# THE ABORIGINAL CHRONIC DISEASE OUTREACH PROGRAM



Submitted to Kidney Health Australia by the Centre for Chronic Disease, The University of Queensland, and Kidney Disease Research and Prevention

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## Acronyms

ACEi Angiotensin Converting Enzyme inhibitor

ACR Albumin Creatinine Ratio

ADSL Asymmetric Digital Subscriber Line

AHW Aboriginal Health Worker

AKF Australian Kidney Foundation (now, Kidney Health Australia)

AOMC Aboriginal Outreach Management Committee

BP Blood Pressure
BGL Blood Glucose Level

CARPA Central Australian Rural Practitioners Association CCTIS Coordinated Care Trials Information System

CD Chronic Disease

CDCIS Chronic Disease Clinical Information System

CDOP Chronic Disease Outreach Program

CDEP Community Development Employment Program

CDR Chronic Diseases Register
CIS Clinical Information System
CNC Clinical Nurse Coordinator

DHCS Department of Health and Community Services

DMO District Medical Officer
GTT Glucose Tolerance Test
HIC Health Insurance Commission
HRN Hospital Record Number
IT Information Technology

KDRP Kidney Disease Research and Prevention

NT Northern Territory

OATSIH Office of Aboriginal and Torres Strait Islander Health

PPP Primary Prevention Program

PCDS Preventable Chronic Diseases Strategy

RR Robinson River

SQL Structured Query Language
UQ University of Queensland
URL Uniform Resource Locator

## **Synopsis**

The purpose of the Aboriginal Chronic Disease Outreach program was to improve chronic disease awareness and management in remote Aboriginal communities. It built on our experience in the mid 1990s in the Tiwi community that systematic screening and treatment dramatically reduced renal failure and nonrenal deaths. The NT Preventable Chronic Disease Strategy, based on similar principles, was unfolding at the same time.

The program rests on the principles that regular testing of all consenting adults for chronic disease and their risk factors must become part of regular health care, that appropriate treatment of people in need should follow, that program control and management should rest with local health workers, and that all activity and outcomes should be followed meticulously. This report summarises the experience and findings on 1070 adults aged (18+ yr) in the three NT communities of Community 1, Community 2 and Community 3, from field work conducted from mid-late 2000 to June 30, 2003. Participation was 62 to >100% of the adult census populations.

Rates of smoking were very high - 41% for females and 72% for males. Drinking was uncommon in women, but usual in men. Marijuana use was very common in young adults in two communities with reliable data. Body habitus ranged from generally lean in Community 1 to generally overweight in Community 3, but waist measurements were relatively more increased than BMI parameters, especially in females.

Confirmed new diagnoses of hypertension were made in 57 people, of renal disease in 196 people, and of diabetes in 48 people. Overall, 40.3% of participants had suspected hypertension, 38% had probable renal disease, and 21.2% of people had diabetes. In all communities, rates of hypertension, renal disease and type 2 diabetes increased markedly with age. However, most people with morbidities were young and middle age adults. There was marked overlap of morbidities, which became more pronounced with age. Although excessive in all, overall rates of morbidities varied markedly among communities: Community 3 had rates of individual morbidities more than twice those in Community 1, and a 3-fold increase in the likelihood of any morbidity. Renal disease and hypertension were early features of the morbidity cluster, with diabetes a later and variable complication. Thus higher blood pressures and albuminuria/proteinuria are earlier manifestations of the metabolic/vascular syndrome, rather than variable complications of diabetes.

The findings have implications for chronic disease health services planning. The age distribution of disease rates and numbers and the overlap of morbidities underlie the need for repeat screening throughout life, (at an optimum frequency still to be determined), anticipate the need for treatment of a large number of people for many years and for multiple conditions, and support integrated rather than disease-specific screening. A diabetes-centric screening focus will miss morbidities in many people and delay diagnoses by years in others. Pilot data on disease burden is essential for informed planning of health services based on need. Planning needs to accommodate, not only regular population screening, but extra visits to confirm diagnoses and to start and titrate treatment. These are proportional to the disease burden, and were especially formidable in Community 3.

Morbidities were significantly correlated with age, with increasing body weight, with waist usually the most sensitive, with gender (more hypertension in males and more renal disease and diabetes in females), with alcohol use (for hypertension) and, inversely, and for females only, with birthweight.

Hypoglycemic medication was begun or modified in 109 people, and vasoactive medicines were started or increased in 241 people for hypertension, cardiovascular or renal protection. Angiotensin converting enzyme inhibitor coverage for diabetics increased from 63% to 82%. There was an average fall in SBP of 14.4 mmHg and in DBP of 12.0 mmHg in people with baseline BPs of ≥140/90, in whom vasoactive medication was started or changed, and in whom a subsequent BP was recorded. These gains varied with community and gender, reflecting, in part, the gender and assiduousness of the chronic disease program worker at each site.

Over the course of the program there was dramatic improvement in adherence of program staff to algorithms for testing and for treatment.

The major impediment to program success was the lack of a health worker in Community 1 and serious absenteeism of health workers in Community 2 and Community 3. This is a complex issue, not confined to our program. Health worker absenteeism limited the numbers of people enrolled in the program, the thoroughness of testing and follow-up, and especially the ability to get people onto treatment and titrated towards treatment goals. At least twice the work in Community 2 and three times the described work in Community 3 could have been conducted, with better outcomes, had health workers attended regularly and followed systematic work schedules.

The program leaves a legacy of heightened consciousness of the importance of chronic disease, of trained and informed health workers, of practices and algorithms, of improved management of individuals, clinical registers by diagnosis, and of information which can inform prospective services planning and funding formulae for Aboriginal health.

Feedback visits in 2004 helped assess subsequent events. A Chronic Disease Coordinator was appointed at Community 1, although other demands detract from time she can dedicate to the issue. The DHCS database was not accessible at Community 1. Problems with lack of resources, space and health worker input persist. Activities at Community 2 have rolled over into a maintenance mode of repeat check-ups on a regular basis, which was potentially manageable. The newly-formed community-controlled health care organization at Community 3, had adopted chronic disease as one of its main priorities, and continued following our protocols, using our database and had adopted point of care diagnostic testing. Grossly unsatisfactory facilities, delay in promised government funding, staff tensions and unsatisfactory health worker performance ultimately led to the devolution of that community-controlled health organisation. A grant from Give2Asia specifically devoted to continue/reinforce chronic disease activities in Community 3 had to be returned because of lack of response and inability of DHCS to define ways for that money to support ongoing chronic disease activities.

Many presentations have arisen from the program. Chronic Disease programs in Western Australia and in Soweto, South Africa and, potentially in Chennai, India are additional elements of a potential legacy.

## **CHAPTER 1**

Program Overview

This is the final report of the chronic disease outreach program (CDOP) in the three Northern Territory communities, Community 1, Community 2 and Community 3.

In this first chapter we summarise some key elements of the program and its history. Chapter 2 describes the Chronic Disease Clinical Information System (KDRP Database). Chapter 3 gives an overview of the last six months' activity and summarizes the final clinical profiles of participants in each community. Chapter 4 develops descriptions of participants further from perspectives of age and gender, health behaviours, body habitus and birthweight. Chapter 5 provides detailed analyses of rates and distributions of morbidities and describes the integrated nature of the morbidities and factors correlating with morbidities. Chapter 6 presents adherence of chronic disease workers to our algorithms for testing and treatment. It also enumerates the number of new diagnoses made through the program activities. Chapter 7 describes initiation and or changes in medications made during the course of the program. It then describes the evolution of clinical parameters in people with morbidities over time. Chapter 8 provides an overall summary of our findings and experiences along with information on feedback sessions to the communities. Chapter 9 details other applications and derivative programs and presentations/publications arising from the program. It also lists the references cited in the body of the report.

## Background and Key Stakeholders

The rates of diabetes, hypertension and renal failure in Australian Aboriginals living in remote areas are higher than in the rest of the Australian population. Age standardised death rates are 3 to >6 times those of non-Aboriginal people, and rates of renal failure, which, in the 1990s were doubling every four years, are now about 1350 per million in the NT (1,2,3,4). Costs for treating people with end stage renal disease are a serious drain on the budget (5).

In 1998, Dr Wendy Hoy developed a proposal titled 'A National Consultancy to Reduce Chronic Disease Morbidity and Mortality among Aboriginal and Torres Strait Islander Peoples', the purpose of which was to support improved chronic disease awareness and management in remote areas (6). This was precipitated, in part, on the experience in the Tiwi Islands, in which systematic treatment of people with renal disease and hypertension produced marked improvement of blood pressure and stabilisation of kidney function, and a 60% reduction in numbers of people coming onto dialysis, as well as a marked fall in nonrenal deaths (7,8,9). Substantial cost savings were estimated in dialysis delayed or avoided (10). Subsequent events showed the importance of sustaining that systematic approach (11).

The Hon Michael Wooldridge, then the Federal Minister for Health, took interest in the proposal, and the Kidney Health Australia (previously Australian Kidney Foundation, AKF) agreed to endorse it. The AKF became the prime contractor for the work. The Chronic Disease Funding Agreement (2000-2003) was established between the AKF and Commonwealth of Australia, represented by the Department of Health and Aged Care and its Office of Aboriginal and Torres Strait Islander Health (OATSIH), who supplied the main body of funding. The AKF in turn contracted with Dr Hoy through a charitable trust called Kidney Disease Research and Prevention (KDRP) to carry out the work. Additional and important, untied support was contributed by Rio Tinto, the AKF itself, Janssen Cilag of Australia and Professor Helen Hayes.

The program's intent was to introduce a practice of regular chronic disease check-ups for all adults in each community (12), with follow-up visits as dictated by preliminary results and need for treatment. Testing and treatment was to follow algorithms (13), which were to be compatible with regional guidelines and flexible as new information appeared and experience dictated (14,15). Responsibility for

the programs was to rest with local health workers, who would be educated, trained and supported in these functions by KDRP's nurse coordinators. Program placement would be by community invitation, where there was a serious level of need and where the program would bring added value. KDRP agreed to pay half the salary support for each health worker, with the other half provided by the community or the regional health service as evidence of their support and commitment.

Discussions ensued with many remote Aboriginal Communities in the NT and elsewhere, and agreements were finally reached with three remote NT communities. The communities and KDRP each signed separate Memoranda of Understanding, and field work began in April 2000 for Community 2, and November/December 2000 for Community 1 and Community 3. Field work continued through June 30, 2003. Data analysis and compilation of the first eight chapters of this report had taken another 15 months.

An Aboriginal Outreach Management Committee, comprising representatives of the pertinent bodies and experts from different fields, was established to oversee different elements of the program. Members met every year, and visited each community once. The Department of Health and Ageing funded an independent evaluation of the program by Barbara Schmidt and Associates.

#### **Staff Profile**

The staff profile had changed over the time. Gaye Gokel and Rebecca Davey were the first KDRP nurse coordinators, assisted by Kiernan McKendry. It was intended that they work with senior health workers in each of the communities. Rebecca and Gaye moved back to positions within the DHCS in February 2002 and were replaced by Suresh Sharma and Jo Scheppingen. Ron Ninnis provided some support on data related issues until January 2003. Mandy Halkett was recruited as a nurse coordinator for the last three months. Dr Paul Lawton was involved part-time in the first year of the program, as a specialist medical officer. Dr Srinivas Kondalsamy-Chennakesavan joined the team in a half-time role in May 2002 and stayed on for the final 13 months as medical director. Phillip Hoy took care of the administrative/financial aspects of the program including database administration and maintenance for KDRP. Dr Wendy Hoy had been the program's director throughout.

With Dr Hoy's appointment to the UQ, there was a graded transfer of program headquarters from KDRP, based in Darwin, to the Centre for Chronic Disease at UQ, in Brisbane in the last part of 2002. Most KDRP staff members continue to work with the Centre for Chronic Disease, UQ, in different capacities, after program funding ceased in June 30, 2003.

Staff members, including the health workers, had participated in major local, national and international conferences, workshops and symposia relevant to the program's activities. Our nurses had given talks in Katherine and in Darwin, and had contributed to presentations made at the Australian and New Zealand Society of Nephrology, the American Society of Nephrology in San Francisco, and the Indigenous Renal Disease Satellite Conference of the International Society of Nephrology.

All staff members have cooperated with the independent evaluation of the program.

## Visitors to the Program

In March 2003, Dr Suresh Sankar, a consultant nephrologist from India, visited Community 2 and Community 3 to learn about the operational elements of the program with a view to developing some

sites for chronic disease screening and prevention programs in India. Dr Ada Asinobi from Nigeria visited Community 3 in May 2003, for the same purposes. Dr Ivor Katz from the Dumisane Mzamane African Institute of Kidney Diseases visited Community 1 and Community 2. Members of the external evaluation team of Barbara Schmidt and Dr Robyn McDermott also visited for chart audits, to provide inputs into the handover process and to communicate Stage 1 findings with all the communities and to develop appropriate action plans.

#### Overview of the Program in Community 1

#### Getting Started

Discussions started in April 2000 for setting up the program in Community 1. A Memorandum of Agreement was signed between Community Government Council, and KDRP in September 2000, committing KDRP for up to three years, to:

- Support funding
- Supply a visiting KDRP nurse coordinator
- Train Aboriginal Health Workers in chronic disease screening and management
- Train AHWs in computer skills for both database entry and email communication
- Provide a database, for the three year period
- Support clinical decision making through KDRP medical officer's review of the clients' clinical data and provision of clinical review comments
- Analyse data and provide community feedback

#### Staffing

The health worker centred model proved not feasible because of the lack of trained and committed AHWs. For a time we used the services of CDEP coordinator/supervisor. Then, a community liaison model was tried for a while.

Visiting KDRP nurse coordinators assigned to Community 1 were Gaye Gokel and then Suresh Sharma, with the support of Kiernan McKendry. Mandy Halkett was recruited in the final phase of the program to increase participation by Community 1 women. Marea Fittock was appointed coordinator for the NT's Preventable Chronic Diseases Strategy (PCDS), and Autumn Goodall worked as the visiting chronic disease (CD) coordinator for DHCS at Community 1 for some time and collaborated closely with the KDRP team. That position remained vacant from September 2002, but was filled in 2004.

The local visiting medical officers included Dr Rosemary Lee and Dr Ian Dumbrell in the initial stages, followed by Dr Peter Fletcher and Dr Cliff Van Der Oest (rotating for two days a week). A resident general practitioner was employed but left soon after starting. An effort to recruit a resident doctor has been underway. During different stages of the program, Dr Paul Lawton, Dr Wendy Hoy and Dr Srinivas Kondalsamy-Chennakesavan of KDRP reviewed clinical data from this community and provided relevant comments and feedback. Ron Ninnis, KDRP, provided computer support from Darwin and Phillip Hoy provided support in database maintenance/administration and budget.

## Main Program Activities Included.

• Screening and annual check-up of the people of Community 1 for chronic diseases – diabetes, high blood pressure, kidney disease, cardiovascular disease or risk.

- Follow-up visits more frequent check-ups and on-going chronic disease management for people with identified or suspected disease, and referral to the doctor
- Education on chronic disease prevention and management for individuals & community groups
- Computer data entry of the check-up results and feedback after data analyses

#### Program Guidelines

- An outline of the concepts and approaches of the program was formulated at the start, and modified along the way. This has been widely disseminated, including to the AOMC Steering Committee, the AKF and OATSIH
- Forms were designed and provided for screening/annual review and follow-up.
- Algorithms provided the AHWs with guidelines for testing and for treatment to ensure best practice and improve their confidence
- Wall Charts served as easy reference for the algorithms. A folder was compiled with all the KDRP Chronic Disease Program guidelines, chronic disease management notes and in-service notes
- Regular recall appointment lists, 'Worry Lists' (people whose results were above the normal range), and clinical review comments lists were generated to assist in streamlining recall of people and ensuring their accurate follow-up

#### Program Resources

- The KDRP Chronic Disease Program Guidelines folder
- CARPA Guidelines for Chronic Disease
- Batchelor Institute of Indigenous Tertiary Education 'Clinical Practice Logbook for Aboriginal Health Workers' which holds the competencies for clinical observation and assessment and specimen collection
- Resources for education including video player, educational videos, flipcharts, diabetes folder etc.

#### Clinical Activity

Nearly 67% of Aboriginal adults in Community 1 had at least one check-up/screening during the course of the program. Community 1 has a high burden of disease, but the prevalence of risk factors and disease rates are not as high as in the other two communities. Most of those identified with chronic diseases are in the 20–59 years age group. The disease burden will increase as this population ages, unless the risk factors earlier in life change. Among participants in whom medications have been started or adjusted, there was a net reduction in blood pressure levels. However, the significance was greater among males than the females, which is probably explained by the lack of female nurse coordinators and female AHWs in this community in the last couple of years of the program.

#### Program Benefits and Barriers

The extra funding, systematic management and technical expertise has improved the status of chronic status in this community. Most of the check-ups/follow-ups and treatment changes would not have occurred had the program not been in Community 1. Benefits in terms of reduction in hospitalisation, morbidity and mortality are likely to follow such chronic disease intervention programs.

The most significant barrier was the lack of properly trained and committed health workers in this community. Most of the activities carried out were by the KDRP nurses. Sometimes the nurses had to extend their assistance to routine clinical activities. Lack of AHW support impacted on the number of people screened and their efficient follow-up. Difficulties in maintaining adequate pharmacy supplies and establishment of new pharmaceutical arrangements also interfered with appropriate treatment recommendations.

#### Program Sustainability

All the KDRP guidelines and manuals were made available to the staff members of Community 1's health centre. Lists of participants due for recalls and repeat tests were left in the chronic disease room at the health centre. The medical records of all the participants were updated along with their recall systems for chronic disease. The DHCS went on a recruitment drive to appoint a chronic disease coordinator. That coordinator is likely to utilise the lists provided by KDRP and maintain the activity levels. When the program came to a close in June 2003, a new form of Indigenous governance was set up in the Community 1 region, following the 'whole of Government initiative'. The newly established Community Government Council has a separate health portfolio managing the health care issues in this community.

## Overview of the KDRP Chronic Disease Outreach Program in Community 2

## Getting Started

A Memorandum of Agreement was signed between Community Government Council and KDRP in February 2000. KDRP has supported the program in Community 2 for the period from July 2000 to June 2003. Commitments by KDRP to Community 2 were similar to those of Community 1, as described in the previous pages.

#### Staffing

Visiting KDRP nurse coordinators assigned to Community 2 were consecutively Rebecca Davey and Suresh Sharma. Kiernan McKendry provided support to Suresh Sharma when required. During different stages of the program, Dr Paul Lawton, Dr Wendy Hoy and Dr Srinivas Kondalsamy-Chennakesavan of KDRP reviewed clinical data from this community and provided relevant comments and feedback. As described earlier, Ron Ninnis, KDRP, provided data related support from Darwin and Phillip Hoy provided support in database maintenance/administration and budget.

#### **Program Activities**

The main program activities were similar to that of Community 1 (refer previous). However, the dynamics of patient recruitment differed somewhat. The health worker and clinic staff developed posters with the help of KDRP CNCs to remind individuals attending the clinic for another reason of the availability of the chronic disease check-up. These posters were hung on the front door within the acute care area of the clinic and at council run facilities elsewhere. Also, a new funding arrangement between the DHCS and the HIC led to the development of a Medicare card number list for people who access the services of the Community 2 community health centre. Cross referencing with this list had identified some individuals who were not screened in the program. After discussion with the health centre staff, a strategy of sending out letters inviting individuals who had not had a screen was decided upon. After 6 to 8 weeks, if the individual did not attend, a second letter was sent. This strategy led to a near complete screening of the entire community. A list was then provided to clinic staff of people who had not been screened at least once so that they could be screened at a later date after the cessation of the CDOP activities.

#### Recall System

Due to the small size of the Community 2 it was decided that a paper-based recall system would be the most cost effective and simplest method to manage chronic disease. The DHCS total recall system, which had been used to manage people with a chronic disease prior to the initiation of CDOP activities, was therefore reinstated in a trial form in January 2003. The CDOP nurse and health worker combined data from the KDRP database with the DHCS chronic disease database to produce cards and care plans

for all individuals recorded as having a chronic disease. An appointment was set for each individual who had a card. During our program, it was noted that individuals with chronic disease attending the clinic for other reasons were not receiving attention for their chronic condition(s). After discussion with the clinic staff, the CDOP nurse developed a flag to be attached to the first page of the individual's health record to prompt the clinic staff to check the chronic disease recall card, and encourage better management and appropriate follow-up. Most of the diagnostic details from the KDRP database were transferred across to the Chronic Diseases, an electronic database maintained by the DMOs, and were updated within the recall systems in place.

#### Guidelines, Procedure Manuals, Teaching and Other Resources

Following the wind-up of the CDOP, the CARPA manual was to be used for chronic disease management. The CDOP nurse and the DMO developed a series of 'in-services' looking at the management of chronic disease, using these new CARPA guidelines. The new CARPA guidelines and KDRP guidelines are very compatible. The CDOP nurse delivered chronic disease in-services to all the staff members at Community 2 in groups and individually, where required. The information in the inservices was displayed in a PowerPoint format and paper-based copies were also made available. Electronic and paper-based copies of the in-services provided by CDOP were handed over to most of the Community 2 health centre staff.

A paper file and a compact disc (CD) were produced for the clinic staff, containing the following:

## CARPA guidelines (Microsoft TM - Word documents)

Diabetes

Health choices for food and activity

Healthy weight

Heart failure

High blood pressure

Kidney disease

Lipids

## CARPA guidelines in-service notes (Microsoft TM - PowerPoint presentations) for

Diabetes

Hypertension

Renal disease

#### Recall List (Microsoft<sup>TM</sup> - Excel spreadsheet)

People who were screened by the CDOP team

People who were not screened by the CDOP team

People who had one or more suspicious BGL readings and may require a confirmatory test

Date of next regular repeat screen for every participant in the Community 2 community

#### Check-Ups and Outcomes

Nearly 234 Indigenous adults in Community 2 have had at least one check-up/screening during the course of the program. That is, almost all Indigenous adults have been tested at least once.

As described in subsequent chapters, Community 2 has a high burden of disease. However, the prevalence of risk factors and disease rates are not as high as in Community 3. Most of those identified with chronic diseases are in the 20–59 years age group. Significant reduction in blood pressure levels were achieved among participants in whom medications have been started or adjusted.

#### Future Staffing

Chronic Disease management has been made a responsibility of all health centre staff. Close coordination of KDRP CNC with the visiting DMO resulted in a number of combined 'in-service' sessions for all the health care staff at Community 2 before the program finished.

#### Sustainability

The staff members of the local clinic are aware of the necessity to diagnose and manage chronic disease at the earlier stages. Also, they know where to find appropriate resources and information. Community 2 has been the most consistent CDOP site in terms of staff levels and stability. If support is reinforced from the DHCS preventable chronic disease team, chronic disease management can be able to be maintained at its current level, both in terms of repeat regular check ups, and in following people on treatment. With more health worker input, better clinical outcomes in terms of treatment goals are possible.

## Overview of the KDRP Chronic Disease Outreach Program in Community 3

#### Getting Started

KDRP has supported the CDOP in Community 3 for the period of July 2000 to June 2003. A Memorandum of Agreement was signed between the local Resource Centre and KDRP in May 2000, and planning started in July 2000.

#### Staffing

Visiting KDRP nurse coordinators assigned to Community 3 were consecutively Rebecca Davey and Jo Scheppingen. Other KDRP nurses provided back up in times of leave or for group screening and follow-up activities – Gaye Gokel, Kiernan McKendry, Suresh Sharma and Mandy Halkett. Dr Wendy Hoy and Dr Srinivas Kondalsamy-Chennakesavan of KDRP reviewed clinical data and supplied comments and feedback. Ron Ninnis, KDRP, provided computer support from Darwin and Phillip Hoy provided administrative support.

#### Program Activities, Program Guidelines and Program Resources

The main program activities, guidelines and resources were similar to that of the other two communities described previously.

#### Check-Ups and Outcomes

Targeted screenings were carried out using electoral and community rolls, and patient follow-ups were focused primarily on optimising treatment for those needing it. There has been substantial ascertainment of new cases of disease, and treatment has been started or intensified in substantial numbers of people. Many people on treatment, however, are still not at optimal medicine dose or at treatment goal, because health worker absenteeism has greatly impaired effective follow-up. There has been a net improvement in blood pressure in people with elevated blood pressure on their first screen and in whom medications have been started or adjusted.

#### Ongoing Check-Ups

At the end of June 2003 – the completion of the KDRP contract - the nurse coordinator compiled a full list of the due dates and tests for each person's next check-up, for all the people on the database. This list was given to the local Health Service Coordinator, Dr Peter Fitzpatrick, the Manager of the Department of Health and Community Services and chronic disease health worker clinic rooms – for the new incoming health workers.

#### Records and Database

All check-ups done in the three-year period to June 2003 were entered onto the KDRP electronic database as well as retained in paper file in the male/female chronic disease rooms. Copies of the paper records were also placed in the doctor's files and at DHCS Clinic. KDRP are happy to assist in transferring data electronically to the Gulf Health Services' database once this is established and offer ongoing support in clinical activities and training for some longer time on a consultancy basis.

#### Program Benefits

All the people seen on the program in the past three years have had screening, follow-up, and treatment changes that they would not have received had the program not been in Community 3. These should produce benefits to many of those people's health if sustained.

Training in the principles of the program, procedures and data entry has up-skilled all health workers in the program. These skills remain a benefit to health services for work in any area in the future.

During the program, the community successfully applied for funds to support a community-controlled health services. Our cooperative approach with the DHCS staff reduced the rivalries that existed before and improved the integration of health care services with clear delineation of activities between the local health service and the NT's DHCS.

#### **Program Barriers**

Health worker absenteeism was a major problem. This was sometimes for legitimate cultural or personal reasons, but was often seemed to derive from a lesser sense of commitment and a different attitude to work. The KDRP nurse was obliged to take up the health worker's role as much as possible. This meant, in turn, that she had less time to devote to the other tasks required of a coordinator. Many 'inservices' planned and some training by the nurses were also not fulfilled due to the health worker absenteeism or the lack of attendance, through diversional activities and tactics by the health workers when a time had been set.

Rapid turnover of non-Aboriginal staff also meant a break in continuity of the program. There are various reasons that account for these- for example, burnout, too much time away from home base, and sickness etc. Also, housing for health care staff members is a serious issue and accommodation facilities are not sufficient.

Regular follow-up lists were generated by health workers/nurses from the KDRP database to avoid duplication of tests, but these lists still required regular manual checking of the doctor's files/pathology to see if these people had been seen by one of the other services in the interim, that is the doctor and DHCS. This problem will become obsolete once the combined services IT system comes into place. Likewise the need for manual entering of pathology results, ordered by the doctor or DHCS, has to be sorted out.

Factors affecting attendance of participants to the clinic for follow-up:

- Distance people out of town or living on an outstation
- A few declined to be screened or followed-up
- Substance abuse especially alcohol and cannabis
- Family problems and cultural issues

#### Program Sustainability

The overall picture of the sustainability of the Chronic Disease Program is very positive. Gulf Health Service places a strong priority on the necessity and benefits of the Chronic Disease Program despite the challenges in setting up the service. Delays in the release of funding have hampered their plans to have the staff positions filled prior to the handover by KDRP. Also, diversion of health care funds to other areas is a major worry. The community people have expressed great concern that there would not be staff to continue the program when the KDRP funding ceased. However, with limited resources, the newly formed Community controlled health service chronic disease team is carrying on the CD activities.

Some suggestions for sustainability of future programs include:

- Adequate staffing in the new health services is needed for improved results. Staffing needs to accommodate regular screening, follow-up visits for further diagnoses and especially for treatment, and for an effective education/prevention program.
- The health workers doing the check-ups need to be skilled in assessing the results of each screening/follow-up visit done to ensure early action is taken where required
- Separate areas are essential for the men's chronic disease clinic and the women's chronic disease clinic in each Aboriginal health service.
- The women health workers would benefit from a woman coordinator and the men by a male coordinator
- More training for AHWs is needed in the area of 'motivational and assertiveness skills'
  - Firstly for health worker confidence, self-esteem and assertiveness
  - Secondly for educating people on effective principles for lifestyle changes in disease prevention and management
- Education is needed on management of chronic disease for those with a disease; and prevention for those without
- More networking is needed with the nutrition people, community groups and the schools

#### Conclusion

The KDRP Chronic Disease Program has provided local health services with strong support to establish a viable and effective chronic disease program for the people of Community 3. Prior to the KDRP program, chronic disease check-ups in Community 3 were limited to what was possible for the general practitioner within a busy practice; and opportunistic check-ups by the DHCS staff.

The KDRP Program has enabled local health service to establish an effective program for hypertension, diabetes, renal disease and high cholesterol screening and management. Despite staffing problems, and health worker absenteeism, the model is viable and effective in reduction of abnormal results. Impressive reduction in blood pressure could be noticed and reductions in long-term complications are likely to follow.

## **CHAPTER 2**

Chronic Disease Clinical Information System (KDRP Database)

In this chapter, we describe the 'information technology applications' used by KDRP for its CDOP in three remote communities in the Northern Territory. According to Sitting (2002), "A clinical information system (CIS) is a collection of various information technology applications that provides a centralized repository of information related to patient care across distributed locations". The information system used by KDRP for the CDOP is a CIS dedicated for systematic screening and treatment for chronic diseases. It is essentially a "computer-based system that is dedicated to the collection, storage, management and presentation of all the clinical information important to delivery of patient care".

## Origin of our CDCIS

The conceptual origin of KDRP's current CDCIS can be traced back to the Tiwi screening and treatment program in the NT during the nineties. In that program, we used an information system for data entry, data management and analyses. This information system based on Oracle™ was hosted within the servers at the Menzies School of Health Research, Darwin. This data repository was used to extract information in the form of structured queries to prepare lists of participants with non-normal or worrying values in their clinical or lab results. Health workers and nursing coordinators worked from those lists faithfully and found them to be of immense help in following-up participants according to pre-determined algorithms guided by evidence based protocols. After the completion and handover of the Tiwi treatment program, Tiwi Health Board's chronic disease nurse utilised these lists to follow-up participants - primarily because of its simplicity when compared to the lists generated through the Coordinated Care Trials Information System (CCTIS).

#### **CDOP** and our **CDCIS**

For the CDOP, we decided to migrate to a different platform based on Microsoft Access<sup>™</sup>. We collaborated with Mr Larry White (Brightfind International and Onsite Solutions) to develop this 'Access' based tool, using similar concepts from the 'Oracle' based information system used for the Tiwi treatment program. This required the staff members to download and install a newer version of the database, whenever any change/upgrade to the database architecture was made. During the initial stages of the program all the three communities were utilising 'dial-up' internet connections to access our database. The dial-up connections were highly unreliable, especially from these remote communities. During busy clinic hours, the telephone lines were often congested in Community 1 and could not be used to access our information system.

Telstra helped by establishing a dedicated/customised two way satellite communication (broadband) in Community 2 and a one way satellite communication in Community 1. Community 3 gained an internet connection based on Asymmetric Digital Subscriber Line (ADSL). In the first 2 years of the program, all the KDRP staff members were using the Microsoft Access<sup>™</sup> based versions of our CIS. The availability of reliable internet connections in 2002 in these communities and the emergence of newer technologies prompted us to switch over from Microsoft Access<sup>™</sup> based database to that of a reliable, robust and performance oriented 'web-based' database. The advantages of the web based databases are described elsewhere.

Planning for migration of this database to the web started in early 2002 and Mr. Peter Warner helped in fine tuning the database for placing it on the web. Entity 1 was contracted to host the database on a web server and to develop applications/interfaces for database access via the internet, using standard

<sup>\*</sup> Sittig, D.F., A Clinical Information System Research Landscape. The Permanente Journal, 2002. 6(2): p. 62-68.

web browsers. This transition took longer than anticipated and some of the screened data were lost during this transition/migration. KDRP used 'SQL server', a noted relational database management system to enter, view, retrieve and manage participant information. The 'front end' or the user interface with our database underwent a series of extensive changes, as experience dictated.

Moving our CDCIS to the web was not without its drawbacks. Internet connection became a prerequisite for data transfer. However, the availability of dedicated internet connection helped in freeing the telephone lines in these under-resourced communities and the clinic staff members could potentially leverage these resources. Permanent access to the internet via these dedicated lines offered reliable internet connections and higher speed in data transfers. The dedicated lines were tested from one of these remote sites and the results proved their efficiency and faster data transfers, when compared to a standard 'dial-up' connection based at Darwin.

To access web based applications, users need standard web-browsers like Internet Explorer<sup>™</sup>, Netscape Navigator<sup>™</sup> etc. Considering the nature of data and the associated risks in storing data online, KDRP had enforced a role based access to our database. This was intended to curtail malicious users from accessing confidential personal health information. Every potential user of the system was provided with an individual 'user name' and a 'password' to access the CDCIS. Application level validation rules are also applied as a measure of additional data security. With a valid username and a password, users could connect to the KDRP database. Please contact Prof. Wendy Hoy for access details.

In our database, data were dispersed across different tables to boost overall application performance and to enhance their availability. Among the different tables we used, the following were vital.

Patient – contains demographic details on all the participants.

Patient History — contains past, family and personal history of participants

Patient Examination — contains details on clinical examinations and their results

Patient Lab Test Results — contains a comprehensive list of all the lab test results

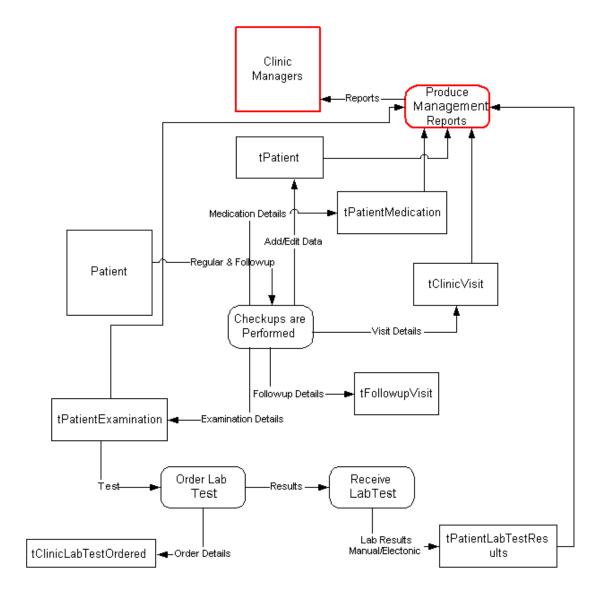
Patient Medication — contains a list of medications administered to the participant

Appointment – contains details about participants' appointment dates

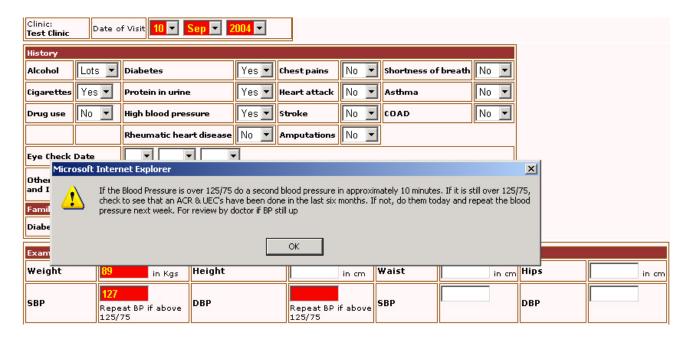
Review – contains details about clinical review for participant's each encounter

User — contains details about registered users of KDRP CDCIS

Each of these tables was interrelated to other tables. For example 'Appointment' could be set only when the patient name (or identification number) was found in the Patient table. These tables might have one or more mandatory fields, which needed to be completed at every encounter. For example, the table 'Patient' may require the 'Name' of the patient and 'date of birth' to generate a unique patient identifier. Associated information like addresses, ethnicity etc. may be needed for clinical and administrative purposes, but were not considered absolutely essential. Users of the CDCIS were grouped based on their roles (doctor, nurse, health worker and specialist etc). The following dataflow diagram explains the way the entered information was utilised in our database.



Appropriate field level validations were set to alert users. For example, while capturing blood pressure information, if the health worker or nurse entered a SBP value greater than or equal to 125 mmHg, the database triggered a reminder in the form of an alert, shown below.



To cite another example for data validation, 'date of death' for a participant could not be earlier than the 'date of birth' etc. These prompts helped the health workers in implementing our protocols in a better way along with capturing the required data without major errors.

#### Flow of CDCIS information within KDRP staff members

The process flow (detailed in page 25) usually started with the addition of a new participant. Whenever a new participant provided informed consent and was screened, their demographic and encounter details were added to the CDCIS. The entered data were readily available for remote review by the nursing coordinators and the doctor. After evaluation of recorded participant's information in the CDCIS, clinical review comments and feedback were provided to the health workers and nursing coordinators. If the participant's results were within normal limits, then regular screening was recommended after approximately 1-2 years, depending on a number of factors. If the results were abnormal, follow-up appointments were scheduled and appropriate courses of action were taken to ascertain or refute our clinical diagnoses. These clinical recommendations and/or feedback comments were based on KDRP's standard guidelines and protocols.

## Reports

KDRP's management generated reports based on the data entered in appropriate fields. Primarily, the reports generated for management included details from the following tables.

- a. Clinic Visit
- b. Patient
- c. Patient Medication
- d. Patient Examination
- e. Patient Lab Test Results

The reports generated were usually for the KDRP staff members to assist them in understanding the way the screening and treatment components of the CDOP were heading. We had the ability to export

our data into standard spreadsheet formats like Microsoft Excel<sup>™</sup> which could then be used by different statistical packages for appropriate analyses. Different types of reports were generated by different staff members based in critical decision making. For example, we generated a visit history report to assist the NCOs and AHWs to check the adequacy of entered data. Also, we produced a report of missed appointments that matched the scheduled and actual appointments. Diagnostic reports provided a summary of diagnoses and or careplan. These reporting capabilities helped the health workers and nursing staff to plan their workload efficiently.

## Electronic Retrieval of Pathology Results

One of the critical elements of our CDOP is to ensure the integrity of entered data in our database. Data entry errors are not so uncommon- especially with lab results. In order to avoid those errors and to avoid multiple data entry processes, we used a program to download lab results in an encrypted format via the internet and added to our database after decrypting. The prompt availability of lab results improved our efficiency in responding to abnormal results. Non-normal clinical and lab results were highlighted in our database to attract the attention of nurses and health workers and the participants were grouped automatically in our 'worry' lists based on clinical and lab results.

## Training Community-Based Health Workers

Our nursing coordinators provided training to community-based health workers in utilising our CDCIS, usually in 'one on one' sessions. Some of the health workers had never used a computer before and were reluctant to use them during the initial stages. However, with proper support and training, they became proficient in using them. Our nursing coordinators trained them in the following skills.

- Orientation to using the keyboards, mouse and windows environment
- Using the internet and problem solving skills
- Secure entry to our database
- Data entry based on screening and treatment encounter with the participants
- Critical elements of the database and the feedbacks
- E-mail communication along with sending/receiving attachments
- Setting up a printer and other peripherals including trouble shooting techniques

E-mail communication resulted in a quick turn around time in completing urgent tasks and follow-ups. However, most of the instructions were through the online database which simplified health worker's tasks at the time of the participant encounter.

## Differing Roles of KDRP Staff within our CDCIS

## The Health Worker Using the System

- CDCIS envisaged that the health worker would turn on the computer each day to review the
  appointments and tasks scheduled for them. We generated a list of appointments that were missed.
  The NCO would monitor this through the TASK list to ensure that missed appointments were
  rescheduled.
- The NCO would monitor the visit history recorded in the database and ensure that the data collected was of sufficient quality for health care decisions, and if necessary, additional

- investigations would be ordered and therapeutic decisions made rapidly. The NCO would liaise between the health worker and doctors to make and implement treatment and careplans.
- The TASKS for the health worker would be reviewed each day and any urgent requests were given
  due attention and prioritised. Tasks were created from the CLINIC REVIEW screen by the NCOs
  and doctors and when they were adequately met they were signed off by the doctor. The list of
  assigned tasks and their responses could be viewed.
- Through the patient information screen, a new patient could be added with the fields name, date of birth and other personal identifiers such as Medicare number, Hospital Record Number (HRN) etc.
- Our database also provided options to search for an existing participant by name, date of birth, Medicare number or HRN and to browse through the entire list of participants in each clinic.

## The Nurse Coordinator Using CDCIS

- The nurse coordinator monitored appointments, clinical review comments and tasks. The system provided lists of forthcoming appointments and missed appointments etc. The NCO had the opportunity to reschedule appointments that had not been carried out. Admin reports helped NCOs to identify gaps in entered information.
- The clinical review comments showed treatment information exchanged between the nurses and doctors. The NCOs were required to attend to this list along with tasks list each day so that the participants received early attention.
- The clinical review screen permitted the information gathered at clinic visits to be reviewed, diagnostic assessments made and treatment plans decided upon.
- The form for the clinical review permitted the following:
  - Review of previous visits last visit, regular health check-up and follow-up visits
  - Task requests to be made
  - Review of history and lab test results
  - Review of medications
  - The diagnostic report with diagnoses and treatment plan
  - Options to list the participant in NCO's 'worry' list if the results were not normal
  - Option to provide a follow-up appointment for the participant.
- The NCOs retrieved the lab results and entered those using appropriate forms for each participant if the lab results did not arrive electronically.

## The Doctor Using CDCIS

The doctor or the specialist played a limited role in our chronic disease program. That role was essentially for education and endorsement of diagnostic and therapeutic decisions.

- The CLINICAL REVIEW COMMENTS section listed review comments made by NCO, doctors and specialists.
- The CDCIS allowed doctors to ASSIGN TASKS and to REVIEW assigned TASKS.
- The data export link provided access to summary information and users could export the data for analyses and reporting.
- The CDCIS was used to check on follow-up visits and to generate lists of diagnostic categories. These diagnostic categories or care-planning information was very helpful to the health workers and NCOs to identify people who needed special or continued attention.

- Lab results were retrieved electronically by the doctor and attended to after being processed.
- Analyses of results from the screening and appropriate feedback to the NCOs.

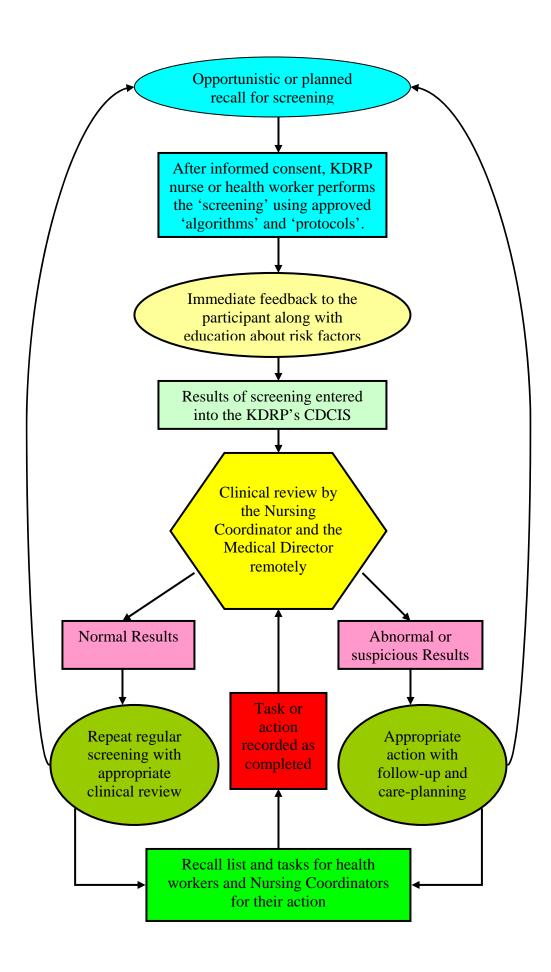
#### **Issues with CDCIS**

We went through a lot of trouble during the development of this database. We now have reached a stage where our views on a clinical information system have matured. Our database is now co-located at the centre for online health, University of Queensland (UQ) with other clinical information systems. The web based database, as with all web-based applications had the following issues:

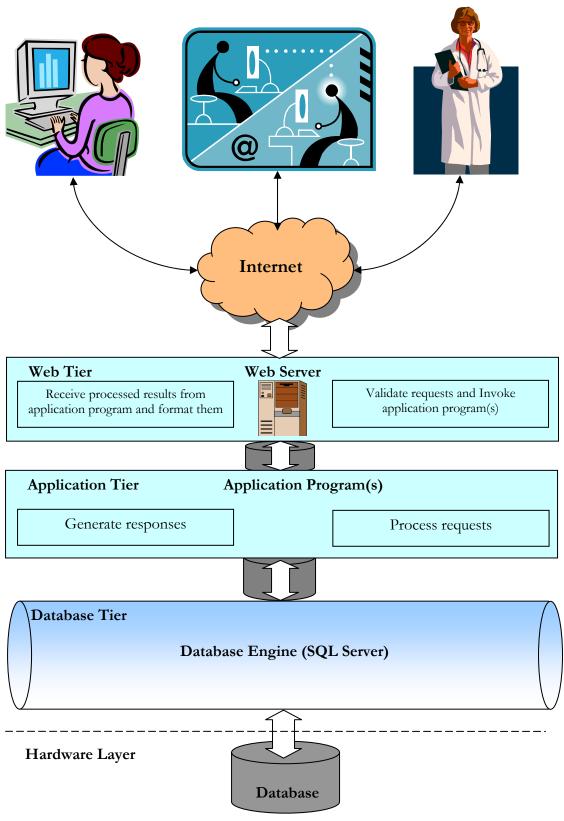
- Requirement for additional skills
- Demand for additional infrastructure like computers and internet connectivity.
- Additional overheads in training the staff at different levels.
- Overheads in hosting and maintaining the CDCIS through a third party.
- Risks associated with storing confidential health information on the internet and associated security vulnerabilities/issues.
- Dependence on variations in connectivity to the internet and sustained availability of computers and power/electricity supplies in remote areas.

## Wider Application of our CDCIS

Our KDRP CDCIS was scalable across clinics. New clinics could be added as needed. Even though our focus was on chronic diseases, the same principles can be utilised to care for other situations (e.g acute care). New diagnostic tests and monitoring tools for clinical assessment can be added as they become commercially available. This system can be utilised as a total clinic management package when combined with appropriate financial management systems and pharmaceutical prescription packages etc. We hope to make this system available in the public domain in the near future.



# KDRP's CDCIS



## **CHAPTER 3**

Final Clinical Profiles of Each Community

In the final 6 months of CDOP, targeted screenings in each community were carried out using electoral and community rolls, and patient follow-ups were focused primarily on optimising treatment for those needing it. As in previous intervals, the major impediments to productivity have been frequent health worker absenteeism in Community 2 and Community 3, and lack of health worker support in Community 1.

After many months of developmental difficulties, the web-based database is almost smoothly operational. Most of the information recorded in the database has been transferred to the clinic charts and attempts have been made to ensure that the recall card system utilised by the DHCS and Gulf Health Services reflect the same scheduled future visits as does the KDRP database. We are happy to assist in transferring data electronically to each of the three clinics and offer ongoing support in clinical activities and training for some longer time on a consultancy basis. Our electronic database remains available to any of these clinics that wish to use it for a small monthly user fee, and is currently (as of October 2004) still in use at Community 3. An adapted version of the same database is being used for the KDRP Primary Prevention Program in Soweto, South Africa, and is under consideration for some other remote settings.

In March 2003, Dr Suresh Sankar, a nephrologist from India, visited Community 2 and Community 3 to learn about the operational elements of the program with a view to developing some sites for chronic disease screening and prevention programs in India. Dr Ada Asinobi from Nigeria visited Community 3 in May for the same purposes. Dr Ivor Katz from South Africa visited the health centres of Community 2 and Community 1 to learn and share his experiences with the transition of his 'pilot' study in Soweto to the 'live' phase. He also plans to start a program in Capetown.

Table 1 shows the timelines of the community interactions to date. A total of 1,124 people aged 15+ years have been screened. In the last six months of the CDOP, there have been 32 new encounters at Community 2, giving a total of 234; 79 new encounters at Community 3, giving a total of 411; and 81 new encounters at Community 1, giving a total of 479. There have been a total of 589 follow-up visits at Community 2 over the course of the program, 461 at Community 3, and 518 at Community 1. Thus, the database has recorded 2,692 encounters related to the program; the total is somewhat higher, as some early data were lost.

Table 1. Timetable of new enrollments in community programs to date

	Population/	Testin	People	People	People	People	People	People
	Population	g	tested by	tested by	tested by	tested by	tested by	tested by
	15+ yrs	Starts	Dec 31, 00	June 15, 01	Dec 31, 01	June 30, 02	Dec 31, 02	June 30, 03
Community 1	1379/802	Dec, 2000	38	129	217	318	398	479
Community 2	309/ 188	May, 2000	141	181	182	190	202	234
Community 3	1086/729	Nov, 2000	66	125	246	315	332	411

Due to database changeovers, numbers of follow-up visits could not be classified and generated in the same manner as done in the previous time periods.

As shown in Table 2, there is a good balance of genders among people aged 15+ years screened in Community 2, an excess of females at Community 3, and an excess of males at Community 1. Mandy Halkett was recruited to assist in reducing the gender imbalance in Community 1 and the entire team of four CNCs spent an intensive week of screening and follow-up in Community 3.

Table 2. Cumulative numbers of females/males having baseline testing by community

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Communities	Up to Dec,	Up to June	Up to Dec	Up to June	Up to Dec	Up to June
	2000	15, 2001	31, 2001	30, 2002	31, 2002	30, 2003
Community 1	26/12	80/49	127/84	134/184	137/261	215/264
Community 2	109/54	105/76	104/78	102/88	110/92	127/107
Community 3	66/0	106/19	148/98	183/132	198/134	237/174

The attrition of females up to 30 June 2002 at Community 2 reflects problems with Medicare numbers and database transfers.

From this point on, the report focuses exclusively on people aged 18+ years, because they qualify as 'adults' and there was a more consistent effort to recruit them into the program. Table 3 shows the estimated proportions of adults in each community/area who have been tested at least once, using denominators supplied from electoral rolls and Medicare lists, and again from the 2001 Census. Ascertainment is almost complete at Community 2, and more than 60% of the adults at Community 3 and Community 1 have been tested at least once.

Table 3. Estimated proportion of adults (18+years) tested at least once, as of June 30, 2003

Tested	Denominator	Population	Number Tested	Percent tested
Community 1	Community rolls	783	456	58.2%
plus outstations	2001 census	682		66.9%
Community 2	Community rolls	233	210	90.1%
	2001 census	164		128.0%
Community 3	Community rolls	535	404	75.5%
plus outstations	2001 census	657		61.5%

Table 4 shows the estimated proportions tested by gender, using the 2001 Census for denominators.

Table 4. Estimated proportion of adults (18+yr) tested at least once, by gender (Using 2001 census for v denominators)

**Communities** Female Females tested Male Males tested, population N & percent population N & percent Community 1 390 209, 53.6% 292 247, 84.6% Community 2 92 115, 125.0% 72 95, 131.9% Community 3 352 233, 66.2% 305 171, 56.1%

The data again shows high rates of smoking in all communities, different rates of drinking among women, very different body habitus by community, and an always excessive, but highly variable disease burden among the three communities. Rates of morbidities also increase with age, so that the highest rates of disease are generally in the oldest people. However, because of the youthful age structure of the populations, the greatest numbers of people with problems are in the 20–59 years age group. This correlation with age means, of course, that the disease burden will increase as these populations age, unless the risk factor exposures earlier in life change. If the temporal trend for increasing body fat documented in some communities is maintained, there will also be an increase in disease burdens on that basis. The clustering of most people with morbidities in early adult life and middle age anticipates that

many years of treatment will be required for lots of people if life expectancy improves. These data are all important for health services planning.

There has been some ascertainment of new probable cases of disease, and treatment has been started or modified in about one-quarter of the screened population. Many people on treatment, however, are still not at optimal medicine dose or at treatment goal, because health worker absenteeism has greatly impaired effective follow-up.

There has been a net improvement in blood pressure in people with elevated blood pressure on their first screen and for whom medications have been started or adjusted, although the most recent blood pressures are still not at goal.

## **Profile of Community 1**

To date there have been 456 first baseline screens, or 209 females and 247 males. Table 5 shows that the largest single group was aged 20–39 years. However, there was substantial participation by young people, including those less than 18 years old, which is encouraging.

Table 5. Age at baseline testing in people age 18+ years, Community 1, n=456

Age	Females (n)	Females (%)	Males (n)	Males (%)
18-24 yrs	42	20.1	72	29.2
25–39 yrs	73	34.9	108	43.7
40–54 yrs	51	24.4	49	19.8
55+ yrs	43	20.6	18	7.3

Table 6 shows some clinical details of participants at baseline. Eighty people were already prescribed vasoactive drugs, mostly ramipril, but with a few other agents as well. Thirty-five were already prescribed hypoglycemic agents, mostly metformin and gliclazide. Twenty women were on depoprovera/implanon. Seventeen people were on aspirin. Nearly 45% of women and almost 80% of the men were smokers. Nearly 68% of men but only 12% of women were drinkers. The average BMI value was in the low 'ideal' range. The average waist measurement was in the 'obese' range for females, but not for males. Blood pressures did not differ significantly by sex. Females had lower hemoglobin levels and higher glucose levels than males. About 12% of people had proteinuria by dipstick, with no significant gender difference, while about 6% of people had microscopic haematuria, which was more common in females.

Table 6. Clinical features at baseline testing, people age 18+ years, Community 1

	Female	Male	All	F vs M, p
Vasoactive/antiHT meds, n= 456	47 (22.5%)	33 (13.4%)	80 (17.5%)	0.011
Hypoglycemic meds, n= 456	25 (12.0%)	10 (4.1%)	35 (7.7%)	0.002
Smokers, n=441	89 (44.5%)	191 (79.3%)	280 (63.5%)	< 0.001
Drinker, n=441	24 (12.0%)	163 (67.6%)	187 (42.4%)	< 0.001
Height, cms, n=403	163.8 (5.8)	176.0 (6.4)	170.6 (8.6)	< 0.001
Weight, kg, n=444	61.1 (17.4)	64.3 (13.4)	62.1 (15.4)	0.032
BMI, mean (SD), n=403	22.3(5.5)	20.7 (3.9)	21.4 (4.8)	< 0.001
Waist, cms n=422	90.9 (15.1)	83.8 (10.6)	86.9 (13.2)	< 0.001
Hips, cms n=391	97.3 (12.7)	90.2 (10.2)	93.1 (11.8)	< 0.001
SBP, mmHg, mean (SD), n=449	119.1 (21.6)	118.7(17.5)	118.9 (19.4)	0.837
DBP, mm Hg, mean (SD), n=449	76.0 (13.2)	76.3 (13.2)	76.0 (13.2)	0.510
Haemoglobin, mean (SD), n=353	12.6 (1.6)	14.7 (1.8)	13.7 (2.0)	< 0.001
Random glucose, gmean (CI), n=440	6.8 (6.4-7.1)	6.0 (5.8–6.2)	6.3 (6.1–6.5)	< 0.001
Urine protein $\geq 1+$ , n=450	21 (11.4%)	32 (13.2%	53 (12.4%)	0.561
Haematuria $\geq$ 1+, n=397 *	13 (8.4%)	9 (3.7%)	22 (5.5%)	0.044

<sup>\*</sup> Menstruating women excluded.

Table 7 shows some parameters of body habitus by category. Nearly forty percent of women and 50% of males were 'underweight' by non-Aboriginal BMI standards, while only 11% of women and 2% of men were 'obese'. Rates of 'obesity' by waist standards were much higher in females and somewhat higher in males, and rates of elevated waist/hip ratio were higher again. Females were more likely to be in the higher categories of all parameters of body weight/fat than males.

Table 7. Parameters of body habitus by category, people age 18+ years, Community 1

	Female	Male	All	F vs M, p
<20, 'underweight'	39.3%	50.2%	45.4%	<0.001*
20–24.9, 'ideal weight'	34.3%	37.3%	36.0%	
25-29.9, 'overweight'	15.7%	10.7%	12.9%	
30 +, 'obese'	10.7%	1.8%	5.7%	
By Waist, "obese" (n=422)	60.1%	6.8%	30.6%	< 0.0001
High W/H Ratio# (n=391)	72.1%	17.0%	39.6%	< 0.001

p value for significance of difference in distribution

<sup>\*</sup> Obese by Waist  $\geq$  88 in females,  $\geq$ 102 in males

<sup>#</sup> High WHR >0.9 in females, and >1.0 in males

Table 8 shows results of urine and blood tests sent to external laboratories, according to predetermined algorithms, in people with suspicious or abnormal results, or those known to have disease prior to testing. Of the 164 people having urine ACRs measured, 50 had microalbuminuria (ACR 3.4−33) and 38 had overt albuminuria (ACR 34+). Of the 114 people tested with HbA1c for the presence or suspicion of diabetes, 43 had a reading in the diabetic range (≥6.5%). Nine people had apparently elevated levels of serum creatinine, of which three or four were probably spurious.

Table 8. Lab results of people at risk who were tested further, age 18+ years, Community 1

	Female	Male	All
Urine ACR gmean (CI), n=164	12.4 (7.5–20.6)	3.3 (2.2–5.0)	5.9 (4.2–8.1)
ACR < 3.4	23	53	76
ACR 3.4–33	27	23	50
ACR 34+	21	17	38
HbA1c %, gmean (CI), n=114	7.2 (6.7–7.8)	6.2 (5.9-6.6)	6.7 (6.4–7.1)
HbA1c ≥6.5 %	29	14	43
Creatinine, gmean (CI), n=157	0.078 (0.074-0.083)	0.094 (0.090-0.980)	.086 (0.083-0.090)
Elevated creatinine**	5	4	9

<sup>\*\*</sup> Elevated creatinine, >0.1 for females and >0.12 for males.

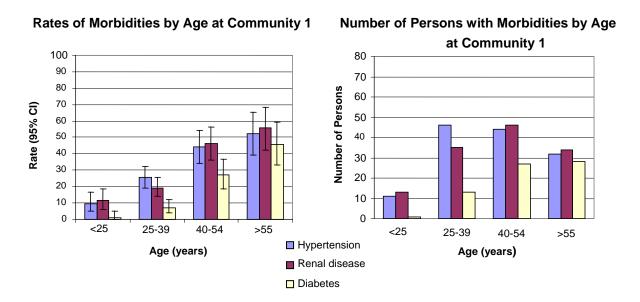
Table 9 shows apparent diagnoses following on from the testing. Twenty-one percent were anemic, with no gender difference. Ten percent had overtly diabetic blood glucose levels, 15% had diabetic ranges of glucose or HbA1c, and 15% had diabetes by exam or by history. Females were more often afflicted than males. About 12% had proteinuria, and 24% had probable renal disease defined by proteinuria or an ACR of 3.4+. These rates are approximations, however, with potential overstatement because some abnormal findings need confirmation, and a potential underestimation, because some people with diabetes have not had ACR measurements, some people with suspicious glucose levels have not been evaluated further, and some people with overt albuminuria have not had creatinine measurements.

Table 9. Apparent diagnoses from screening, number (%), people age 18+ years, Community 1

	Female	Male	All	p
Anaemia* (n=353)	34 (21.4%)	42 (21.7%)	76 (21.5%)	0.952
Uncontrolled BP (≥140/90)	44 (21.1%)	52 (21.1%)	96 (21.1%)	0.999
Hypertension by exam or history	66 (31.6%)	67 (27.17%)	133 (29.21%)	0.297
Proteinuria ≥1+	21 (11.4%)	32 (13.2%)	53 (12.4%)	0.561
Probable renal disease**	57 (27.3%)	53 (21.5%)	110 (24.1%)	0.148
Glucose >11 mmol/L	34 (16.3%)	10 (4.1%)	44 (9.7%)	< 0.001
Diabetes by glucose or HbA1c	48 (23.4%)	19 (7.7%)	68 (14.9%)	< 0.001
Diabetes by exam or history	48 (23.0%)	22 (8.9%)	70 (15.4%)	< 0.001

<sup>\*</sup> Anaemia: Hb <11 for females and <14 for males. \*\* Probable renal disease: proteinuria and/or ACR ≥3.4

The next figure shows that *prevalences* of hypertension, suspected renal disease and diabetes all increased with increasing age. This supports the case for repeated screening throughout life.



Due to the youthful age of the population, however, the greatest *number* of cases was in people aged 20–59 years. This finding anticipated many years of treatment after diagnosis if peoples' life spans begin to approximate that of non-Aboriginal people.

In the next chapter, these clinical findings are interpreted, their rates across communities compared, and their associations analysed.

## Health Profile of Community 2

Of the 210 adults tested since the program began, 115 were women and 95 were men. More than half the people were aged 25-54 years, as shown in Table 10.

Table 10. Age at baseline testing, people age 18+ years, Community 2, n=210

Adults	Females (n)	Females (%)	Males (n)	Males (%)
<25 yrs	23	20	27	28.4
25–39 yrs	43	37.4	35	36.8
40–54 yrs	31	27.0	26	27.4
55+ yrs	18	15.7	7	7.4

Table 11 shows some clinical features of participants on baseline exam. Forty-five people had already been prescribed vasoactive agents, mostly ramipril, with a few on enalapril or monoplus. Twenty-one were already on hypoglycemic agents, mostly metformin and gliclazide. In addition, eleven people are on aspirin, and four on lipid lowering agents, while eight females were on contraception with either regular depoprovera or implanon. Thirty percent of females and 67% of males were smokers. Nearly half of the women and 85% of the men were drinkers. Average BMI was slightly above the 'ideal' range in females and within the ideal range for males, while the average waist measurement was in the 'obese' range by non-Aboriginal standards for females (≥88 cm), but not in males (≥102). Females tended to have lower blood pressures than males, but the difference was not significant, and had significantly lower hemoglobin levels. The average random glucose level tended to be higher in females. Eighteen percent had proteinuria and about 7% had microscopic haematuria, without significant gender differences.

Table 11. Clinical features at baseline testing, people age 18+ years, Community 2

	Female	Male	All	F vs M, p
Vasoactive/antiHT meds, n=210	29 (25.2%)	16 (16.8%)	45 (21.4%)	0.141
Hypoglycaemic meds, n=210	14 (12.2%)	5 (5.3%)	19 (9.1%)	0.082
Smokers, n=204	33 (29.5%)	62 (67.4%)	95 (46.6%)	< 0.001
Drinker, n=204	50 (45.1%)	78 (84.8%)	128 (63.1%)	< 0.001
Height, cm, n=178	164.0 (5.8)	175.5 (6.6)	169.3 (8.5)	< 0.001
Weight, kg, n=209	67.9 (18.0)	73.2 (15.1)	70.3 (16.9)	0.024
BMI, mean (SD), n=177	25.8 (6.6)	23.4 (4.6)	24.7 (5.9)	0.006
Waist, cm, n=172	95.3 (15.7)	91.2 (11.9)	93.6 (14.4)	0.068
Hips, cm, n=162	98.7 (14.7)	94.3 (9.8)	97.0 (13.2)	0.037
SBP, mmHg, mean (SD), n=208	120.8 (22.6)	124.1 (14.2)	122.3(19.3)	0.224
DBP, mm Hg, mean (SD), n=208	78.3 (11.6)	80.3 (11.4)	79.2 (11.5)	0.235
Haemoglobin, mean (SD), n=183	12.8 (1.8)	14.8 (1.6)	13.7 (2.0)	< 0.001
Random glucose, gmean (CI), n=199	6.6 (6.1–7.0)	5.7 (5.3–6.2)	6.2 (5.9–6.5)	0.004
Urine protein ≥1+, n=187	14 (13.6%)	19 (22.6%)	33 (17.7%)	0.107
Haematuria ≥1+, n= 167 *	7 (8.3%)	5 (6.0%)	12 (7.2%)	0.563

<sup>\*</sup> menstruating women excluded

Table 12 shows some parameters of body habitus by category. About one quarter of people were underweight' by non-Aboriginal BMI standards, while 28% of females and 9.8% of males were obese. Rates of obesity by waist measurement were substantially higher, and the proportions of people with 'elevated' waist hip ratio were higher still. Females were more likely to be in the higher categories of all parameters of body weight or fat than males.

Table 12. Parameters of body habitus by category, people age 18+ years, Community 2

	3 8 7/1	1 0 1		
	Female	Male	All	F vs M, p
By BMI: <20, 'underweight'	21.1%	28.1%	24.3%	0.012*
20–24.9, 'ideal weight'	24.2%	36.6%	29.9%	
25–29.9, 'overweight'	26.3%	25.6%	26.0%	
30 +, 'obese'	28.4%	9.8%	19.8%	
By Waist, "obese" *	64.1%	17.4%	45.4%	< 0.0001
High W/H Ratio#	77.8%	27.9%	58.8%	< 0.001

p value for significance of difference in distribution

Table 13 shows the values of urine and blood tests sent to external laboratories, according to predetermined algorithms, in people with suspicious or abnormal results, or those known to have disease prior to testing. Of the 129 people who had an ACR, 35 had microalbuminuria (ACR 3.4–33) and 28 had overt albuminuria (ACR 34+). Of the 86 people tested with Hba1c for the presence or suspicion of diabetes, 31 had a reading in the diabetic range (≥6.5%). Three females and one male had an elevated serum creatinine level by laboratory standards, ranging from 0.12 to 0.49.

Table 13. Lab results of people at risk who were tested further, age 18+years, Community 2

	Female	Male	All
Urine ACR, gmean (CI), n=129	6.4 (3.8–10.8)	2.6 (1.6–4.4)	4.3 (3.0–6.3)
ACR < 3.4	32	34	66
ACR 3.4–33	21	14	35
ACR 34+	19	9	28
HbA1c %, gmean (CI), n=86	6.5 (6.0-6.9)	6.6 (6.0–7.3)	6.5 (6.2–6.9)
HbA1c <u>≥</u> 6.5 %, n	18	13	31
Creatinine, gmean (CI), n=120	0.072 (0.067–0.078)	0.089 (0.083–0.094)	0.078 (0.074-0.083)
Elevated creatinine *, n	3	1	4

<sup>\*</sup> Elevated creatinine, >0.1 for females, >0.12 for males

Table 14 shows apparent diagnoses following testing. About 18% were anaemic, without significant difference between females and males. Blood pressures were elevated on testing in 27% of people, without much of a gender differential, while 36% had hypertension by history or exam. Diabetes, diagnosed by glucose and HbA1c levels at testing alone, was identified in 20.0%, while 21% had these characteristics and/or a history of diabetes. Proteinuria by dipstick was present in 18%, with arguably more males than females affected, while 36% had either proteinuria and/or an elevated ACR. The total numbers of people with each condition represent the burden of illness currently identified. In this community, where most adults have had baseline screening, these figures could help inform health services planning. These rates are approximations, however, with a potential overstatement because some abnormal findings need confirmation, and potential underestimates, because some people with diabetes have not had ACR measurements, some people with suspicious glucose levels have not been evaluated further for diabetes, and some people with overt albuminuria have not had serum creatinine measurements. Some of these issues are discussed in later chapters.

<sup>\*</sup> Obese by Waist  $\geq$  88 in females,  $\geq$ 102 in males.

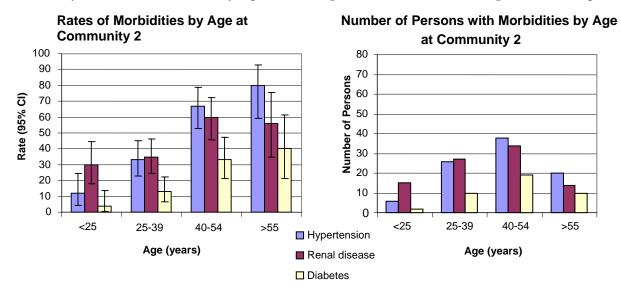
<sup>#</sup> High WHR >0.9 in females, and >1.0 in males.

Table 14. Apparent diagnoses from screening, number (percentages), people age 18+ years, Community

	Female	Male	All	p
Anaemia*	19 (19.2%)	13 (15.5%)	32 (17.5%)	0.51
Hypertension at exam (≥140/90)	34 (29.6%)	23 (24.2%)	57 (27.1%)	0.385
Hypertension by exam or history	52 (45.2%)	38 (40.0%)	90 (42.9%)	0.447
Proteinuria ≥1+	14 (13.6%)	19 (22.6%)	33 (17.7%)	0.107
Probable renal disease**	44 (38.3%)	31 (32.6%)	75 (35.7%)	0.397
Glucose >11 mmol/L	15 (13.0%)	10 (10.5%)	25 (11.9%)	0.575
Diabetes by glucose or HbA1c	24 (20.9%)	18 (19.0%)	42 (20.0%)	0.729
Diabetes by testing or history	25 (21.7%)	19(20.0%)	44 (21.0%)	0.758

<sup>\*</sup> Anaemia: Hb <11.5 for females and <13 for males

The next figure shows that *prevalences* of hypertension, renal disease and diabetes all increased with increasing age. These hint at the pathophysiology of these conditions, and shows that prevention needs to occur early in life. It also shows why repeated testing for chronic disease throughout life is required.



Due to the youthful age distribution of the population, however, the greatest *numbers* of cases were among people aged 20–59 years, as in the next figure. This information anticipates need for many years of treatment in people who are diagnosed in early and mid adult life.

<sup>\*\*</sup> Probable renal disease: proteinuria and/or ACR > 3.4

## Health Profile of Community 3

Of the 404 adults who have been tested, 233 were females and 171 were males. The largest group was aged 20–39 years, shown in Table 15.

Table 15. Age at baseline testing, people age 18+ years Community 3, n=404

Adults	Females (n)	Females (%)	Males (n)	Males (%)
18-24 yrs	42	18	29	17.0
20–39 yrs	97	41.6	66	38.6
40–59 yrs	57	24.5	36	21.1
60+ yrs	37	15.9	40	23.4

Table 2 shows some clinical features of participants at baseline testing. One hundred and eighteen, or nearly 28%, had already been prescribed vasoactive/hypotensive drugs, mostly ramipril, but also enalapril, irbesartan, felodipine, nifedipine, amlodipine, atenolol, indapamide and lasix. Seventy-eight, or 19% of the total, were already prescribed hypoglycemic agents, mostly metformin and gliclazide, with some also on insulin or acarbose. This profile demonstrates the very large burden of disease already recognized and treated in this population. In addition, and not shown on the table, 27 people were receiving aspirin and 17 were on lipid lowering agents, while 29 females under the age of 45 years were receiving depoprovera/implanon.

Table 16 also shows that 44% of females and 66% of males were smokers, and 40% of females and almost 70% of males drank alcohol. Females were significantly lighter than males. The average BMI was in the 'overweight' range, and higher in females than males. The average waist measurement was in the 'obese' range for females but not for males. Systolic blood pressure was significantly higher in males than in females. Females had lower haemoglobin levels than males. The average random glucose level was in the 'suspicious' range, with females having higher levels than males. Twenty-six percent of people had proteinuria, with no difference by gender, while 8.7% had microscopic haematuria, with females tending to have higher rates than males.

Table 16. Clinical features at baseline testing, people age 18+ years, Community 3

	Female	Male	All	F vs M, p
Vasoactive agents, n= 411	69 (29.6%)	49 (28.7%)	118(28.2%)	0.834
Hypoglycemic agents, n= 411	48 (20.6%)	30 (17.5%)	78 (19.3%)	0.442
Smokers, n=401	100(43.5%)	112 (65.5%)	212 (52.9%)	< 0.001
Drinker, n=401	93 (40.4%)	119 (69.6%)	212 (52.9%)	< 0.001
Height, cm, n=363	163.5 (5.7)	173.6 (6.2)	167.7 (7.8)	< 0.001
Weight, kg n=395	76.8 (18.4)	82.5 (19.6)	79.2 (19.1)	0.003
BMI, mean (SD), n=361	28.6 (6.4)	27.0 (6.2)	28.0(6.4)	0.019
Waist, cm n=368	97.8 (14.1)	96.8 (14.8)	97.4 (14.4)	0.527
Hips, cm n=319	108.9 (14.9)	99.2 (12.1)	104.8 (14.3)	< 0.001
SBP, mmHg, mean (SD), n=395	119.0(19.6)	125.1(19.1)	121.6(19.6)	0.002
DBP, mm Hg, mean (SD), n=395	77.6(12.8)	79.9 (13.4)	78.6(13.1)	0.087
Haemoglobin, mean (SD), n=365	12.7 (1.9)	15.2 (1.8)	13.7 (2.2)	< 0.001
Random glucose, gmean (CI), n=403	7.2 (6.9–7.6)	6.6 (6.2–6.9)	6.9 (6.7–7.2)	0.002
Urine protein $\geq$ 1+, n=376	52 (24.4%)	45 (27.6%)	97 (25.8%)	0.483
Haematuria <u>&gt; 1+, n=345</u> *	21 (11.4%)	9 (5.6%)	30 (8.7%)	0.060

<sup>\*</sup> menstruating women excluded.

Table 17 shows some parameters of body habitus by category. Less than 10% were underweight by BMI, while 41% of females and 30% of males were obese by BMI standards. Rates of obesity by waist measurement were substantially higher; whereas rates of elevated waist hip ratio were intermediate. Females were more likely to be in the higher categories of all parameters of body weight/fat than males.

Table 17. Parameters of body habitus by category, people age 18+ years, Community 3

	Female	Male	All	F vs M, p
<20, 'underweight'	6.2%	13.9%	9.4%	0.034*
20–24.9, 'ideal weight'	26.7%	26.5%	26.6%	
25–29.9, 'overweight'	26.7%	29.8%	28.0%	
30 +, 'obese'	40.5%	29.8%	36.0%	
By Waist, "obese" (n=368)	75.0%	39.7%	60.1%	< 0.0001
High W/H Ratio# (n=319)	48.1%	36.0%	43.0%	0.031

p value for significance of difference in distribution

Table 18 shows the values of urine and blood tests sent to external laboratories, according to predetermined algorithms, in people with suspicious or abnormal results, or those known to have disease prior to testing. This testing, however, is still not entirely complete. Of the 228 people who had an ACR ordered, 83 had microalbuminuria (ACR 3.4–33) and 72 had overt albuminuria (ACR 34+). Males more often had elevated blood pressure than females at first exam. Of the 191 people tested with HbA1c for the presence or suspicion of diabetes, 95 had a reading in the diabetic range (≥6.5%). Twenty people had serum creatinine levels that were apparently raised (at 115 to 355 umol/l), of which 16 were probably genuine indications of renal insufficiency.

Table 18. Lab results of people at risk who were tested further, age 18+ years, Community 3

	Female	Male	A11
Urine ACR gmean (CI), n=228	12.4 (9.1–17.0)	8.3 (5.4–12.9)	10.5 (8.1–13.6)
ACR < 3.4,	38	35	73
ACR 3.4–33	53	30	83
ACR 34+	43	29	72
HbA1c %, gmean (CI), n=191	7.1 (6.8–7.5)	7.0 (6.6–7.4)	7.1(6.8–7.4)
HbA1c ≥6.5 %,	58	37	95
Creatinine, gmean (CI), n=274	72.3 (68.6–76.2)	90.2 (86.5–94.0)	79.8 (76.9–82.7)
Elevated creatinine**	9	11	20

<sup>\*\*</sup> Elevated creatinine, >106 for females, >120 for males

Table 19 shows apparent diagnoses following on from the testing. About 20% were anaemic, with females more often affected than males. Twenty-six per cent had diabetic levels of glucose or Hba1c at exam, while 30% of people were diabetic at exam or by history, with no difference by gender. Forty-two percent of people had proteinuria or pathologic albuminuria, with no gender difference. These rates are approximations, however, with potential overstatement because some abnormal findings need confirmation, and potential underestimation, because some people with diabetes have not had ACR measurements, some people with suspicious glucose levels have not been evaluated further for diabetes, and some people with overt albuminuria have not had serum creatinine measurements. Some of these issues are discussed in subsequent chapters.

<sup>\*</sup> Obese by Waist  $\geq$  88 in females,  $\geq$ 102 in males

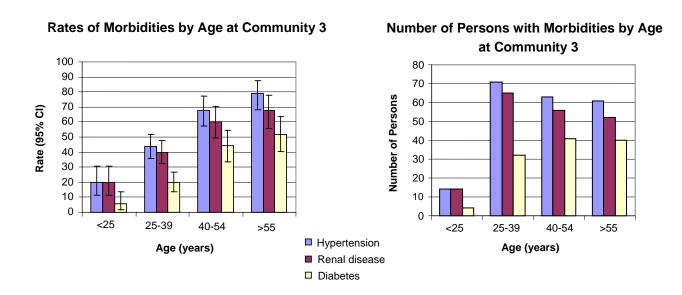
<sup>#</sup> High WHR >0.9 in females, and >1.0 in males

Table 19. Apparent diagnoses from screening, number (percentages), people aged 18+ years, Community 3

•	Female	Male	All	P
Anaemia* (n=365)	54 (24.4%)	20 (13.9%)	74 (20.3%)	0.014
High BP at exam (≥140/90)	60 (25.8%)	65 (38.0%)	125 (30.9%)	0.008
Hypertension by exam or history	111 (47.6%)	98 (57.3%)	209 (51.7%)	0.055
Proteinuria 1+	52 (24.4%)	45 (27.6%)	97 (25.8%)	0.483
Proteinuria and/or ACR≥3.4	102 (43.8%)	66 (38.6%)	168 (41.6%)	0.297
Glucose >11 mmol/L	35 (15.0%)	21 (12.3%)	56 (13.9%)	0.431
Diabetes by glucose or HbA1c	63 (27.0%)	40 (23.4%)	103 (25.5%)	0.406
Diabetes by exam or history	70 (30.0%)	50 (29.2%)	120 (29.7%)	0.861

<sup>\*</sup> Anaemia: Hb <11.5 for females and <13 for males

The next figures shows that the rate of apparent hypertension, renal problems, and diabetes all increased with increasing age. This provides the case for repeated testing throughout life. However, owing to the youthful age structure of the population, the greatest *number* of cases was among people aged 20–39 years, followed by those in middle age, as shown below. This means that we should anticipate many years of treatment in a large number of people.



<sup>\*\*</sup> Probable renal disease: proteinuria and/or ACR ≥3.4

# **CHAPTER 4**

**Description of Participants** 

Age and Gender Health Behaviours Body Habitus Birth Weight In this chapter we give a more detailed description of participants aged 18+ years, their rates of smoking and drinking, and their body habitus. We then present morbidities by age, gender and community and describe the phenomenon of overlapping morbidities. Finally we evaluate correlations with, and predictions of morbidities.

## **Participants**

The number of people aged 18+ years who had at least one examination was 1,070. There were 557 females, or 52% of the group, and 513 males, or 48%. Their ages ranged from 18 to 86 years. Age, shown in the figure below, is not normally distributed, and the population is on average very youthful, with a mean (SD) age of 37.4 (15) years, but a more appropriately applied median age of 34.6 years.

# 

## Age Distribution at Baseline Screen

Ages were assigned into four categories, as shown in Table 1 below, to allow moderately robust numbers in each group. There were too few people aged 55+ years to allow further categorization. As it is, the low numbers of males aged 55+ years in Community 1 and Community 2 are quite limiting. There were relatively more people aged 55+ years screened in Community 3 (19%) than in Community 1 (13%), and Community 2 (12%). This is borne out by the median ages of 37 (CI 35-38) in Community 3, vs 34 (33-35) in Community 1 and 35 (33-37) in Community 2.

Age

Table 1. Age categories of participants age 18+ years, by gender and community

		18-24.9 yrs	25-39.9 yrs	40-54.9 yrs	55+ yrs
Community 1	Females	42	73	51	43
	Males	72	108	49	18
	Total	114	181	100	61
Community 2	Females	23	43	31	18
	Males	27	35	26	7
	Total	50	78	57	25
Community 3	Females	42	97	57	37
	Males	29	66	36	40
	Total	71	163	93	77
All	Females	107	213	139	98
	Males	128	209	111	65
	Total	235	422	250	163

#### Health Behaviours

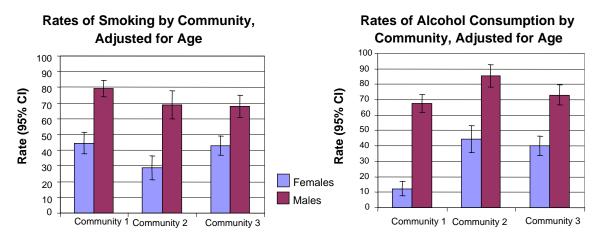
Ascertainment for questions about smoking and drinking was excellent, at 97.8%. Table 2 shows about 45% of females in Community 1 and Community 3, and about 30% in Community 2 were current smokers. About 80% of men in Community 1, and 67% of men in Community 2 and Community 3 were smokers. The lower rates of smoking in females are significant in all communities, p<.0001.

Only 12% of women in Community 1 and fewer than half in the other two communities were current drinkers, while 68% to 85% of males were current drinkers. The lower proportions of current drinkers among females were significant in all three communities (p<0.0001).

Table 2. Smoking and drinking by gender and community

		Females	Males
Current Smokers	Community 1	44.5%	79.3%
	Community 2	29.5%	67.4%
	Community 3	43.5%	65.5%
Current Drinkers	Community 1	12%	67.6%
	Community 2	45%	84.7%
	Community 3	40.4%	69.6%

These data are also shown graphically in the next two figures.



Rates of smoking in Community 1 were fairly consistent across age groups in females and males. They varied across age groups in Community 2, and fell with age in Community 3. Rates of drinking were generally highest in the youngest age group, except among the very low prevalence of drinking in females in Community 1.

Drinking and smoking were tightly correlated (p<0.0001 for both sexes in all communities). Among females, 54.5% of smokers were also current drinkers vs 20.7% of nonsmokers (p<0.0001). In males, 81% of smokers were also current drinkers, compared with 46% of nonsmokers (p<0.0001).

Smokers generally had lower weight, BMI, waist and hips, both in crude and adjusted data. In females, only the BMI difference was significant, however, the effect was stronger in males and significant for all parameters except WHR, as shown in Table 3.

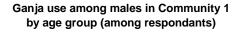
Table 3. Parameters of body size, mean (SE) by smoking status, adjusted for age, current alcohol use and community

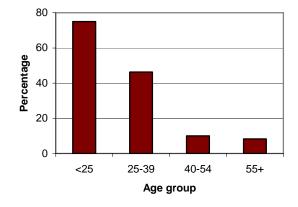
	Weight	BMI	Waist	Hips	WHR
Females					
Smokers	68.2 (1.0)	25.0 (0.4)	93.6 ( 1.0)	101.1 (1.1)	0.93 (0.01)
Nonsmokers	69.9 (0.9)	26.3 (0.4)	95.7 (0.9)	103.3 (0.9)	0.92 (0.01)
	P=0.312	P=0.0326	P=0.12	P=0.13	P=0.372
Males					
Smoker	70.2 (0.9)	22.7 (0.3)	87.9 (0.6)	92.8 (0.6)	0.95 (0.01)
Nonsmoker	76.8 (1.4)	24.9 (0.5)	93.3 (1.1)	96.0 (1.1)	0.96 (0.01)
	P<0.0001	P<0.0001	P<0.0001	P=0.01	P=0.09

There were no significant differences and no trends in any parameters of body habitus between current drinkers vs nondrinkers, in females or in males, both in the crude data and with adjustment for age, smoking status and community.

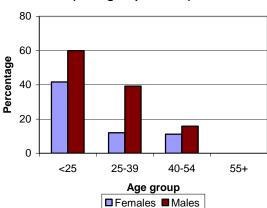
Questions were included about the use of other substances, in a yes/no fashion, with some attempt to quantitate the amount used. Some workers found these questions difficult to ask, and did so reluctantly or not at all. Some of these responses were lost with database problems, and were the most difficult items of the screening to recapture from the clinical record. In any case, ascertainment was incomplete; responses were recorded for 58% of females and 72% of males in Community 1, 59% and 81% respectively in Community 2 and of 49% and 64% in Community 3 respectively. Our nurse coordinators sense that the quality of data from females in Community 1 and from both sexes at Community 3 is probably too poor to present. However, the data on males in Community 1, (where our nurse coordinators were both male), and on both sexes in Community 2, (where the Health Worker knew all participants personally), is probably fairly reliable.

Overwhelmingly the most common substance used was marijuana or ganja. The rates of declared use among documented responders in those two communities are shown in the next figure. The majority of young males in both communities were users, as were >40% of young women in Community 2. Rates fell with increasing age.





# Ganja use among participants by age group in Community 2 (among respondants)

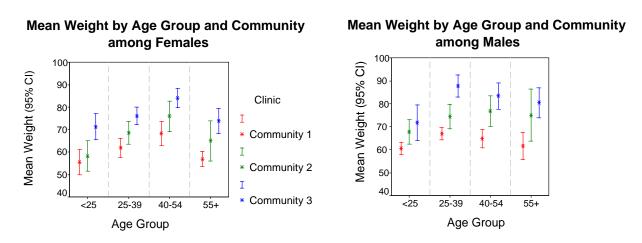


People who used ganja were much more likely to be smokers and drinkers (p<0.0001 for both). They did not differ significantly from non-users in weight or BMI when age, smoking and drinking were accounted for.

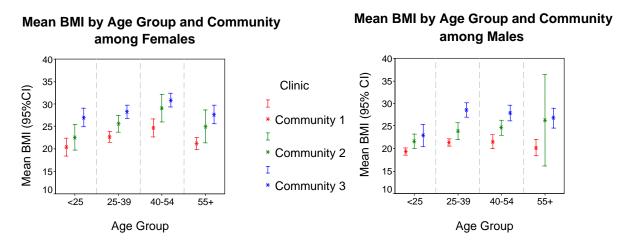
# **Body Habitus**

There was no significant difference in height among females or males across communities, and only a small (<1 cm) and non significant decrease in height, in people aged 55+ years, relative to younger age groups.

As shown in the next figure, in every community and in both sexes there was a steady increase in mean weight with increasing age up through ages 40-54 years, then a lower mean in those aged 55+ years. There was also a very significant difference in weights across communities, with lowest weights in Community 1 and the highest weights in Community 3 in females and males, p<0.0001 for both sexes.



Mean BMI values generally demonstrated similar trends, shown in the next figure.



Waist, shown in the next figure, followed similar patterns, with p<0.0001 for differences across communities in both sexes. Females generally had larger waist measurements than males, (p<0.0001), which is opposite to the differentials in weight and BMI.

# Mean Waist Circumference among Females by Age Group and Community

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# Mean Waist Circumference among Males by Age Group and Community

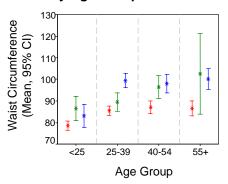


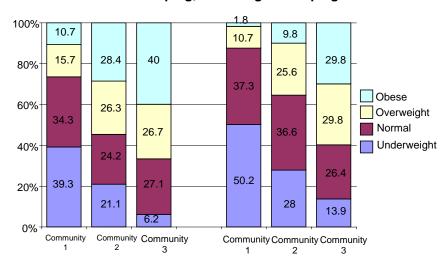
Table 5 confirms these differences in weight, BMI and waist after adjustment for age, and shows a similar differential for hips. Waist/hip ratios did not follow the same pattern, being highest in Community 2. Thus, higher hip measurements accompanying higher waist measurements in Community 3 meant that WHR did not show the full extent of central obesity.

Table 5. Parameters of body weight (mean (95%CI) by community, adjusted for age

	Weight	BMI	Waist	Hips	WHR
Females					
Community 1	61.1 (59-64)	22.3 (21-23)	90.8 (89-93)	97.1 (95-99)	0.93 (.9295)
Community 2	67.9 (65-71)	25.8 (25-27)	95.6 (93-98)	99.0 (96-102)	0.97 (.9599)
Community 3	76.9 (75-79)	28.5 (28-29)	97.8 (96-100)	108.7 (107-111)	0.90 (.8991)
	P<0.0001	P<0.0001	P<0.0001	P<0.0001	P<0.0001
Males					
Community 1	64.6 (63-67)	20.9 (20-21)	84.6 (83-86)	90.4 (89-92)	0.94 (.9395)
Community 2	73.4 (70-77)	23.6 (23-25)	91.8 (89-95)	94.1 (94-97)	0.97 (.9599)
Community 3	81.9 (79-84)	26.7 (26-28)	95.1 (93-97)	98.4 (97-100)	0.96 (.9598)
			P<0.0001	P<0.0001	P=0.0008

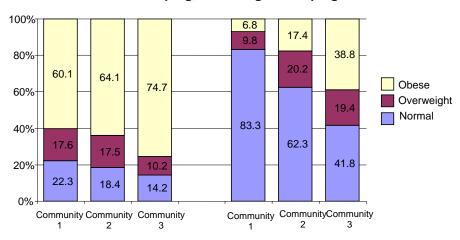
The distribution of BMI categories, shown in the next figure, emphasizes these differences by community for males and females, (p values for differences in distribution of categories by community <0.0001 for both sexes). Note that 40% of females and 50% of males in Community 1 are 'underweight' by conventional standards, with 10% and only 1.8% respectively being obese. However, only 6% of females and 14% of males in Community 3 were 'underweight', while 40% of females and 30% of males were obese.

# BMI Categories by Gender and Community: Females Left Grouping, Males Right Grouping



Waist categories showed similar gradients by community in females and males, demonstrated in the next figure (p<0.0001 for differences by community <0.0001 for both sexes). However, the great majority of women in all communities were overweight or obese by waist criteria for non-Indigenous Australians (17), even in Community 1, where BMI were the lowest. Males did not show the same dramatic discrepancies between waist and BMI categories of overweight and obesity.

# Waist Categories by Gender and Community: Females Left Grouping, Males Right Grouping



For females, overweight is 82-87 cm, obese is 88+cm. For males, overweight is 94-101 cm, obese is 102+ cm.

## Birth Weights

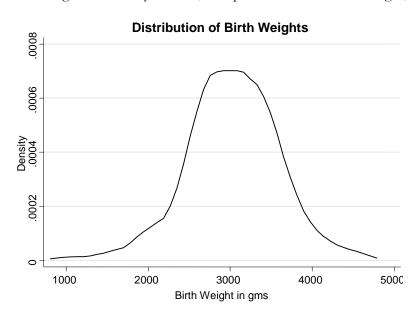
Recording of birth weights began sporadically in about 1956 in remote communities across the NT, and became more systematic throughout the 1960s and 1970s. Birth weights were extracted from clinic charts and community logs. They were available on 395 people, or 37% of the entire adult populations screened. More birth weights might be available at the hospitals where some of these babies were delivered in more recent times (The Royal Darwin Hospital for Community 1 and Community 2, and the Katherine Hospital for Community 3), but access to these records has not been easy.

Table 6 shows that the ascertainment was better for younger people, and particularly good in Community 1 and Community 2. This probably reflects the operations of the Catholic missions which ran the clinics in these sites; they instituted deliveries in the clinic earlier and maintained log books of delivery details.

Table 6. People whose birth weights could be ascertained, by community

	Community 1	Community 2	Community 3	All
<25 yrs	104/114, 91.2%	42/50, 84%	30/71, 42.3%	176/235, 74.9%
25-39 yrs	118/181, 55.2%	31/78, 39.7%	51/163, 39.3%	200/422, 47.4%
40-48 yrs	17/70, 14.3%	2/34, 5.9%	0/62, 0	19/166, 11.4%

The distribution of birth weights was fairly normal, except for a few below 1800 gm, shown below.



Birthweights ranged from 950gm to 4649g, with a mean (95%CI) of 3032gm (2977-3088) and a median of 3035 gm. Eleven-point-nine percent (11.9%) had been low birth weight (LBW) or <2500 gm. The mean birth weight is about 300gms lighter than an average non-Aboriginal birth weight, and about 470gms lighter than a full-term non-Aboriginal baby, and the LBW rate more than twice the rate of <6% for non-Aboriginal babies (18).

Females had significantly lower birth weights than males, 2940gms (CI 2856-3022) vs 3108 (CI 3034-3182) after adjustment for gender, clinic and age, p=0.0034. Among females 13% had been LBW vs 10% of males, which is not significant, p=0.57.

Table 7 shows that birth weights were lower in Community 1 than the other communities.

Table 7. Birth weight by community, adjusted for age and gender

	n	Birthweight, mean (CI)	LBW (<2500 gm)
Community 1	239	2947 (2877-3018)	14.6 % (11-20%)
Community 2	75	3198 (3072-3322)	7.9 % (4-17%)
Community 3	81	3129 (3008-3250)	7.1 (3-15%)
		p=0.009	P=0.097

There was a trend towards a cohort effect of higher birth weights in younger people in Community 1, as shown in Table 8, although not quite significant (p=0.136). This was not evident among the higher birth weights of people in Community 2 or Community 3.

Table 8. Trends in birth weight in Community 1, by birth cohort, adjusted for gender

	Mean (CI)	LBW (<2500 gm)
<25 yrs	3020 (2913 -3126)	11.5 % (6.6-19)
25-39 yrs	2937 (2836-3037)	16.0 % (10-24)
40-48 yrs	2741 (2476-3006)	24.1 % (9-49)

In addition to its associations with gender and community, birth weight in females was significantly and directly correlated with weight, height, BMI, waist and hip measurements, and marginally, with WHR. In males, birth weight was significantly and directly correlated with weight, height, BMI and waist measurements, although not with hip measurements. As a result of the last two relationships, it was directly associated with WHR. These correlations are shown in Table 9.

Table 9. Birth weight and body habitus

	Females, n=171	Males, n=217
Weight	R=0.32, p<0.0001	R=0.18, p=0.0099
Height	R=0.28, p=0.001	R=0.25, p=0.0002
BMI	R=0.29, p=0.0035	R=0.21, p=0.0024
Waist	R=0.28, p=0.0002	R=0.20, p=0.0045
Hips	R=0.23, p=0.0037	R=0.09, p=0.1967
WHR	R=0.15, p=0.067	R=0.19, p=0.0088

#### **Discussion**

The people screened were a relatively young group of adults, reflecting the age structure of remote communities more broadly. This must be considered in any comparisons of data on non-Aboriginal adult populations, especially in assessment of relative levels of chronic disease, which correlate strongly with increasing age in every population.

The data confirmed very high rates of smoking in all communities, in both sexes. Males had relatively higher rates than females. We believe this history is reliable, and have little grounds to think that self-declared smokers smoke less or inhale less, as a study in Angurugu on Groote Eyelandt has confirmed similar oral histories of smoking by urinary cotinine levels (19). These levels of smoking undoubtedly pose major health hazards, regardless of whether we could model them with these data (Chapter 4). The association of smoking with lower indices of body weight are not unexpected, but the more marked effect in males is unexplained.

While most men were current users of alcohol, current alcohol use in women was not the norm, and in Community 1, was almost systematically avoided. Thus, we should not generalize or stereotype about alcohol use and its health effects across communities.

The history of ganja might only be reliable in Community 1 males, and in Community 2 females and males. The high rates of use in younger adults are consistent with other contemporaneous, mostly anecdotal reports. Ganja use is correlated with smoking and drinking. This is presumably a fairly new habit. A lot of illegal activity now revolves around importing and selling drugs in some communities, and much dysfunctional behaviour, psychoses and suicides have been associated with ganja use, especially in conjunction with alcohol.

The substantial differences in weight, BMI, waist and hips across communities in both females and males show that it is inappropriate to generalize about these parameters among Aboriginal groups, even in traditional people living in remote areas. While nearly 60% of adults in Community 3 were overweight or obese, nearly half the adults in Community 1 were 'underweight' by Australian BMI standards (17). We don't have convincing explanations for the differences in body habitus across communities, not for the preferential central fat distribution in women in all communities. Thus, we should not generalize assumptions about body habitus among Aboriginal people across communities and regions.

The much higher rates of overweight or obesity by waist than by BMI standards in females show a difference in body fat distribution relative to non-Aboriginal people. In view of the important associations of waist measurements with morbidities, described in the next chapter, we probably need different yardsticks to estimate optimal ranges of body weight and fat measures in these groups.

The lower birth weights recorded here are compatible with broader NT data (18). Our information, representing birth weights only of people who have thus far survived the infant, childhood and adult hazards to survival associated with lower birthweight, understate the prevalence of lower birth weights in the original birth cohorts to which these people belonged. Lower birth weight people, in general, are destined to be shorter, lighter adults. The cohort effect on birth weights seen in Community 1 is mirrored in some other communities across the NT (20,21,22,23), and is thought to reflect better nutrition and care of pregnant mothers in the more recent past. We do not know the bases for the lower birth weights in Community 1, but they are consonant with the leaner body habitus of the adults. The association of birth weights with morbidities is discussed in Chapter 5.

# **CHAPTER 5**

Rates and Distributions of Morbidities

Multiple Morbidities and their Integration

Factors Correlating with Morbidities

Suspected Morbidities

There are problems with the categorical yes/no definition of any morbidity. First, they ignore the fact that most of the physiologic and biochemical parameters of relevance to chronic disease are correlated with one another over a continuum. Second, all definitions are somewhat arbitrary, and higher rates of 'disease' will be exposed by lower defining thresholds. For example, if ACR was uniformly tested, more renal disease would be exposed than through urine dipstick findings, regardless of whether a 'likely abnormal' level of  $\geq 1.1$  (95th percentile for 'normal' populations) or ACR at the microalbuminuria threshold of  $\geq 3.4$  were applied. Hypertension defined by the threshold for 'high risk groups' of  $\geq 130/80$  would seem more appropriate than the WHO definition of  $\geq 140/90$ , especially in view of the mean BP of 121/77 in the overall study population which has such a high burden of disease. Finally, lower levels of 'suspicious' glucose would define much more 'dysglycemia'. All of the more sensitive definitions would allow intensified surveillance and interventions at earlier stages of the progression of the parameter in question.

However, we need to start somewhere. As presented in Chapter 2, the following categorical definitions of *suspected morbidities* were used, based on assessment of results after the first visit:

- Diabetes: an existing history, current hypoglycemic medications, random blood glucose >11 mmol/L and/or HbA1c ≥6.5%
- Renal disease: an existing history, current urine protein 1+ by dipstick, and/or urine ACR, when ordered, of ≥3.4 gm/mol
- Hypertension: an existing history, or baseline BP>140/90
   We will compare these suspected diagnoses with confirmed diagnoses in Chapter 5.

Five hundred and eighty-four of the 1070 people tested, or 54.6%, had one or more suspected morbidities. The most frequent diagnosis was hypertension, present or suspected in 432 people, or 40.4%, followed closely by renal disease in 405 people, or 38%, and then diabetes, in 234 people, or 22%. Because many people had multiple morbidities, there was substantial overlap.

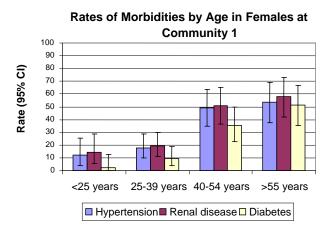
The number of people with diabetes was substantially lower than the number with hypertension and/or renal disease. The next figure shows this for each community.

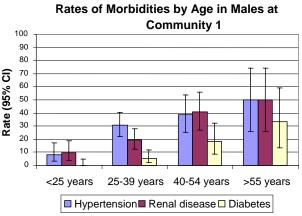
#### Community 1 90 ■ Hypertension Community 2 90 ■ Renal Disease 44 Diabetes 209 Community 3 187 120 0 50 100 150 200 250

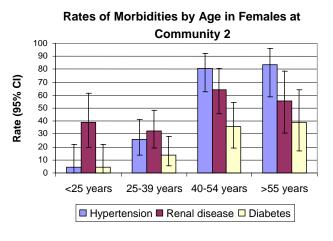
## **Numbers of People with Morbidities by Community**

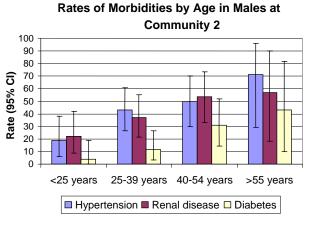
Females constituted 52% of all people tested, but constituted 61.1% of the diabetics, (for female excess, p=0.002), 58.5% of the people with renal disease (p=0.001) and 53% of the people with hypertension (p=0.61).

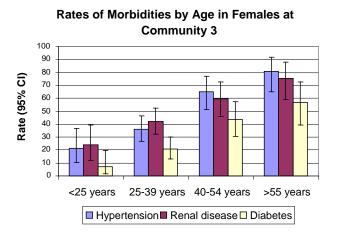
Rates of suspected diabetes, renal disease and hypertension in each community by age, category, and gender are shown in the Figures below. There were substantial rates of renal disease and hypertension in both sexes even in the youngest age group, and dramatic increases in rates of all morbidities with age. Rates seemed higher in females.

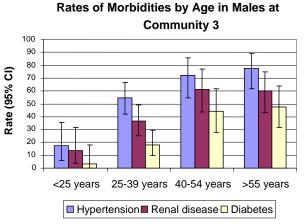






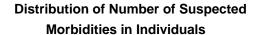


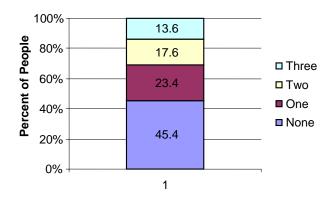




# **Multiple Morbidities**

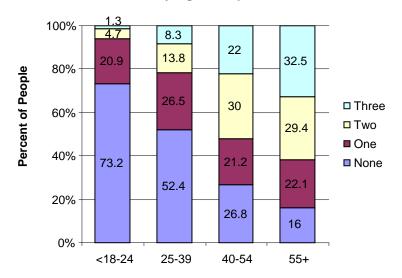
People were classified according to the number of morbidities suspected at first testing: As shown in the figure below, most people (54.5%) had one or more morbidity, and 31.1% had two or three morbidities.





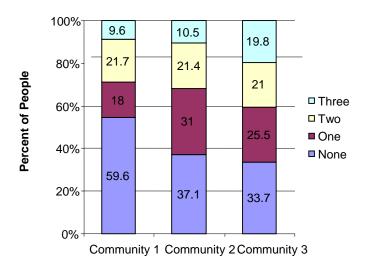
There was a marked increase in the number of morbidities with increasing age, as shown below. While almost 75% of people aged 18-24 years had no morbidities, only 16% of people aged 55+ had no morbidities, and nearly one third had three (p for difference in distribution <0.0001).

# Distribution of Number of Morbidities by Age Group



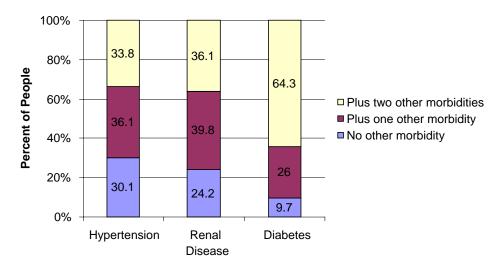
The next figure shows the significant differences in distribution of numbers of morbidities across communities (p<0.001). People in Community 1 were least likely to have any diagnosis and to have multiple diagnoses, and people in Community 3 were most likely to have one and multiple diagnoses. Odds ratios for these differences are presented later.

# Distribution of Number of Morbidities by Community



Diabetes was least likely to occur in isolation: only 10% of diabetics failed to qualify for another diagnosis, 26% had one additional diagnosis and 64% of diabetics had both renal disease and hypertension when screened as well. One quarter of people with renal disease and 30% of people with hypertension had those conditions as their sole diagnosis.

# Association of Index Morbidity with One or Two Additional Morbidities

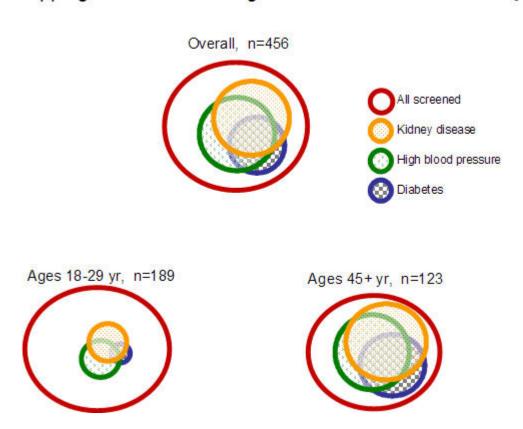


# **Overlapping Morbidities**

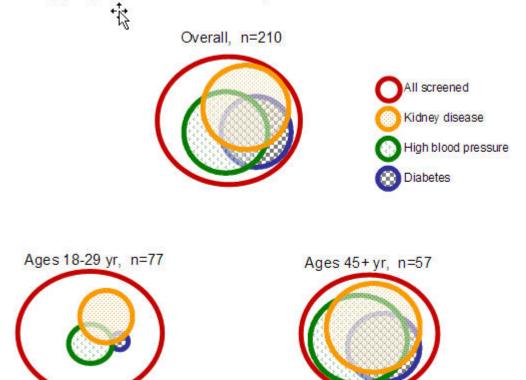
The following Venn diagrams also demonstrate the overlap of morbidities by community. Data are presented in aggregate and again in the youngest and oldest age groups in each community. They show:

- 1. The great degree of overlap of morbidities
- 2. The strong effect of age on morbidities and on overlap of morbidities
- 3. The gradation in numbers of morbidities from Community 1 to Community 3
- 4. That hypertension and renal disease are often isolated morbidities in young people
- 5. That diabetes is always the least frequent morbidity and exists in isolation very infrequently

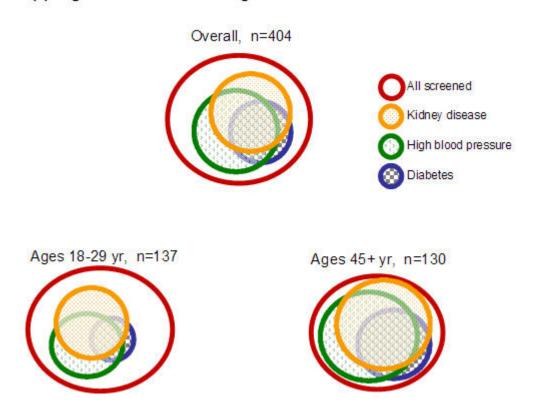
# Overlapping Morbidities among Screened Adults in Community 1



# Overlapping Morbidities among Screened Adults in Community 2



# Overlapping Morbidities among Screened Adults in Community 3



Note that only 26% of people aged 55+ years at Community 1, and 8% and 10% respectively at Community 2 and Community 3 were free of morbidities. The vast majority of people in this age group will need treatment for two or three conditions.

This dramatic demonstration supports the justification for integrated, rather than disease-specific, chronic disease testing.

## **Factors Correlating with Morbidities**

Factors with significant correlations with one or more morbidity included smoking, alcohol use, age, indices of body weight, gender, community, and birth weight.

## Smoking

Smoking, as shown in Table 2, was associated with *lower* rates of diabetes and, marginally, of renal disease, in females, but not in males. There were trends for higher rates of morbidities in males who smoked, but none approached significance.

#### Current Alcohol Use

Current alcohol use was associated with a 73% increase in risk of hypertension in females, also shown in Table 2. It was not correlated with renal disease or diabetes in females, and did not correlate with any morbidity in males.

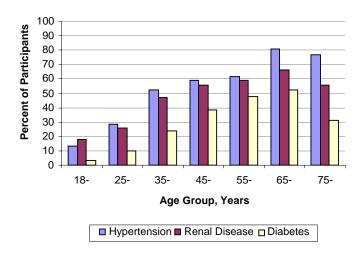
Table 1. Odds ratio (CI) of smokers (vs nonsmokers) and current alcohol user (vs nonusers) for morbidities, adjusted for all other factors

	Hypertension	Renal disease	Diabetes
Smokers vs Nonsmokers			
Females	0.72 (0.5-1.1), p=0.135	0.68 (0.5-1.0), p=0.057	0.48 (0.3-0.8), p=0.004
Males	1.10 (0.7-1.8), p=0.711	1.13 (0.7-1.9), p=0.649	1.40 (0.7-2.7), p=0.295
Drinkers vs NonDrinkers			
Females	1.73 (1.1-2.8), p=0.022	0.93 (0.6-1.5), p=0.766	0.82 (0.48-1.4), p=0.474
Males	1.23 (0.7-2.1), p=0.436	1.12 (0.7-1.9), p=0.464	0.78 (0.4-1.5), p=0.474

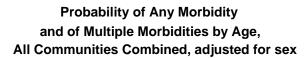
#### Increasing Age

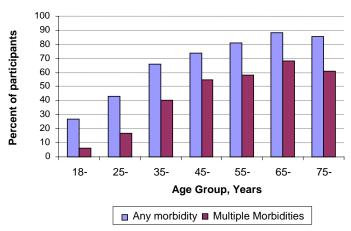
Age was the most powerful risk factor. Its effects, in all participants combined, are demonstrated by the figures below. They show substantial rates of hypertension and renal disease but relatively low rates of diabetes in the youngest people, a rise in rates with age of all morbidities through ages 65-70 yr, and lower rates, at least for diabetes, in those ages 75+ years. This is probably a combination of cohort and survivor phenomena.

Rates of Morbidities by Age,
All Communities Combined, adjusted for sex



The probabilities of having any morbidity and more than one morbidity showed a similar pattern. Almost 90% of those aged 65+ years had at least one morbidity and nearly 70% had multiple morbidities.





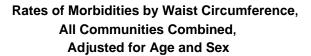
The effects of age were still strong after accounting for waist measurements, (which were themselves strongly correlated with age), demonstrated graphically later.

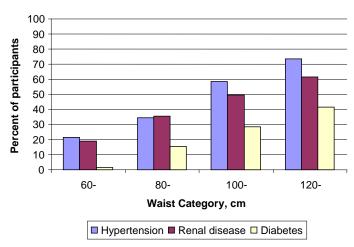
## Indices of Body Weight

Parameters of body weight or fat were powerfully associated with morbidities. Waist was superior to BMI, weight and hips in predicting diabetes and renal disease, while waist and weight were of comparable strength in predicting hypertension. WHR uniformly gave the weakest correlations. The effects persisted after adjustment for age.

The next figure shows the relationship of individual morbidities to waist circumference, adjusted for age and sex. There were substantial rates of hypertension and renal disease in people with the lowest waist

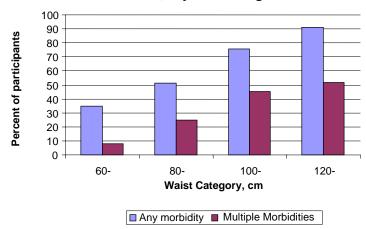
measurements, but diabetes rates were very low. All increased with higher waist measurements, with the gradients most marked for hypertension and diabetes.





The next figure shows the proportions of people with any morbidity and with multiple morbidities by waist measurement, after adjustment for age and sex. More than 90% of people with waist measurements of  $\geq$  120 cm had at least one morbidity, and more than half had multiple morbidities.

## Probability of Any Morbidity and of Multiple Morbidities, by Waist Measurement, All Communities Combined, adjusted for age and sex



Most of the waist measurements of the participants, however, were less than 120+ cm. Table 2 and Table 3 show the effects of increasing waist over the waist quartiles of the study population (females and males combined) on rates of morbidities, after adjustment for age, gender and community. People in the lowest waist quartile had substantial rates of renal disease and hypertension, with much lower rates of diabetes. All morbidities increased with increasing waist quartile, but diabetes most powerfully. People in the highest waist quartile had an odds ratio for diabetes of almost fourteen relative to those in the lowest quartile; however, their odds ratios for renal disease and hypertension were about four, reflecting, in part, the higher rates in the leanest people.

Table 2. Rates of morbidities (percent of people and 95%CI) by quartiles of waist measurement,

adjusted for age, gender and community

Waist Quartile	Hypertension	Renal disease	Diabetes	Any morbidity	2+ morbidities
<81.5 cm	24.3 (18-31)	20.3 (15-27)	2.7 (1-6)	38.9 (32-46)	9.8 (6-15)
81.5 - 90.9	29.7 (24-36)	28.1 (22-34)	11.7 (8-17)	46.2 (39-53)	16.4 (12-22)
91 – 101.9	39.8 (33-47)	44.8 (38-51)	20.0 (15-26)	57.3 (50-64)	35.0 (29-42)
102 - 147	60.1 (53-67)	50.2 (43-57)	28.4 (23-35)	79.6 (73-85)	44.7 (38-52)

Table 3. Odds ratios (95% CI) for morbidities in higher waist quartiles, relative to the lowest quartile,

adjusted for age, gender and community

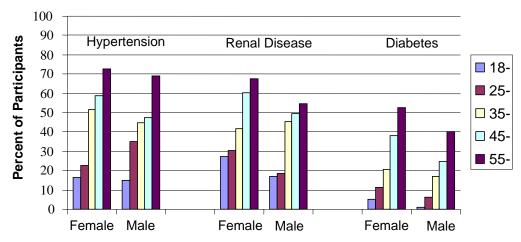
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Waist Quartile	Hypertension	Renal disease	Diabetes	Any morbidity	2+ morbidities
<81.5 cm	Referent	Referent	Referent	Referent	Referent
81.5 - 90.9	1.3 (0.8-2.0) *	1.6 (1.0-2.5) *	4.8 (2-12)	1.4 (0.9-2) *	1.8 (1-3.3) *
91 – 101.9	2.0 (1.2-3.1)	3.1 (2.0-5.0)	9.0 (4-22)	2.1 (1.4-3)	5.0 (3-9)
102 – 147	4.4 (2.8-7.0)	4.0 (2.5-6.3)	14.2 (6-34)	6.1 (4-10)	7.5 (4-13)

<sup>\*</sup> p<0.05

## Female Gender

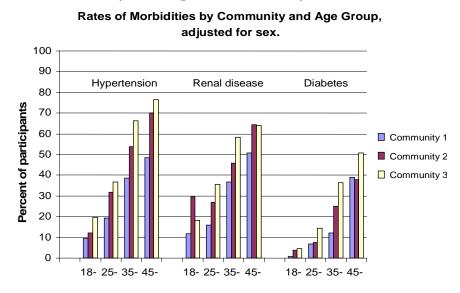
Females had, marginally, higher rates of renal disease than males, and significantly higher rates of diabetes and, marginally, of renal disease, even after adjustment for waist, as shown in the next figure. After adjustment for age, waist and clinic, the odds ratio (95%CI) of females versus males for hypertension was 0.8 (0.6-1.1), NS, for renal disease 1.3 (1.0-1.7), p=0.1, and for diabetes 1.5 (1.1-2.2), p<0.05. Gender contributed relatively little to overall LR chi² or explanation of these conditions.



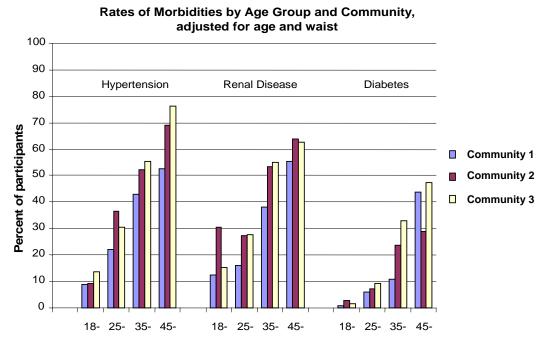


## **Community**

Rates of all morbidities differed among communities, as shown by age group in the next figure. They were generally lowest in Community 1 and highest in Community 3.



This was, in part, associated with higher waist measurements, but differences still persisted after these were taken into account, as shown in the next figure.



The next table shows the odds ratios for morbidities of Community 2 and Community 3, compared with Community 1, after adjustment for other factors. Hypertension and renal disease were twice as common in Community 2 as Community 1, and all conditions in Community 3 were more than twice those in Community 1. It is important to note that the frequencies of *any morbidity* in Community 2 and Community 3 were almost three times those in Community 1. This explains the large burden of clinical activity generated in the treatment stream, especially in Community 3.

Table 4. Odds ratios (CI) for conditions by community

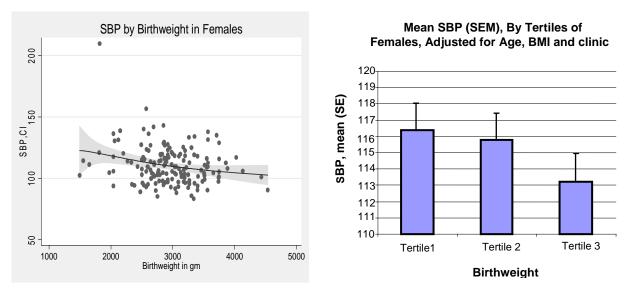
Adjusted for	Hypertension	Renal disease	Diabetes	Any morbidity	2+morbidities
Age & sex					
Community 1,	referent	referent	referent	Referent	referent
Community 2	2.0 (1.4-2.8)	2.0 (1.4-2.8)	1.4 (0.7-2.2)	2.8 (1.9-3.9)	1.7 (1.2-2.6)
Community 3	2.6 (1.9-3.6)	2.1 (1.5-2.8)	2.1 (1.5-3.0)	2.9 (2.2-4.0)	2.4 (1.7-3.3)
Age, sex & waist					
Community 1,	referent	referent	referent	Referent	referent
Community 2	1.7 (1.1-2.6)	1.9 (1.3-2.9)	1.0 (0.6-1.7) *	2.6 (1.6-4.0)	1.4 (0.9-2.3) *
Community 3	1.9 (1.4-2.7)	1.6 (1.1-2.2)	1.6 (1.1-2.4)	2.2 (1.6-3.0)	1.6 (1.1-2.4)

<sup>\*</sup> p<0.05

## Birth Weight

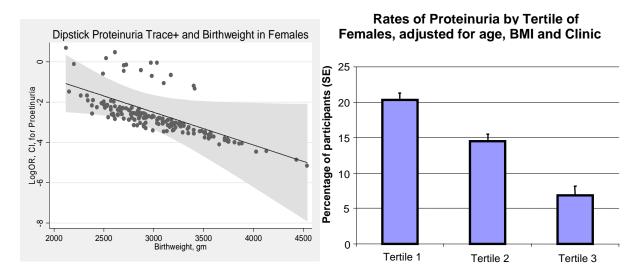
The associations of birth weights with morbidities were all inspected in the context of other potentially significant variables, including age, gender where appropriate, clinic and weight or BMI. Adjustment for weight or BMI always enhanced or reduced birth weight effects.

The next figure shows that SBP was inversely correlated with birth weight over a continuum of birth weights in females, after accounting for age, BMI and clinic. The data predict an increase in SBP of 3.3 mmHg (CI 0.8-5.7) for each 500 gm reduction in birth weight, p=0.009. There was no significant correlation with DBP. Blood pressure did not correlate significantly with birth weight in males.

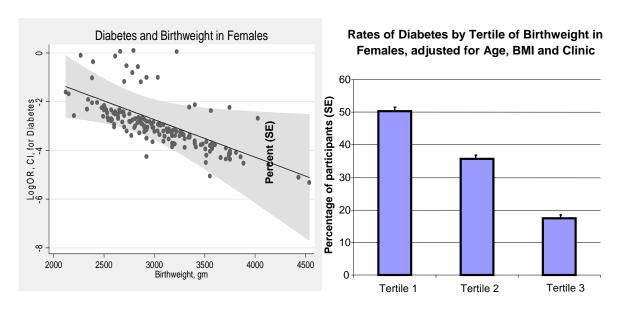


The associations of birth weight with renal disease and diabetes were not straight line functions, and morbidities had a different relationship to birth weights less than <2100 gm (n=24) than to the vastly greater numbers of more robust birthweights. The relationships with birthweights >2000 gm are shown below.

Proteinuria by dipstick was significantly correlated with birth weight in females, as shown in the next figure. The equation yields an odds ratio (CI) of 2.28 (1.01-5.1) for each 500 gm reduction in birth weight, p=0.046. There was no significant relationship in males.



The next figure shows an inverse relationship of diabetes to birth weight in females, after adjustment for age, BMI or weight and clinic. The equation yields an odds ratio (CI) for diabetes of 2.12 (1.04-4.34) for every 500 gm decrease in birthweight, p=0.038.



There is some suggestion of an upturn in rates among females of the highest birthweights. This and other complexities are undergoing further analysis.

# Multivariate Modeling of Suspected Morbidities

Potential predictors of various diagnoses were evaluated in multivariate models if they had significant univariate correlations (p<0.05) with the outcome of interest, and were retained in the final model if their p values in the models were <0.10. Birth weight was not added to these models because of the restricted number and age range of people with available birth weights.

As shown in Table 5, age and waist had the most powerful correlations with each morbidity, any morbidity, and multiple morbidities. They had significant collinearity, but strong independent effects as well. Although contributing relatively little extra explanation, the community of origin was also

correlated with every category of diagnosis. Female gender was significantly correlated with diabetes and renal disease, and male gender with hypertension (the last two at p<0.1). Because of its opposing effects on separate morbidities, gender had no relationship to the presence of any morbidity or multiple morbidities. Smoking was correlated (negatively) with hypertension, and with any morbidity and multiple morbidities, while alcohol use positively correlated with hypertension.

The most complete explanation for separate morbidities, reflected by the likelihood ratio (LR) (chi square statistic), is for hypertension, followed by diabetes, then, last, renal disease. The explanations for any morbidity and for multiple morbidities are more complete than for morbidities separately.

Table 5. Significant independent predictors of morbidities from multivariate models.

(p values, adjusted for other factors)

	Hypertension	Renal disease	Diabetes	Any morbidity	2+ morbidities
Age category	< 0.0001	< 0.0001	< 0.0001	< 0.0001	< 0.0001
Waist category	< 0.0001	< 0.0001	< 0.0001	< 0.0001	< 0.0001
Community	=0.001	0.011	0.038	< 0.0001	0.022
Sex	0.091 **	0.063 *	0.051 *	NS	NS
Smoker ***	0.052	NS	NS	0.059	0.024
Alcohol use	0.013	NS	NS	NS	NS
Total LR chi <sup>2</sup>	244	182	227	277	292

<sup>\*</sup> females at greater risk \*\* males at greater risk

Finally, the correlations of morbidities with one another were examined. Table 6 shows a 9.9-fold increase in rates of renal disease in diabetics, and vice versa. This differential was almost halved, but still remained very powerful, after adjustment for other significant factors. Diabetics had a 7-fold increase in rates of suspected hypertension, (and vice versa) which fell to a 3-fold difference after adjustment for other factors. People with hypertension were 6.8 times as likely to have renal disease (and vice versa), with a 4-fold difference persisting after adjustment.

Table 6. Odds ratios (95% CI) for associations of morbidities with each other

Adjustment	Diabetes and	Diabetes and	Hypertension and	
	Renal Disease	Hypertension	Renal Disease	
None	9.9 (6.9-14)	7.2 (5.1-10.1)	6.8 (5.2-9.0)	
For age	7.1 (4.9-10.2)	4.5 (3.2-6.5)	5.1 (3.8-6.8)	
For age & waist	5.8 (3.8-8.7)	3.3 (2.2-4.9)	4.3 (3.1-6.9)	
For age, waist, sex & community	5.7 (3.8-86)	3.3 (2.2-4.9)	4.3 (3.1-6.0)	

In multivariate models already containing the independent risk factors for each morbidity, inclusion of each of the other two diagnoses progressively increased the LR chi<sup>2</sup>, as shown in Table 7.

Table 7. Potential predictors of morbidities from multivariate models

Morbidity predicted	Adjusted for	LR chi <sup>2</sup>
Hypertension	Age, waist, clinic, smoker, alcohol	246
	Plus renal disease	324
	Plus diabetes	339
Renal disease	Age, waist, clinic, sex	182
	Plus hypertension	264
	Plus diabetes	317
Diabetes	Age, waist, clinic, sex	227
	Plus renal disease	306
	Plus hypertension	317

<sup>\*\*\*\*</sup> Note; smoking reduces the risk of hypertension, any morbidity and multiple morbidities.

#### Discussion

Rates of suspected morbidities, especially diabetes and renal disease, appeared excessive in all communities. Rates of morbidities increased strongly with increasing age and parameters of body weight, especially waist circumference. Females had a moderate increase in risk for diabetes, and, possibly, for renal disease, than males.

Although excessive in all, the prevalence of morbidities varied across communities, with rates at Community 2 and Community 3 sometimes twice those at Community 1. The differences are partly, but not entirely, explained by differences in body weight or waist circumferences. We cannot comment on the likely causes of this 'inherent' difference in disease predisposition, if it is real. It might reflect differences in diet or activity or the burden of infection and/or inflammation, which were not analysed, or differences in early life events, or other factors, including genetic factors. The different rates of morbidities across communities, however, show that pilot studies of risk factors and disease markers are needed in every region to gage the disease burden and to plan the appropriate level of resources to deal with it. This is a critical issue: with the rates of persons having *any morbidity* in Community 3 almost three times those of people in Community 1, the clinical stream accommodating people needing further diagnostic tests, and most especially needing treatment and ongoing intensified surveillance, will be much greater, on a per capita basis, than the same service load in Community 1.

The increase in rates of morbidities and of multiple morbidities with age is very powerful. It tells something about the pathogenesis of disease. When inspected in conjunction with the baseline health profile of an individual community, and with knowledge of the age structure of that community, it allows tentative projections of future disease burdens as these populations age. This could assist health service planning. It also provides the strong rationale for repeat testing for chronic disease risk factors and markers throughout adult life. The optimal frequency of such testing, which should represent a balance between operational and cost-efficiency at the clinic level, and timely diagnosis in people needing interventions is not known, but baseline data like these could be used to make such estimates. The best way to assess the optimal efficiency of timing of repeat screening, however, is to follow-up these baseline studies with longitudinal observations.

The distribution of the numbers (as opposed to rates) of morbidities by age category, presented for each community in Chapter 2, tells us where the greatest burden of disease currently lies. These are the people needing intervention now. Although *rates of morbidities* are highest in the oldest people, the *majority of people with morbidities* are young or middle age adults: thus many years of treatment, and often multiple drug treatment must be anticipated for many, if they are to have a life expectancy approximating that of non-Aboriginal people. These data, too, should inform strategic health services planning.

The frequent co-existence of more than one morbidity, and the usual presence of multiple morbidities in people aged 40+ years in all communities provides a pressing case for integrated screening at every chronic disease testing encounter. No more time or resources should be spent on 'disease-specific' screening programs. The coexistence of multiple morbidities probably indicates that they are manifestations of a single syndrome. This might be termed a 'renal/vascular/metabolic syndrome', although chronic lung disease should probably be added in the Aboriginal context, given the shared risk factors of low birth weight, infant malnutrition, infections and smoking. The elements of the syndrome share a substantial menu of risk factors, and also have cause-and effect relationships. The integration of the syndrome means that preventative programs should reduce risk for all morbidities, and need not be tailored to single condition. The presence of multiple morbidities also means that interventions and

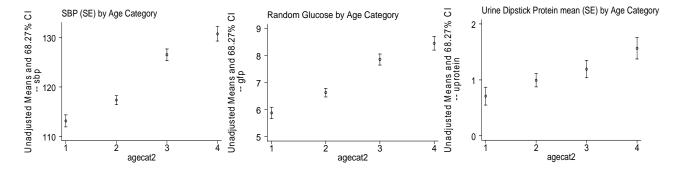
usually medicines for more than one condition will be required in most people of 40 years of age and above, and maintained for the rest of their lives. The significance of profiles such as these for health services projections and planning is discussed further in Chapter 7.

The position of diabetes in this renal/vascular/metabolic syndrome needs reassessment. The traditional teaching that hypertension and renal disease are largely due to diabetes is not supported by these data. While rates of all conditions increase with age, renal disease and hypertension are much more common than diabetes at all ages. Renal disease and hypertension are quite common in young adults, and in people who are quite lean. The majority of diabetes occurs substantially later in life, at lower rates, and nearly always in the presence of proteinuria and/or hypertension, and is more critically related to increasing parameters of body fat. These data suggest that proteinuria and hypertension are early manifestations of Syndrome X, or the metabolic/vascular syndrome, and that diabetes, is a variable and advanced manifestation of the syndrome, rather than its cause.

Tiwi data support this view. In the Tiwi screen, ascertainment of renal disease was more accurate and sensitive because urine ACR was the universal screening test. The profile showed that pathologic albuminuria was the earliest manifestation of the syndrome, and was always, in every age and gender-specific group, the most common 'morbidity' (24).

There are additional causes for renal disease and hypertension beyond Syndrome X-specific risk factors. Promotion of hypertension by alcohol has been demonstrated by this outreach information, and infections, including scabies, group A streptococcal infections, and post-streptococcal glomerulonephritis are known to be risk factors for renal disease (25, 26).

As emphasized earlier, the use of categorical variables obscures the evolution of blood pressures, proteinuria and dysglycemia over a continuum with age, and their inevitable correlations on a continuum, as demonstrated in the screened population by the three graphs below.



These observations provide an additional rationale for early diagnosis and intervention for albuminuria and rising blood pressures, and for using an antihypertensive drug regimen that improves insulin sensitivity and glucose tolerance (and the whole metabolic profile). Angiotensin converting enzyme inhibitors have such effects, that are most dramatically evidenced by incidental findings of a consistent 25 to 35% reduction in the incidence of new onset type 2 diabetes several years of follow-up in people randomized to the ACEi arms vs the nonACEi arms of several large trials of antihypertensive agents or cardiovascular protection, including HOPE, ALLHAT, RENAAL, and EUROPA. The HOPE experience has been described by Yusuf et el, cited in Chapter 8: Results of some of the other trials were summarised by Prof Colin Johnson, Third Annual Heart and Vascular Disease Symposium, International Institute of Health/Baker Institute Vascular meeting: Sydney, Oct 25, 2003.

We could not define an adverse effect of smoking on morbidities, although this is contrary to observations in many other non-Aboriginal settings. Rather, there was an apparent protective effect of smoking in females, but its contribution to overall rates was small. The interpretation of this is problematic. It could be mediated in part through differences in body weight, although our limited modelling techniques indicated that the effect was independent of parameters of body weight. A protective effect of smoking on morbidities has also been demonstrated in the Tiwi kidney disease study (26) and in the Angurugu community on Groote Eyelandt (27). In the latter study, smoking status was confirmed by urinary cotinine measurements, leaving no doubt about the validity of the history (19). In addition, Tiwi data fail to show an adverse effect of smoking on mortality. One potential explanation is that smoking might mark relative affluence in these settings, and relative affluence itself is associated with better health profiles and lower mortality. Our findings need more explanation and should not adversely influence vigorous interventions to reduce smoking in these settings.

The association of alcohol use with hypertension in females is important, as it is one potential modifiable factor. The Tiwi data takes that one step further, also permitting modelling of heavy alcohol use with albuminuria by the more sensitive ACR test (26).

The association of morbidities with parameters of body weight and central fat deposition over a continuum are powerful indeed. The higher waist measurements in women relative to their BMI seem to be critical. The gender differences in morbidities are the same as described in Tiwi. Finally, the differences by community, not entirely due to differences in body size, still require explanation. These matters are discussed further in Chapter 8.

The inverse association of birth weight with blood pressure, proteinuria and diabetes in females seems to confirm the Barker hypothesis of the predisposition of lower birth weight people to chronic disease in adults (28). The demonstration of the phenomenon in this population is remarkable in that the number of subjects is small, they are relatively young, and the relationship exists for all three morbidities simultaneously. Tiwi data support the observation, in a study of people up to 38 years of age (of maximum age 10 years less than those with birth weights in this cohort), birth weights in females was inversely correlated with SBP, with albuminuria, and with fasting hyperinsulinemia (21,22,23). In both, birth weight seemed to contribute about 30% of the explained variance for the abnormalities in females. It is important to note that in both groups, the relationships show no threshold, indicating that improvements of birth weight within the 'normal' range, as well as those below 2500 gm, will have benefit. There is considerable scepticism in the Australian environment about the implications of such findings. Suffice to say that, while lower birth weights in isolation might have little influence on chronic disease profiles, their effects in amplifying risk in the presence of other risk factors, most notably increase in body fat, appears to be quite significant.

# CHAPTER 6

# Adherence to Testing and Treatment Algorithms

**Initial and Confirmed Diagnoses** 

New Diagnoses

This chapter is divided into three sections. The first is an evaluation of 'adherence' to testing algorithms by the staff in the chronic disease program. The second is a comparison of 'initial' diagnoses, based on assessment of data from the first or baseline visit with 'confirmed' diagnoses, reached by review of all baseline and subsequent information over the entire follow-up course. The third presents the number of new diagnoses made in the course of the program.

## Adherence to Testing Algorithms

We cannot reliably describe the completeness and time course of adherence to the full menu of tests required in the regular check-up, and in the follow-up visits, because we have filled most of the initial deficits in information retrospectively. We can, however, evaluate the extent to which special tests or repeat readings were performed, when the protocols called for them.

Aboriginal participants in the chronic disease program aged 18 years and above who were screened at least six months prior to the cessation of KDRP's involvement (up to December 31, 2002), were included in these analyses. This, in theory, allowed at least six months to pursue an abnormal or suspicious finding after it was first detected. There were 801 people in this group, of whom 47.8% were females.

We assessed adherence to algorithms through evaluating the proportion of participants in whom a specified test of treatment was performed, when needed or indicated, as recorded in our database. Our protocols call for the following tests at, or following on from, results on the baseline screen:

- A glycosylated haemoglobin measurement on all diabetics
- Further assessment of glycemic status in patients with elevated blood glucose at baseline visit, who were not previously known to be diabetic, by a repeat random glucose measurement, a fasting glucose measurement, a glucose tolerance test of an HbA1c measurement or glucose tolerance test (GTT)
- An ACR on people with proteinuria ≥1+ and on all those with past history of proteinuria
- An ACR on all diabetics
- An ACR on people with hypertension
- A serum creatinine on everyone with overt albuminuria (ACR 34+) and on those with known or suspected renal insufficiency
- A repeat blood pressure measurement on all those with elevated blood pressure, who were not previously known to have hypertension.

Although the "adherence" data are accurate, the time frames in which the required observations or tests were made to comply with protocols were not necessarily as specified or ideal.

#### Results

The next figure summarises adherence to seven protocol requirements in the aggregate community experience. Compliance was best at >90% for measuring HbA1c in diabetics and serum creatinine in people with overt albuminuria, and least for repeat blood pressure measurements in people with suspected hypertension. Nonetheless adherence was more than three quarters in all the seven required protocols.

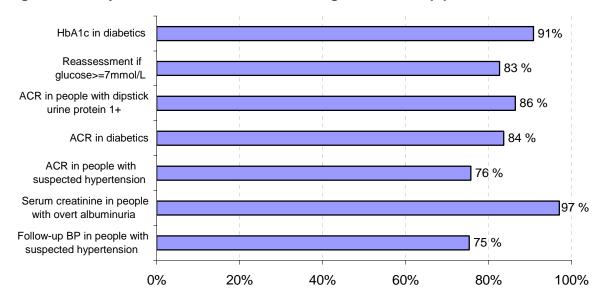


Fig 1. Summary of 'adherence' to our screening and follow-up protocols

Table 1 lists this information by community and by gender.

- Among confirmed diabetics, ordering of HbA1c was lowest among females at Community 1 at 68%, and best at Community 3 at 98%.
- Among people with a random blood glucose level ≥7 mmol/L, and no known history of diabetes, ordering a repeat glucose measurement- either random or fasting glucose or a GTT, and/or an HbA1c measurement was lowest among males at Community 3 (at 67%) and highest among males at Community 1 (at 95%).
- Among people with 1+ protein by dipstick, without a known history of renal disease, adherence was only 40% among the five index females at Community 1, but otherwise ranged from 90% to 100% among other community and gender-specific groups. The highest rates at Community 3, recording 90%.
- Among people with suspected diabetes, compliance for ACR was lowest (60%) among females at Community 1, but ranged from 86% to 90% in the other gender and community-specific groups. Overall, adherence was best at Community 2 and Community 3, at 88% each.
- Among people with an initial diagnosis of hypertension, the lowest compliance was among females at Community 2 (at 40%), while the other gender and community-specific rates ranged from 65% to 86%. Overall, compliance was best at Community 3 at 80%.
- Among people with a recorded urine ACR of 34+ gm/mol (overt albuminuria), compliance in ordering and recording serum creatinine was excellent in all communities.
- Compliance with the requirement of repeating a blood pressure on a different day in people with suspected hypertension ranged from 59% in males at Community 1 to 95% in females at Community 3.

Table 1. Adherence to protocols for further testing or for repeat observations

Adherence Criteria	Females	Males	Total
HbA1c levels in confirmed diabetics			
Community 1	17/25 (68.0%)	17/19 (89.5%)	34/44 (77.3%)
Community 2	14/15 (93.3%)	10/11 (90.9%)	24/26 (92.3%)
Community 3	51/53 (96.2%)	30/30 (100.0%)	81/83 (97.6%)
Total	82/93 (88.2%)	57/60 (95.0%)	139/153 (90.8%)
Reassessment of glycemia * in people		<u> </u>	
with random glucose $\geq$ 7 mmol/L and no			
prior history of diabetes			
Community 1	16/19 (84.2%)	38/40 (95.0%)	54/59 (91.5%)
Community 2	12/13 (92.3%)	5/6 (83.3%)	17/19 (89.5%)
Community 3	28/39 (71.8%)	10/15 (66.7%)	38/54 (70.4%)
Total	56/71 (78.9%)	53/61 (86.9%)	109/132 (82.6%)
Urine ACR in people with dipstick			
protein ≥1+ and no prior history of renal			
disease		,	,
Community 1	2/5 (40.0%)	16/18 (88.9%)	18/23 (78.3%)
Community 2	4/4 (100.0%)	9/11 (81.8%)	13/15 (86.7%)
Community 3	28/29 (96.6%)	17/21 (81.0%)	45/50 (90.0%)
Total	34/38 (89.5%)	42/50 (84.0%)	76/88 (86.4%)
Urine ACR in people with			
initial diagnosis of diabetes		.= / (2.2.7.0)	
Community 1	15/25 (60.0%)	17/19 (89.5%)	32/44 (72.7%)
Community 2	16/18 (88.9%)	12/14 (85.7%)	28/32 (87.5%)
Community 3	46/53 (86.8%)	27/30 (90.0%)	73/83 (88.0%)
Total	77/96 (80.2%)	56/63 (88.9%)	133/159 (83.6%)
Urine ACR in people with			
initial diagnosis of hypertension	20/21/51/50/	5 + / 5 <b>5</b> + (0 <b>5</b> + <b>0</b> (0)	= + /o + /= o = o /o
Community 1	20/31 (64.5%)	54/63 (85.7%)	74/94 (78.7%)
Community 2	29/39 (74.4%)	10/25 (40.0%)	39/64 (60.9%)
Community 3	72/87 (82.8%)	46/60 (76.7%)	118/147 (80.3%)
Total	121/157 (77.1%)	110/148 (74.3%)	231/305 (75.7%)
Serum creatinine in people with ACR 34+			
Community 1	12/12 (100.0%)	16/17 (94.1%)	28/29 (96.6%)
Community 2	14/15 (93.3%)	7/7 (100.0%)	21/22 (95.5%)
Community 3	32/33 (97.0%)	16/16 (100.0%)	48/49 (98.0%)
Total	58/60 (96.7%)	39/40 (97.5%)	97/100 (97.0%)
Follow-up BP in people with elevated BP			
at baseline, and no prior history of			
hypertension			
Community 1	5/6 (83.3%)	10/17 (58.8%)	15/23 (65.2%)
Community 2	10/14 (71.4%)	8/9 (88.9%)	18/23 (78.3%)
Community 3	18/19 (94.7%)	13/20 (65.0%)	31/46 (67.4%)
Total	33/39 (84.6%)	31/46 (67.4%)	64/85 (75.3%)

#### Discussion

Adherence to adapted evidence-based guidelines and protocols is a crucial factor for a successful community-based program. Implementing guidelines in a primary health care setting is a major challenge in remote underserved Aboriginal communities.

The adherence to protocols for evaluating or confirming apparent abnormalities is understated in this report, because substantial numbers of encounters and lab results were lost from the database during the early and mid phases of its development, and particularly its transfer from ACCESS to web-based form. The adherence, nonetheless, appears generally good. There are, however, a few qualifications, as follows:

First, although recommendation for such testing usually occurred fairly promptly after review of the suspicious or abnormal values by KDRP staff, the execution of the confirmatory testing/readings were often considerably delayed, due to health worker shortages, absences, non responses or work overload. We cannot claim that all these confirmatory steps were taken within three or even six months of an initial reading, and in some cases the full diagnostic data were not in hand or nor acted upon for long periods. Neither can we claim to have established regularity for repeated testing at scheduled intervals-, for example, for HbA1c levels every three months for diabetics, as the NT Chronic Disease Guidelines call for.

Second, evaluation of adherence to protocols is principally targeted at assessing the extent to which health workers follow algorithms and work semi-independently. However, many of the follow-up activities we describe here were recommended by KDRP nurse coordinators and a substantial number performed either during, or on the instigation of, a nurse coordinator visit to a community. In addition, confirmatory testing was not always distributed smoothly over the working weeks or months of routine chronic disease activity: A substantial amount of 'catch-up' activity in batches was also performed at intervals to flesh out or confirm diagnostic profiles.

Adherence to protocols improved over time. At the start of the program, local health workers were already comfortable performing routine blood glucose measurements, ordering HbA1c levels without prompting in diabetics and checking blood pressures in people already known to be hypertensive. The regular testing of ACR in diabetics took some time to establish, but is now fairly well systematised, while the regular ordering of urine ACR in hypertensive people still requires prompting. The acquisition of knowledge and skills in the KDRP nurse coordinators followed a very similar sequence, a few months earlier.

The availability and productivity of same-gender health workers made a big impact on adherence to protocols. With no local health worker support at Community 1 and an all-male team of KDRP nurse coordinators, the chance to test and follow-up females was seriously restricted, and largely relied on the good will of the otherwise busy female clinic staff, and collaboration with the female THS chronic disease coordinator, at times when that position was filled. The fall-off in productivity and ultimate resignation of the female health worker in Community 3 left follow-up of females to intermittent visits by KDRP's female nurse coordinator (Jo Scheppingen) in the last year, except for a couple of group visits by the broader KDRP team. It also compromised chronic disease activity among males at Community 3, as the task of directing the two, much less experienced and more tentative part-time male health workers/assistants also fell to Jo. Suboptimal health worker productivity at Community 2 also resulted in much delay in confirmatory tests and follow-up visits.

Finally, it is self evident that the size of the population and the disease burden will influence the chronic disease work load in any community, including the proportion of the population that can participate in regular screening in any interval and the extent of adherence to testing and treatment algorithms. The high rates of all morbidities in Community 3, especially, means it will need to be more expansively resourced for good, complete chronic disease care than the much smaller population of Community 2 with an arguably lower disease burden, or the marginally larger population at Community 1 with the lowest disease rates at this point in time.

#### Part 2

## Initial Diagnoses, Confirmed Diagnoses and New Diagnoses

This section compares initial diagnoses based on baseline (first) examinations with confirmed diagnoses.

*Initial (suspected) diagnoses,* as outlined already in this chapter, were based on the following categories, based on assessment of results after the first (baseline) visit:

- Diabetes: an existing history, current hypoglycemic medications, random blood glucose >11 mmol/L and/or HbA1c ≥6.5%
- Renal disease: an existing history and/or on vasoactive medications (with negative history of hypertension), current urine protein 1+ by dipstick, and/or urine ACR, when ordered, of ≥3.4 gm/mol
- Hypertension: an existing history and/or on vasoactive medications (with negative history of renal disease) or baseline BP≥140/90

The analyses of rates of morbidities and their associations in Chapter 2 are based on initial suspected diagnoses. These include people in whom an initial diagnosis was not subsequently confirmed, and omit people without a history of a morbidity nor evidence of a morbidity on first examination, in whom subsequent findings were abnormal, thus missing a few 'confirmed' cases.

Confirmed diagnoses included people with a previous history of a morbidity and those without a previous history but with abnormal readings/values at first or later examinations that were subsequently supported by one or more additional abnormal readings/values. In general, confirmed diagnoses will be fewer than suspected diagnoses, although they include a number of people in whom abnormalities, subsequently confirmed, were not picked up on the initial examination (see above).

**New diagnoses** were confirmed diagnoses in people without a prior recorded history of, or treatment for, the relevant condition.

A final, unresolved category consists of patients whose diagnostic status remains unclear at this time. These are people without a previous history of a morbidity, in whom a result during first or follow-up testing was abnormal or suspicious, but was not confirmed by subsequent testing or in whom subsequent testing/readings have yet been performed.

Table 2 compares initial and confirmed diagnoses of hypertension by community and gender. Their correlation was very strong (Chi² 82, p<0.0001). There were 62 fewer people in the 'confirmed' than the suspected diagnosis category.

Table 2. Suspected and confirmed diagnoses for hypertension

Communities	Females		Males		Total	
	Initial	Confirmed Initial Confirmed		Initial	Confirmed	
	Diagnoses	Diagnoses	Diagnoses	Diagnoses	Diagnoses	Diagnoses
Community 1	66	58	67	54	133	112
Community 2	52	48	38	35	90	83
Community 3	111	98	98	77	209	175
Total	229	204	203	166	432	370

We could not confirm elevated blood pressures in 7 of the 54 people who had elevated readings at first visit, but no prior history. Conversely we detected and confirmed elevated blood pressures in 10 of 81 people who had no prior history and had normal blood pressures at first visit.

The positive predictive value of a high initial blood pressure reading in a person without a prior history of hypertension for one or more high subsequent readings was 82% (CI 70-91%). We were unable to evaluate the number of people without hypertension on first visit who were truly normotensive, because many people with a normal baseline screen did not have a subsequent visit in which normal blood pressures could be confirmed.

Table 3 shows initial and confirmed diagnoses of renal disease by community and gender. There were 31 fewer people with confirmed diagnoses than people with initial diagnoses.

Table 3. Initial and confirmed diagnoses for renal disease

Tuble 5. Initial and committee diagnoses for remark disease							
Communities	Females		Males		Total		
	Initial	Confirmed	Initial	Suspected	Initial	Confirmed	
	Diagnoses	Diagnoses	Diagnoses	Diagnoses	Diagnoses	Diagnoses	
Community 1	71	63	57	47	128	110	
Community 2	53	49	37	30	90	79	
Community 3	113	112	74	73	187	185	
Total	237	224	168	150	405	374	

The positive predictive value of a urine dipstick protein of 1+ for a subsequent abnormal ACR was 45% (38-53%). Thus, almost half the people without a prior history of renal disease, who tested positive for urine protein by dipstick, were correctly identified as having renal disease. We cannot comment about sensitivity, specificity or negative predictive value, as we do not know the reservoir of pathologic albuminuria in people who had a normal urine protein dipstick reading.

Table 4 compares numbers of people with suspected and confirmed diagnoses of diabetes by community and gender. All suspected diabetics had their diabetic status confirmed. No additional cases were detected through further follow-up.

Table 4. Initial and confirmed diagnoses for diabetes

Communities	Females		Males		Total	
	Initial	Confirmed Initial Confirmed		Initial	Confirmed	
	Diagnoses	Diagnoses	Diagnoses	Diagnoses	Diagnoses	Diagnoses
Community 1	48	48	22	22	70	70
Community 2	25	25	19	19	44	44
Community 3	70	70	50	50	120	120
Total	143	143	91	91	234	234

#### Discussion

The good correlation between initial vs confirmed diagnoses lends support to the validity of the rates and correlations of morbidities that were described in Chapter 2, which were based on initial diagnoses. The correlation is driven, in large part, by the inclusion of people with an existing history of a condition in both categories. However, the data also confirm that initial impressions of abnormality in people without a prior history are very often valid. The lack of confirmation in some cases supports the need for follow-up testing. However, while follow-up testing can confirm a diagnosis, it can never entirely

refute a tentative diagnosis made on an earlier abnormal finding, unless an individual is followed for a lifetime.

The accrual of confirmed cases after normal baseline findings also emphasizes the need for repeated testing over intervals. This is driven both by the inherent variability in some of the readings and tests, as well as frankly erroneous values, as well as the documented increase in all morbidities with increasing age, as already discussed in Chapter 2.

#### Part 3

# **New Diagnoses**

This section presents the number of confirmed new diagnoses made through testing in the chronic disease program. In a substantial number of participants chronic disease diagnoses were made that were previously unidentified, or at least not reflected in the participant's medical records or in their medications.

The number of existing and of new diagnoses are summarised in the next figure. Fifty seven more people were diagnosed with hypertension, or an additional 18.2%; renal disease was newly diagnosed in 196 people, or an additional 110%; diabetes was diagnosed for the first time in 48 people, or an additional 25.8%.

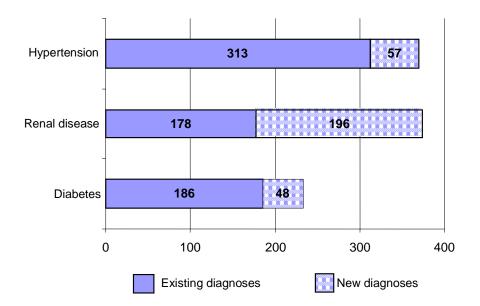


Figure 2: Existing and New Diagnoses among 1070 screened people

Table 5 shows initial and new diagnoses of hypertension by community. Although the numbers in each were appreciable, there are undoubtedly others, derived in part from the 21 people who had an initial high blood pressure reading who have not had a repeat blood pressure.

Table 5. Confirmed new diagnoses for hypertension

Communities	Females		Males		Total	
	Past	New	Past	New	Past	New
	History	Diagnoses	History	Diagnoses	History	Diagnoses
Community 1	51	7	48	6	99	13
Community 2	34	14	26	9	60	23
Community 3	87	11	67	10	154	21
Total	172	32	141	25	313	57

Table 6 shows the existing and additional diagnoses of renal disease in each community. Diagnoses were increased by more than 80% in Community 1 and Community 2, and by 150% in Community 3.

Table 6. Confirmed new diagnoses for renal disease

Communities	Females		Males		Total	
	Past	New	Past	New	Past	New
	History	Diagnoses	History	Diagnoses	History	Diagnoses
Community 1	42	21	19	28	61	49
Community 2	27	22	16	14	43	36
Community 3	48	64	26	47	74	111
Total	117	107	61	89	178	196

Table 7 shows the number existing and new diagnoses of diabetes by community. Fourteen additional people were identified with confirmed diabetes in Community 2, 14 in Community 1, and 20 in Community 3.

Table 7. Confirmed new diagnoses for diabetes

Communities	Females		Males		Total	
	Past History	New Diagnoses	Past History	New Diagnoses	Past History	New Diagnoses
Community 1	42	6	14	8	56	14
Community 2	21	4	9	10	30	14
Community 3	60	10	40	10	100	20
Total	123	20	63	28	186	48

#### Discussion

This screening program has defined previously unrecognised morbidities in substantial numbers of people: a 26% increase in the numbers of diabetics, a 110% increase in the numbers with renal disease and an 18.2% increase in the numbers of people with hypertension.

The data indicate that the existing health services in these communities had been more comfortable with, and vigilant and aware of, diabetes and hypertension, than renal disease. Where awareness of renal disease has existed, it has been mainly in the context of diabetes, and hypertension. There is little awareness that renal disease might antedate these problems and also be a significant health issue in people without these diagnoses. Finally, there has not been consensus on the utility of the relatively crude instrument of the urine dipstick as a first stage screening tool in this circumstance. These issues

have undoubtedly applied to most Aboriginal and non-Aboriginal settings up to this point. Our data shows the high yield of unrecognised renal disease in high risk populations by measuring urine ACR in people with known diabetes and/or hypertension, and of screening with urine dipsticks in people without recognised risk factors. The full reservoir of undiagnosed renal disease, manifest by subtle levels of pathologic albuminuria in people without diabetes or hypertension remains unknown, as we did not do urine ACRs on these people unless their urine dipsticks were positive.

Community-wide testing programs can be useful to update community health profiles to identify a problem, make a case for grant purposes, to plan current and future health services, and to project future burdens of disease. From all these perspectives, the recognition of additional cases in these proportions is useful and important.

From the perspective of improved outcomes, however, identification of new cases is only important if heightened surveillance and intensified/appropriate care follow in the newly diagnosed people. This can be inspected in the context of the three diagnoses:

- Benefits from better management of the new diabetics are potentially clear
- All people with overt albuminuria will benefit from renal-protective treatment. Treatment
  protocols already exist for diabetics and hypertensive people with microalbuminuria. However,
  although we know from the Tiwi study that microalbuminuria progresses to overt albuminuria
  over time, and also predicts or marks cardiovascular disease, we do not yet have endorsed
  treatment protocols for people with microalbuminuria, without diabetes or hypertension at this
  point in time
- The appropriate management of the extra cases of hypertension discovered in the program should certainly improve their outcomes. However, there is additional and major advantage to the regular blood pressure testing in people with known hypertension that is not adequately controlled, and for people with diabetes and renal disease whose blood pressures are below the 140/90 cut-off, but nonetheless higher than the desired goals of 130/80 or 125/75

Our experiences with some of these treatment issues are discussed elsewhere in this report.

# Summary of Chapter 6

The adherence to protocols for special testing and repeat readings in specific individuals in this program has improved over time, and, overall, is now quite good. However, due largely to poor health worker support, it has not necessarily been performed in a timely fashion, and in many instances the testing has been done by KDRP nurse coordinators rather than health workers, as originally intended.

The good concordance between tentative diagnoses on the basis of findings associated with the first visit and subsequent confirmed diagnoses validated the use of the initial diagnoses for description of rates and associations of morbidities. Some degree of discordance between these diagnoses, however, supports the importance of follow-up to confirm abnormal and suspicious results.

The substantial numbers of new diagnoses validate the use of such regular community-wide testing, especially in the area of renal disease, where accentuated awareness is just developing. Improved outcomes, however, will only flow if these new diagnoses result in altered and appropriate management.

# **CHAPTER 7**

Initiation and Changes in Medications

**Evolution of Clinical Parameters over Time** 

## Introduction or Changes in Medication

The systematic management of people needing treatment or treatment changes has been a serious challenge, in largest part due to insufficient staffing to adequately develop the treatment arm. The majority of changes were in vasoactive medicines (usually angiotensin converting enzyme inhibitors, ACEi) and in hypoglycaemic agents. The changes included manipulation of doses (always increases) and/or addition of other agents of that class for those already on treatment, and start of medication, with or without subsequent manipulations, for those not already on treatment. recommendations for medicine changes were also made, but if these were not converted into prescriptions by the DMOs, they are not reported here.

Changes in medical management of blood pressure and/or glucose levels occurred in 259 people or 24.2% of the screened population: 83 people at Community 1, 66 at Community 2, and 110 at Community 3. In many, medicine changes were made more than once, as doses were titrated towards goals.

Table 1 shows the activity by class of drug in each community.

Table 1. Number of people with hypoglycemic or antihypertensive agents started or manipulated

new starts/adjustments of preexisting doses

·	Community 1	Community 2	Community 3	Total
Hypoglycemic agents	13/21	8/14	16/37	37/72
	Total 34	Total 22	Total 53	Total 109
Antihypertensive agents	26/49	26/34	31/75	83/158
	Total 75	Total 60	Total 106	Total 241

The next figure shows these treatment additions and changes in the aggregate community data by the major categories of medicine.

60 72 37 Hypoglycemic agents Vasoactive agents 158 84 83 50 100 150 200 250 300 350 **Existing treatment** Existing treatment changed or manipulated

Fig 1. Introduction and Changes of Major Categories of Medicine, among 1070 screened people

Treatment introduced, w/wo subsquent manipulation

Hypoglycemic agents were already prescribed for 132 diabetics (56.4%); medicines were started for the first time in another 37, and existing regimens were manipulated in 72. Thus treatment was introduced or intensified in 109, or 46.6%, and overall coverage was increased from 56.4% to 72.2%. Insulin was recorded to be part of the regimen in only eight diabetics.

Vasoactive treatment was already prescribed in 243 people at baseline, or 22.7%. Drug was started for the first time in 83 people and existing regimens were intensified in 158. Thus treatment was introduced or intensified in 241 people, or 22.5% of the entire population, and overall coverage was increased from 243 or 22.7% to 326 people, or 30.5% of the entire population.

Among the 234 diabetics (already recognized and newly identified), 145 were already on vasoactive coverage (62%). Treatment was started for the first time in 47 and existing regimens were intensified in 94. Thus treatment was introduced or intensified in 131, or 60% and overall coverage was increased from 60% to 82.1%. Ninety-one diabetics were started on, or had dose adjustments to, existing prescriptions, of both antihypertensive and hypoglycemic agents.

Non-diabetics were less frequently prescribed vasoactive drugs, the indications being hypertension and renal disease without diabetes (to this point!). In the 98 nondiabetic people already on vasoactive drug, the dose was manipulated in 64 people, and 36 people were started on drugs for the first time, increasing coverage from 11.7% to 16.0 %.

#### **Evolution of Clinical Parameters over Time**

Tests that potentially lend themselves to longitudinal assessment which might reflect changes in management are the random glucose and HbA1c in diabetics, blood pressure in people with initially elevated readings and urine ACR in people with renal disease. However, our protocols did not require repeat dipstick urinalysis or ACR between regular check-ups, so these were not analyzed.

There was an attempt to regularize HbA1c testing in diabetics, but because recall was poor, it fell well short of goal. When repeat HbA1c levels remained out of range, changes in medication sometimes did not follow. The DMOs sometimes elected to attempt better control with lifestyle advice and/or reinforced adherence to already prescribed regimens, and often felt that other issues (for example, heavy drinking, ganja) were getting in the way of compliance or were relative contraindications for greater doses or a regimen change. These matters are developed in more detail in the Discussion.

Table 2 compares HbA1c at baseline and on their most recent testing, in diabetics who had more than one test. HbA1c levels at baseline exam ranged from 4.4 to 16.7%, with a mean (SD) of 8.5% (2.5%). The average values were unchanged in those who had a repeat measurement, although one quarter had a fall in Hba1c of 1% or more. The change in people in whom vasoactive treatment was introduced or intensified is the more impressive, although still far from significant.

Table 2. Trends in HbA1c over time in diabetics

	N	Baseline	Most Recent	Sig, ranksum	Proportion Fall <b>&gt;0.5</b> %	Proportion Fall <u>&gt;</u> 1%
All	167	8.5 (2.5)				
With repeat value	107	8.8 (2.7)	8.8 (2.9)	p=0.837	32.7%	27.1%
Hypoglycemic medication	62	9.1 (2.5)	9.2 (2.8)	p =0.826	30.7%	25.8%
change and repeat value						
Vasoactive medicine	76	8.9 (2.6)	8.6 (2.8)	p=0.282	34.2%	29.0%
change and repeat value						

#### Trends in Blood Pressure over Time

Our protocols call for treatment of blood pressures in people with confirmed BP  $\geq$ 140/90. Target blood pressures were originally specified as <125/75, but have been unofficially modified to <130/80, based on levels the providers are more comfortable with. However, a blood pressure <125/75 is still, in theory, our target for people with albuminuria. All blood pressures require confirmation at least once more if treatment is to be started or changed based on a BP reading.

Changes in blood pressures were assessed by comparing the blood pressure on the first visit with that on the most recent visit. Blood pressure trends are shown in some detail in aggregate, but, community-specific data only show the trends in people in whom vasoactive medication was started or changed. Community-specific data, are, however, also shown by gender, for different factors influence response by gender in each environment.

## **All Communities Combined**

The next figure shows the changes in blood pressure in 174 people who were started on, or had an adjustment to, antihypertensive medication, regardless of baseline BP, and in whom the last BP reading was *after* manipulation of medications. These included 105 people with baseline BPs ≥140/90, and 69 people with a lower baseline BP. These latter were a mixed group; some were already on medicines and had further adjustment in dose, or were people with diabetes or albuminuria, in whom we prescribed or adjusted vasoactive medicines for cardiovascular and/or renal protection.

Fig 2. Blood pressure changes in people in whom vasoactive medicines were started or changed, n=174.

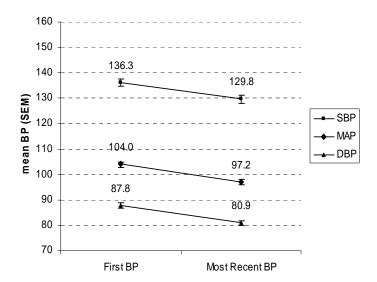


Table 4 shows these numerical values. Mean SBP fell by 6.4 mmHg, and mean DBP fell by 6.9 mmHg, with both changes highly significant. The changes were more marked in non-diabetics, who started out with higher blood pressures, than for diabetics.

Table 4. Evolution of BP in everyone who was started on, or had a change in, vasoactive medications. All communities combined: n=174

	<b>Baseline Visit</b>	Last Follow-Up Visit	P
Aggregate, n=174			
SBP, mmHg	136.3 (21.9)	129.9 (19.2)	0.0037
DBP, mmHg	87.8 (13.1)	80.9 (11.8)	< 0.0001
MAP, mmHg	104.0 ( 14.9)	97.2 (12.7)	< 0.0001
Diabetics, n=104			
SBP, mmHg	133 (20.5)	128.7 (18.7)	0.114
DBP, mmHg	84.7 (12.7)	79.6 (12.0)	0.0029
MAP, mmHg	100.8 (14.2)	96.0 (12.6)	0.0095
Non-diabetics, n=70			
SBP, mmHg	141.3 (23)	131.6 (20.1)	0.0093
DBP, mmHg	92.4 (12.5)	82.9 (11.3)	< 0.0001
MAP, mmHg	108.7 (14.8)	99.2 (12.7)	0.0001

Among the 174 people who had a repeat blood pressure after a start or change in vasoactive medication, 45% had a drop in SBP of  $\geq$ 5 mmHg and 37% had a drop of  $\geq$ 10 mmHg. MAP fell by  $\geq$ 5 and  $\geq$ 10 mmHg in 52% and 40% respectively. The proportion of people with MAP >102 fell from 53% to 33% (p<0.001).

Among the subgroup of 104 diabetics, the data were almost identical. SBP fell by  $\geq 5$  and  $\geq 10$  mmHg in 41% and 36% respectively, and MAP fell by  $\geq 5$  and  $\geq 10$  in 52% and 31% respectively. The proportion with MAP >102 mmHg dropped from 46% to 31% (p=0.023).

Figure 3 and Table 5 show the blood pressure changes in the 105 people with baseline BP≥140/90 in whom medicines were subsequently started or adjusted. Mean SBP fell by 14 mm Hg and mean DBP by 12 mmHg, both highly significant. The response was good in diabetics and non-diabetics.

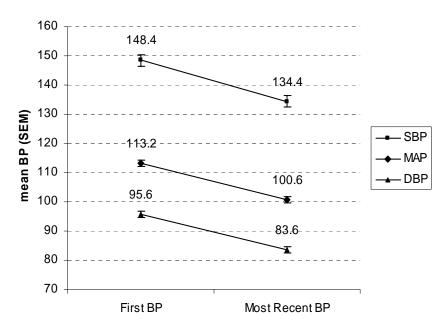


Fig 3. Blood pressure changes in people with BP≥140/190 at baseline, in whom vasoactive medicines were added or adjusted, n=105.

Table 5. Evolution of BP in people with elevated BP ( $\geq$ 140/90) at baseline who had a treatment start or change. All communities combined: n=105

	Baseline Visit	Last Follow-Up Visit	P
Aggregate, n=105			
SBP, mmHg	148.4 (18.7)	134.4 (20.2)	< 0.0001
DBP, mmHg	95.6 (9.9)	83.6 (11.4)	< 0.0001
MAP, mmHg	113.2 (10.8)	100.6 (12.4)	< 0.0001
Diabetics, n=57			
SBP, mmHg	147.2 (14.9)	134.5 (19.4)	0.0001
DBP, mmHg	93.1 (9.3)	83.0 (11.1)	< 0.0001
MAP, mmHg	111.1 (9.0)	100.1 (11.7)	< 0.0001
Nondiabetics, n=48			
SBP, mmHg	149.8 (22.4)	134.8 (21.3)	0.0008
DBP, mmHg	98.5 (9.8)	84.4 (11.8)	< 0.0001
MAP, mmHg	115.6 (12.3)	101.1 (13.4	< 0.0001

Table 6 shows the proportions of these hypertensive people who had reached various blood pressure goals on their most recent exam. About 55% -58% of people registered a fall in SBP and MAP of >10 mmHg. The proportions with MAP<102 was increased about four-fold. The responses in diabetics were similar to those of the aggregate group.

Table 6. Proportion of people with elevated BP (≥140/90) at baseline, who had certain BP changes after a treatment start or change. All communities combined

1111 001111111111110						
	Proportion with	Proportion with				
	>10mmHg fall	>5mmHg fall				
Aggregate, n=105						
SBP, mmHg	58 (55.2%)	64 (61.0%)				
DBP, mmHg	47 (44.8%)	68 (64.8%)				
MAP, mmHg	61 (58.1%)	74 (70.5%				
Diabetics, n=57						
SBP, mmHg	32 (56.1%)	35 (61.4%)				
DBP, mmHg	24 (42.1%)	24 (59.7%)				
MAP, mmHg	33 (57.9%)	33 (57.9%)				
Non-diabetics, n=48						
SBP, mmHg	26 (54.2%)	29 (60.4%)				
DBP, mmHg	23 (47.9%)	34 (70.8%)				
MAP, mmHg	28 (58.3%)	32 (66.7%)				

Table 7. Changes in blood pressure in people with elevated BP (≥140/90) at baseline who had a treatment start or change. All communities combined

	Baseline Visit	Last Follow-Up Visit	P
Aggregate, n=105			
SBP <140, mmHg	23 (21.9%)	58 (55.2%)	< 0.001
DBP <90, mmHg	14 (13.3%)	64 (61.0%)	< 0.001
MAP <102, mmHg	14 (13.3%)	59 (56.2%)	< 0.001
Diabetics, n=57			
SBP < 140, mmHg	9 (15.8%)	30 (52.6%)	< 0.001
DBP <90, mmHg	12 (21.1%)	39 (68.4%)	< 0.001
MAP <102, mmHg	9 (15.8%)	33 (57.9%)	< 0.001
Nondiabetics, n=48			
SBP <140, mmHg	14 (29.2%)	28 (58.3%)	< 0.001
DBP <90, mmHg	2 (4.2%)	25 (52.1%)	< 0.001
MAP <102, mmHg	5 (10.4%)	26 (54.2%)	< 0.001

There was no significant fall in blood pressure among the 69 people with BPs <140/90 at baseline who had treatment started or changed. Thus, the blood pressure response in the aggregate group of 174 in whom vasoactive medicines were started or changed was largely driven by the good responses in the people with elevated BP at baseline.

An additional group of people had elevated blood pressure at baseline but were not started on, or did not have an adjustment of medication. In many cases the second BP was to confirm or refute the first reading. Table 8 compares their first with their most recent blood pressure. Their mean SBP at baseline was about 10 mmHg lower than the group with baseline BP≥140/90 who subsequently had a treatment change. On their most recent visit their mean SBP and DBP were 9.4 mmHg and 11.9 mmHg lower,

both highly significant. A large part of this effect represents regression of initially elevated BPs to the mean, so that a final diagnosis of 'hypertension' was not assigned. Encouragement of better adherence to a treatment regimen already prescribed might also have had a good effect. Finally, there might, in theory, have been benefit from either consciousness-raising or education associated with the program and/or individual visits.

Table 8. Evolution of BP in people with elevated BP ( $\geq$ 140/90) at baseline without a start or change of treatment. All communities combined: n=79

	Baseline Visit	Last Follow-Up Visit	P
SBP, mmHg	137.4 (16.4)	128.0 (17.2)	0.0004
DBP, mmHg	93.2 (8.4)	81.3 (12.2)	< 0.0001
MAP, mmHg	107.9 (8.8)	96.8 (12.3)	< 0.0001

Table 9 shows that there were no significant changes in mean blood pressure in people who were normotensive at baseline and on whom no changes of antihypertensive medicines were made.

Table 9. Evolution of BP in people with normal blood pressure at baseline without a history of hypertension, in whom no treatment changes were made. All communities combined: n=241

	Baseline Visit	Last Follow-Up Visit	P
SBP, mmHg	111.8 (12.1)	113.4 (13.5)	NS
DBP, mmHg	73.1 (9.8)	73.4 (9.8)	NS
MAP, mmHg	86.0 (12.4)	86.7 (9.4)	NS

# Changes in Blood Pressure by Community

# Community 1

Table 10 shows the BP changes among the 56 people at Community 1 who were started on vasoactive medicines or had a change in dose, regardless of baseline BP, where the most recent BP was *after* that change. In the aggregate group mean SBP fell by 8.3 mmHg, and mean DBP fell by 7.8 mmHg, with both changes highly significant. The responses were significant in males, but not in females. Our nurses attribute this to the fact that there was no female health worker on the team.

Table 10. Evolution of BP in people at Community 1 and for whom vasoactive medicines were started or adjusted

	Baseline Visit	Last Follow-Up Visit	P
Combined: n=56			
SBP, mmHg	141.4 (23.6)	133.1 (19.5)	0.0447
DBP, mmHg	89.7 (12.9)	81.9 (12.5)	0.0017
MAP, mmHg	106.9 (15.3)	99.0 (13.6)	0.0046
Females, n=30			
SBP, mmHg	140.7 (27.6)	136.0 (20.2)	0.4613
DBP, mmHg	86.4 (13.1)	80.8 (11.7)	0.0799
MAP, mmHg	104.5 (16.8)	99.2 (13.4)	0.1772
Males, n=26			
SBP, mmHg	142.3 (18.6)	129.7 (18.3)	0.0176
DBP, mmHg	93.5 (11.9)	83.3 (13.6)	0.0063
MAP, mmHg	109.7 (13.3)	98.8 (14.2)	0.0061

Table 11 shows significant falls of 14.4 and 10.3 mmHg in mean SBP and DBP in Community 1 people with elevated BP at first visit, in whom antihypertensive medicine was started or adjusted. Again the responses were arguably better and were more significant in males.

Table 11. Evolution of BP in people at Community 1 with elevated BP at baseline (≥140/90)

and for whom antihypertensive medicines were started or adjusted

	Baseline Visit	Last Follow-Up Visit	P
Combined: n=38			
SBP, mmHg	152.3 (20.6)	137.9 (19.2)	0.0024
DBP, mmHg	95.6 (11.0)	85.3 (11.7)	0.0002
MAP, mmHg	114.5 (12.4)	102.9 (12.7)	0.0001
Females, n=19			
SBP, mmHg	154.9 (24.5)	142 (18.6)	0.0750
DBP, mmHg	92.6 (11.7)	83.7 (9.6)	0.0146
MAP, mmHg	113.4 (14.2)	103.2 (11.1)	0.0183
Males, n=19			
SBP, mmHg	149.6 (15.9)	133.8 (19.4)	0.0096
DBP, mmHg	98.5 (9.6)	86.9 (13.6)	0.0046
MAP, mmHg	115.5 (10.5)	102.6 (14.4)	0.0031

## Community 2

Table 12 shows the changes in BP of people at Community 2 in whom a treatment change was made, regardless of baseline BP. SBP and DBP both fell significantly when both genders were combined, although the significance was diminished or lost when the sexes were inspected separately.

Table 12. Evolution of BP in people at Community 2 in whom vasoactive medicines

were started or adjusted

	Baseline Visit	Last Follow-Up Visit	P
Combined, n=43			
SBP, mmHg	138.1 (19.8)	129.4 (20.6)	0.0497
DBP, mmHg	88.4 (9.7)	84.2 (19.2)	0.0400
MAP, mmHg	105.0 (11.5)	92.2 (11.0)	0.0204
Females, n=23			
SBP, mmHg	140.9 (25.3)	134.8 (26.3)	0.2240
DBP, mmHg	88.6 (10.2)	84.9 (10.3)	0.0497
MAP, mmHg	106 (13.6)	98.8 (13.3)	0.0769
Males, n=20			
SBP, mmHg	134.9 (10.0)	126.7 (14.9)	0.0483
DBP, mmHg	88.3 (9.4)	86.3 (6.7)	0.4450
MAP, mmHg	103.7 (8.7)	99.7 (7.9)	0.1289

Table 13 shows the changes in BP in people at Community 2 who were hypertensive at baseline and for whom antihypertensive medicines were started or changed. Mean SBP and mean DBP fell by 13.8 and 8.1 mmHg respectively.

Table 13. Evolution of BP in people at Community 2 with elevated BP at baseline (≥140/90) and for whom antihypertensive medicines were started or adjusted

	Baseline Visit	Last Follow-Up Visit	P
Combined: n=27			
SBP, mmHg	145.6 (21.4)	131.8 (23.4)	0.0277
DBP, mmHg	93.9 (7.1)	85.8 (9.1)	0.0006
MAP, mmHg	111.1 (9.9)	101.1 (12.1)	0.0016
Females, n=16			
SBP, mmHg	149.3 (26.2)	134 (26.9)	0.1120
DBP, mmHg	93.5 (8.0)	84.8 (19.7)	0.0164
MAP, mmHg	112.0 (11.9)	101.2 (14.3)	0.0277
Males, n=11			
SBP, mmHg	140.1 (10.2)	128.5 (17.8)	0.0002
DBP, mmHg	94.9 (5.7)	87.3 (6.6)	0.0088
MAP, mmHg	110.0 (6.2)	101.0 (8.6)	0.0111

## Community 3

Table 14 shows the BP changes in people at Community 3 and for whom vasoactive medication changes were made, regardless of baseline BP. Changes in females were significant or almost significant, but there were no significant trends in men. Our nurse coordinator attributes this to the fact that the chronic disease health worker at Community 3 was female. The two male members of the team were trainees, often absent, and reluctant to work independently or be involved with treatment. Male participants were followed less closely, and were often reluctant to comply with medication changes.

Table 14. Evolution of BP in people at Community 3 and for whom vasoactive medicines were started or adjusted

·	Baseline Visit	Last Follow-Up Visit	P
Combined: n=75			
SBP, mmHg	131.5 (20.9)	127.7 (18.2)	0.2387
DBP, mmHg	86.1 (14.8)	78.3 (12.1)	0.0006
MAP, mmHg	101.2 (16.0)	94.8 (12.6)	0.0070
Females, n=44			
SBP, mmHg	135.3 (22.1)	127.2 (17.2)	0.0587
DBP, mmHg	88.2 (13.9)	77.1 (11.1)	0.0001
MAP, mmHg	103.9 (15.7)	93.8 (11.5)	0.0009
Males, n=31			
SBP, mmHg	126.1 (18.1)	128.5 (19.8)	0.6315
DBP, mmHg	83.1 (15.8)	80.1 (13.4)	0.4229
MAP, mmHg	97.5 (16.0)	96.2 (14.1)	0.7497

Table 15 shows the BP changes in people at Community 3 who had BP≥140/90 at baseline and for whom vasoactive medicines were changed or adjusted. Mean SBP fell by 13.8 mmHg and mean DBP by 12.2 mmHg, with both changes highly significant. Females had an excellent response in both parameters, with mean SBP falling by 19.3 mmHg, and mean DBP falling by an average of 14.3 mmHg. Males had a significant average fall of 13.9 mmHg in DBP, but no significant change in SBP.

Table 15. Evolution of BP in people at Community 3 with elevated BP (≥140/90) at baseline

and for whom vasoactive treatment was started or adjusted

	Baseline Visit	Last Follow-Up Visit	P
Combined: n=40			
SBP, mmHg	146.7 (14.1)	132.9 (18.8)	0.0004
DBP, mmHg	96.7 (10.4)	80.5 (12.0)	< 0.0001
MAP, mmHg	113.3 (9.9)	98.0 (12.2)	< 0.0001
Females, n=26			
SBP, mmHg	149.8 (14.6)	130.5 (19.7)	0.0002
DBP, mmHg	93.3 (10.9)	79.0 (11.0)	< 0.0001
MAP, mmHg	114.2 (10.2)	96.1 (12.2)	< 0.0001
Males, n=14			
SBP, mmHg	140.9 (11.7)	137.4 (16.6)	0.5246
DBP, mmHg	97.3 (9.7)	83.4 (13.6)	0.0047
MAP, mmHg	111.8 (9.6)	101.4 (11.8)	0.0166

#### Discussion

As stated many times, the productivity in the chronic disease program was seriously compromised by sparse health worker staffing, due to the lack of health workers to recruit, and poor attendance and/or performance of some who were recruited. This problem had some impact on the number of people screened, but the most serious impact was on the follow-up of people with suspicious or abnormal results, and the treatment of people who needed it. Treatment was compromised at two levels—initiation, and at titration of treatment to goal. Thus, some people needing treatment did not get started, and many did not get upward titration of their medicines towards the treatment goals. Many recommended follow-up appointments for these purposes never occurred or were seriously delayed, sometimes by a year or more. In some instances the follow-up visits and treatment changes were done by our program nurse coordinators, which was not the original intent of the program structure. Treatment outcomes would also have been better beyond June 30, 2003, if the same treatment goals in individuals were further pursued.

The clinical status and management of patients with chronic conditions in these communities was already quite good before the outreach program began, with blood pressures better than reported in ANDIAB2, average HbA1c comparable with the ANDIAB2 and DEMAND studies, and treatment of 63% of diabetics with ACEi (29,30). This is a tribute to dedicated staff working under difficult circumstances.

The program reflects substantial additional treatment activity, with 259 people having treatment changes in the major areas of antihypertensive or glucose lowering therapy. The number of drug manipulations (dose increases, adding agents etc) was much greater. The treatment activity was quite vigorous in all three communities.

The start or intensification of hypoglycaemic medication in 47% of diabetics, and an increase in overall coverage from 56% to 72%, scarcely represents "therapeutic nihilism" on behalf of the DMOs (31), who prescribed every change. The failure of the mean HbA1c to change in people with repeat testing is an additional issue; it probably reflects resistance to treatment, advanced and terminal disease, poor compliance and insufficient medicine dosage, and is sometimes an indication for addition of insulin, where feasible. Obviously, good control is hard to achieve in these circumstances. It is some comfort to

consider that dysglycemia becomes progressively worse in individuals over time, without intervention. Studies in other Aboriginal communities, such as the Laramba Diabetes Project, the Umoona Kidney project and the Tiwi Kidney Treatment Program, have likewise shown resistance of glycaemia to change (32). Health care providers have many justified concerns about vigorous hypoglycaemic treatment in this environment. There are dangers of metformin treatment in older people, those with renal insufficiency, and with alcohol abuse, there is potential weight gain with gliclazide and related drugs and hypoglycaemia in people who are often hungry, and there are concerns with self-administration of parenteral medication and lack of safe storage facilities and refrigeration for insulin treatment. The trend towards a lowering of HbA1c, although still not significant, in diabetics in whom ACEi treatment was introduced or intensified is compatible with the glycaemia-modulating effect of angiotensin blocking medicines noted in several large trials with a blood pressure or cardiovascular endpoint (see below).

Vasoactive medication was started or manipulated in 22.5% of the population. Coverage was increased from 22.7% to 30.5% overall, and from 60% to at least 82% of diabetics. The significant drop in blood pressure among people in whom these drugs were added or manipulated, regardless of the indication, shows that the medicines had the anticipated physiologic effect, even if optimal dosages were not always attained. The more marked changes in people who were hypertensive at baseline also support the anticipated effect. The fall in mean SBP and DBP of nearly 20 mmHg and 14.3 mmHg respectively in females with hypertension at Community 3 is especially impressive. The reduction of blood pressure to <140/90 in 42% of the people with elevated BP at baseline, and the 55% of hypertensive females who achieved this goal at Community 3 are respectable achievements.

The blood pressure response of diabetics in whom ACEi was started or changed was as good as that in non-diabetics, and those who were hypertensive at the start had the same absolute BP reductions of 13 mmHg SBP and 11mmHg DBP, as non-diabetics. These activities should be inspected in the context of potential sparing of cardiovascular morbidity, as well as their renal-protective effects.

The mean BPs of people in whom antihypertensive treatment was started or changed did not reach treatment goal of <125/75 in any group analysis, and the BP reductions fell short of the 26 mmHg reduction in SBP in hypertensive people in the Tiwi treatment program, where we had more control over intensity of follow-up and a longer period to work on titrating medicines to treatment targets (7,8,9).

Nonetheless, in view of data from the Asia Pacific region which predict a 56% reduction in stroke and a 46% reduction in ischemic heart disease in people <60 years old for every 10 mmHg reduction in SBP (33), the blood pressure reductions achieved here predict major lowering of mortality from stroke and ischemic heart disease, as well as reduced complications and hospitalisations from chronic disease more broadly. They also predict major reductions in the development and the rate of progression of renal disease. With 31% of the population taking ACEi at the end of the program, there is also the intriguing possibility that the incidence of type 2 diabetes will also be reduced in those who are currently not diabetic, based on an incidental but consistent finding in several recent large randomized trials targeting cardiovascular endpoints (HOPE, ALLHAT, EUROPA, ANBP2, PROGRESS etc), and summarised for the HOPE study by Yusuf (34).

Where treatment was given on schedule, and in appropriate doses, the effect was good. There was no suggestion that people were either resistant to treatment, or had adverse effects that compromised their compliance. The global issues of health worker understaffing underlie the suboptimal results. It is also reassuring to understand why specific differences have occurred, such as the gender differences in response, in opposite directions, at Community 1 and Community 3. All these factors point to feasibility of excellent outcomes in an adequately staffed program, which has long-term continuity. There can be no doubt these programs would be cost-effective.

# **CHAPTER 8**

Summary of the Program's Activities and Findings
Feedback Sessions and later Developments, 2004

## Summary of the Program's Activities, Findings and Experience

We have a near-complete chronic disease profile in Community 2, and two-thirds to three-quarters representation of adults in Community 1 and Community 3.

Very high rates of smoking were confirmed in all communities, with overall rates of 41% for women and 72% for men, which are twice and 3.4 times the respective nationwide rates of 18% for women and 21% for men (35). This is undoubtedly a major health hazard, regardless of the findings in these analyses. While most men were current users of alcohol, most women were not. Ganja (marijuana) use was very common among young adults in two communities with good data; others have described its association with behavioural and societal problems.

Body habitus profiles differed strikingly among communities, with a 15.7 kg difference in average weight of females and an 18.3 kg difference between males in Community 1 and Community 3. This survey could not address the causes of those differences. Higher proportions of women were 'obese' by waist than by BMI measures, most markedly among women, confirming preferential central fat deposition.

Average birth weights in people in whom they were recorded, (most under age 30 years) were about 330 gm less than contemporary non-Aboriginal birth weights, and rates of low birth weight (<2.5 kg) about twice that of Australian-wide current data (36). Birth weights were the lowest in Community 1, which has the lowest adult weights. These weights overstate birth weights in the original birth cohorts to which these people belonged, as survival disadvantages in infancy, childhood and adult life will have selectively depleted those of lower birth weights.

Rates of chronic diseases or their markers were excessive in all communities. Overall, 21.2% of people had diabetes, 38% had probable renal disease and 40.3% had hypertension. However, rates differed strikingly among the communities- Community 3 had rates of individual morbidities more than twice those in Community 1, and a 3-fold increase in the likelihood of any morbidity. In every community there was a marked increase in rates of morbidities with increasing age: rates were highest among older people, but, due to the young age structure of the population, most of the people with morbidities were in early or middle adult life. There was striking overlap of morbidities, with most people having two or three conditions by early middle age. Renal disease is an early and central member of this morbidity cluster, with diabetes a late and variable complication peaking decades later. This is all vital information, for predicting future disease burdens, for estimating clinical and cost-effectiveness of interventions and for informed strategic planning of health services for chronic disease, as discussed in more detail in Chapter 5.

Factors significantly correlated with morbidities included age (noted above), gender, with more diabetes and renal disease in females and more hypertension in males, alcohol use for hypertension, measures of body weight and fat, most notably waist circumference, and community, as already noted. This community effect was only partly due to the higher measures of body fat in Community 3. Finally, lower birth weights, examined in the context of current weight, predisposed to diabetes, higher blood pressures and to proteinuria in females.

Consideration of risk factors is critical to formulate informed strategies for primary prevention. Can the excess morbidities in these communities be entirely explained by the factors measured in this program? Almost certainly not. The powerful correlations of morbidities with parameters of body fat suggest that the body build was previously much leaner in these groups, which is known from formal reports (Dr John Hargrave, unpublished reports, 1956, and discussed in ref 20), anecdotes and photographs. With

the influence of waist especially strong, the greater waist measurements in females relative to the non-Aboriginal population probably explain much of their excessive morbidity and the 'virilisation' of their cardiovascular disease profile. This term refers to the fact that females in these populations, as in some other Indigenous groups, do not show the same relative protection against metabolic and cardiovascular disease evident in non-Indigenous groups (36). We have shown, in the Tiwi population, that waist is a better marker of cardiovascular risk than BMI, weight, hips or WHR (37). The huge rates of smoking are a potentially modifiable factor. Nonetheless, Tiwi data suggest that 'traditional' risk factors only account for about 40% of the aggregate coronary heart disease risk, and are especially poor in predicting risk in younger adults and in females generally (38), and we assume that the same applies in these communities. This discrepancy indicates that other risk factors are operating. Candidates are infections and inflammation, nutritional disorders and early life effects, including intrauterine growth retardation marked by lower birth weights. Tiwi and Groote Eyelandt data support the role of infections and inflammation (25,26,40,41,42), Groote Evelandt data suggest a role for micronutrient deficiency (43), our data support the contribution of heavy drinking (25), and Tiwi data support the contribution of low birth weight (43). The current data also predict that diabetes and renal disease rates in females would be reduced by half if average birth weights were 500 gm heavier, other things being unchanged. It is likely that the simultaneous operation of several or many risk factors have a multiplicative effect on risk, as we and others have modelled for renal disease (25,45). These are all modifiable factors, regardless of whether there are additional elusive contributors or not.

While primary prevention is the ultimate goal, the chronic disease program and the ongoing experience of health care providers in Indigenous health more broadly in the NT and nationwide, is showing that secondary prevention can have a strong ameliorating effect on disease manifestations and progression. Critical to such programs are regular testing of people at risk and appropriate treatment for people who need it.

Over the course of the program there has been dramatic improvement in adherence of program staff to algorithms for testing, and for treatment. HbA1c and ACR have been measured at least once in 85% and 91% of diabetics and suspicious glucose levels followed-up in 83% of people without known diabetes. An ACR was performed to confirm renal disease in 86% of people with proteinuria by dipstick and a serum creatinine in 97% of people with overt albuminuria. Follow-up of suspicious blood pressures in people without known hypertension and measurement of ACRs in people with confirmed hypertension was less well pursued, at rates of about 75%. Sometimes, however, this compliance has been optimised with periodic 'catch-up' activity, but there is no doubt that health workers are familiar and confident with the algorithms.

Confirmed new diagnoses of diabetes were made in 48 people, or an increase of 26%, of renal disease in 196 people, or an increase of 110%, and of hypertension in 57 people, an increase of 18.2%. These increases reflect the benefit of intermittent testing, in a situation where disease rates are changing with increasing age over time. The great increase in renal disease reflects the systematic approach to screening and the broadened definition, and the possible over-diagnosis in some cases, as discussed in the relevant chapters.

Of 1,070 adults tested, (excluding 53 people screened aged 15-17 years), 241 were started on, or had dose modifications of, antihypertensive agents, mostly angiotensin converting enzyme inhibitor, and 109 people were started on, or had dose changes in, hypoglycaemic agents. In all, we initiated or intensified vasoactive treatment in 55% of diabetics and increased their overall coverage with these agents from 63% to 82%. We started or intensified hypoglycaemic treatment for 64% of diabetics and increased their coverage overall from 58% to 74%. We had more influence on ACEi treatment than with hypoglycaemic

treatment, as local practitioners had stronger individual preferences about introducing or modifying the latter. By the end of the program, optimal streams of management has been recommended for almost everyone identified with one of the targeted chronic conditions, although this was not necessarily achieved. A recent audit by our program evaluators showed that 98% of diabetics with renal disease in these communities were on ACEi (46).

There have been significant improvements in blood pressure in people in whom vasoactive medicines have been started or increased. The success in lowering blood pressures in specific groups has been determined by the community-specific program activity level and the gender of the chronic disease staff there. Although blood pressures are still not at goal in many people, the improvements, if sustained, predict reductions in death and renal failure.

Activities at Community 2 have rolled over into a maintenance mode of repeat check-ups on a regular basis during its final stages. The ideal frequency of such check-ups still needs to be worked out, and probably can be estimated from the data we have.

In Community 3, there is a serious competing need to serve the large number of people identified who need treatment or treatment adjustments. As people enter treatment streams, the numbers of visits have multiplied, and increased the workload tremendously.

At Community 1, most of the information recorded in our database has been transferred across to inform registers for the DHCS Chronic Disease Strategy. However, with the absence of a dedicated health worker on the team in Community 1, we have not left a health worker trained in chronic disease at that site. Placement of a chronic disease coordinator by Department of Health and Community Services as part of their Preventable Chronic Diseases Strategy, should assure ongoing clinical activity, however.

The major impediment of the program has been the lack of a health worker in Community 1 and the high rate of absenteeism of health workers in Community 2 and Community 3. These problems are not unique to the chronic disease program. The problem in Community 1 was lack of appropriately skilled health workers who were willing to work, but the causes of absenteeism and low productivity in the other communities were more complex. Issues apparent to us, over which we had little control, included not only absences for personal and cultural events, and cultural and community hierarchical restraints on whom health workers could care for, but job dissatisfaction related to disputes about pay scales, source of pay (CDEP vs mainstream sources), conflicts among staff, and probably attitudes cast in an historically authoritarian clinic structure that did not empower, or appropriately acknowledge the work of, health workers. The causes of this phenomenon are worthy of further study. This serious issue has constrained the numbers of people enrolled in the program, the thoroughness of testing and follow-up, and especially the ability to get people onto the correct treatment and get them to treatment goals. We estimate that twice the work in Community 2 and three times the described work in Community 3 could have been conducted with health workers attending and following systematic schedules of regular testing and follow-up.

The program leaves a legacy of heightened consciousness of the importance of chronic disease, of trained and informed health workers, of practices and algorithms, of improved management of individuals, clinical registers by diagnosis, and of information which can inform the process of prospective planning of health services as funding formulae for Aboriginal health services improve.

# Feedback to Communities and Recent Developments, 2004 Community 1

After this report had been developed to its semifinal stage, two separate feedback sessions were held at Community 1 in Sept 2004, 15 months after our field work in the program ceased. Our NCO, Suresh Sharma organised and conducted the visit.

The first meeting was held at the council office and was attended by community councillors. The attending councillors were given feedback about the CDOP and were presented with an edited version of our "Final CDOP Report" (the other two communities were de-identified). They were also informed about the scientific manuscripts, which were then forwarded to the town clerk. The councillors were receptive to the information and were very interested in the "lifestyle choices" component of our presentation. They also provided their suggestions and views of the broader clinical situation. Discussions ranged from the necessity for a separate facility at the clinic for men's health to the role of the community council in chronic disease prevention and management.

The second feedback meeting was held at the Community 1 community health centre. It is important to note that a resident chronic disease nurse, Gaynor Garstone, has now been appointed through the NT Preventable Chronic Disease Strategy, so chronic disease activities are ongoing.

Attendees at the health centre meetings included the manager, our previous CDOP community liaison officer, clinic AHWs, a trainee AHW, and DHCS staff, including nurses.

After our presentation, discussion ensued. Attendees were interested in how these findings compared with other Indigenous communities/groups. There was an extensive discussion about current management practices for chronic diseases after the cessation of our CDOP. The health centre manager and resident chronic disease nurse received a copy of our final reports.

Some issues raised by the health centre manager & chronic disease nurse included the following:

- The manager and nurses were grateful for the assistance of our program and for boosting the awareness and importance of chronic disease care in this community. They were especially thankful for the substantial base of chronic disease screening profiles we had established, for updating their chronic disease recall system, and for our lists of participants with worrying results.
- Demands from acute care in an under-staffed health centre had overwhelmed the system and clinic manager could dedicate only two days per week to chronic disease activities. This mirrors our experience, where visiting KDRP CDOP staff were often called away from their chronic disease activities to assist with other programs because of clinic understaffing or clinical emergencies.
- Health worker involvement with chronic disease care continues to be minimal because of the lack of trained health workers in this community. This, too, mirrors our experience.
- As before, clinic space is inadequate, and acute and chronic care compete for workspace.
- The clinic staff cannot access DHCS's CDR-II database in Community 1.
- Not all the staff members considered chronic diseases as an integral part of adult health care.

Communications will be ongoing, and a system of how manuscripts needing review and other information will be handled, and approved or amended by the communities was discussed.

## Community 2

Two separate feedback sessions were held at Community 2 on August 31<sup>st</sup> 2004, organised by Suresh Sharma. One was at the community health centre and the other at the community council chambers.

It is important to note that responsibility for clinic management has passed from the community council back to DHCS.

The meeting at the community health centre was attended by all the clinic staff, including DHCS nurses, Aboriginal Health Workers, as well as other interested community members and staff. There was a good understanding of our findings, and a lively discussion. The clinic staff were particularly interested in the coexistence of morbidities in this community. The clinic reported that they were still using the paper based chronic disease recall system, which we updated before the CDOP finished in the community. The health workers reported that they have not received any regular support in relation to chronic disease care from the DHCS. At the end of the feedback session and discussion, a copy of the "Final Report to AKF" (the other two communities were de-identified) was presented to the health centre manager.

The second community feedback meeting was held at the community council chambers. In attendance were current council members, the town clerk, interested individuals and invited guests of the council. The attendees were very interested in the program, although the council itself was/is no longer running the health service (see above). They were particularly interested in issues regarding body habitus, ganja usage and smoking in the community. At the end of the session, the council was presented with a copy of the "Final Report to AKF" (the other community information de identified).

Ongoing feedback has been established. We discussed systems for community review, amendment and approval of manuscripts and other information.

# Community 3

There were two feedback sessions in Community 3, to share information as these analyses proceeded. Both were done by Jo Scheppingen.

The first session, on 27<sup>th</sup> January 2004, included the Community Final KDRP Report - November 2003- Hard Copies were given to local health services Operations Manager; Coordinator; & Aboriginal Health Worker. An electronic copy was sent via email Dec 13<sup>th</sup> 2003 to the Operations Manager. It also included a Laminated Poster entitled "Summary of the three years of the KDRP CDOP", with photos depicting –

- Health Workers on the program
- The Check-Up process BP, Weight, etc
- Health Worker computer training
- Education for the community
- Community controlled health service Staff meetings
- Numbers of people with chronic disease of the 411 people tested
- Healthy lifestyle message
- Message to invite people to come in for a check-up

The second feedback session occurred on 7<sup>th</sup> September 2004. It included feedback of results as described in the complete report to AKF. The major feedback session occurred with local health services Board, DHCS and members of the Community, all of whom had received an open invitation to attend.

The following were presented

- Hard copies of the overhead presentation were given to the Operations Manager, the Board members and Nurse Coordinator/AHW
- Hard copies of the Full Community 3 Final Report were given to the same recipients.
- Electronic copies of the full report and overhead presentation were also given to the operations manager on compact disc, with the nurse coordinator & AHW being aware of its location.
- An explanation of the presentation (in full) was given individually to two Board members and to DHCS Doctor, Julie Graham

The Full Report, left with the local health services and DHCS in both hard and electronic copy, included the following:

- Program overview
- Overview of the last six months and final clinical profiles of each community
- Program Summary, participants, age and gender, health behaviours, body habitus and
- Birth weight
- Rates and distributions of morbidities, multiple morbidities and their integration,
- Factors correlating with morbidities
- Adherence to testing & treatment algorithms, initial & confirmed diagnoses & new diagnoses.
- Initiation and changes in medications, evolution of clinical parameters over time
- Summary, presentations, publications, derivative programs and references

The information was well received and some lively discussion followed. Many pressing issues were discussed, which included those operating when the CDOP was in place and those subsequently developing.

*Program staffing.* Since our fieldwork ceased in June 2003, the local health services had had serious problems recruiting and retaining health workers for chronic disease management.

Location. The local community controlled health centre was relocated to temporary premises in the old Council Building at the end of 2003. These are totally unsuitable for the operation of health programs. They lack running water and there is no privacy for clients to see the AHWs. The current plan is to acquire demountable buildings and place them next to the current DHCS Clinic if DHCS give assurance that the land beside the clinic can be utilised for this purpose. Health & Aging Representatives are visiting Community 3 on September 23<sup>rd</sup> to formalize the agreement with DHCS

Funding. Funding challenges continue for this health service. February funds were released in May. A satellite dish, IT equipment, portable screening equipment, normal rental/phone, etc, expenses were secured. Restrictions on what the funds were used for were imposed by the Commonwealth Dept Health & Ageing from March onwards after a change over of personnel in that department and equipment/resources deemed important by the health services were blocked. Funds for the July Quarter have not yet been released (now September) and this will only occur when the Commonwealth

Department of Health & Aging are satisfied that all performance indicators, service agreements and plans for the relocation of the health services are complete.

Collaboration. Community controlled health service remain the prime deliverer of Chronic Disease Care to Community 3 with DHCS doing opportunistic follow-up as patients present to their clinic. Community controlled health service also continues to screen the population of Community 3 for chronic disease from the local council's population list. Access to DHCS patient pathology results and current medication schedules became essential with the departure of Dr Fitzpatrick in mid 2003, and was negotiated in January 2004. Collaboration with DHCS has improved enormously in the past nine months. Community controlled health service & DHCS share the same Chronic Disease "Total Recall Card System", which was compiled from the DHCS Client register. Community controlled health service also print out appointment/follow- up lists from the KDRP database for any client who needs follow-up for any specific reason or abnormal results.

Data Entry. Community controlled health service continued to use the KDRP database for chronic disease management for which we KDRP/UQ continue to pay. However, electronic transfer of pathology results has not occurred over the past seven months due to problems with the installation of the Westerns/Mayne Health programs' phone system & satellite. This is being remedied now. Use of our database will continue until Community controlled health service has been able to secure an integrated IT System. Between February and September 2004, 284 client visits have been entered into the database, with the total client numbers on the program being 515. These data will all be transferred to the definitive system when it is in place. At the request of Community controlled health service we will continue to follow the dynamics and outcomes.

Point of Care Testing. In large part based on our suggestions, Community controlled health service have purchased two DCA2000 machines for onsite HbA1c and ACR analyses. This reduces the quantity of blood tests sent to Mayne Pathology. Community controlled health service are now part of the QAAMS DCA2000 Point of Care Program under the direction of Mark Shepherd. Annie, Muki, Donny and Marion all attended training in Alice Springs in July.

Continued Involvement. We were awarded a grant from Give2Asia to continue to help Community 3 with chronic disease management. However, the devolution of the community controlled health service and inability of DHCS to respond to ways in which this grant could be spent for ongoing chronic disease activities made us to return that grant.

# **CHAPTER 9**

Other Applications and Products of the Program

Presentations and Publications arising from the Program

References cited in the Report

## Other Applications and Products of the Program

The deliberations leading to, and the experience of, the Tiwi program, the Groote Eyelandt program (Dr Stephen McDonald), the NT Chronic Disease Outreach Program and the ongoing chronic disease programs in Broome and Kalgoorlie have put Australia at the front of program development for chronic diseases in the developing world, and the only country with outcomes yet described.

In the developing world, primary and secondary prevention are the only modalities affordable to stem disease manifestations and complications. The application of a version of the KDRP program in Soweto, under the guidance of Dr Ivor Katz, has been embraced enthusiastically by the Department of Health in South Africa, and we are helping them with staff training, computer use, database issues and data analyses. We will soon be hosting another doctor from South Africa, who plans to set up a similar program in Durban. Dialogue has begun with health professionals in Chennai, India, about similar applications there.

In collaboration with health economist, Carol Beaver, we have joined forces with Professor Kathy Eagar's group from Centre for Health Services Research at the University of Wollongong, to explore ways of using similar health profiles for needs-based health services planning. One special initiative will be exploring application of the HBG/HRG (Health Benefit Group/Health Resource Group) to community-based chronic disease profiles (47,48,), and one particular challenge will be the development of frameworks that address the integration of conditions, rather than further pursuit of individual disease-specific disease models. We are awaiting the outcomes of an NHMRC health services planning grant application as one of the first steps in this direction.

Three manuscripts are in press at this time, which address the broader issues of chronic disease in high risk and Indigenous groups. They have been submitted to the communities for review, comment and approval. Drafts on three or four more topics might be finished in the next 12 months, addressing health profiles, program logistics and experience, comparison with AUSDIAB data and birth weight effects. More could follow in 2005, to include potential health services applications, when our thoughts on these issues have matured some more. Many presentations have been given at regional, national and international meetings, some abstracts of which are accessible (cited in Chapter 9, P&P 1-46).

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