one leading to the other. The first is **follicular trachoma** (FT), after the follicles which characterise it; the second is **cicatricial trachoma** (CT), from the word 'cicatrix', meaning scar, and refers to the scarring and other damage to the eyelids and eye as a result of follicular trachoma.

Follicular trachoma occurs mainly in children and adolescents. The signs which may be seen in follicular trachoma are:

1. Follicles

These are small raised white or creamy objects found in the conjunctiva, lining the undersurface of the upper eyelids and the membrane which covers the white of the eye (see Fig. TOC 1). Follicles are usually less than half a millimetre in diameter and consist of collections of white blood cells, called lymphocytes.

The National Trachoma and Eye Health Program uses a four-point scale to assess the presence of follicles, scoring each eye 0 if the sign is absent, 1 if it is just present, 2 if it is obviously present, and 3 if it is grossly present.

2. Limbal Follicles

These are follicles appearing at the limbus, the area where the white of the eye and the cornea meet. Usually, they occur on the upper part of the limbus, but sometimes they extend around the cornea. (See Fig. TOC 2)

The program's grading system records the presence of limbal follicles according to the following scale:

- 0 — the sign is absent
- 1 — up to three limbal follicles observed
- 2 — four to seven limbal follicles observed
- 3 — eight or more limbal follicles observed

3. Papillae

Papillae are tiny, red raised dots usually about a tenth the size of follicles and found in the same area of the conjunctiva (see Fig. TOC 3). They consist of tufts of small blood vessels surrounded by inflammatory cells and occur with many forms of conjunctivitis. They are graded according to the same scale as follicles.

4. Pannus

The word pannus means cloth, and refers to the band of whiteness or cloudiness at the top of the cornea, the clear part of the eye (see Fig. TOC 4). Pannus formation begins early in trachoma when the cornea becomes inflamed and blood vessels begin to grow into it, usually beginning from the top and occasionally extending across the pupil of the eye. Inflammation may lead to the formation of scar tissue, seen in the cornea as whiteness or cloudiness. If a pannus becomes sufficiently large and opaque, it will interfere with vision and may cause blindness.

The presence or absence of pannus in each eye was graded according to the following scale:

- 0 — no pannus was observed
- 1 — a pannus less than 2mm in width was observed
- 2 — a pannus greater than 2mm but less than 3mm was seen
- 3 — a pannus greater than 3mm but less than 4mm was seen
- 4 — a pannus greater than 4mm but less than 5mm was seen
- 5 — 5mm or more of pannus was seen

Some or all of these signs are seen during the follicular form of trachoma. In the cicatricial stage of the disease, three other signs may be seen. These are:

5. Scarring of the undersurface of the eyelid (see Fig. TOC 5). As follicles disappear, they may leave scars, seen in their mildest form as fine white lines of scar tissue, but in more severe forms as broad sheets or bands of scar tissue going deep into the eyelid. Scars are the result of follicles; probably not all follicles become scars but the amount of scarring which occurs may be related to the number and size of the original follicles and the amount of papillae and inflammation present during the follicular stage of the disease. In the most severe forms, the eyelid becomes thickened and distorted, causing an irregular surface to sweep across the eye, irritating and damaging it.

Scar tissue caused by trachoma may contract and continue to do so for many years, long after all signs of follicular trachoma have disappeared.

The program grading systems for conjunctival scarring was the same

as for follicles, scars being graded as absent (0), just present (1), obviously present (2) and grossly present (3).

6. Trichiasis

Trichiasis means the touching of the eyeball by the eyelashes (see Fig. TOC 6). Trichiasis caused by trachoma occurs when the scarring of the eyelid is severe enough to buckle the lid and turn it inwards so that the eyelashes rub against the eye. Trichiasis is usually uncomfortable and can cause severe damage to the eye.

Trichiasis is graded on a four-point scale:

- 0 — no trichiasis present
- 1 — trichiasis is present involving one-third of an eyelid
- 2 — trichiasis present with two-thirds of the eyelids involved
- 3 — trichiasis is present with the whole eyelid involved

7. Herbert's Pits

These are small divots or notches on the limbus which are left when limbal follicles resolve (see Fig. TOC 7). They have little clinical significance except that they are a valuable sign that trachoma existed because they occur only with trachoma. Their grading is the same as for limbal follicles.

It may take many years before the damage caused by follicular trachoma causes blindness or significant loss of vision. The scarring and other damage caused by follicular trachoma can also be aggravated by other eye conditions and infections, which flourish because the damage caused by trachoma has lessened the protective ability of the eye. A scarred conjunctival membrane appears to be a secondary protecting membrane.

If scarring causes trichiasis, the eye is constantly abraded by the eyelashes, causing damage to the cornea and making it prone to infection.

In mild cases of trachoma, the eye may not be severely affected because its defence mechanisms can still operate. In more severe cases, however, the eye's defence mechanisms may completely collapse, allowing constant infection and irritation, abrasion of the eyeball, opacity of the cornea and finally, loss of the eye.

The grading system used by the program enables a trachoma grader to assess the severity of the trachoma and its consequences.

The program has adopted strict criteria for deciding whether follicular or cicatricial trachoma, or both, are present. The criteria are conservative: not admitting most individual signs if they are found alone, unless they are very obvious. This means that the findings presented by the program may understate the level of trachoma in communities visited by the program: the understatement has been estimated to be less than 0.2 per cent in communities where the prevalence of trachoma is more than 50 per cent, and up to 0.5 per cent in communities where the prevalence is lower.

Follicular trachoma was said to be present when the following trachoma signs were observed in one or both eyes:

- Follicles grade 2 or 3
- or Limbal follicles grade 2 or 3
- or Follicles grade 1 with papillae grade 1, 2 or 3
- or Limbal follicles grade 1, with papillae grade 1, 2 or 3
- or Follicles 1, with Herbert's Pits 2 or 3

Herbert's Pits grade 2 or 3 is added because previous sequential photographic grading trials had demonstrated that limbal follicles from which Herbert's Pits derive are frequently underscored.

This means that follicles 1 alone, or limbal follicles 1 alone, Herbert's Pits grade 1, and papillae unaccompanied by follicles were insufficient to diagnose follicular trachoma. This is the reason for the slight understatement mentioned in the preceding paragraph.

Cicatricial trachoma is said to be present when the following signs are present in one or both eyes.

- Trichiasis grade 1, 2 or 3
- or Scarring grade 2 or 3
- or Herbert's Pits grade 2 or 3
- or Scarring grade 1, with pannus grade 2, 3, 4 or 5
- or Scarring grade 1, with Herbert's Pits grade 1

This means that scarring grade 1 alone, or scarring grade 1 with pannus 1, pannus grade 1 alone, or Herbert's Pits grade 1, were not considered sufficient to diagnose cicatricial trachoma.

These criteria indicate the presence of either forms of trachoma, but do not give an indication of its severity. The program used the various grades