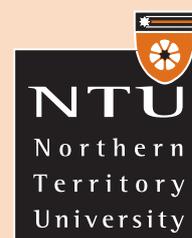
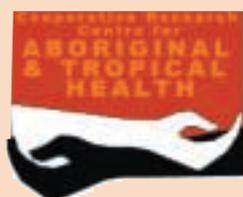


CNAAR Evaluation Reports: February 2003

# A Follow-up Study of Outcomes of the Tiwi Renal Treatment Program

Gary Robinson, Ross Bailie, Zhiqiang Wang,  
Paul Snelling, Srinivas Kondalsamy-Chennakesavan



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## **Chronic Diseases Management and the Coordinated Care Trials: Outcomes of Renal Treatment on the Tiwi Islands:**

### **1 Introduction**

The present study arose at the end of the live phase and transition year of the Tiwi Coordinated Care Trial, in early 2001. Dr Wendy Hoy, who had lead the Renal Treatment Program on the Tiwi Islands, expressed concern that there may have been some deterioration of blood pressure levels among patients of the Menzies Renal Treatment Program (MRTP) now under the care of the Tiwi Health Board. The Tiwi Health Board supported a suggestion that a study be undertaken to ascertain the current status of former MRTP patients and to attempt to ascertain those aspects of care which might account for any changes observed after the cessation of the MRTP.

A team was formed consisting of researchers at NTU, Menzies School of Health Research and the Cooperative Research Centre for Aboriginal and Tropical Health, and a submission for funding to conduct a study approved by CRCATH in July/August 2001. Further funding was made available by the Commonwealth Department of Health and Ageing to conduct clinical audits and field investigations. In December 2001/January 2002, clinical audits of files of the entire population of persons eligible for treatment according to the MRTP protocols (irrespective of whether they had participated in the MRTP) were undertaken, with analysis of data conducted throughout 2002. Discussion and interview with practitioners took place during the audit period and subsequently, and informs the interpretation and concluding discussion. A dissertation for the Master of Public Health at Northern Territory University was submitted for examination by the team's project officer and accepted by examiners in February 2003 (Kondalsamy-Chennakesavan, 2003). That report is available on request, and should be consulted for further detail about methods, analysis and findings. The present report summarizes the findings of the study and situates them in the context of the Coordinated Care Trials and their contribution to the development of chronic disease care in the NT. It partly synthesizes the findings of the renal follow-up study with the findings of the CCT evaluations.

### **The Context of the CCT**

Throughout 1999 and 2000, the Tiwi Health Board had attempted to develop an approach to chronic disease care in the three health centers, the management of which it had taken over from Territory Health Services (now the Department of Health and Community Services, DHCS) and the Nguiu Community Government Council. The Renal Treatment Program had been run in the community health centers by a team based at the Menzies School of Health Research since 1995. This program had been independently funded, and was conducted by a dedicated team of practitioners under the direction of leading renal researchers. Funding for the MRTP ended in 1999, and at the end of that year the program was "handed over" to the Tiwi Health Board, to be managed in modified form by THB practitioners, who were to maintain the focus of the MRTP using the

infrastructure of computerized care plans and CCTIS, the Coordinated Care Trial Information System.

The central intervention of the CCT was the pooling of existing NT Government and Commonwealth funds expended on health services to the trial populations, and a further contribution of funds based on a “cashing out” of MBS and PBS funds calculated at the number of trial participants multiplied by the national per capita expenditure on those schemes. This was accompanied by the development and implementation of CCTIS and related supports for care coordination. Chronic disease care was to be based on the implementation of standard chronic disease care plans for renal disease, diabetes and hypertension. These were consistent with the treatment protocols developed for the Renal Treatment Program.

### **Resources and Management**

Despite the addition of new funds, taking over the Renal Treatment Program represented a problem for the Tiwi Health Board. The MRTP had been externally funded, and no funds had been pooled to cover its operation. In 1999, the Board argued strenuously for additional government funds to assist it to sustain the services provided by the MRTP. The arguments were rejected and THB decided to draw on funds from within the funds pool to establish a dedicated Chronic Disease Team (CDT), consisting of a registered nurse (RN) who would act as CDT Manager, two Aboriginal Community Health Workers who had worked on the original MRTP, with AHWs at the two smaller health centers rostered to work with the CDT nurse as required. The position of the CDT nurse was eventually abolished in late 2001 when THB encountered financial constraints. By this stage there was little resemblance between the approach of the MRTP and that of the THB, at least in terms of the application of dedicated and specialized resources to chronic disease care.

Leading up to and after the ‘handover’, there was some disagreement between management and staff about whether chronic disease management would be integrated in everyday health center work, or whether a separate, resourced facility would be maintained. GPs and other staff at Nguuu, for example, were reluctant to have chronic disease care imposed on them as an additional burden. After the CDT was established, these debates continued, with attempts to roster GPs and RNs from the other clinics to work in the chronic disease room for one or more days a week during 2000 and 2001. This was unsatisfactory. GPs and RNs felt that this strategy unnecessarily withdrew them from other important work, such as the provision of acute care, for relatively small, if any gains in terms of the quality and comprehensiveness of chronic disease care. During 2001, when the position of the CDT nurse was terminated, the male Aboriginal Community Health Worker on the CDT was assigned to carry out chronic disease work from the Nguuu men’s clinic, consulting the male RN clinic manager.

It is not possible to establish to what extent the CDT was able to identify a small group of at risk patients who might otherwise slip through the net. Anecdotal reports suggest that the CDT manager may have been more effective in this respect in the two smaller communities on Melville Island, where she was more easily able to follow up the relatively small numbers of patients, working in collaboration with the District Medical

Officer. Overall, the program was not subject to consistent medical oversight. In summary, it is difficult to assess the output of the CDT; it was responsible for a comparatively small number of consultations. By far the majority of care plan consultations received by renal patients were delivered opportunistically by other health center staff during ordinary consultations.

At the commencement of the Tiwi CCT, it was noted that systems of recall pre-existing the CCT and the implementation of CCTIS were to some extent dependent on information provided to health center practitioners by the MRTP team. These included access to data from the program, including “worry lists” listing high risk adult patients, lists of children’s ACRs, and so on. While this helped better inform routine health care in the health centres, it also largely removed the burden of providing particular elements of service from the health center practitioners: that is to say, active recall of patients and routine checks were undertaken by the MRTP team in their own vehicle. Thus, as a stand-alone program, the MRTP did not compete with other health centre processes for resources; rather, it provided a service to primary health care practitioners in the health centers.

The MRTP had the capacity to provide analysis of service levels and feedback to its own practitioners about priorities, gaps in services and patients’ health gains, a capacity lacking in the primary health care system. At the time the initial concerns about client outcomes were raised, it became apparent that the Tiwi Health Board, using CCTIS and data from SHILO, did not have the capacity to undertake analysis of data on services and outcomes. This is because, firstly, the infrastructure had not been adequately developed to allow THB personnel to readily access data; secondly, as evaluation audits had shown, (Robinson 2002), levels of data entry in CCTIS are for many items too low to support analysis without supplementary audits; finally, the functions of data extraction and analysis for purposes of feedback to practitioners is not yet highly developed within Tiwi Health Board.

In terms of clinical protocol, the MRTP intervention and care coordination using the standard care plans consist of the same formal elements. This included the elements of patient education and counseling about lifestyle and treatment, which are formally embodied in the standard care plan as services due. However, in this as in other respects, the actual pattern of delivery of services appears to have differed considerably for the reasons outlined. While the MRTP patients received intensive education and review in the first six months, there was in most cases no intensive phase of patient education and review at and after the assignment of standard care plans in the CCT. The ‘handover’ of the Renal Treatment Program nominally entailed a transfer of responsibility from the MRTP team to the THB’s Chronic Disease Team. However, both observation and report by practitioners suggest that the specific disciplines and processes of the clinical intervention trial were not maintained after the handover. These differences were generally apparent at the outset of the study. The critical question is, whether and how they may have contributed to any observed patient health outcomes.

**Table 1: Comparison of MRTP and CCT models**

	<b>MRTP</b>	<b>Tiwi CCT</b>
<b>Eligibility criteria for treatment</b>	<ul style="list-style-type: none"> <li>• Hypertension (BP<math>\geq</math>140/90)</li> <li>• Diabetics with ACR<math>\geq</math>3.4 g/mol</li> <li>• Clients with progressive overt albuminuria (ACR<math>\geq</math>34 g/mol)</li> </ul>	<ul style="list-style-type: none"> <li>• The same evidence-based criteria as used in Menzies program incorporated in standard care plans</li> </ul>
<b>Management method</b>	<ul style="list-style-type: none"> <li>• Systematic recall and active follow-up</li> <li>• Monthly review of medication first six months; 3 monthly 6-12 months; six monthly after 12 months</li> <li>• Rapid feedback to RN/AHW by physician enabling adjustment of medication in cases of high/uncontrolled BP</li> </ul>	<ul style="list-style-type: none"> <li>• Assignment of Care Plan</li> <li>• Opportunistic follow-up with occasional recall.</li> <li>• Review every 3-6 months depending on the type of care plan.</li> </ul>
<b>Interventions</b>	<ol style="list-style-type: none"> <li>1. Education about <ul style="list-style-type: none"> <li>• Diet</li> <li>• Exercise,</li> <li>• Health behaviours</li> </ul> </li> <li>2. Medical treatment.</li> </ol>	<ol style="list-style-type: none"> <li>1. Education about care plan</li> <li>2. Counselling on alcohol, smoking and activity</li> <li>3. Inquiry regarding symptoms, diet and weight loss.</li> <li>4. Medical treatment</li> </ol>
<b>Major Differences</b>	<p>Single focus on renal disease by a dedicated clinical team including specialist physician and research resources. No provision of acute care.</p> <p>No competition for resources such as vehicle, practitioner time, etc.</p> <p>Clear determination of clinical priorities; stringent application of protocols; systematic medical oversight by physician.</p> <p>High level research capacity to monitor and analyse services and health outcomes; prompt feedback to practitioners and patients.</p>	<p>Multiple focus in a comprehensive system of primary care; limited or no dedicated resources for renal treatment; continuous pressure to provide acute care.</p> <p>Competition for resources between health center units &amp; priorities.</p> <p>Limited ability to identify clinical priorities; limited, less systematic medical oversight by GPs</p> <p>Limited or no capacity to monitor and analyse service levels and patient outcomes to support care coordination and medical oversight</p>

## **2 Objectives of the Study**

The primary objectives of the study were as follows:

- a) To ascertain the current status (specifically blood pressure and metabolic control) of Tiwi patients formerly enrolled in the MRTP, and to measure changes in key parameters over time

- b) To establish whether any such changes could be attributed to the pattern of clinical management after “handover” of the program to THB
- c) To examine the relative effectiveness of the care coordination through a comparison with outcomes achieved for other eligible patients who were not enrolled in the MRTTP but had been managed using standard care plans
- d) To explore the implications of findings for the further development of chronic disease care by THB and under CCT arrangements more generally.

In addition, the general question of the sustainability of the intervention was to be considered in terms of:

- e) the maintenance of the health benefits of the intervention after the change in program management
- f) the maintenance of service levels and activities of the intervention after the change in management
- g) the development of those elements of capacity necessary to sustain the health benefits, including the institutionalization of the key elements of the intervention within Tiwi Health Board health center practices.

#### **Indicators of sustainability**

In order to address the question of the sustainability of health benefits of the MRTTP program, a number of indicators were used. Some of these outcome indicators and specific cut-off points were derived from the locally followed GSAT guidelines (Territory Health Services 1998) and some others from published sources of literature (Davidson 1998; Acton, Shields et al. 2001).

Outcome indicators for overall and specific subgroups were:

- Mean systolic and diastolic blood pressure at 6 monthly intervals
- Proportion of clients with systolic blood pressure less than 140mmHg and diastolic blood pressure less than 90mmHg
- Proportion of clients with systolic blood pressure less than 130 mmHg and diastolic blood pressure less than 80mmHg
- Proportion of diabetics with glycosylated haemoglobin <7% & 9.5%
- Proportion of diabetics with glycosylated haemoglobin >12%

Indicators of service levels for overall and specific subgroups are:

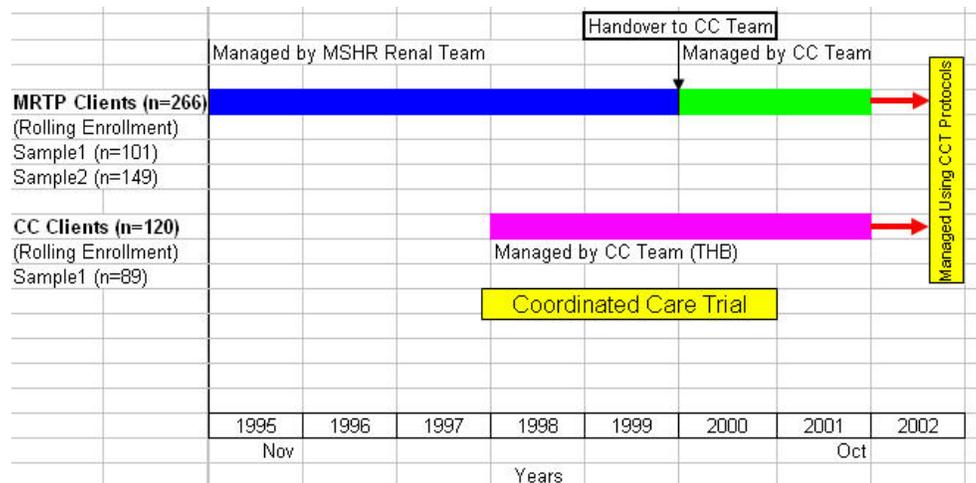
- Proportion of clients with blood pressure measurements at 6 monthly intervals
- Proportion of diabetics with 6 monthly glycosylated haemoglobin measurements (HbA1c)

### 3 Study Design and Methodology<sup>1</sup>.

#### Study Population and Samples

Two groups of clients were identified for the purposes of the study: 266 clients of the MRTP, and 120 clients who met eligibility criteria for MRTP, but who had not participated in the program, but were treated according to Care Coordination protocols only. It should be kept in mind that the handover was not an abrupt process but a transition from the last quarter of 1999 till the first quarter of 2000. For the purposes of statistical analysis, 31<sup>st</sup> Dec 1999 was assumed to be the handover date. Considerable interaction took place between the two chronic disease teams during this process of handover. Relevant data were gathered up to and including October 31, 2001.

**Figure 1: An overview of programs and participants in this study**



Two samples were extracted from the MRTP group: one, (n.=101), had had treatment for 66 months consisting of all the clients who were part of the renal treatment program offered by the Menzies School of Health Research from Nov 1995 till 31st Dec 1999. The handover occurred approximately between the 42<sup>nd</sup> and 51<sup>st</sup> month<sup>2</sup>. A Care

<sup>1</sup> The scientific protocol was approved and the permission to collect personal information on all the participants granted by joint institutional ethics committees of the Menzies School of Health Research (MSHR) and Territory Health Services (THS), also known as the Top End Human Research Ethics Committee (TEHREC). The proposal for this study also had approval from the 'Aboriginal subcommittee' of the TEHREC. In addition, the study received approval from the human ethics committee of the Northern Territory University. The Tiwi Health Board expressed its strong support for the evaluation of its chronic diseases strategy and granted permission for the study to proceed. See Kondalsamy-Chennakesavan, 2002, this volume, Appendix, sections 2.1-2.2.

<sup>2</sup> All the clients who completed at least 66 months of follow-up started their treatment during a period that stretched from Nov 1995 till June 1996. One of the drawbacks is therefore that the handover occurred not at a single point in time but over a period of 6-9 months stretching from 42-51 months after being initiated onto the treatment program. For example, handover would have occurred at or after 48 months if a patient started the treatment program in November 1995 and at 42 months if they started the treatment program in March 1996.

Coordination (CC) only sample (n.=89) was selected, consisting of persons who met MRTP eligibility criteria but who had been treated solely by THB practitioners using standard care plans for 30 months<sup>3</sup>. A second sample of MRTP clients (n. = 149) was selected to match the baseline characteristics of the Care Coordination 30 month sample; they had had treatment for 30 months before the handover to THB. Data on services and results of laboratory investigations was derived from both the MRTP database and SHILO for the MRTP group, and from SHILO only for the CC group. Manual audits of files were required for both groups, since data in CCTIS/SHILO is incomplete both for basic services and measurements and for some pathology results.

The eligibility criteria for inclusion in the MRTP were as follows:

- All those with hypertension (defined as systolic blood pressure  $\geq 140$  and or diastolic blood pressure  $\geq 90$ )
- Irrespective of blood pressure, all diabetics with albumin creatinine ratio greater than or equal to 3.4 gm/mol
- Irrespective of hypertensive or diabetic status, all those with progressive overt albuminuria ( $ACR \geq 34$  g/mol)

All who participated in the MRTP were prescribed perindopril®, an angiotensin converting enzyme inhibitor (ACEi) and other drugs as appropriate.

The end points for this group are as follows:

- Renal death (defined as a necessity for dialysis)
- Death due to all other causes
- Handover date of 31<sup>st</sup> Dec 1999
- Lost to follow-up
- Exclusion criteria within the study period like pregnancy and or breastfeeding. Data for those clients during this exclusion period were considered to be lost to follow-up and later on re-entered the program under the same identity.

Two hundred and sixty six clients from the MRTP database were identified who had satisfied the inclusion criteria and had been followed up until they reached one of the endpoints mentioned above<sup>4</sup>.

For the Care Coordination sample, most clients who satisfied the above inclusion criteria had been assigned one of the renal, diabetic or high blood pressure care plans developed for the Coordinated Care Trials by the Guidelines, Standard and Audit Team (GSAT). Nearly 180 clients who were never part of the MRTP were allocated one of the above chronic disease care plans. However, the auditing of medical records revealed inconsistencies in allocation of care plans and not all those who were on one of the above

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<sup>3</sup> The Coordinated Care Trial began Dec 4<sup>th</sup> 1997; however assignment of renal care plans only occurred at the end of 1998, in effect restricting the analysis to clients with thirty months of follow-up.

<sup>4</sup> Eleven participants developed renal failure and twelve patients died from other natural causes. One person died a suicide death. Six persons chose not to participate in the program even though they satisfied the inclusion criteria. Six patients dropped out of the study because of adverse effects (cough, angioedema and itching). Eight persons moved away from the Tiwi Islands and two patients entered into palliative care.

chronic disease care plans fitted the same inclusion criteria as those of the MRTP. Only 120 patients from this CC group fitted the same inclusion criteria as the MRTP clients. Of this group, eighty-nine patients had completed at least 30 months of follow-up, all of whom were included in the comparative analysis. Much heterogeneity exists among drugs prescribed to this group of clients, and, unlike the MRTP group, not all had been prescribed perindopril. Eighty three (93.3%) patients were identified to be on at least one class of antihypertensive/vasoactive medications.

#### **Extraction and compilation of longitudinal data**

The data had to be collected from 3 related but different sources. The THB by its agreement with MSHR owns the MRTP data and Dr. Hoy in consultation with the THB released the data for all the MRTP participants. This dataset contained details about all the MRTP participants including their clinical and bio-chemical profiles. The data for the CC clients as well as the post-handover Menzies clients had to be obtained from the CCTIS/SHILO. Under-entry of data in certain areas of the electronic system (Bailie and Robinson 2000; Robinson and Bailie 2000) meant that auditing of medical records was essential to bridge the identified gaps in the electronic files. Methods of data gathering and merger, and influences on data quality are described in detail by Kondalsamy-Chennakesavan, (2003, section 2.4.1 – 2.4.4).

#### **Statistical methodology**

Merger of all data sources resulted in a longitudinal or panel dataset which contained repeated measurements on a particular variable (e.g. systolic blood pressure) across different time periods (6 monthly intervals) for a particular individual. This enables analysis of the effects of treatment or changes over time. Descriptive statistics are used to illustrate the baseline characteristics. For continuous outcomes with independent observations, results of t-tests testing the significance of differences between the means are presented. For categorical outcomes, results of  $\chi^2$  test statistic are reported. To illustrate the differences between the management groups over time, crude ‘summary’ measurements have been utilized (Tables 2 & 3). Univariate measures are not without drawbacks and hence extensions of linear models, taking into account the correlated nature of the data, have been utilised.

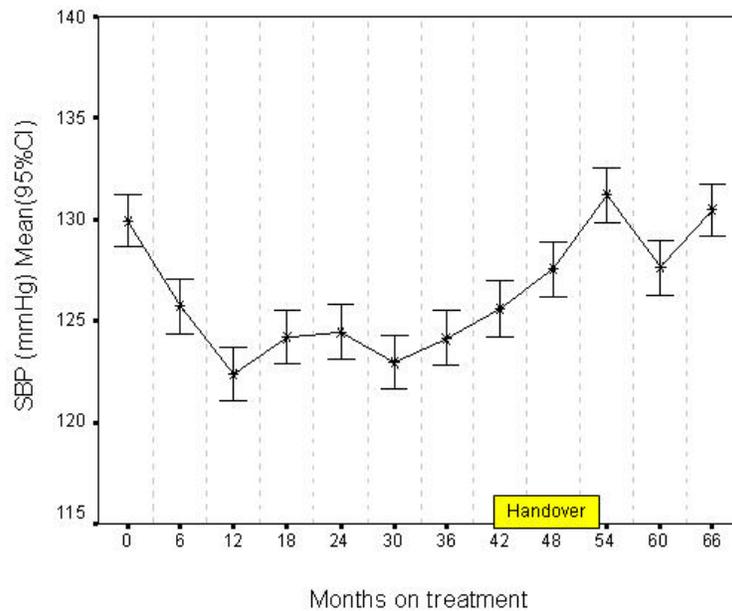
Most of the results presented here are based on cross sectional time series regression analysis (Random Effects Model, REM). The cross sectional time series regression models (REM) included time of measurement, management group to which individuals belong and an interaction term of time of measurement with the management group. Also included in the model were baseline blood pressure, age and sex as ‘time-invariant’ covariates. After the models were estimated, post-estimation checks were carried out which included but not limited to Breusch and Pagan’s Lagrange multiplier test for random effects (Breusch and Pagan 1980; Baltagi and Li 1990) and also Hausman’s specification test to ensure that the model was not ‘misspecified’ or violated the “*assumption that the random effects were uncorrelated with the regressors*” (Hausman 1978; Greene 2000). Stata Statistical Software Release 7.0 was used for most of the statistical analyses (Statacorp, 2001).

## 4 Outline of Main Findings

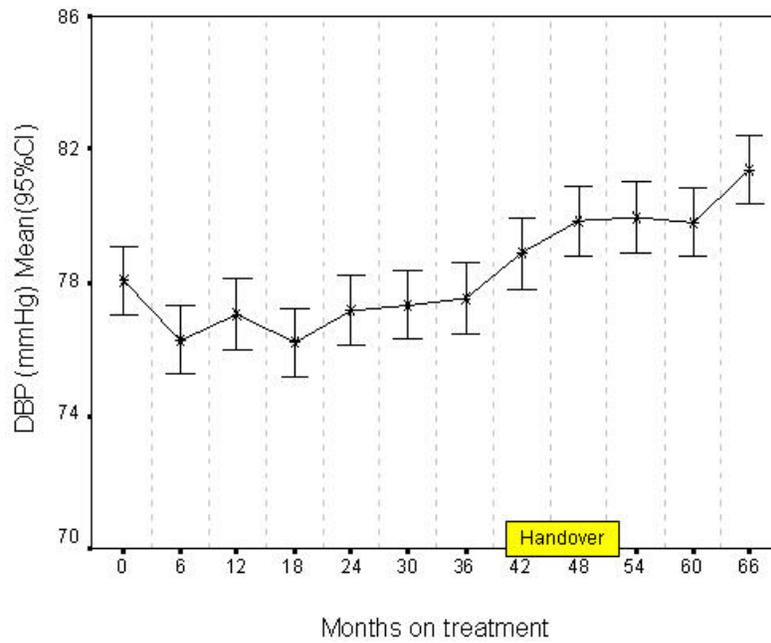
### MRTP Clients before and after handover

The MRTP had achieved a statistically significant reduction in systolic blood pressure in the first six months of treatment, and sustained this improvement in the subsequent 3-4 years of treatment (Figure 2). Changes in diastolic BP were not as pronounced as for systolic BP (Figure 3). At approximately 18 months after the reductions in blood pressure, renal function (GFR) improved markedly. The mean levels of control of blood pressure achieved under the MRTP were not maintained after the withdrawal of the MRTP team and ‘handover’ of the program to the local health centre staff. It should, however, be noted that there were some signs of increase in mean levels of BP control before the handover. Whether this observed increase constituted a trend which would have persisted had there been no withdrawal of the MRTP treatment regime, and whether this would have been a result of a combination of a) declining efficacy of treatment b) natural disease progression, cannot be established by this study.

**Figure 2: Trends in mean systolic blood pressure among MRTP clients with 66 months of follow-up (n=101)**



**Figure 3: Trends in mean diastolic blood pressure among MRTTP clients with 66 months of follow-up (n=101)**



**Figure 4: Proportion of MRTTP clients with 66 months of follow-up who had BP measurements (by community)**

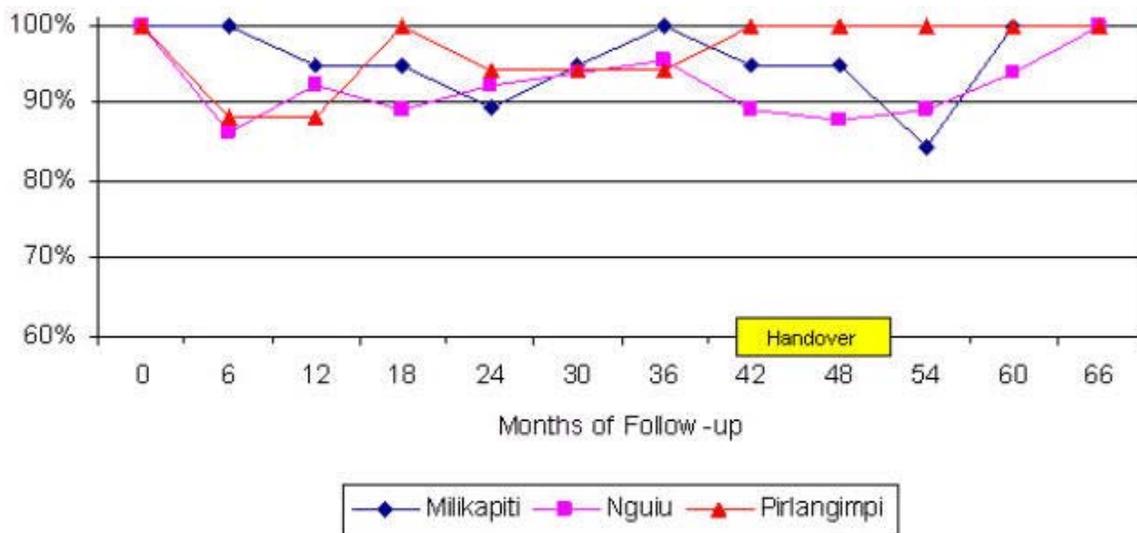


Table 2: Summary measures MRTTP cohort 66 months from baseline with subgroups

Indicators	Prehandover	Posthandover	P
<b>66 Months Cohort (n=101)</b>			
SBP	<b>124.0 (1.4)</b>	<b>129.3 (1.5)</b>	<b>0.013</b>
DBP	<b>77.0 (0.9)</b>	<b>80.3 (1.1)</b>	<b>0.020</b>
BP<140/90	<b>71.0%</b>	<b>60.4%</b>	<b>0.010</b>
BP<130/80	42.9%	34.9%	0.069
<b>Diabetics (n=54)</b>			
SBP	123.5(1.8)	126.8(1.9)	0.210
DBP	76.5(1.2)	78.0(1.4)	0.394
BP<140/90	73.4%	65.9%	0.142
BP<130/80	45.3%	41.4%	0.519
HbA1C<7%	29.8%	26.2%	0.491
HbA1C<9.5%	72.5%	66.9%	0.338
HbA1C>12%	5.4%	6.4%	0.704
<b>Hypertensives (n=24)</b>			
SBP	132.1 (2.8)	137.0 (3.4)	0.259
DBP	82.5 (1.5)	86.1 (2.1)	0.174
BP<140/90	55.9%	42.9%	0.136
BP<130/80	25.0%	16.7%	0.233
<b>Male (n=47)</b>			
SBP	129.3 (1.8)	130.8 (2.1)	0.577
DBP	81.0 (1.2)	82.6 (1.6)	0.454
BP<140/90	62.8%	56.7%	0.297
BP<130/80	30.3%	30.3%	0.990
<b>Female (n=54)</b>			
SBP	<b>119.6 (1.9)</b>	<b>127.9 (2.2)</b>	<b>0.006</b>
DBP	<b>73.7 (1.2)</b>	<b>78.5 (1.5)</b>	<b>0.012</b>
BP<140/90	<b>77.9%</b>	<b>63.6%</b>	<b>0.011</b>
BP<130/80	<b>53.6%</b>	<b>38.9%</b>	<b>0.015</b>

Caution must be exercised in interpreting this table: The mean values are unadjusted for age and sex. Data are mean(SE) or proportion. Pre-handover results, excluding baseline measurements, include measurements up to and including 42 months. Results shown in **bold** are statistically significant.

Abbreviations: SBP, Systolic Blood Pressure; DBP, Diastolic Blood Pressure; HbA1C, Glycosylated Haemoglobin.

Significant variations exist among specific subgroups of clients after the handover. These are summarized in Table 2. Although for all subgroups there were observed increases in mean systolic and diastolic BP, and declines in the proportion of the samples with BP under target levels of <130/80 & <140/90, for diabetics, hypertensives, and males, these were not statistically significant. Glycemic control for diabetics showed no significant

change. For female patients, there were statistically significant increases in mean systolic and diastolic BP, and significant declines in the proportion of the sample with BP under target levels of <130/80 & <140/90. These proportions were similar to those for females in the group who had been managed by care coordination only for 30 months (Table 2).

Records of delivery of services for selected clinical measurements (BP & weight) were sustained at the same levels as pre-handover MRTP clients. Among other things, this suggests that opportunity to deliver all required services according to protocol did not decline as a result of declining attendance.

### Comparison of Outcomes for MRTP and Care Coordination Clients

For purposes of comparison of the two regimes of treatment, samples were selected, one of which had undergone 30 months of treatment under the MRTP, while the other consisted of persons who had not been enrolled in the MRTP, but had received 30 months of treatment for a relevant condition using standard care plans.

One hundred and forty-nine people from the MRTP and 89 clients from CCT completed at least 30 months of follow-up. The participants' ages (at baseline) ranged from 21.7-72 years for the MRTP clients and from 18.3 to 82.1 years for the CC clients. The mean levels of systolic blood pressure, estimated glomerular filtration rate and serum creatinine values differed significantly between the 2 groups. Baseline characteristics suggest that the two groups are broadly comparable, although the CC group was slightly younger with significantly lower systolic BP and less advanced renal pathology at baseline than the MRTP group.

**Table 3: Baseline characteristics of participants who completed 30 months of follow-up**

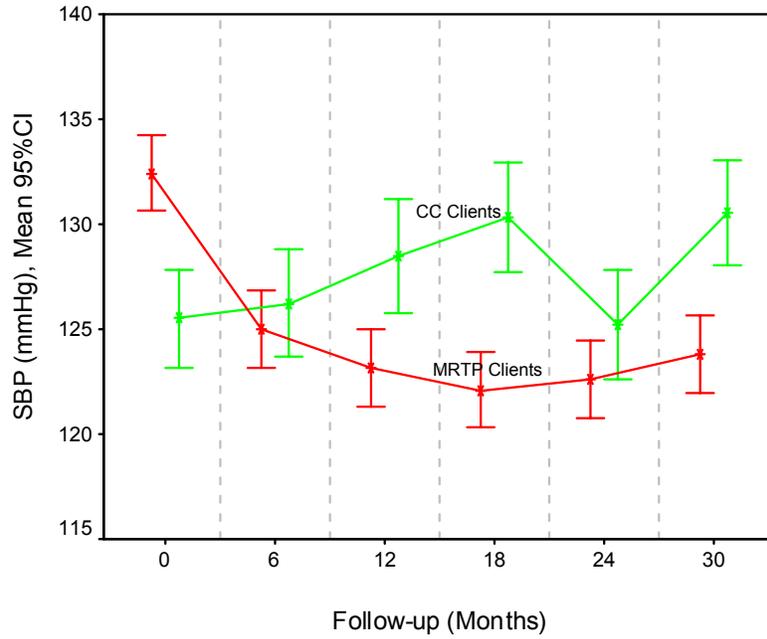
<b>Baseline Parameter</b>	<b>MRTP Clients (n=149)</b>	<b>CC Clients (n=89)</b>	<b>p</b>
Age (in years)	44.6(10.9)	42.1(13.2)	0.115
Male	66(44.3%)	39(43.8%)	0.943
Hypertensive	40(26.9%)	27(30.3%)	0.562
Diabetic	80(53.7%)	42(47.2%)	0.332
SBP (mm Hg)*	<b>132.4(22.2)</b>	<b>125.5(19.9)</b>	<b>0.017</b>
DBP (mm Hg)	77.8(14.5)	78.6(13.8)	0.675
GFR (ml/min)*	<b>91.25(32.3)</b>	<b>105.05(29.5)</b>	<b>&lt;0.001</b>
Serum Creatinine (umol/L)*	<b>92.52(26.44)</b>	<b>81.52(24.13)</b>	<b>0.002</b>
Median ACR (g/mol)	60	37	

Data are mean (SD) or proportion

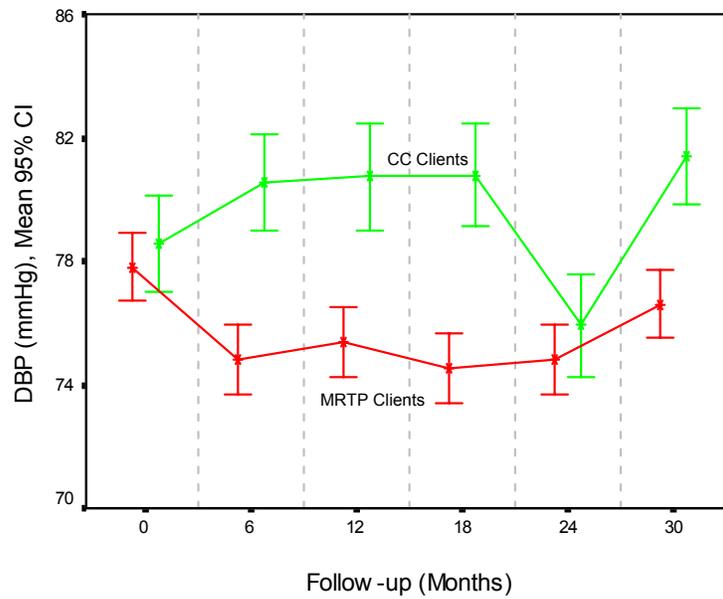
Abbreviations: SBP, systolic blood pressure; DBP, diastolic blood pressure

\*Mean values significantly differ between the 2 groups

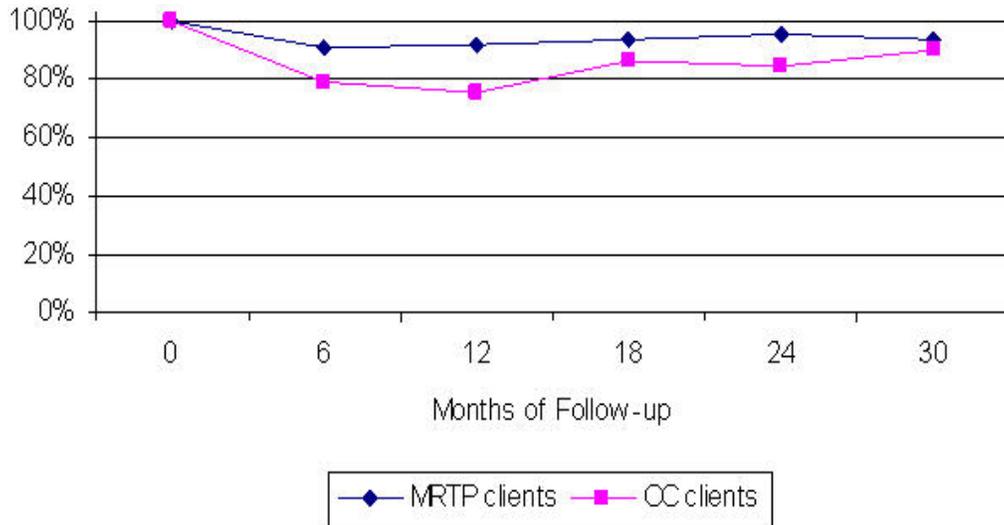
**Figure 5: Trends in mean levels of systolic blood pressure between MRTP and CC Clients (adjusted for Baseline blood pressure, Age and Sex)**



**Figure 6: Trends in mean diastolic blood pressure among MRTP and CC Clients (adjusted for Baseline blood pressure, Age and Sex)**



**Figure 7: Proportion of clients receiving blood pressure measurements among MRTP and CC clients**



**Figure 8: Proportion of MRTP and CC clients with BP < 130/80**

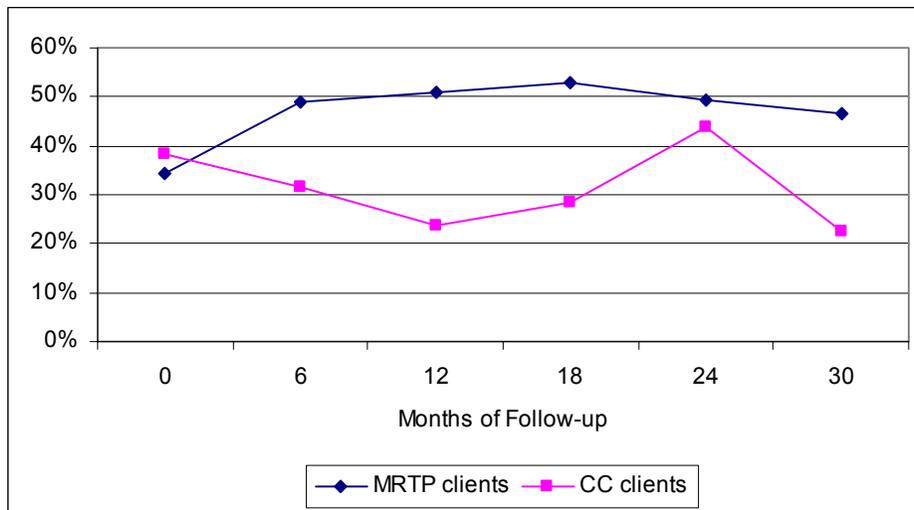


Figure 3 presents the changes in systolic blood pressure (adjusted for baseline blood pressure, age and sex) for each of the 2 groups after commencement in the respective treatment programs. The MRTP participants showed a significant drop in their SBP within 6 months of treatment, whereas the changes in the CC clients was in the adverse direction, albeit not significantly. For the MRTP clients, diastolic blood pressure showed a significant drop at 6, 18 and 24 months (Figure 4), although the differences from

baseline at 12 and 30 months were not significant. Changes in DBP for the CC clients did not differ significantly from their baseline values.

**Table 4: Summary measures of two different management strategies MRTP & CC cohorts 30 months from baseline by subgroups**

<b>Indicators</b>	<b>MRTP Clients</b>	<b>CC Clients</b>	<b>P</b>
<b>30 Months Cohort</b>	N=149	N=89	
SBP	<b>123.3 (1.3)</b>	<b>128.1 (1.7)</b>	<b>0.022</b>
DBP	<b>75.2 (0.8)</b>	<b>79.9 (1.1)</b>	<b>&lt;0.001</b>
BP<140/90	<b>72.4%</b>	<b>59.4%</b>	<b>0.002</b>
BP<130/80	<b>48.7%</b>	<b>38.1%</b>	<b>&lt;0.001</b>
<b>Diabetics</b>	N=80	N=42*	
SBP	124 (1.8)	128.8 (2.6)	0.126
DBP	74.9 (1.1)	78 (1.4)	0.077
BP<140/90	72.1%	62.7%	0.124
BP<130/80	<b>48.6%</b>	<b>31.4%</b>	<b>0.011</b>
HbA1C<7%	24.3%	30.3%	0.398
HbA1C<9.5%	71.9%	71.7%	0.986
HbA1C>12%	5%	8.3%	0.361
<b>Hypertensives</b>	N=40	N=27	
SBP	130.7 (2)	132 (2.4)	0.692
DBP	<b>79.4 (1.2)</b>	<b>86 (1.9)</b>	<b>0.005</b>
BP<140/90	<b>61%</b>	<b>43.4%</b>	<b>0.019</b>
BP<130/80	<b>32.1%</b>	<b>17.2%</b>	<b>0.033</b>
<b>Male</b>	N=66	N=39	
SBP	<b>127 (1.7)</b>	<b>133.4 (2.3)</b>	<b>0.027</b>
DBP	<b>79.5 (1.1)</b>	<b>85.7 (1.5)</b>	<b>0.001</b>
BP<140/90	<b>65.6%</b>	<b>46.8%</b>	<b>0.005</b>
BP<130/80	<b>36.0%</b>	<b>16.2%</b>	<b>&lt;0.001</b>
<b>Female</b>	N=83	N=50	
SBP	120.4 (1.8)	124.3 (2.2)	0.166
DBP	<b>71.9 (0.9)</b>	<b>75.7 (1.2)</b>	<b>0.011</b>
BP<140/90	77.6%	68.4%	0.070
BP<130/80	<b>58.5%</b>	<b>40.0%</b>	<b>0.031</b>

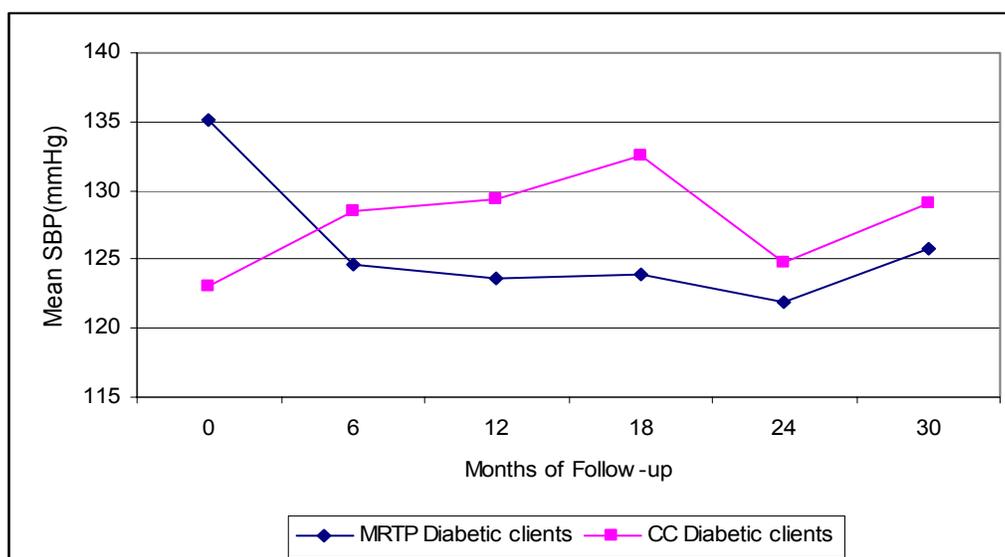
Data are mean (SE) or proportion. Abbreviations: SBP, Systolic Blood Pressure; DBP, Diastolic Blood Pressure; HbA1C, Glycosylated Haemoglobin; SE, Robust Standard Error. Data shown in **bold** differ

significantly between the two groups. \*Only 39/42 diabetic clients had had at least one HbA1C measurement among the CC group.

However, CC clients showed a significant but un-sustained drop in both the systolic and diastolic blood pressures from their mean levels at 18 months to mean levels at 24 months. It is likely that this improvement coincides with the period at or around the “handover”, during which the MRTTP team had a considerable interaction with the Tiwi Health Board’s Chronic Disease Team. It can not be discounted that mean BP levels for CC clients might have been worse if the Board’s chronic disease team had not been in operation.

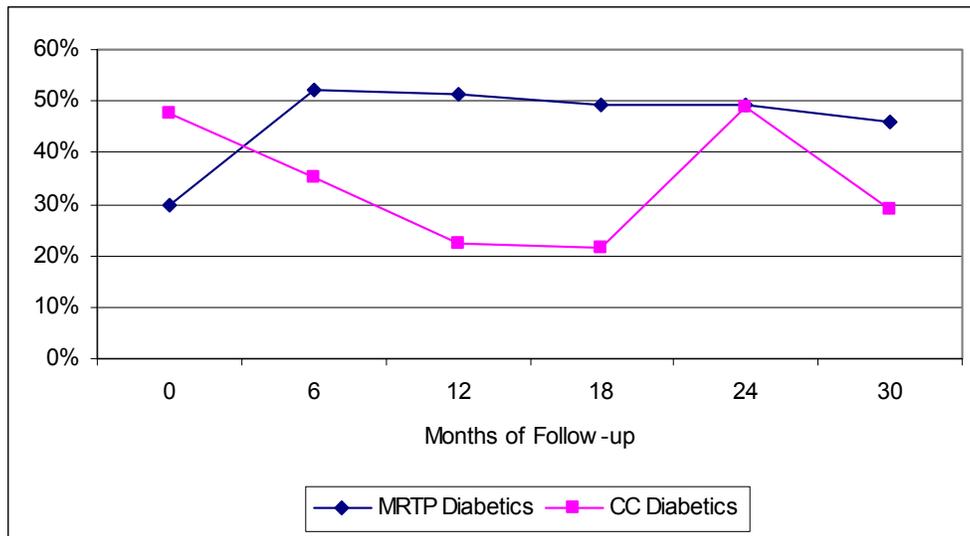
Outcomes for diabetics in the two 30 month cohorts warrant some attention. The MRTTP had achieved a significant fall in SBP within the first six months of treatment, and sustained the improvement (Figure 9). For the CC group of diabetics, commencing with a significantly lower mean SBP<sup>5</sup>, there is a significant worsening of the proportion of persons with blood pressure under the target of <130/80 over the first 12 months (Figure 10).

**Figure 9: Comparison of mean systolic blood pressure between diabetic MRTTP and diabetic CC clients**



<sup>5</sup> This difference in baseline blood pressure values may in part be due to the lower number of hypertensives in the CC group (Kondalsamy-Chennakesavan, 2002: 37 Table 8) and partly due to medical treatment for hypertension in this group prior to assignment of care plans.

**Figure 10: Proportion of diabetic clients with BP<130/80**

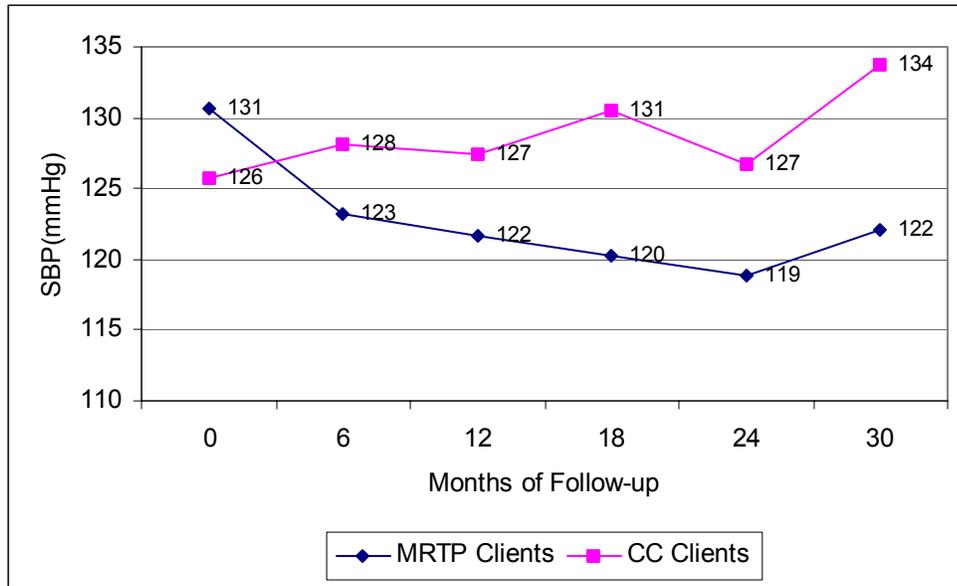


For the hypertensive subgroup in the two samples the MRTP achieved a significant improvement in the proportions of persons with blood pressure under target levels in the first six months, which was sustained (Kondalsamy-Chennakesavan 2003, fig. 23). It is clear that major gains in blood pressure control is potentially achievable among both diabetics and hypertensives. The care coordination process not only was not able to achieve that gain, but saw a worsening of BP control for diabetics. It is not clear to what extent this reflects variations in care. As noted above, it is possible that, without the operation of the CDT, outcomes could have been still worse than recorded. In the circumstances of the CCT, there may have been reduced effectiveness of treatment for diabetics not under MRTP management at commencement, perhaps as a result of the distraction of practitioners by CCT implementation processes early in the trial. This was followed by the significant but unsustained improvement of blood pressure for this group at around 24 months, indicating that the CDT was able to have some influence. However, the data provided in this study do not allow us to reach firm conclusions about these matters.

**Outcomes according to care plan type**

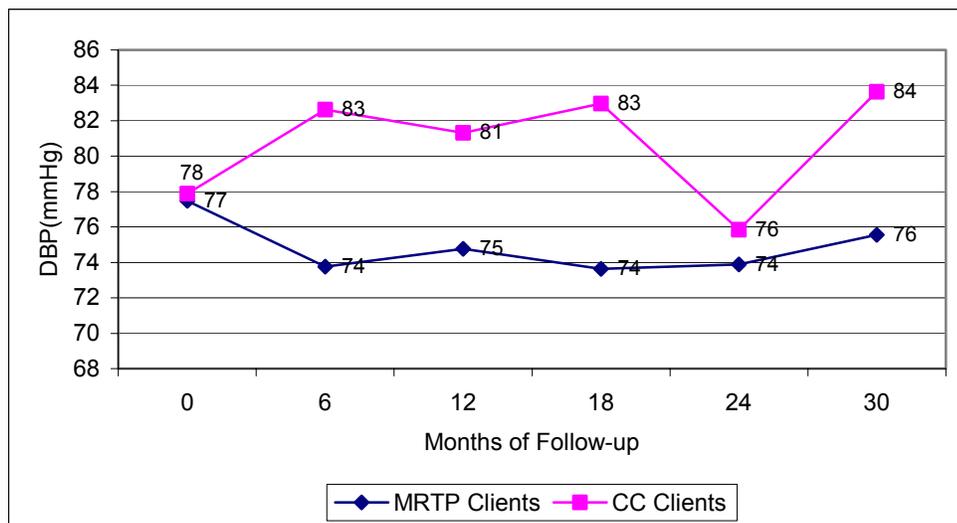
Albumin-creatinine ratio is the marker of severity and progression of renal disease which differentiates the standard care plans. Those at high risk of progression to ESRD are persons with  $ACR \geq 34$  g/mol. Figure 11 shows that for this group the MRTP was successful in reducing mean levels of SBP, while the CC process was not.

**Figure 11: Mean systolic BP for MRTP and CC clients with ACR $\geq$ 34 g/mol & 30 months follow-up**



Similarly, Figure 12 shows that the MRTP was able to achieve and sustain a significant reduction in mean diastolic blood pressure among patients with ACR $\geq$ 34 g/mol over 30 months, while DBP rose for CC clients, with the exception of a period 6 – 12 months after handover.

**Figure 12: Mean diastolic BP for MRTP and CC clients with ACR $\geq$ 34 g/mol & 30 months follow-up**



**Figure 13: Mean BP for MRTTP clients with ACR $\geq$ 34 g/mol over 66 months follow-up**

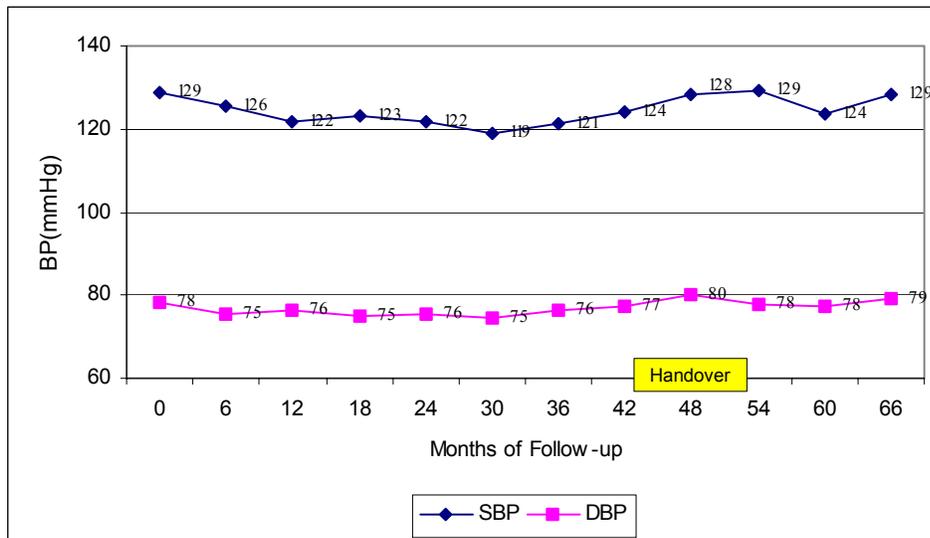


Figure 13 shows that the MRTTP program was able to maintain BP for persons with overt albuminuria below the target level of 125/80 until handover, when mean levels rise.

**Service levels and blood pressure control**

Service levels and follow-ups (measured by number of records of BP taken) have been consistently maintained above 90% for the MRTTP clients over the first 30 months of treatment, whereas follow-ups for the CC clients showed a gradually improving trend starting from 79% at 6 months to 90% at 30 months (Figure 7). The proportion of clients with uncontrolled hypertension started to decline (from 42% to around 30%) within 6 months of treatment among the MRTTP clients; this was sustained throughout the 30 month follow-up period (not shown, but see Figure 2 above). For CC clients, the proportion of uncontrolled hypertensives remained above 52% throughout (except at 24 months where 43% were uncontrolled). Figure 6 shows the proportion of clients with target blood pressure for each of the 2 groups. At least 44% of clients were maintained below the target blood pressure levels by the MRTTP team, whereas the CC clients show an initial decline during the first 12 months and gradually improve in the next 12 months with levels dropping again at 30 months to well below the baseline level.

While mean systolic and diastolic BP were significantly lower for diabetics in the MRTTP group at 30 months than for diabetic Care Coordination patients at 30 months, glycemic control for Care Coordination patients was as good as if not better than for MRTTP clients at 30 months from baseline.

Records of delivery of services for selected clinical measurements (BP & weight) were sustained at the same levels as pre-handover MRTP clients. Among other things, this suggests that opportunity to deliver all required services according to protocol did not decline as a result of declining attendance, as indicated by the frequency of recording these measures. However, the number of records of BP taken is an insufficient indicator of clinical action.

## **5 Discussion: Organization of services and treatment of chronic disease**

The following summarizes the main findings in relation to the key questions of sustainability of health benefits and of program activities and service levels. It then provides a discussion of elements of management under the two regimes and their relevance for sustainable chronic disease care in the service environment of the CCT.

On the sustainability of health benefits:

- a) The initial significant improvement in BP control for MRTP participants was sustained up to 36-40 months after commencement, after which BP control deteriorates to levels generally above baseline levels
- b) Although in general terms the health benefits of the program were not sustained, on many measures the MRTP clients retain an advantage over CC clients
- c) The increase in BP in the cohort may have begun before the handover to THB, suggesting that natural progression of disease may have contributed to the increase, in combination with changes in treatment regimes

On the sustainability of service levels:

- d) The monitoring of BP appears to have been conducted at comparable levels for MRTP and for CC clients.
- e) A slight decline in recording of BP for MRTP clients after handover was followed by improvements in recording of BP to levels equal to or better than under MRTP program.

### **CCTIS, Care Plans and Care Coordination**

Care Coordination as implemented in the Coordinated Care Trials rested on two main elements: the electronic data system, CCTIS, and the best practice protocols, known as care plans, which are propagated for each patient on the computer system. The latter are of two kinds: population care plans, for infants, school aged children, adults from 16 – 49 years and adults from 50 years of age; secondly, standard care plans have been developed for a range of conditions, including renal disease, diabetes and hypertension. These care plans set out the major elements of service, including basic measures, clinical examinations and screening, vaccinations, counseling and advice, laboratory investigations, and periodic review of treatment, according to appropriate schedules. On initiating a consultation for any purpose, the computer lists all services due according to the client's population and standard care plans, which will have been integrated by the clinicians on assignment. CCTIS has limited search functions for monitoring certain

services due and results. Data for aggregate analysis is requested from the central datamart, SHILO, maintained by DHCS.

Aspects of the functioning of care plans on CCTIS represent a challenge for prioritization of clinical tasks. The MRTP had a simple list of items due at fixed intervals, with the key measures and tests central priorities. By contrast, the effect of care plans on CCTIS is to present practitioners with a large number of due and overdue items from both population and health problem care plans; services not done accumulate in the client diary. This characteristic of the system does not assist and to some extent may undermine the establishment of clear priorities for service delivery. The accumulation of due and overdue items may increase the likelihood that when services are being opportunistically delivered, the patient's perception of immediate needs rather than clinical desirability determines which services are actually delivered. In addition, the proliferation of due items, and the inclusion of counseling and inquiry as service items may have contributed to the low and inconsistent levels of data entry for many service items. Many services in the care plans have no possible value for aggregate data analysis of service activity or outcomes.

Finally, there are nine separate care plans for renal disease, including combination renal & diabetes care plans and the hypertension care plan. The resultant complexity may increase the probability that care plans are mistakenly assigned, or are not appropriately reviewed and reassigned. The array of care plans represents a cumbersome framework for monitoring risk, since they rely on correct assignment of care plans and regular review of results and adjustment of care plans assigned; during the period under review, the system did not provide lists of results-based assessments of individual clients within selected parameters. CCTIS could not produce "worry lists", based on recent laboratory results or recorded BP. CCTIS and the care plans have been intended to incorporate a very wide range of functions. As a consequence, they remain inefficient instruments for monitoring programs which target specific outcomes. They at best inefficiently support medical oversight of targeted health programs, given the inadequacies of data entry, the resultant incompleteness of data in SHILO and the cumbersome turnaround of data extracted from SHILO.

The inefficiency of the data system and the care plans are not matters which can be resolved simply by training and work practice development. The complexity and range of functions which the system has sought to accommodate produce a situation where the possible gains from training are constantly dissipated by the inability of the system to support a focus on specific clinical needs for monitoring, feedback and alerts. The analysis here shows clearly that there is a need for training to reinforce the basics of clinical action as required by protocol, rather than routine taking of BP and entry into CCTIS. Secondly, there must be the capacity to provide feedback on the results of action. A simpler system focused on key parameters for clinical monitoring would be compatible with more effective training. An over-demanding system not focused on clinical outcomes competes with these priorities.

There should perhaps be a warning not to throw the baby out with the bathwater and abandon the CCTIS project. However, developers of the data system and the care plans need to re-examine the real needs of the health services for efficient instruments to support specific clinical programs.

**Effectiveness of monitoring: opportunistic delivery and action taken.**

One of the striking findings of the study is that although levels of monitoring of blood pressure are generally comparable in the two programs (Figure 7), the proportion of clients with BP under target levels is significantly lower for the Care Coordination group (Figure 9). This indicates that there are differences in the effectiveness of monitoring and action according to protocol in the two programs. These may rest on differences between the context in which records of BP are taken, and in the action taken when instances of BP over target levels are recorded.

Firstly, as noted, the Care Coordination regime relies primarily on opportunistic delivery of care plan services, rather than on recall by appointment which involves, as appropriate, picking up clients in vehicles or house visits to secure attendance or delivery of services when due. Opportunistic delivery means that many services required by the treatment protocol are in fact taken in a context in which patients present at the health center for other reasons, for example in cases of acute illness or trauma. Routine blood pressure monitoring in such cases may therefore not always lead to action required – for example, review of care plan, medication or advice - from the standpoint of chronic disease management.

Doctors, RNs and AHWs in the Tiwi health centers all indicated that acute care left little room for adequate preventive monitoring and review. Research in other settings suggests that in situations of acute care characterized by reactive service delivery, practitioners are reluctant to aggressively target BP reduction and tolerate higher levels of BP than protocol for effective management demands (Oliveria 2002). According to Wagner, (Wagner 1996), “Because primary care practices and practitioners are so oriented to acute illness, they may not differentiate their clinical approaches to patients with acute and chronic illness, relying instead on patient-initiated visits, relief of symptoms, normalization of aberrant physiological measures, and assurance that there is no medical crisis.”

**Practitioner type and interaction between practitioners.**

The medical oversight characteristic of the research program was not achieved by the Tiwi Health Board. MRTP practitioners reported that systematic consultation of the senior physician (by telephone if not present) enabled speedy adjustments to medication or review of other elements of treatment to occur where necessary. The RNs on duty had advanced authorization to vary dosages under specified circumstances. By contrast, for normal health center work, consultations by AHWs and to some extent by RNs may not always lead to timely action or review of treatment by a GP. Confidence may be lacking on the part of members of the team to act according to protocol without explicit medical authorization, so that adjustments to treatment will not occur without consultation with a GP.

Other data (Kondalsamy-Chennakesavan 2003) indicate that, over a two-year period, MRTP clients at Nguiu (the largest group in both MRTP and CC samples) did not receive more consultations per patient than the CC group. They may have received slightly less AHW consultations, absolutely and proportionately, than the CC group, slightly more RN consultations, but less GP consultations than the CC group. Females tended to see AHWs more often and RNs less often than males (ibid. p. 46).

In general, it is likely that differences in effectiveness of management may have less to do with the absolute numbers of consultations received, than with the kinds of consultations received. While the numbers or proportions received from different practitioner types may in some circumstances have an influence, it is likely that the proportion of consultations initiated for purposes of chronic illness monitoring and the adequacy of interaction between practitioner types when responding to chronic illness management issues are the more important influences. This suggests that a combination of basic training around protocols for clinical action, and work practice development regarding interaction between practitioners may be desirable to improve care coordination in the general health center setting.

It must be noted that, at around 24 months after commencement of treatment, a significant improvement in blood pressure control was achieved for CC clients (Figures 5, 6 & 8). Although this must be treated with caution, this may have been matched by a brief improvement in mean SBP in the MRTP cohort at around 60 months<sup>6</sup>. This period appears to follow the “handover” period, that is, after a transition during which MRTP personnel (including one experienced RN who had been with the program for at least two years before handover) had assisted THB personnel. The intensified interaction between practitioners during the transition, and the subsequent concern among practitioners about how to make the chronic disease strategy work, almost certainly contributed to the observed improvements. This is an indication that, with appropriate processes, improvements in outcomes can be achieved even when the initial intensive induction of clients to a treatment regime has been foregone.

An important element of the success of the MRTP program has been the close teamwork between specialized RNs and the Aboriginal Community Health Workers in the program. This can be difficult to achieve in some general health center contexts, in which the AHWs may be under pressure to be, and may wish to be independent and autonomous, but may lack effective interaction with other practitioners as a result. The area of best performance in service delivery in the Tiwi CCT over three years was delivery of services to 0-3 year olds, a clinical field which has long been based on effective teamwork involving RNs and AHWs (Robinson 2002). It is important to ensure that AHWs enjoy constructive interdisciplinary support from RNs or GPs if they are to maintain and improve the effectiveness of their clinical work.

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<sup>6</sup> Note that the time period in months refers to time from baseline, i.e., from commencement in a program for each individual in the sample; given staggered recruitment to the programs, it therefore only diffusely coincides with the historical timescale of program development and activity.

**Intensity of initial treatment and patient education.**

In the comparison between MRTP and CC groups, it was noted that there was a significant improvement in blood pressure management for MRTP clients in the first six months of treatment. This was not achieved for CC clients, whose BP continued to rise after assignment of a relevant care plan. This suggests that the early intensity of management under the MRTP regime is an important element of its success in control of BP. The Coordinated Care Trials had initially intended a similar intensive induction of all clients to treatment using standard care plans. However, this was abandoned due to a lack of resources. Electronic care plans were propagated by practitioners without conducting an interview of clients to review treatment and discuss the individual's care plan. Furthermore, as care plans were propagated without initial interview, and as services have been delivered largely opportunistically, it is likely that adjustment of medication was not systematically pursued after assignment of care plans, as was rigorously done in each case in the first six months of MRTP treatment.

There may be multiple effects of initial intensity of monitoring and treatment: firstly, if BP is quickly brought under control, many patients may perceive early gains in wellbeing; secondly, early and intense patient involvement in education about requirements of treatment, about lifestyle, and other related issues may improve the likelihood of patient self-responsibility, responsiveness to recall, and general compliance with treatment. The early effect of the MRTP intervention and the ability to sustain the reductions achieved early in the program must be considered to be a central mechanism underpinning that program's effectiveness. It undoubtedly also required active recall to follow-up all instances of uncontrolled hypertension, as well as systematic work to ensure adherence to protocol by all clients.

A cautionary note must be sounded: the comparison of the baseline profiles of the MRTP and CC 30 months samples indicates that these groups were generally comparable. There were only slight differences in age, morbidity, and gender composition of the two samples at baseline. However, there was a somewhat larger number of hypertensives in the MRTP group, and both mean systolic BP and indices of renal functional status were worse for the MRTP group (Table 3). This may suggest that the CC patients were less likely to perceive themselves as ill, and may have tended to be less readily compliant than MRTP clients. Furthermore, during the MRTP a number of patients did not enter, withdrew or were excluded from the program, either on screening, or during the first months of treatment. For at least some of these exclusions, the reasons can be characterized as non-consent or non-compliance. Some of these patients are included in the CC sample. It is therefore possible that the CC sample includes some patients less compliant and more difficult to treat than those of the MRTP. This means that, although a clear health gain has been demonstrated for a significant proportion of the adult Tiwi population, the assumption does not follow that an extension of the MRTP model on a population basis, or an intensification of clinical demands on all clients will generate the health gains of the treatment model *equally* across the population.

## 6 Implementation and sustainability of renal treatment in the CCT context.

One aim of this analysis has been to examine the sustainability of a research-based clinical intervention in the general health center setting in a remote community. A second aim was to examine how best to build sustainable capacity in health care, and in particular sustainable improvements in chronic disease care in the context of the Coordinated Care Trials.

The MRTP program has demonstrated that a significant health gain flows from the treatment regime as implemented from 1995 to 1999, with potential savings in terms of life years saved and delay of progression to high-cost treatments such as renal haemodialysis (Hoy 2000). The present analysis can not quantify such savings. Further, it could not resolve some questions about the sustainability of that effect beyond the first four years; it is not clear whether natural progression of disease, or some lessening of client responsiveness to the treatment program might necessitate review of the MRTP clinical strategy after five years of treatment. This might involve a reinvigoration of the health promotional/motivational components of delivery. Aside from natural progression, there may be a need to better understand aspects of patient compliance with medication and responsiveness to health messages, as well as to re-examine the effectiveness or consistency of practitioner actions and interaction with clients. In addition, for reasons outlined, the ability to achieve hypothetically possible levels of success across the entire eligible population may be limited.

However, this study suggests that a comparable effect is *not* readily achievable by the general approach to capacity building undertaken with the implementation of care coordination. The study has shown that it was not possible to sustain the MRTP outcomes in a general health center context which was unable to achieve a number of disciplines in clinical delivery. In other words, if the intervention strategy is not undertaken then the health gain demonstrated to be possible for a significant proportion of the adult population will not be achieved, or certainly not in the short to medium term. Furthermore, outside of the constraints of the research intervention, the attempt to widen the intervention to persons formerly excluded or self-excluding is still more likely to generate improvements in outcomes among those persons than the general population-based care coordination model as currently practiced (Wagner 1998).

### **The real tasks of capacity-building: passive and active delivery of care**

The CCT evaluations have indicated that the implementation of best practice protocols on CCTIS may provide an infrastructure to support some improvements in practice. However, they by no means automatically support more effective organization of priorities in clinical care and more effective clinical work practices involving multiple providers. Evidence-based guidelines are, by themselves, not a sufficient template for organizing everyday clinical work. The most recent audits show that there are questions over the sustainability of even the general improvements in delivery of population health care and diabetic care according to protocol achieved during the first two years of the CCT (Robinson 2002).

The CCT implementation of care coordination can be characterized as a *passive* intervention strategy, in that it was an attempt to achieve change through a general improvement in infrastructure and technology (including hardware, software, and the care plan protocols) with development and management of clinical process left to follow its own course according to local determinants. Partly despite contrary intentions and early efforts of CCT implementers, there was:

1. little or no training beyond initial familiarization with care plans and use of CCTIS for consultations and care plan creation
2. no sustained development of work practices to optimize outcomes for specific care plan groups; practitioners were largely left to develop their own ways of accommodating the system and using it to enhance patient management according to the demands of the local context
3. a variable degree of commitment to formalize and to maintain interdisciplinary partnerships based on assignment of practitioner roles and responsibilities according to the requirements of a program
4. very limited capacity to analyse service levels to specific client groups and monitor activity in an ongoing way
5. no capacity to target particular outcomes (e.g. levels of BP control in a care plan group) and provide analyses of data on these target outcomes
6. limited capacity to generate alerts or “worry lists” and prioritise actions for high risk clients
7. no intensive induction of patients into treatment on assignment of care plans
8. limited willingness on the part of practitioners to confront compliance and non-compliance in a given group of patients.

Importantly, the particular disciplines and objectives of the research program are important determinants of the effectiveness of practitioner engagement with patients. Thus, concerning point 7 above: from the standpoint of the practitioner’s immediate objectives, patient compliance is less emphasized in an opportunistic system of delivery, as care coordination in the CCTs has become. In routine health care, the motivation to engage with clients remains essentially at the level of response to individual, self-initiated requirements for care, with at most a limited capacity to actively pursue follow-ups. Management of basic health services does not demand that patients attend, and while it may *offer* care plan services to clients, from a managerial viewpoint, it does not require that they accept<sup>7</sup>.

The difference between the two regimes, the passive system of care coordination and the active strategy of the research program needs to be underlined: without high levels of patient compliance, there *is* no research program, or at best one which excludes members of the target group to a scientifically unacceptable degree. There is no equivalent for this research-driven motive to engage with clients and overcome non-compliance in the passive, opportunistic system of care coordination as it has developed to this point. All practitioners undoubtedly follow up patients whose wellbeing is of concern to them to

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<sup>7</sup> This refers to general compliance with the clinical model, not specifically to compliance with medication; this study unable to say whether there are substantial differences between compliance with medication in the differing treatment regimes.

varying degrees. However, this is less likely to be done systematically if there is no requirement to achieve aggregate health outcomes by securing high levels of patient participation and general “compliance”<sup>8</sup>.

The Tiwi Health Board has only achieved a very limited capacity to integrate the elements outlined above into an actively managed, targeted program. By contrast, the research program of the CCT was characterized by simplicity of its organization and a high degree of vertical integration, with the rationale for clinical activity disciplined by the need for reliable and complete data for analysis and interpretation of outcomes. The MRTP had been institutionally semi-separate from the health centers, in a collaborative relationship with them. The Board was unable to *institutionalize* the key elements of the MRTP model of practice either as a semi-separate and internally self-sufficient ‘vertical’ program (Shediac-Rizkalla 1998), or by integrating them within the existing systems of organization in the health centers, since this appeared to conflict with the patterns underpinning the existing subsystems of delivery within the health centers (Steckler 1989). These elements include not only the formal processes and disciplines, but also the crucial element of effective, even charismatic program leadership by a visible figure with expert authority able to build local prestige, such as the MRTP had enjoyed (*ibid*, 39). The Board has not yet achieved clear clinical leadership within its own organization and therefore had no ability to delegate authority to a CDT program leader. Even so, the CDT briefly showed the potential to be effective during the first months of its operation.

The pattern of development described would favor a return to a semi-separate system, provided the resources can be found. Nominally, the resources available to THB when it established its chronic disease team (a nurse, three-four AHWs) were comparable to those operating within the MRTP. However, these were only similar to the resources applied by the MRTP during the later stages of its operation. The early, intensive engagement of the program with the communities from 1995 to 1997 was sufficiently resourced to engage with around 500 persons through a screening program, and induct eligible participants into an initially intensive treatment regime. A single RN working with three to four Aboriginal community health workers may not have been able to achieve either the authority within the health centers, nor the influence on patients, to mobilize the degree of response which the MRTP had achieved. It was therefore under-resourced in important ways, in particular in terms of managerial support, medical oversight and interdisciplinary collaboration.

The question debated by the Tiwi Health Board before the “handover” of the MRTP may need to be revisited in light of the foregoing: does a chronic disease strategy targeting renal disease, diabetes, and hypertension need to be separately resourced and housed and to that extent separated from routine clinical care? Can it achieve the same disciplines as a separate, single focus program which does not have to resolve competing priorities for

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<sup>8</sup> Recent discussion of compliance neglects to consider the motivational elements of clinical effectiveness and the degree to which clinical interventions are managerial systems which set a higher or a lower price on patient compliance with the requirements of treatment. Cf. Weeramanthri, T., Humphery, K., & J. Fitz (2000). *Forgetting Compliance*. Darwin, NTU Press.

use of time and resources on a day-to-day basis? The transition year evaluation (Robinson 2001) suggested that it may be important to insulate care plan service delivery from the demands of acute care. A proportion of resources must be set aside to support planned, proactive intervention and monitoring and shielded from the continual destructuring effects of acute care. However, a mixture of acute and care-plan focused delivery for the client group may be possible without sacrificing the ability to target outcomes of that defined client group, provided the acute care group and the target group largely coincide.

Can it be concluded that, without at least some additional resources, the attempt to create a semi-separate, “vertical” system would withdraw resources from other areas? There are other examples of separate or semi-separate programs in the health centers where this combination of acute and targeted care is highly successful: as indicated, the best performed area of service delivery in the CCTs was that of population care plan services to 0-3 year olds. Maternal and baby health has been established as a distinct area of practice over decades; it is characterized by a number of elements: strong interdisciplinary partnerships involving GPs, paediatricians, nurses and AHWs; an emphasis on protocol for preventive services and for intervention in cases of high risk; strong external demands for information with consequent emphasis on recording of a range of basic measures, and a clientele which largely understands the need for and demands the delivery of services offered. At Nguiu, there is a separate baby clinic, while at the smaller health centers on Melville Island, most nurses have been effective in their collaboration with AHWs in this fairly clearly delineated area of work.

Workshops with staff of the Tiwi Health Board and other stakeholders to explore and develop suggestions for action on chronic diseases which might flow from this study are recommended.

### **Wider implications**

The analysis presented here suggests that to achieve and sustain the health effects of the MRTP program it is necessary to create equivalents for a number of the key disciplines of the program: medical oversight; high levels of adherence to practice protocols with appropriate training for staff; effective interdisciplinary partnerships; active intervention and, as appropriate, intensive engagement with patients; adequate data for monitoring outcomes and feedback to practitioners and patients. Achievement of these elements is partly a question of dedicated human resources and skills, and partly a question of a system of management to enable the development of an active intervention strategy. These disciplines cannot be achieved in the short term through uncoordinated practitioner response to protocols.

The system needs secured resources, a partially separate, *functioning* capacity to monitor activity and outcomes, staff training and acceptance of accountability for performance. A successful program also needs the less clearly definable quantity – here glossed as medical oversight – clinical leadership (Shediac-Rizkalla & Bone, 1998: 102). The discussion of resources at handover, noted in the introduction, focused almost entirely on

funding for positions and barely considered many of the elements critical to the successful functioning of the program.

This study has implications for the further development of the existing CCTs and for the application of PHCAP funding to build capacity in the Northern Territory and nationally. Taken together with the findings of the earlier evaluations of the coordinated care trials, it is now increasingly clear that general capacity building, even with large injections of new funding, does not by itself lead to significant health outcomes in the area of chronic disease care in the short to medium term. Health Boards established to manage health services to regional populations rapidly confront constraints on their ability to develop targeted programs which can achieve important, hypothetically available health gains for sectors of the populations under their care. The ability to make choices about the best investment of resources in a combination of population care and targeted interventions and the ability to establish systems of active management which can deliver and sustain more effective interventions over time is not a given. It has to be explicitly supported and developed. These objectives and the associated developmental requirements should be much more clearly enunciated in the early stages of development of new regional health care organizations. A decentralized system of health care service delivery will need greater and more differentiated investment in research and evaluation which can be applied directly to the needs of regional Boards, within a Territory-wide strategy.

In order to significantly improve diagnosis, treatment and care of chronic illness through the implementation of care coordination, thought should be given to incorporation of the following elements in any new developments:

- initially more resources may be needed to establish a degree of specialized capacity in a given health service context: these resources include staffing, clear processes of management and medical oversight, along with ancillaries such as vehicles, IT support, etc.
- clear delineation of clinical roles to ensure high quality interdisciplinary collaboration
- strategy to reduce the impacts of acute care through effective delineation of responsibilities and processes
- simplified care plan protocols supported by clear basic training
- information system able to support ongoing monitoring of services and patient outcomes
- resources to ensure intensive induction of new clients to treatment regime

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## Acronyms

ACEi	Angiotensin Converting Enzyme inhibitor
ACR	Albumin Creatinine Ratio
AHW	Aboriginal Health Worker
AIHW	Australian Institute of Health and Family Welfare
ANZDATA	Australia and New ZeaLand Dialysis and Transplant Registry
ATSIC	Aboriginal and Torres Strait Islander Commission
BP	Blood Pressure
CC	Care Coordination
CCT	Coordinated Care Trial
CCTIS	Coordinated Care Trial Information System
CDEP	Community Development Employment Program
CRCATH	Cooperative Research Centre for Aboriginal and Tropical Health
CRI	Chronic Renal Insufficiency
DBP	Diastolic Blood Pressure
DHCS	Department of Health and Community Services
DMO	District Medical Officer
ESRD	End Stage Renal Disease
GEE	Generalised Equation Estimator
GFR	Glomerular Filtration Rate
HbA1C	Glycosylated haemoglobin
HD	Haemo-Dialysis
HRN	Hospital Record Number
MSHR	Menzies School of Health Research
M RTP	Menzies Renal Treatment Program
NCO	Nursing Coordinator
NHMRC	National Health and Medical Research Council
NT	Northern Territory
NTU	Northern Territory University
OATSIH	Office of Aboriginal and Torres Strait Islander Health
PD	Peritoneal Dialysis
QML	Queensland Medical Laboratories
RDH	Royal Darwin Hospital
REM	Random Effects Model
RN	Registered Nurse
RRT	Renal Replacement Therapy
SHILO	Strategic Health Information Logically Organised
SBP	Systolic Blood Pressure
TEHREC	Top End Human Research Ethics Committee
THB	Tiwi Health Board