CENTRE FOR HEALTH PROGRAM EVALUATION

RESEARCH REPORT 25

Evaluation of the Southern Health Care Network Coordinated Care Trial

Full Report

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CENTRE PROFILE

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The evaluation team was contracted to the SHCN CCT, with funding through the Commonwealth Department of Health and Aged Care. Additional resources were contributed to the evaluation through the Centre for Health Program Evaluation, by the Health Economics Unit of Monash University and the Program Evaluation Unit of the University of Melbourne.

Research Team and Team Member Roles

Each member of the evaluation team had specific areas of responsibilities consistent with their expertise, as well as a broader peer review role. The particular responsibilities were:

Leonie Segal: Manager of the evaluation and responsibility for the health economics aspects. Preparation of the Executive Summary, Chapter 1 Primary hypothesis-overview, Chapter 5 Resource use and costs, Chapter 7 Care coordination model, Chapter 8 Funds pool, Chapter 10 Risk assessment tool and Chapter 11 Administrative arrangements;

Neil Day: Data manager, responsible for implementation and analysis of the SF36 and AQoL, preparation of Chapter 3 Quality of life;

Susan Day: Survey manager, responsible for field work related to the questionnaires, development and analysis of the patient questionnaire and the diary, analysis of the GP questionnaire. Preparation of Chapter 3 Quality of life, Chapter 4 Patient perceptions, Chapter 6 Patient diary, Chapter 11 Administrative arrangements and Chapter 12 Impact on providers and the service system;

David Dunt: Advisor on evaluation design and epidemiological aspects of the evaluation. Design and interpretation of GP questionnaire. Preparation of Chapter 2, Introduction to the local Evaluation, Chapter 9 Care protocols;

Hannah Piterman: Responsible for qualitative research and preparation of thematic reports.

Iain Robertson: Collation and analysis of all costing data, and assistance with preparation of figures and graphs. Conduct of survival analysis;

Graeme Hawthorne: Analysis of the risk assessment tool, Preparation of Volume IV which formed the basis of Chapter 10.

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Primary Hypothesis

Chapter 1

The local evaluation: an introduction

1.1 Australian coordinated care trial

The Southern Health Care Network Coordinated Care Trial (SHCN CCT) was one of two Victorian trials and one of nine national trials that together formed the Australian coordinated care trials. In common with other local trials, the SHCN CCT sought to determine whether coordinating care for people with chronic illness and complex care needs could improve their health outcomes within existing budgets and within a context of pooling of funds by both Commonwealth and State/Territory governments.

The care coordination function principally consisted of the development, by the care coordinator, of a client care plan that was subsequently implemented, monitored and reviewed. Care coordination also involved the use of care protocols for clients with a single diagnosis in some trials. The care coordination function was undertaken either by a GP alone, a GP in association with a service coordinator/case manager, or someone other than a GP alone[1]. The intention was to better marshal services and so better meet client needs while, at the same time, reducing unnecessary service use (including hospital admissions) or replacing it with lower cost options. More formally, the primary hypothesis of the Australian Coordinated Care Trial was:

> 'That coordination of care of people with multiple service needs, where care is accessed through individual care plans & funds pooled from existing Commonwealth, State & joint programs, will result in improved individual client health & well-being within existing resources.' (Hypothesis 1).

The secondary hypotheses were:

That the success of coordinated care would be affected by the:

- extent of substitution between services within a Funds Pool (Hypothesis 2);
- range of services in the Trial and size of Funds Pool (Hypothesis 3);
- characteristics of clients (Hypothesis 4);
- quality of clinical and services delivery protocols (Hypothesis 5);
- characteristics of care coordination function (Hypothesis 6);
- type of administrative arrangements (Hypothesis 7);
- extent that health consumers are partners in the Trial organisation, in developing care; plans and empowered through the coordination process (Hypothesis 8).

That the primary hypothesis can be achieved without detriment to clients inside or outside the Trial (Hypothesis 9).[2]

1 Some Trials, including the SHCN CCT, employed a bimodal approach combining two of these models depending upon the characteristics of the client group.

2 These hypotheses were later grouped into four domains (the model of care coordination, the client population, the care plan and the funds pool) by the national evaluator.

1.2 Southern Health Care Network Coordinated Care Trial

Unlike the other eight trials however, the SHCN CCT offered coordinated care to the whole group of individuals with recent, high cost service use in public sector acute services in the area which the SHCN serviced. All diagnoses and age groups were represented in this group[3]. This was in contrast to other trials, where care was offered to clients with current complex care needs. In one trial - HealthPlus in SA - these clients were restricted to particular diagnoses. In the other seven trials, they were not. Four were age-specific - Care21 (SA), CareNet (NSW), Careworks (TAS), TEAMCare (QLD). The other three trials were not - are Plus (ACT), Linked care (NSW) and North Eastern (Vic). A presumption of the SHCN CCT was that high, recent use of acute services was predictive of high future service use and cost, and that coordinated care could modify this with benefit to the client. This group of recent, high cost users consisted of both clients suffering from one or several chronic illnesses requiring ongoing care as well as clients with one or two high cost episodes of non-recurrent illness or injury, not requiring ongoing care. It was believed that this mixed group of patients was larger and more able to manage the financial risk associated with the expected small number of clients with unpredictable but extreme costs in their use of services, than a smaller group consisting of clients with chronic illness alone.

The SHCN services a total population of approximately 740,000 people in the southern, bayside and south-eastern growth corridor areas of Melbourne. The Trial population consisted of the residents who had incurred costs of $4,000 or more during a two year period between 1994 and 1997 within the two main SHCN hospitals - Monash Medical Centre (MMC) and Dandenong and District Hospital (DDH). This group of 10,092 persons were residents in 30 post code areas in south-eastern Melbourne, covering the municipalities of Casey, Cardinia and Greater Dandenong. The cost of their services was the highest of all acute sector users in the area. They were responsible for a substantial proportion of total SHCN expenditure during the period specified.

1.2.1 Recruitment

Recruitment of clients from this group was made directly by the Trial, using what the national evaluators termed an ‘institutional approach’. Clients expending more than $4,000 in service use in the two-year period were identified from SHCN records. The Trial then directly approached the client by letter, followed up with telephone contact, an information pack, consent form, telephone freecall hotline, and access to interpreters. This ‘institutional approach’ was chosen, as it was believed it would yield higher recruitment rates and faster take up than the ‘general practitioner approach’.

[3] The most common Primary Problem ICD-9 codes in descending order were:- Other acute and subacute forms of ischaemic heart disease, Angina pectoris, Osteoarthrosis and allied disorders, Cholelithiasis, Abnormality of organs and soft tissue of the pelvis, Hypertension complicating pregnancy, childbirth and the puerperium Disorders relating to short gestation and unspecified low birth weight.

From this eligible group of 10,092 individual, 6,716 were contacted and 2,742 of these (41%) consented to participate in the Trial. Around three quarters (2,074) were assigned on a random basis to the intervention (coordinated care) group and one quarter (667) to the control (usual care) group. If the client was randomised into the coordinated care group, an approach was made to the GP nominated by the client and a separate consent process pursued. If clients did not attend a care planning session, they were not activated and were classified as 'withdrawn from the Trial'. As a result of which no health service use and cost data was gathered for those individuals. This recruitment approach differed from other trials which used a 'GP approach' or 'multifocal approach' where, for the latter, numerous health practitioners and organisations made referrals.

1.2.2 Care coordination model

The care coordination model in the SHCN CCT was devised to reflect the diversity of the Trial population and its variable need for ongoing care and, therefore, care coordination. Care coordination was performed by a GP, plus a service coordinator or case manager depending upon clients' needs. A Risk Assessment Tool (RAT) was developed to determine this need. It classified clients into three risk levels reflecting their future risk of hospital admission and need, therefore, for coordinated care support. The care coordination packages they received are set out beneath:

- *Low risk clients* - 1,254 (70.1% of 1,789[4] intervention group clients) with a recorded RAT assessment of level 1 at the initial care plan were treated by their GP alone with 12 monthly reviews of their care plans.
- *Medium risk clients* - 441 (24.7% of 1,789) with recorded RAT assessment of level 2 at the initial care plan were treated by their GP and service coordinator with six monthly GP reviews of their care plans. The service coordinator provided phone-based support to monitor implementation of the care plan, assist the client to access services nominated in the plan and address emergent problems as required [5].
- *High risk clients* - 94 (5.3% of 1,789) with recorded RAT assessment of level 3 at the initial care plan were treated by their GP and case manager with three monthly GP reviews of their care plans. The case manager provided traditional case management, incorporating an advocacy role and if required and intensive direct support. The case manager, where appropriate, could extend support to the family members, particularly to assist them in their role of carer. The caseload of the case manager was around 35 clients.

The general application of clinical protocols to clients in identifiable disease groupings was believed not to be appropriate for the SHCN CCT, as was true for all other trials with the exception of HealthPlus (SA). This was because eligibility of clients in the Trial was not restricted to a small number of disease categories. However at Trial midpoint, further allocation of Commonwealth monies made possible a number of additional special initiatives, principally the development of clinical protocols within care panels, based around clients in disease groupings shown to be common such as chronic obstructive lung disease, diabetes and cardiac disease.

[4] RAT score missing for 285 intervention group participants .

[5] The service coordinator compiled a service directory for the information of the care coordinator in order to promote client access to the full range of available health and community services.

These supplementary initiatives[6] consisted of:

1 four clinical care panels (Respiratory, Cardiovascular, Mental Health and Diabetes) each with suitable multidisciplinary membership and administrative support from the Trial, and involving the development of clinical protocols and access to practitioners with specialist knowledge;
2 a clinical pharmacist attachment initiative, to provide GPs and their coordinated care clients, access to expert pharmacy advice;
3 an unplanned readmission initiative, to review all unplanned admissions in order to establish if a prevention strategy was feasible;
4 feedback to GPs concerning the entire pattern of health service use (all medical services, pharmaceuticals captured through the HIC, and hospital admissions), of clients for whom they were the nominated care coordinator.

1.2.3 Auspice and fund pooling arrangements

The SHCN manages five acute hospital sites (university affiliated tertiary services and community acute care) a residential-based and a community-based aged care service, rehabilitation and six community health centres. Together, these service the population of 740,000 (approximately) residing in the southern, bayside and south-eastern growth corridor areas of Melbourne, as previously recorded. In partnership with the Dandenong Division of General Practice and five Community Health Centres, it also auspiced the Trial. This included planning, start up, client and GP recruitment, ongoing management of the Funds Pool, advisory committees and mounting special initiatives. As its contribution to the auspice, the Dandenong Division of General Practice managed the care coordination process. This included GP education, involving group and individual training sessions, review of the care plans of individual GPs and the provision of advice to the Trial through a GP advisory committee.

The SHCN and the Health Insurance Commission (HIC) were the only two (large) contributors to the Funds Pool (being joined by the Royal District Nursing Service (RDNS) during the Trial). The Funds Pool covered payment of SHCN general inpatient and outpatient services principally from MMC and DDH (including psychiatry and renal services), MBS medical services and PBS pharmaceuticals.[7] Nursing home care, Health and Community Care services and private hospital in-patient services were not included in the Funds Pool. Contributions to, and payments from, the Pool were based on full average prices except for inpatient services, which were based on a marginal casemix adjusted price. Payments from the Pool were paid to only Funds Pool contributors, or to care coordinators (GPs). Brokerage funds for other services did not become available.

6 Initiatives 1, 2 and 4 are described more fully in the Endnote to Chapter 9.

7 The SHCN charged the Trial $1,295 multiplied by the WEIS value of the DRG allocated to that client's episode of inpatient care, adjusted for outlier status. The multiplicand ($1,295) is equivalent to direct patient costs and represented about two-thirds of total hospital costs. Pharmaceutical use excludes non-PBS drugs, PBS drugs where patient costs do not exceed the co-payment and safety net purchases except where the client is a single person (member family).

The Funds Pool was actuarially calculated, based on projections of service use derived from the high cost service use period between 1994-7 using supplementary data obtained during the tracking phase of the Trial.[8] Payments from, and monitoring of, the Funds Pool required the development of a purpose built information system, that included a Participant File of clients' utilisation of SHCN hospitals, MBS and some PBS services. Expenditures relating to these were recorded, including WEIS-adjusted costs for hospital inpatient care. This Participant File formed the basis of a linked patient record covering most health service use and cost over the Trial period. It was combined with client's socio-demographic and other data that was relevant to the Trial's evaluation.

1.3 Local evaluation

The evaluation had both summative and formative dimensions. The former was broadly concerned with accountability and addressed the primary and secondary hypotheses concerning to what extent the SHCN CCT achieved its objectives. The latter was more concerned with providing feedback to better develop the Trial during the tracking phase and to further improve the delivery of the coordinated care model in Australia in the future. It is believed this will enhance the future funding and delivery of health care in Australia. The evaluation of the SHCN CCT can only make a contribution to the evaluation of the national model, however, if it (and other local trials) conforms to the core characteristics of the national model of care coordination outlined above. Local diversity in the nature of funds pooling, eligible client population, the care coordinator(s) involved, special initiatives and service delivery culture can be tolerated but only to the extent that conformity to the core characteristics of the national model of care coordination are not compromised.

The evaluation plan is best understood in terms of the Trial hypotheses, set out above. The current evidence in support of these hypotheses can be judged from the research literature concerning the effectiveness and cost-effectiveness of coordinated care, particularly as it applies to clients with recent high-cost service use. It provides strong but not definitive guidance to the probability that results of the evaluation study will support the study hypotheses. This literature is briefly considered in Chapter 9.

1.3.1 Summative evaluation

The summative evaluation in regard to the primary hypothesis employed a quantitative randomised control trial methodology and observed the intention to treat principle. It aimed to establish if client's health outcomes (measured by SF36 and AQoL question inventories) in the intervention (coordinated care) group were better at the end of the Trial period than those in the control (usual care) group. Further this had to occur within existing budgets, to be established by comparing health service use and cost data derived principally from the client's Participant File, but also the client's diary. The RCT study design is set out in Figure 1.1 below.

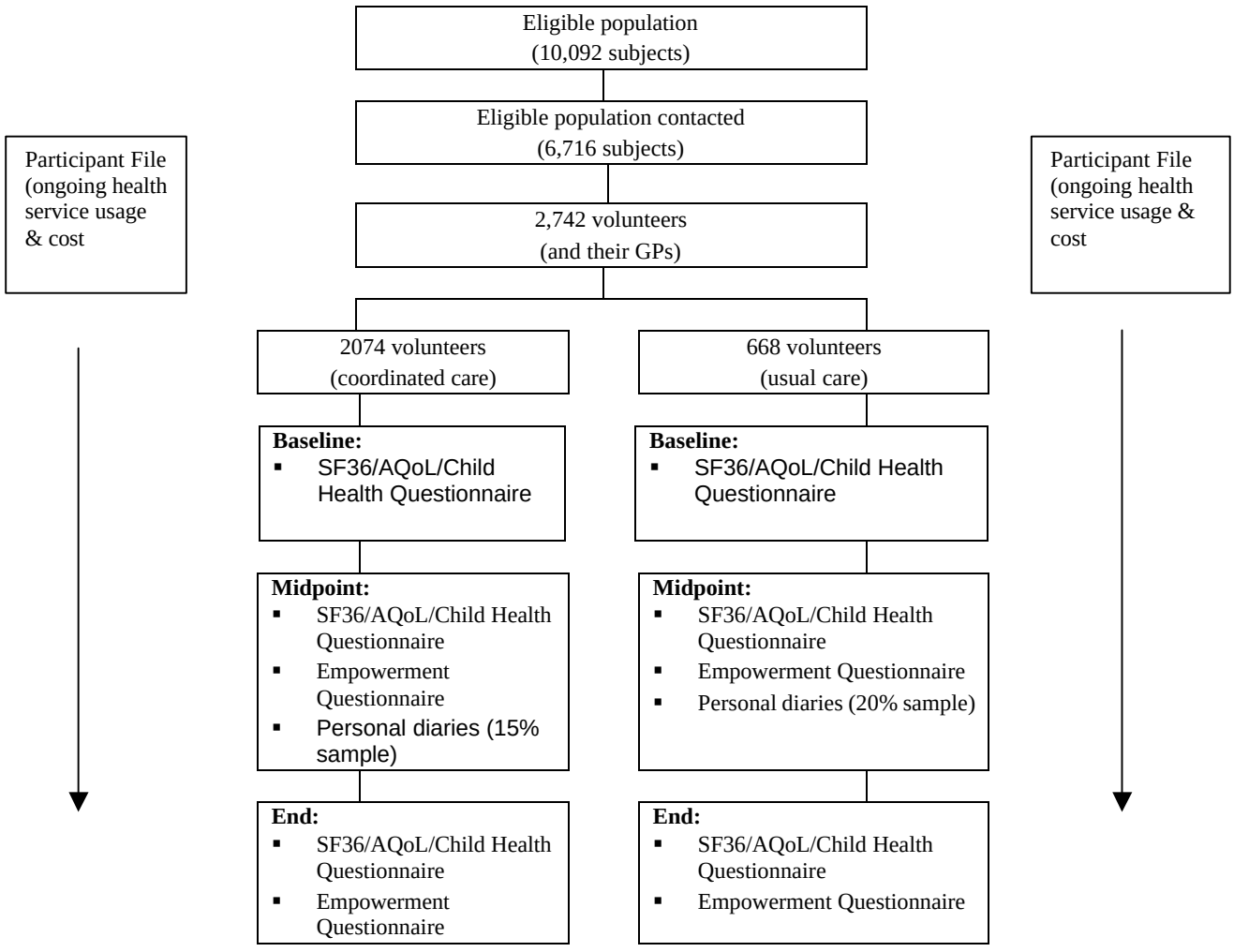
[8] The Funds Pool could not be set as identical to expenditures made during this earlier high cost period. This is because the client population with chronic illness would be older and perhaps sicker while the client population without chronic illness might be expected to have recovered somewhat from the illness/injury that produced the 1-2 episodes of high cost care during the earlier period. Cost data from the tracking phase alone was deemed to be too short and to involve insufficient numbers of episodes of care to reliably estimate the size of the Funds Pool alone.

Simple, unstratified randomisation was used (on 3:1 basis to the intervention and control groups) given that the sample was large and no one single factor had been identified a priori as having a major impact on the outcomes of the Trial. Randomisation occurred according to protocols within blocks of time as subjects were progressively recruited to the study. A sample size of 1,231 (924 intervention and 307 control) was calculated on the basis of a significance level of 0.05, power of 80% and minimum meaningful effect to be detected of 10% in the Role Limitation - Physical subscale of the SF36, the scale with the greatest variance. Adjustment for the 3:1 unequal randomisation was made. One hundred percent over-sampling (1,848 intervention and 614 control) was estimated to be needed to take into account factors such as:

- client loss to follow-up;
- withdrawal from the Trial and/or evaluation;
- exclusion of clients under 12 in the analysis of health-related quality of life;
- no replacement of clients permitted;
- lack of compliance by GPs and clients; and
- variable effects of coordinated care on different age and disease groups.

In the event, 2,742 subjects (2,074 intervention and 668 control) formed the sample population (see Figure 1.1).

Figure 1.1 Randomised control trial study design - quantitative data



Baseline socio-demographic and clinical characteristics of the clients in the two groups were demonstrated not to differ significantly, indicating that randomisation had been successfully undertaken:

- Illness characteristics for the intervention and control groups during the Trial are set out in the annexure to this chapter (Table A.1 – (a) ICD-9 codes – Primary Problem, (b) ICD-9 codes – Co-existing problems (multiple responses) and (c) AN-DRG3). They are expressed in terms of top ranking disease categories in descending order for each group. While these refer to illnesses during the Trial period and are subject to the impact of the Trial, they are very similar for both groups.
- Socio-demographic characteristics of the intervention and control group are set out in Table 1.1 (next page) for 13 variables. None are significantly different - with only mean age being marginally so.

Data collection methodologies included[9]:

i) **Participant File** (ongoing during Trial) contained:-
   - clients' health service use and cost data, originating from the SHCN, MBS & PBS records,
   - clients' socio-demographic, illness & RAT characteristics derived from network records, and
   - Minimum Data Set socio-demographic questions (modified for clients aged 0-12) included in with the baseline SF36/AQoL mail questionnaire.

ii) **Health-related quality of life scales** (mail questionnaires at start, midpoint & end of trial) included:-
   - The SF36 consisting of eight scales - Physical Functioning, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Emotional and Mental Health. It also has two summary scales - a Physical Component and a Mental Component, each of which is scaled to produce a mean of 50 and standard deviation of 10. It was administered to all clients, 12 years and over. It was also administered to the parent/guardian of the 248 clients aged less than 5 years with regard to themselves not the client, along with 14 extra questions on caregiver strain.
   - The AQoL which is a generic health-related quality of life instrument developed by Richardson & Hawthorne at the Centre for Health Program Evaluation. It produces a single quality of life utility score ranging from -0.04 for the worst possible health state, through 0.0 for death, to 1.0 for perfect health. It also provides four subscores relating to Independent living, Social relationships, Physical senses, and Psychological wellbeing. AQoL 3 was used in this study and supplements the SF36 as a measure of Trial impact on client health and wellbeing. It was administered to all clients, 12 years and over. It was also administered to the parent/guardian of the 248 clients, aged less than 5 years with regard themselves, not the client.
   - The Child Health Questionnaire was administered to the parent/guardian of the 73 clients aged 5 – 12 years with regard the client, instead of the SF36 and the AQoL.

[9] For information about the data collection instruments contact Leonie Segal, Deputy Director, Health Economics Unit, Faculty of Business & Economics, Monash University
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Table 1.1 Socio-demographic characteristics of randomised study population

	Total Records*	Coordinated Care Group		Usual Care Group		Significance level
Age [(a)]	2742	Mean 45.8	SD 23.2	Mean 47.7	SD 23.5	0.06**
Gender (Male) [(a)]	2741	N 862	Percent 41.6%	N 269	Percent 40.3%	0.55
Country of Birth (Australia) [(a)]	2719	1176	57.2%	398	60.0%	0.20
Aboriginal/TSI (Yes) [(a)(b)]	2634	5	0.3%	0	0%	
Language spoken at home (English) [(a)(b)]	2567	1732	89.1%	556	89.2%	0.92
Marital Status [(a)]	2672					.682
Never married		443	22.0%	136	20.8%	
Widowed		180	8.9%	66	10.1%	
Divorced		86	4.3%	26	4.0%	
Separated		28	1.4%	13	2.0%	
Married		1280	63.5%	414	63.2%	
Living arrangements (House unit or flat) [(b)]	2255	1622	96.8%	553	95.3%	0.24
Employment Status [(b)]	2228					0.61
Child/Student(<12)		209	12.6%	70	12.2%	
Employed FT		258	15.6%	83	14.5%	
Employed PT		181	10.9%	65	11.3%	
Unemployed		56	3.4%	13	2.3%	
Home duties		336	20.3%	119	20.7%	
Retired		500	30.3%	174	30.3%	
Income status[+ #] (< $20,000) [(b)]	1641	983	80.6%	344	81.6%	0.67
DVA status[+ #] (Yes) [(b)]	2076	42	2.7%	10	1.9%	0.29
Pension/benefits status[+ #] (Yes) [(b)]	2115	963	61.2%	342	63.2%	0.40
Health insurance status[#] (Yes) [(b)]	2157	218	13.6%	88	16.0%	0.16
Educational status (TAFE college/Uni)[+] [(b)]	2087	313	20.2%	100	20.6%	0.26

Source:
(a) SHCN Record
(b) Socio-demographic mail questionnaire

Notes:
* Number of records on which the analysis was based, missing data mean Total Records ≠ 2,742
** 2-sample t-test - all other tests are χ^2 tests
[#] Voluntary question in questionnaire
[+] Parent characteristic if subject aged 12

iii) **Mortality Data** (end of Trial) in which the names of all enrolled subjects were used to search the National Death Register in March 2000. Any matches where death had not been previously notified during the Trial period were checked by contacting the last contact address and/or the general practitioner. The date of death of the positive identifications was recorded.

iv) **Client empowerment questionnaires** (Trial midpoint and end) were mailed with SF36/AQoL questionnaires and related to clients' perceptions regarding their:

- level of participation in their own health care,
- level of understanding about their health problems.
- level of confidence in their health knowledge and skills.
- capacity for self care and their ability to make decisions about their health care.

Coordinated care clients were also asked about the care planning including their level of involvement and its value.

v) **Self-completed client diary** (1 month daily record at Trial midpoint) requesting information about the use of health related products and services and associated out-of-pocket expenditure (where relevant) that was not available from the Participant File including:-

- health care products (drugs especially non-PBS) and other health care products and equipment bought or hired during the period,
- formal service including HACC services but excluding GP and medical specialist services and services provided at MMC and DDH, and
- informal services (care & community support provided by family and friends).

vi) **GP impact questionnaire** (Trial midpoint and end) was a mail questionnaire asking GPs for their perceptions about the impact of Trial on their role as care coordinators and coordinated care effects on:-

- identifying the medical and other needs of their clients and arranging the full range of services to meet those needs,
- understanding, self-management and care decisions by clients and their families,
- communication with other health practitioners, and
- Australian general practice if it was more widely introduced.

GPs' perceptions regarding care panels were also sought in the Trial end questionnaire.

vii) **Client and stakeholder interviews** (ongoing during the Trial) with a sample of 40 clients and their families, care coordinators, GPs, case managers and service coordinators (where relevant), Trial management and other service providers and participants.

- *Client interviews* focused mainly on their perceptions of care coordination, their experience of care planning and the broader health care system. Clients were drawn from all risk subgroups in the coordinated care group as well as the control group. One semi-structured interview lasting about 1-2 hours was conducted for each client. A family member, their care coordinator and (where relevant) service coordinator, case manager were also interviewed.
- *Stakeholder interviews* focused on the experiences & perceptions of other service providers, Trial managers and staff, State and Commonwealth government officers.
- *Reference group insights* were gleaned included focus groups and non-participant observation of the GP reference group and consumer reference group.

This data was contained in two confidential thematic reports to the evaluation team and which have been used to inform the preparation of this report.

The way in which the qualitative and quantitative data relate to the secondary hypotheses is set out in Table 1.2.

Table 1.2 Secondary hypotheses and the sources of data

Hypothesis		Data Source
2	Substitution of services	– Participant file – Client diary
3	Range of services in Funds Pool	– Inter-trial comparisons by national evaluator
4	Client characteristics	– Participant file (RAT scores) – Stakeholder interviews, – Case study interviews – GP impact questionnaire (clients in care panel)
5	Quality of protocols	– GP impact questionnaire (clients in care panel)
6	Care coordination	– Case study interviews – GP impact questionnaire – Client empowerment questionnaire
7	Administrative arrangements	– Stakeholder interviews
8	Consumer empowerment	– Client empowerment questionnaire – Case study interviews
9	Equity	– Case study interviews – Stakeholder interviews

Data analyses were undertaken in the following ways:

i) **Survival data** was analysed on an intention-to-treat basis and included both subjects in the coordinated care group who were never activated as well as subjects in either group who withdrew from the date of randomisation to December 31 1999 (the censoring date for the analysis). The duration of time (days) for each subject alive at the end of the Trial was calculated from these two dates. For subjects who died during the Trial, their date of death defined their exit from the study. The rate ratio of deaths in the coordinated care and control groups was calculated using the Cox proportional hazards model, adjusted for 5-year age groups. (Chapter 3)

ii) **Health-related quality of life** - Changes in levels of the two Component Summary Scales and eight sub-scales of the SF36, the one overall utility measure and four sub-scores of the AQoL from Trial start to end for each subject were estimated. These were used to calculate means and standard deviations in individual subject's change of score for the coordinated care and control groups. These were compared using simple 2-sample t-tests.[10] (Chapter 3)

[10] The national evaluator has demonstrated that these change in SF36 were normally distributed (and therefore suitable for parametric testing) unlike baseline SF36 which were skewed to the right, invalidating the use of ANCOVA (dependent variable being SF36 at Trial end in the coordinated care & control group, adjusting for baseline SF36 levels).

Clients aged under 12 were excluded from analysis of SF36 scores since SF36 scores for clients under 5 years applied to their parent/guardian rather than the client and Child Health Questionnaire were completed for clients aged 5-12 years. Clients aged between 5-12 were also excluded from analysis of AQoL scores since carers of clients aged 5-12 years completed the Child Health Questionnaire. Clients under 5 years were included in the analysis even though scores applied to their parent/guardians. (Chapter 3)
Since death is imputed a (zero) value in the AQoL utility measurement, it is possible to perform two different analyses of AQoL scores – one that includes and one that excludes clients who have died during the Trial period. Both were performed here. (Chapter 3)

Subgroup analysis of quality of life measures within risk groups is possible but is problematic given its reduced statistical power, the loss of randomised status and the unavailability of RAT scores for the control group. Meaningful differences in levels between coordinated care and control groups would need to occur to make subgroup analysis useful.

iii) **GP impact, client empowerment and client diary** - Nominal data and ranked data (including change in ranked data) were analysed using appropriate non-parametric statistical tests. Statistical analysis of RAT scores of clients in the coordinated care group and their relationship with service use was conducted to better understand the client group characteristics most able to benefit from coordinated care (Hypothesis 4). (Chapters 4, 6, 10 & 11)

iv) **Cost data** for individuals (plus number of services used) was used to calculate means and standard deviations (weighted to reflect the length of participation of each subject in the Trial) in the coordinated care and control groups. These were expressed as annualised per diem costs. Though the distribution of both service use and costs was known to be highly skewed, the 2-sample t-test was employed as the sample was large and the t-test is robust to departures from normality (Chapter 5). Results on service and out-of-pocket expenditure as obtained from the client diary are also reported (Chapter 6).

v) **Qualitative Data** - The process of qualitative data collection and analysis can not be separated in the same way as quantitative data collection and analysis. Refining and probing of the narrative during the interview, and where possible later, is necessary to develop generalisations. Reducing and ordering of this narrative involves a further process of selection and interpretation by the researcher. Insights regarding these secondary hypotheses were also obtained from the stakeholder interviews using Grounded Theory. Interviews were supplemented by non-participation observation, trial documents and group discussions. They involved the care coordinators, service coordinator and case manager, Trial manager and staff, members of the evaluation group, CEO of the SHCN, members of the Division of General Practice as well as staff of the State and Commonwealth Governments associated with the Trial. (Confidential Reports to the Evaluation Team)

1.3.2 Formative evaluation

The evaluation design and data collection strategy outlined above provided insights about the delivery of coordinated care in Australia and how it might be better delivered in the future, most specifically in the second round of Trials. In doing so it is able to contribute to the wider health system reform debate. This occurs as a result of:

- the results of the summative evaluation with regard to both primary and secondary hypotheses in the context of results obtained from other studies in the academic literature;
- other observations concerning barriers to the implementation of the Trial gained from stakeholder and case study interviews and observations made by the Local Evaluation Team during the Trial;
- reflection on the nature of these results and observations, principally by the Local Evaluation Team;
- an appreciation of the significance of the results of the SHCN CCT within the national trial, principally by the national evaluator.

A formative evaluation dimension is also relevant during the developmental (tracking) phase of a trial. It is typically concerned with reviewing the program logic usually with stakeholders and/or the provision of data on process and impact of the pilot phase of a program with early feedback to trial managers. In the SHCN CCT it mainly concerned discussions with the Trial management concerning restrictions on eligibility on the Trial population so as to more clearly define a population in need of current care coordination.

1.4 Potential sources of bias

1.4.1 Contamination of the study design

It is likely that GPs would find it impossible to quarantine their care coordination activities to the intervention group and will extend these to the control group. This effect is always present in trials of new practitioner behaviour where the practitioner treats both coordinated care and control group. However, this does not introduce bias (reduce validity). Rather it introduces inefficiency into the design as a result of the non-differential misclassification of care coordination and usual care between the intervention and control groups and underestimation of the effects of the Trial. This source of inefficiency in the SHCN CCT was reduced, but not removed, since the conduct of a Care Plan was time consuming and one would expect it would only occur when it was recompensed. (This only occurring for the coordinated care group.) It would be further reduced since the GP was also not informed of the identification of clients in the usual care group[11].

[11] Paradoxically, if GP behaviour did change in relation to both coordinated care and control group clients, it would represent the successful embedding of system change.

1.4.2 Differential withdrawal

Bias can occur in some circumstances when withdrawal of large numbers of subjects from the study occurs. It was apparent this was occurring at the midterm report. It may occur through death, notification of withdrawal from the Trial or through non-return of evaluation proformas. Withdrawal is only important when the subgroups withdrawing from the coordinated care and control group differ in regard to both independent and dependent variables. The end effect of this is that different levels in, for example, SF36 levels (a dependent variable) in the withdrawing subgroups of the two groups causes differences in the SF36 levels in non-withdrawing subjects in the two groups, producing possibly biased study results. This is only likely to occur if differential withdrawal affects particular independent variables (some, not all) such as socio-demographic and illness characteristics and these in turn affect SF36 levels. The import of this is that bias is introduced not by different numbers of subjects withdrawing in the two groups or by these having different socio-demographic and illness characteristics but only when these impact on the levels of (change in) SF36 or other dependent variables. It is important to determine if all and any of these various events occur.

Relevant data existed with regard to many but not all of these events. For example, at Trial midpoint, it was apparent that a significant number of subjects in both coordinated care and usual care groups had withdrawn from the Trial. In the coordinated care group, withdrawals might have arisen due to the added burden/level of involvement imposed on the coordinated care group subjects. Thus, coordinated care group subjects, having agreed to participate prior to randomisation, might withdraw when asked to present for a care plan or at some later time. In the usual care group, subjects might withdraw at either of these times, as a reaction to not being allocated to the coordinated care group.

By Trial midpoint, it could also be established that the withdrawal rate was higher in the coordinated care than usual care group, peaking at the time when care planning was required[12]. The rate of withdrawal was also uneven across participants in the coordinated care group, with a higher rate of withdrawal with increasing risk level, only partly explained by a higher death rate. While it might be expected that the same phenomenon might occur in the usual care group, this is not known as RAT scores were not collected in this group. If there was evidence that differential withdrawal between the groups was occurring and was impacting on the SF36/AQoL or cost results, sensitivity analysis would need to be conducted to estimate the bias that was introduced and to protect the study's validity. This is consistent with the intention to treat principle.

The number of clients withdrawing from the SHCN CCT is set out in Table 1.3 below. It includes all withdrawals for the originally designated Trial period but not for the Trial extension period (July 1 – December 31 1999) for which reconsent was necessary. Twenty-six percent of all consenting subjects had withdrawn by Trial end. They included 325 subjects randomised to intervention group but for whatever reason never activated (i.e. not in receipt of a care plan). Withdrawal from the intervention group was higher than withdrawal from the control group (29% compared to 15%) and this difference is statistically significant.

[12] This was both a real phenomenon and an artifact arising from greater contact in the coordinated care group leading to earlier notice of their withdrawal.

Table 1.3 Withdrawals from the consenting study population (all age groups)

Status at 30/6/1999	Intervention Group		Control Group	
	Number	Percent	Number	Percent
Not withdrawn	1471	71%	565	85%
Withdrawn	603	29%	103	15%
Total	2074	100%	668	100%

Notes: $\chi^2 = 49.279$, df =1, p = .000

As set out in Table 1.4, 'client decision' was much more common as a reason for withdrawal in the coordinated care group and death was much more common as a reason for withdrawal in the control group, though this was artefactual. Analysis of deaths as a proportion of the whole group rather than as a proportion of the withdrawals subgroup within the whole group, as presented here, is considered in Chapter 3.

Table 1.4 Reasons for withdrawal from the consenting study population (all age groups)

Reason for withdrawal		Intervention Group		Control Group	
		Number	Percent	Number	Percent
1	Client decision to leave – due to dissatisfaction	18	3%	6	6%
2	Client decision to leave – other stated reason	268	44%	5	5%
3	Client enters residential care	21	4%	5	5%
4	Change of residence outside trial catchment area	68	11%	11	11%
5	Death – incidental, unrelated to conditions at basis for trial eligibility	23	4%	6	6%
6	Death – related to conditions at basis of trial eligibility	1	<1%	0	0%
7	Death – other reason cause unknown	62	10%	30	29%
5-7	Death *	86	14%	36	35%
8	Client lost to trial follow-up	102	17%	36	35%
9	Other reason for exit	40	7%	4	4%
	TOTAL	603	100%	103	100%

Notes: $\chi^2 = 75.724$, df = 6, p = .000, but 2 cells have expected count less than 5 (min. expected count 3.50)
* For the χ^2 test the collapsed data was used.

Given the higher withdrawal rate in the intervention group, it is necessary to determine if this has disturbed the similarity in the 13 socio-demographic characteristics of the two study groups achieved through randomisation at the start of the study. These characteristics are compared in Table 1.5 below.

Table 1.5 Socio-demographic characteristics of randomised non-withdrawn study population at 30/06/1999

Characteristic	Total records*(N=2074)	Coordinated care (N =1505)		Control (N = 568)		Significance level
Age	2073	Mean 45.4	SD 23.0	Mean 46.4	SD 23.1	0.40**
Gender (Male)	2073	626	41.5%	221	40.7%	0.70
Country of Birth (Australia)	2068	867	57.7%	343	60.6%	0.24
Aboriginal/TSI (Yes)	2030	3	0.2%	0	0%	
Language spoken at home (English)	1981	1285	88.9%	482	89.8%	0.62
Marital Status	2025					0.94
Never married		308	21.0%	121	21.7%	
Widowed		129	8.0%	49	8.8%	
Divorced		62	4.2%	21	3.8%	
Separated		18	1.2%	9	1.6%	
Married		951	64.0%	357	64.3%	
Living arrangements (House unit or flat)	1883	1333	97.4%	493	95.1%	0.06
Employment Status	1909					0.64
Child/Student(<12)		183	13.2%	67	12.9%	
Employed FT		216	15.6%	79	15.2%	
Employed PT		170	12.0%	65	12.5%	
Unemployed		50	3.6%	15	2.9%	
Home duties		291	21.0%	106	20.4%	
Retired		398	28.7%	145	27.9%	
Income status$^{+\#}$ (< $20,000)	1292	691	74.5%	263	72.1%	0.36
DVA status$^{+\#}$ (Yes)	1737	32	2.5%	9	1.9%	0.45
Pension/benefits status$^{+\#}$ (Yes)	1764	511	39.7%	184	38.6%	0.67
Health insurance status$^{+\#}$ (Yes)	1801	172	13.1%	81	16.6%	0.06
Educational status(TAFE college/Uni)$^{+}$	1755	260	20.4%	92	19.0%	0.23

Notes:

* Number of records included in the analysis, missing data means Total Record ≠ 2074

** 2-sample t-test - all other tests are χ^2 tests

@ Hospital networks record

@@ Socio-demographic mail questionnaire

Voluntary question in questionnaire

+ Parent characteristic if subject aged 12 or under

Subjects could additionally fail to return data to the study by failing to return evaluation proformas. Estimation of the overall non-response rates for the study is not straightforward principally due to the use of different health-related quality of life proformas for different age groups. Non-response rates are expressed in Table 1.6 below for the 2,421 of the 2,742 subjects who were aged 12 years or more.

Non-response from the intervention group was also much higher (13%) than the control group. This is similar to the difference in withdrawal rates from the two groups, suggesting that this is responsible for the higher rate of non-response in the coordinated care group. A comparison of non-response rates in continuing subjects (non-withdrawn) at the time of survey confirms this.[13] Higher non-response rates in higher compared to lower risk clients in the coordinated care group were similarly explained by higher withdrawal rates in higher risk groups.

Table 1.6 Response rates in coordinated care & control groups (subjects 12+ years)

	Intervention Group		Control Group		Both Groups	
	Number	Percent	Number	Percent	Number	Percent
Baseline	1829	100%	592	100%	2421	110%
Response Start SF36	1548	84.6%	537	90.7%	2085	86.1%
Response Midpoint SF36	1259	68.8%	493	83.3%	1752	72.4%
Response End SF36	1015	55.5%	405	68.8%	1420	58.7%
Response Start & Midpoint SF36	1220	66.7%	474	80.1%	1694	70.0%
Response Start, Midpoint & End SF36	963	52.7%	386	65.2%	1349	55.7%

1.5 Threats to evaluability

The SHCN CCT had some distinctive features. At one level this was consistent with the national model which, by its nature, needed to embrace diversity and not be monolithic. Such features included, for example, the particular Trial population, their methods of recruitment, the particular model of the care coordination function and the limited number of organisations participating in the Funds Pool. Nevertheless these had some implications for the Trial's evaluability. For example, the very diverse illness and other characteristics of client groupings in the Trial meant it was not possible to use disease-specific health status measures which are more sensitive to program effects than broad health-related quality of life measures such as the SF36. Important effects may not therefore have been detected.

At another level some distinctive features of the SHCN CCT (and other local trials) diverged from the national model. This particularly concerned the Funds Pool arrangements. As it eventuated, the SHCN and other smaller organisations, rather than the State Government, represented State involvement in the Funds Pool. This meant that to manage their financial risk and undertake their fiduciary responsibilities, they only agreed to enter the Pool on the basis that services could only be purchased from participating organisations (with the exception of care coordination function). This effectively established a buy-back principle. It had the consequence that care coordinators and case managers did not have brokerage funds at their discretion. This limited their ability to implement the care plan, particularly to purchase services previously not affordable and unavailable under prior existing programs. Furthermore, the SHCN did not fully contribute to the Fund Pools for acute services, entering it on a basis of direct patient cost which is less than full average cost.

[13] Response for each of the three mailouts (Start, Midpoint and End) were separately calculated rates for subjects, 12 years and over, and classified as continuing (ie non-withdrawing) at that time. For the Start mailout, it was 95.3% and 93.2% in the coordinated care and control group respectively, for the Midpoint mailout, 92.7% and 92.5% and for the End mailout, 79.2% and 80.7%.

There are also some aspects of the design and implementation of the national model that have implications for its ability (and therefore the SHCN CCT) to demonstrate significant program effects. These concern, for example, the lack of specification of mechanism(s) indicating how care coordination will achieve its objectives. There was debate even about its broad philosophy – whether to empower clients to better self manage their health care or rather for care coordinators to organise the health care of clients, on their behalf. With regard the latter, the use of clinical protocols was promoted but these did not exist for clients with a number of chronic illnesses and with complex care needs. Thus, while the role of the care coordinators was broadly defined, there was limited good information regarding those high priority activities of the care coordinators that would ensure the success of the Trial.

In addition the very strong focus on health outcomes in the national trial did not encourage study of other important parallel or intermediary goals of coordinated care such as the ability to self–manage (self-efficacy, empowerment).

At an implementation rather than design level, the limited period of development (as distinct from tracking costs) meant that it was unlikely that the local features of the Trial, such as stakeholder involvement and data management would be optimal. While these matters constitute threats to evaluability, it needs to be recognised that the national trial is a first generation one and much will be learned from it leading to better delivery of health care in the future either within the rubric of coordinated care or without. For example, the development of the RAT to predict future client service use levels has been an important outcome of the SHCN CCT with wide applications already outside the Trial.

Annexure to Chapter 1

Table A.1 Illness characteristics of intervention and control groups

INTERVENTION GROUP Problem	Clients Number	CONTROL GROUP Problem	Clients Number
(a) ICD-9 codes – Primary Problem			
Other acute/subacute forms of ischaemic heart disease	79	Other acute/subacute forms of ischaemic heart disease	27
Angina pectoris	58	Cholelithiasis	18
Osteoarthrosis & allied disorders	39	Osteoarthrosis & allied disorders	15
Abnormalities of organs of &soft tissue of the pelvis	35	Angina pectoris	15
Hypertension complicating pregnancy, childbirth & labour	36	Acute myocardial infarction	14
Disorders relating to short gestation & unspecified birthweight	34	Abnormalities of organs of &soft tissue of the pelvis	12
Acute myocardial infarction	34	Other forms of chronic ischaemic heart disease	11
Cholelithiasis	33	Hypertension complicating pregnancy, childbirth & labour	10
Disorders of menstruation & other abnormal bleeding from female genitalia	29	Disorders relating to short gestation & unspecified birthweight	10
Other complications of procedures not elsewhere specified	29	Encounter for other & unspecified procedures & aftercare	10
Other current conditions in the mother classifiable elsewhere but complicating	29	Fracture of neck of femur	10
(b) Co-existing problems (multiple responses)			
Essential hypertension	327	Essential hypertension	91
Other forms of chronic ischaemic heart disease	218	Other forms of chronic ischaemic heart disease	79
Diabetes mellitus	173	Cardiac dysrthymias	48
Disorders of lipoid metablism	132	Disorder of lipoid metabolism	42
Cardiac dysrthymias	123	Diabetes mellitus	41
Complications affecting specified body systems, not otherwise classified	107	Non-dependent drug use disorder	34
Bacterial infections in conditions classified elsewhere & of unspecified nature	105	Bacterial infections in conditions classified elsewhere & of unspecified nature	33
Asthma	95	Asthma	33
Non-dependent drug use disorder	82	Complications affecting specified body systems, not otherwise classified	30
Other unspecified anaemias	69	Other foetal & placental abnormalities affecting management of mother	25
		Other & unspecified anaemias	25

Table A.1 (Cont'd)

INTERVENTION GROUP Problem	**Clients** Number	**CONTROL GROUP** Problem	**Clients** Number
(c) AN-DRG 3			
Admit for renal dialysis	973	Admit for renal dialysis	430
DVA – chemotherapy	62	Admit for apheresis	30
Cranial & peripheral nerve disorder	59	Other gastroscopy +n-m dig dis-cc	29
Unstable angina + cc	58	DVA – rehabilitation	28
DVA – rehabilitation	55	Chest pain	28
Chronic obstructive airways disease	53	Chronic obstructive airways disease	25
Other gastroscopy +n-m dig dis-cc	53	Other colonoscopy –cc	15
Unstable angina - cc	46	Headache	14
Other colonoscopy –cc	41	Unstable angina + cc	13
Heart failure & shock	40	Dementia & glbal distrbs cerebral function	12
		Abdmnal pain, mesenteric adenitis –cc	12
		Oesphs, gast& mdd a >74 /a10-74 +cc	12

Chapter 2

The primary hypothesis: overview

2.1 Approach to testing the primary hypothesis

The National Coordinated Care Trials, of which the Southern Health Care Network Coordinated Care Trial (SHCN CCT) is a part, are designed to test an alternative model of health funding and delivery, incorporating funds pooling and care coordination. The primary research question to be tested by the trials, and which the evaluation of the SHCN CCT has addressed, is that coordinated care, as implemented by the SHCN, is associated with an improvement in the health and wellbeing of persons with complex chronic conditions enrolled in the Trial, and that this is achieved within current resources. Chapters 3 to 6 are directly concerned with this primary research question. This chapter presents an overview of that work.

Evidence concerning impact on health and wellbeing is derived from:

i) a survival analysis to establish impact on death rate (Chapter 3);

ii) responses to the two quality of life instruments (the SF 36 and the AQoL), applied at trial commencement, after 12 months, and at Trial end (Chapter 3);

iii) patient perceptions derived from a series of specially designed questions (closed and open ended), distributed with the final quality of life instrument to all persons enrolled in the SHCN CCT (Chapter 4);

iv) the role of unpaid carers as determined through a patient diary (Chapter 6).

The net impact on health and wellbeing is determined primarily through comparison of the experience of intervention and control group participants. A simple comparison between observations at base line and trial end, is not acceptable, as it provides no means for attributing any observed change, or lack of change to the Trial.

The randomised control trial has been adopted as the 'gold standard' for evidence in relation to health interventions, for compelling reasons. While it is not always possible to implement a randomised control trial, and there can be concerns with the Trial influencing the behaviour of control participants, it is the most robust means for determining the effect of an intervention. Thus most analysis is based on a comparison between intervention and control group experience, and is the central means for testing the primary hypothesis. As noted in Chapter 1, the randomisation process appears to have been highly successful based on the virtual equivalence in observed control and intervention group characteristics. This gives confidence that comparisons between control and intervention group participants provides a sound basis for establishing the effect of the Trial.

The experience of the SHCN CCT would certainly support use of the randomised control trial as the preferred trial design for testing health system reform options, provided that design is feasible.

2.2 Health and wellbeing

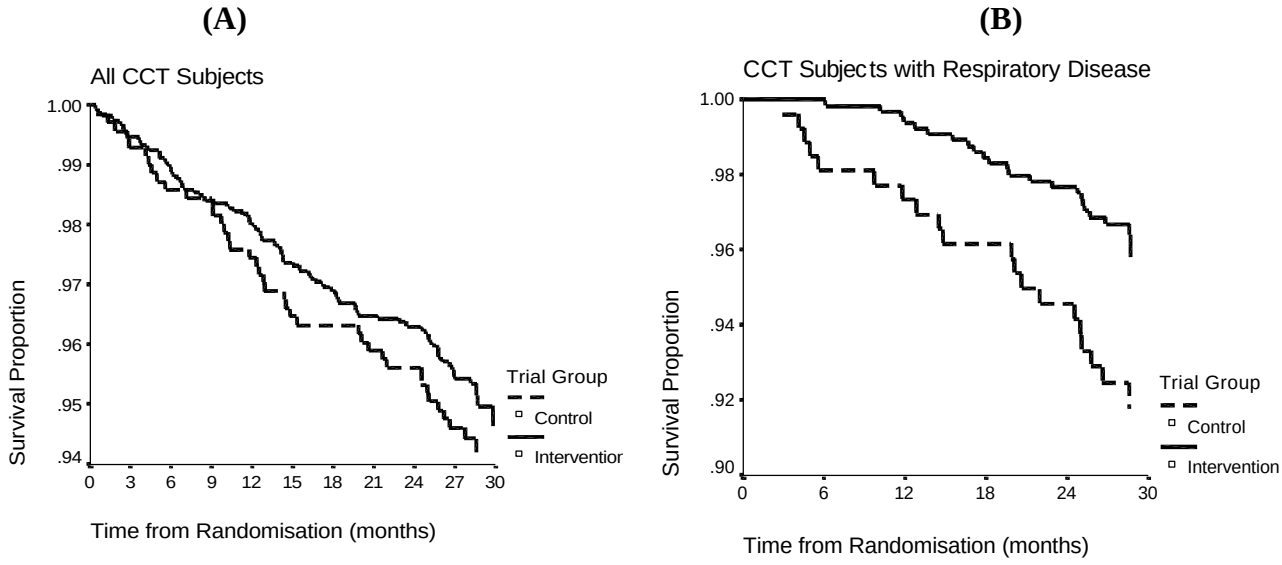
Mortality

As the Trial was targeted at persons who had incurred high acute care costs the Trial population included many persons who were very ill and had a higher than average chance of dying during the course of the Trial. It was thus decided to test for an impact of the Trial on survival as survival is a central element of health and wellbeing.

A total of 148 deaths occurred amongst Trial participants, based on a search of the National Death Register in March 2000. This consisted of 108 deaths in the intervention group, 5.2% of the 2,074 persons randomised to the intervention group, and 40 deaths in the control group, representing 6% of persons randomised to the control. A survival analysis has been computed, as reported in Figure 2.1 and in Table 2.1.

This analysis shows a non-significant mean reduction in the death rate for intervention group participants of 15%, (Cox hazard ratio of 0.853). When deaths were analysed by major clinical group, a large and significant difference in mortality over the two years was observed in persons with respiratory illness. This disease group (as well as the cardiac group) was looked at, as it constituted a large sub-group within the Trial and was a target of the care panel activity. The mean reduction in mortality rate for persons with respiratory illness in the intervention group was 54% (Cox hazard ratio of 0.457 and p value of 0.012), with the reduction observed across all age groups. The adoption of better quality care for persons with respiratory illness could potentially improve health outcomes and reduce death rates within a modest time frame, although no difference in survival was observed between those who had actively participated in the respiratory care panel activity and others. It is possible that those identified for the respiratory care panel (with chronic obstructive pulmonary disease) had more advanced disease in which case the failure to detect a difference may well represent a positive result.

Figure 2.1 Survival analysis: intervention group compared with control group (A) all participants and (B) participants with respiratory disease



The survival analysis suggests that care coordination as introduced in the SHCN CCT may have enhanced survival rates, at least for some patient groups. While there was an observed improvement in survival rate for the intervention group as a whole, with a 15% lower death rate, this was not statistically significant. (The observed survival rate for those without respiratory illness was poorer for intervention group than control group participants, the difference was not significant p= 0.35.)

The reduction in the death rate across all Trial participants over the follow-up period is equivalent to a gain of ~18 life years, based on the area between the two survival curves of chart (A), Figure 2.1. Whether this is a true result, rather than a chance finding, and whether further gains might be achieved in the longer term, is important to establish. This would require a continuation of the Trial or corroboration (or failure to corroborate) in other trials.

Table 2.1 Survival analysis SHCN CCT all randomised subjects over a 30 month follow-up (a)

	Deaths (b)						Cox Hazard Ratio (c)	p value	95% Confidence Intervals	
	Intervention			Control			Intervention v			
	Nd	Ns	%	Nd	Ns	%	Control		Lower	Upper
All Subjects	108	2074	5.2	40	668	6.0	0.853	0.391	0.592	1.228
All Respiratory disease (d)	24	327	7.3	20	150	13.3	0.457	0.012	0.248	0.839

Notes:

a) Analysis performed on an intention-to-treat basis from time of randomisation until 31st Dec. 1999.

b) Nd = number of deaths, ascertained by a search of the National Death Register in March 2000.
Ns = number in sample frame.
% = deaths as a percent of the sample frame to end December 1999.

c) Cox Hazard Ratio adjusted for age group in each case. A hazard ratio of 1.0 indicates no effect of intervention, and a ratio below 1.0 indicates a beneficial effect of the intervention.

d) Respiratory Disease was defined by the use of PBS data: Respiratory drugs: $_2$-stimulants, inhaled corticosteroids, theophyllines and mast-cell stabilisers.

Quality of life

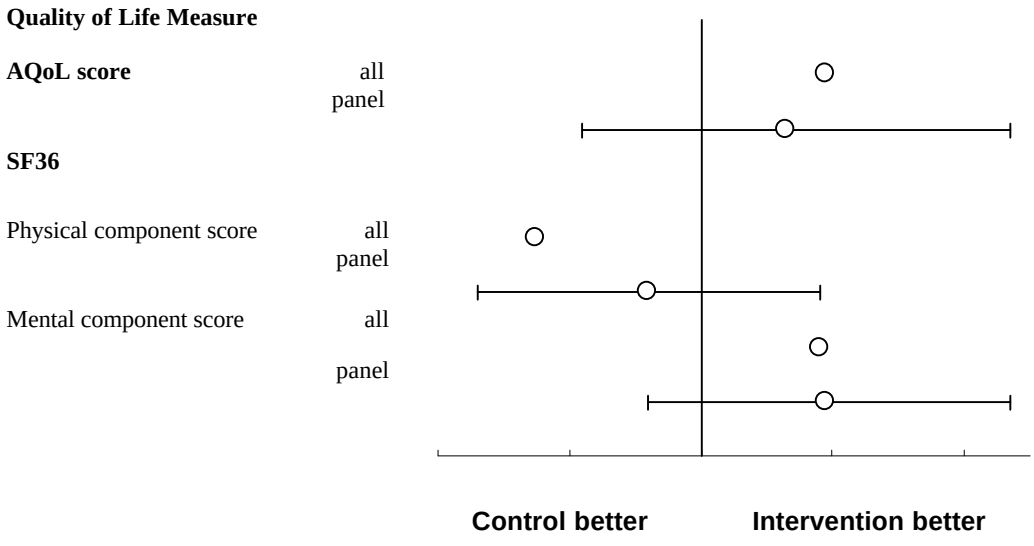
SF36 and AQoL scores have been computed at Trial commencement, after 12 months and at the conclusion of the Trial. Health status as observed through the SF36 or the AQoL, show no significant difference between the control and intervention cohort at either point of time, or between mean scores at trial end and Trial commencement. The turnover value, which computes the difference in score for each participant between Trial end and Trial commencement also shows no difference between the control and intervention group. Results are summarised in Table 2.2 and Figure 2.2. There is also no significant difference in any of the subscales of either instrument.

The lack of a mean net improvement suggests either there has been no overall gain in quality of life, or that the quality of life instruments applied are not sufficiently sensitive to detect an improvement that has occurred. Alternatively the gains may have occurred in too small a subgroup to influence the mean quality of life of the group as a whole.

Table 2.2 Mean SF36 and AQoL scores, baseline and Trial end

Quality of life measure		Intervention group		Control group	
		Trial start	Trial end	Trial start	Trial end
AQoL total score	all	0.6213	0.6408	0.6284	0.6362
	panel	0.6493	0.6398	0.6553	0.6375
SF36 physical comp. score	all	42.64	42.92	41.87	43.23
	panel	42.7	42.8	42.6	43.2
SF36 mental comp. score	all	45.71	46.68	46.03	45.98
	panel	46.7	46.7	46.5	46.1

Figure 2.2 SF36 physical component score, mental component score and AQoL: change in mean score between Trial commencement and Trial end(a)



Notes:

(a) for values see Table A.1, Annex to Chapter 2

% per cent change in mean score of intervention group score (end compared with base line), less per cent change in mean score of control group.

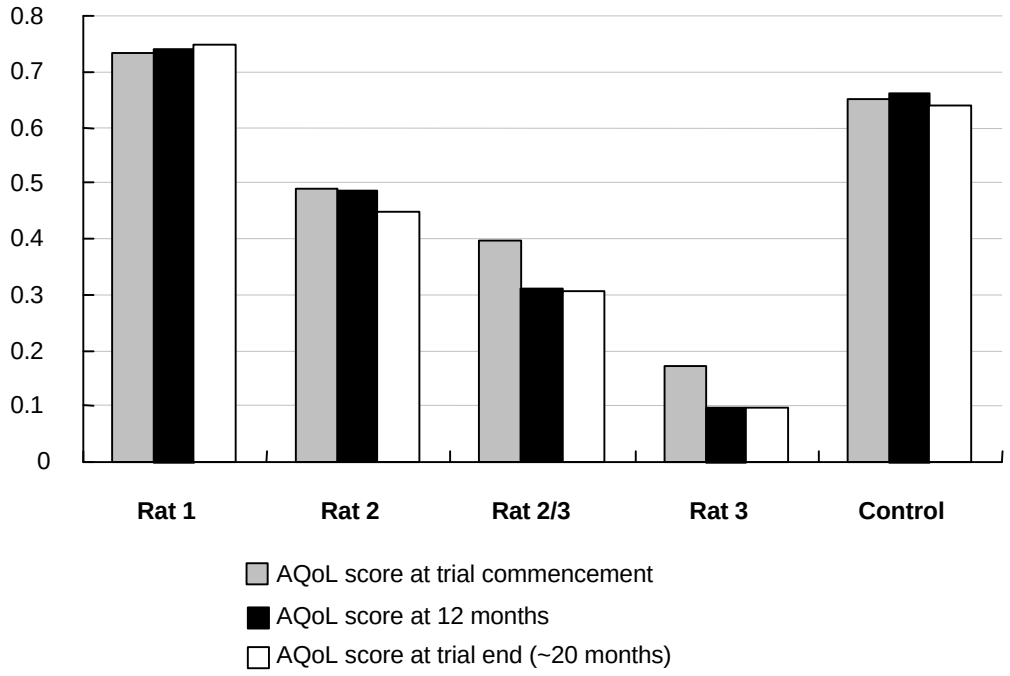
'panel' based on individual comparisons for those for whom baseline and end scores available.

'all' based on mean scores for all completed baseline and completed end questionnaires.

A comparative analysis by risk level cannot be conducted even though this would be of interest, because the risk assessment tool was only applied to intervention group participants. Quality of life score, by risk level can be observed for the intervention group and shows a strong relationship with risk level, as illustrated in Figure 2.3. This analysis also suggests a reduction in quality of life over the course of the Trial for persons at higher risk levels. This suggests an overwhelming influence of the underlying health condition.

In Figure 2.3, Rat 2 and Rat 2/3 include persons who have moved from a lower to a higher risk level over the course of the Trial, denoting a worsening of their health state (or an incorrect allocation in the first instance). All those in level 3 are in very poor health, often with progressive conditions.

Figure 2.3 AQoL scores by risk level and time: Intervention group participants and control group who completed the AQoL on three occasions



Notes:

Rat 1 Risk level 1 (low risk) throughout the trial n= 658
Rat 2 Risk level 1 or 2 (medium risk) throughout the trial, n=231
Rat 2/3 Risk level 3 (high risk), but also 2 (or 1) at some stage during the trial, n=20
Rat 3 Risk level 3 (high risk) throughout the trial, n=26

Direct questions to patients concerning the effect of coordinated care on their quality of life suggests that a sizable group of intervention clients believe that coordinated care has made a difference and that, for some, the effect has been substantial, while for others it has been slight. This conclusion is based on the questionnaire put to all intervention and control group participants concerning their views about the impact of coordinated care and the qualitative interviews.

The questionnaire was answered by 1,499 Trial participants (intervention and control group), and while most nominated no change in their quality of life attributable to their involvement in the SHCN CCT, a higher proportion of the intervention group did indicate a positive impact on wellbeing, 24% compared with 16% (see Table 2.3). The difference was statistically significant ($p < 0.05$). Further, in written comments on the reasons for improved wellbeing, intervention group participants were far more likely to nominate factors central to the care coordination process, such as assistance with access to services and improved GP care and better liaison between services, than control group respondents.

Respondents were far more likely to indicate CCT had improved their quality of life if they felt they had been actively involved in the care planning process. For instance 45 percent of participants who indicated their care pan was very useful also indicated that their quality of life had improved through their involvement in the coordinated care trial.

This compares with 33% of persons who found the care plan moderately useful, and 11% of those who found the care plan of little use. Or looked at in another way, only 22% of persons whose quality of life had not changed found the care plan very useful, compared with 82% of those who said their quality of life had improved a lot. This tends to supports a causal relationship between a perceived improvement in quality of life and the Trial (for some participants).

Table 2.3 Participant perception of impact of CCT on quality of life

Perceived impact of CCT on quality of life	Control group		Intervention group		
	n	%	n	%	% found care plan very useful (a)
Worse	3	1%	5	1%	(i)
No change	356	83%	807	75%	22%
Improved a little	37	8%	180	17%	47%
Improved a lot	33	8%	78	7%	82%

Notes:

a) for instance for those in the intervention group for whom their quality of life had 'improved a little', 47% indicated that they had found the care plan very useful.

i) number too small to quote.

The comments written on the questionnaires returned at the end of the Trial identified mixed experiences of coordinated care for the intervention group. Some participants had difficulty reflecting on care coordination as it was a minor experience for them. This particularly applied to low risk clients for whom the intervention amounts to, from their perspective, a single visit to the GP for a Care Plan, in which they may have had only a peripheral involvement.

> *I don't feel I have really taken part in any trial, since apart from filling in forms, I have not done anything differently.* (Trial End Survey Id 2608)

For patients in level 2 and level 3 who have a service coordinator or case manager, because of their more complex care needs and serious health problems, coordinated care is more visible. Their view of coordinated care depends very much on their personal experience with the service coordinator and case manager and the support they obtain.

> *I have been given medical aids for my use in my home. They are a great help to me, and a lovely nurse comes once a month to see me. [I have liked] getting more help and speaking to the service coordinator on the phone, lovely to talk to.* (Trial End Survey Id 117)

> *[I have liked] visits from someone who listened and attended to my needs appropriately and was able to get me the help I needed so I can stay living at home. My carer and family are also happier.* (Trial End Survey Id 2046)

Participants often expressed concerns about the health system more generally, relating negative experiences with the hospitals and the difficulty of accessing much needed services, such as dental and prescription glasses or health products not subsidised through Medicare.

> *I had to pay $2,100 for extractions and dentures in the last one to one and a half years.* (Trial End Survey Id 2569)

> *We have, despite being aged pensioners, had to pay for all dental treatment. With failing eyesight, the replacement of lenses is becoming a burden.* (Trial End Survey Id 204)

Access to the social security system also posed problems for people. The combination of poor health and poverty seriously, and visibly, undermines the quality of life of many. Without the support of coordinated care, many in very difficult circumstances receive no support other than medical care, which is not always enough.

> *The problem is Parkinsons and it is not going to go away. I have had to learn to live with it and its problems. The system tells me my assets and income debar me from help. The outcome of the trial has been a carer and her on-hand experience on how to handle difficulties.* (Trial End Survey Id 1024)

On balance the data suggests coordinated care has improved the health and quality of life of some, and that for certain patient groups, the effect has been substantial, but the net effect across the entire intervention group has been very small. A reduction in the death rate for persons with respiratory illness is indicated. In short coordinated care has probably contributed to a net improvement in health and wellbeing, but across the entire intervention group the mean effect has been small.

2.3 Resource use

The meaning of 'within current resources'

The second component of the primary hypothesis requires precise interpretation of the concept 'within current resources'. The primary hypothesis postulates that gain in health and wellbeing is achievable within current resources through the mechanism of funds pooling and care coordination which provides health funding and delivery arrangements that are more responsive to consumer needs. This, it is postulated, would result in a more appropriate mix of services generating improved outcomes without the application of additional resources.

It is expected that if additional resources are applied, improved outcomes can be achieved, even within existing health funding and delivery arrangements. Thus improved health outcomes alone, would not be seen as an adequate test of alternative health funding and delivery arrangements.

The concept of 'current resourcing' has been interpreted from the community perspective and related to the concept of economic cost - the lost opportunity for achieving benefits elsewhere. The value of resources applied to health services that would 'normally' have been consumed by Trial participants is taken as the meaning of current resources. This is precisely the role of the control group, to establish impacts, both in terms of health and wellbeing as well as resource use, that would have occurred in the context of usual care. That is the control group can perform the function of estimating 'current resources'.

If a control group was not available to perform this function, the alternatives would be to use historic service use adjusted for disease progression or remission/cure, aging of the cohort, change in treatment patterns over time, change in the supply of services etc. The other option is to develop a risk adjusted capitation model, in which health service use and cost is determined as a function of basic demographic and socio-economic and health characteristics. Such a model could be derived for the enrolled population, based on health service use and cost of trial participants prior to trial commencement, or potentially based on experiences recorded in a broader regional or national data set. The Funds Pool has been calculated using an extremely simplified version of the former approach.

Essentially historic use of services has been taken to indicate future service use, without adjustment, except for in-patient services, which were taken to be equivalent to historic use (over a previous 2 year period for a group of patients taken from the same sample frame as the SHCN CCT enrolees), but less a single in-patient admission. There was no opportunity to test the validity of the model and the Funds Pool would form an extremely doubtful basis for establishing 'current resourcing'.

Fortunately in relation the SHCN CCT, because of the existence of a randomised control, the cost of usual care could be derived from the control group experience. Resource use of the intervention group could then be compared with the control group to establish the impact of the Trial on total health service use, (or at least that captured by the Trial). Because eligibility for the SHCN CCT was based on high use of in-patient services over a 2-year period, use of historic costs to determine 'current resources' or expected service use would be problematic. Historic costs would include the period of high in-patient use, which might not be typical of normal use of health services by the client group. The failure of the Funds Pool calculation to provide a reasonable estimate of expected service use, based on historic data, especially in relation to in-patient services is clearly demonstrated by the comparison with the experience of both control and intervention group participants. (As reported in Chapter 8, while PBS and MBS were predicted to within 10% and 20% respectively, in-patient costs were out by over 50%, that is they were less than half predicted value).

To establish real resource use, the ideal would be to include all health services, those which are publicly funded as well as the financial contributions of patients and the direct care activities of patients' families and other unpaid carers. Further, the cost of health services is ideally included at full average cost. This is not always the same as the price paid. Where trials have negotiated a price that differs from full average cost, it is preferable to use average cost not price, to calculate the net impact on resource use.

Use and cost of MBS services, hospital in-patient and outpatient services, pharmaceuticals (on the PBS) and use of RDNS have been collated and analysed, for control and intervention group clients from Trial commencement to June 30th 1999. In-patient data cover all admissions to public and private hospitals across Victoria, while out-patient visits relate just to Monash Medical Centre (MMC) and Dandenong and District Hospital (DDH). Total use and cost of mainstream health services for the period of the trial, is in statistical terms equivalent for control and intervention clients. Observed values were $3,609 for intervention clients and $3,558 for control clients per equivalent participant year, with in-patient services priced at full average operating cost, WEIS $2,200. These observations are reported in Table 2.4 and illustrated in Figure 2.4.

Table 2.4 Average service use and cost per equivalent participant year(a) Control and intervention group clients, July 1st 1997 to June 30th 1999 (b)

Type of service	Intervention Dollars	Control Dollars	Difference Dollars	Difference Percent	p Value
In-patient:					
- @ $2200/WEIS	2,028 (c_1)	2,057 (c_1)	-29	-1.4%	0.92
- @ $2200/WEIS adj. for patient LOS	2,043 (c_2)	2,031 (c_2)	+12	+0.6%	0.97
- @ $1275/WEIS	1,177 (c_3)	1,194 (c_3)	-17	-l.4%	0.92
PBS (d)	486	479	+ 7	+1.5%	0.84
MBS	944	882	+62	+7.0%	0.21
Out-patient services DDH & MMC	112	90	+22	+24.0%	0.24
RDNS	40	50	-10	-20.0%	0.61
Sub-total	3,609 (c_1)	3,558 (c_1)	+52	+1.4%	0.88
	3,625 (c_2)	3,532 (c_2)	+93	+2.6%	0.80
	2,758 (c_3)	2,695 (c_3)	+63	+2.3%	0.77
Care planning (e)	126	n/a			
Service coord./case management (f)	164	n/a			
Management (g)	430				
Total	4,330 (c_1)	3,558 (c_1)	+772	+21.2%	
	4,345 (c_2)	3,532 (c_2)	+813	+23.0%	
	3,478 (c_3)	2,695 (c_3)	+783	+29.1%	

Notes:

a) Annualised patient cost based on mean cost per participant day x 365.25.

b) Health service use and cost data analysed until June 30, the original end date for the Trial.

c) In-patient costs cover all admissions in Victoria. MMC and DDH were based on tracking of all SHCN CCT participants. Admissions to other hospitals derived from matching against the VMID, thought to track ~ 60% of admissions. Loss of capture should be similar between control and intervention.
   c_1 - cost of in-patient services based on DRGs priced at full average cost of $2200/WEIS
   c_2 - inlier admissions adjusted for patient length of stay, outlier admissions as costed.
   c_3 - cost of in-patients at payment rate to Pool, variable WEIS rate of $1175

d) PBS partial data only as captured by the HIC.

e) Care coordination services covering, care planning, $358,00 ($283,000 to GPs for care planning plus 50% of $150,000 paid to division of GP, remainder appears in management), averaged across 2837 equivalent participant years = $126.

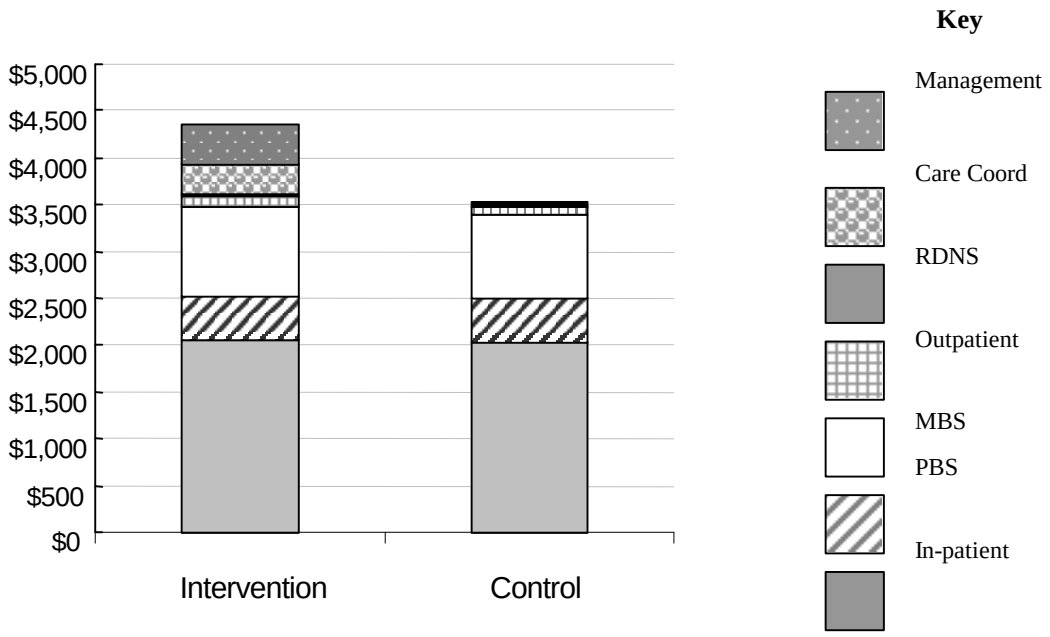
f) Service coordination and case management at $465,000, averaged across 2837 equivalent participant years = $164. While a small number of control clients will have had case managers through existing programs (such as Linkages or mental health), the costs of this has not been recorded. Generally such costs will also not have been recorded for intervention group clients.

g) Trial management on-going costs only, estimated at $852,000 or $300/participant year, plus an attribution of establishment costs, of $370,00 or $130, (necessary to replicate this model).

The largest observed difference between control and intervention group clients is for out-patient services and medical services, both of which were more costly in the intervention group. Expenditure on RDNS is the only service category for which the control group cost is higher. Use and cost of in-patient services and PBS by intervention and control clients is equivalent. Costs have been expressed in relative terms to compare the experience for control and intervention group clients, by type of service, as illustrated in Figure 2.4. The trial has had no net effect over the two years on the use of hospital in-patient services, except for those who have died, for whom in-patient costs are higher. The Trial has encouraged slightly greater use of medical services.

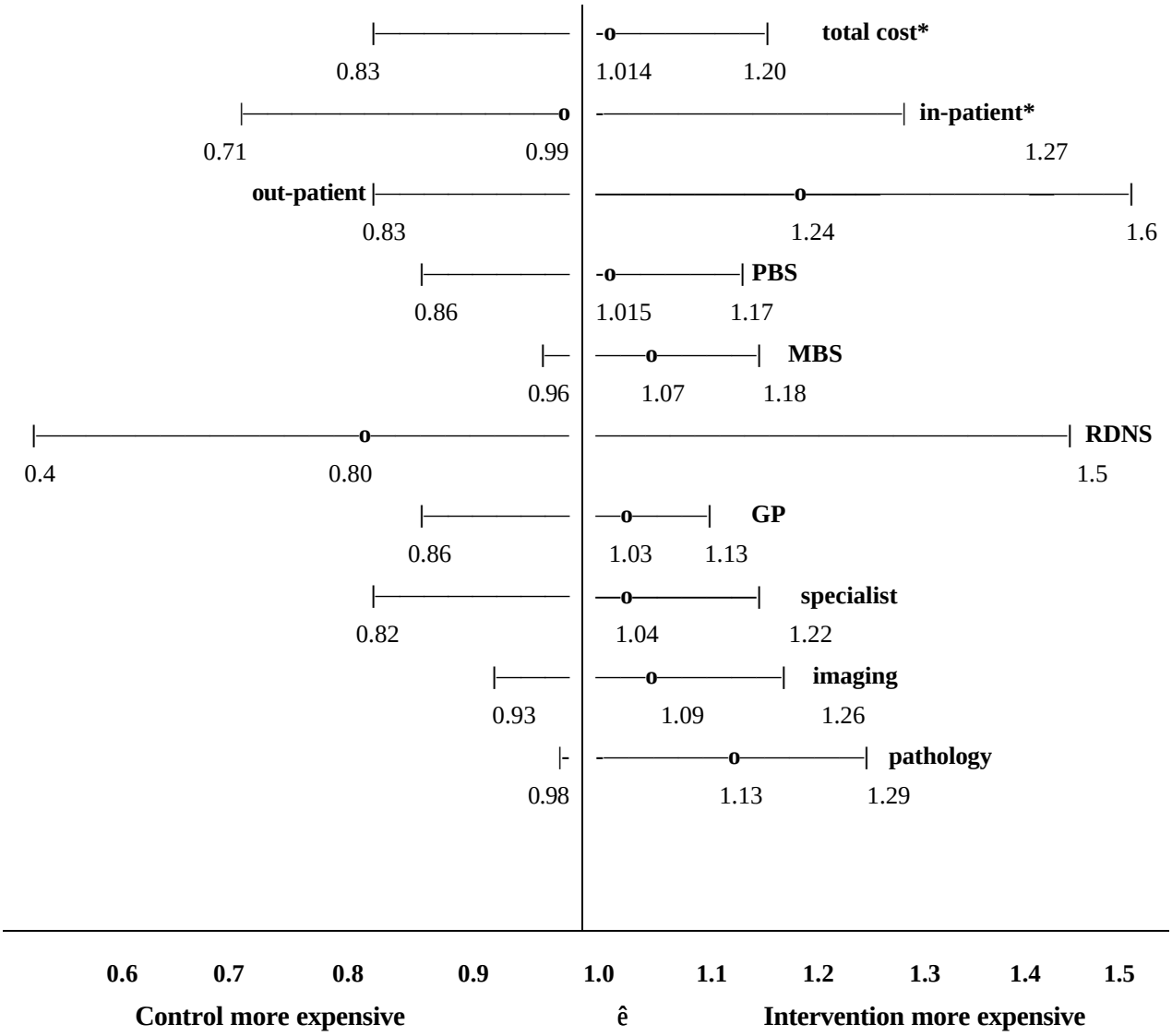
Including care coordination services[14] as well as the Trial management costs (costs that would be incurred if this health service model were to continue), use and cost of health services by intervention clients was substantially higher than for control clients. The cost difference is a mean $813 per equivalent person year, or an extra 23%. The overall impact on resource use is illustrated in Figure 2.5

Figure 2.4 Intervention and control group mean resource cost
Annualised cost/participant for Trial period



[14] Care coordination services cover both GP care planning activity and the role of the service coordinators and case managers.

Figure 2.5 Relative cost control and intervention group clients, total and by service type (a)



Notes:

a) At 1.0 control and intervention group costs are equivalent, 1.05 would mean intervention group 5% more expensive/client day over course of the trial or at 0.8 intervention group 20% less costly.

- WEIS @ $2200

While costs of service use by intervention clients is higher over the two year period taken as a whole, there is a clear trend for a reduction in the cost differential. Comparing relative expenditure in the first and second twelve month periods, mean total cost for intervention group participants moves from 9% higher to 9% lower than the control group. (See Table 2.5)

The main categories to turn around are medical services and in-patient costs. The high initial cost of medical services is entirely consistent with the objectives of the Trial, of encouraging the adoption of best practice care, which in the first instance is likely to involve GPs in a higher referral rate to specialists and for tests. In relation to in-patient costs, when the LOS adjusted patient level costing is used, the turn around in cost between the first and second twelve month period is considerable, from 15% higher to 11% lower, suggesting a reduction in both admissions and length of stay.

If the observed turnaround is an indication of a real trend this is an important qualification to the view that the Trial has resulted in an increase in the cost and use of health services. (See Table 2.5 and Figure 2.6.)

Table 2.5 Cost of health services: intervention group participants, first and second twelve months, $ and comparison with control

Cost category	**July 1 to June 30 1997-8**		**July 1 to June 30 1998-9**	
	$ (a)	relative to control (b)	$ (a)	relative to control (b)
in-patient (c_1)	2,241	1.08	1,863	0.91
in-patient (c_2)	2,370	1.15	1,792	0.89
MBS	997	1.15	903	1.00
other costs (d)	654	1.03	623	1.02
TOTAL (b)	3,883	1.09	3,390	0.91

Notes:

a) mean cost for intervention group per equivalent participant year

b) mean value for intervention group participant compared with control, for instance at 1.09 intervention 9% more expensive, or 0.91 intervention group 9% less expensive than control.

c) (c_1) based on WEIS at $2200 (average operating cost)

d) (c_2) based on WEIS @ $2200 adjusted for patient length of stay

e) PBS, RDNS, out-patient

Figure 2.6 Costs over the Trial period, total cost, in-patient cost and MBS.

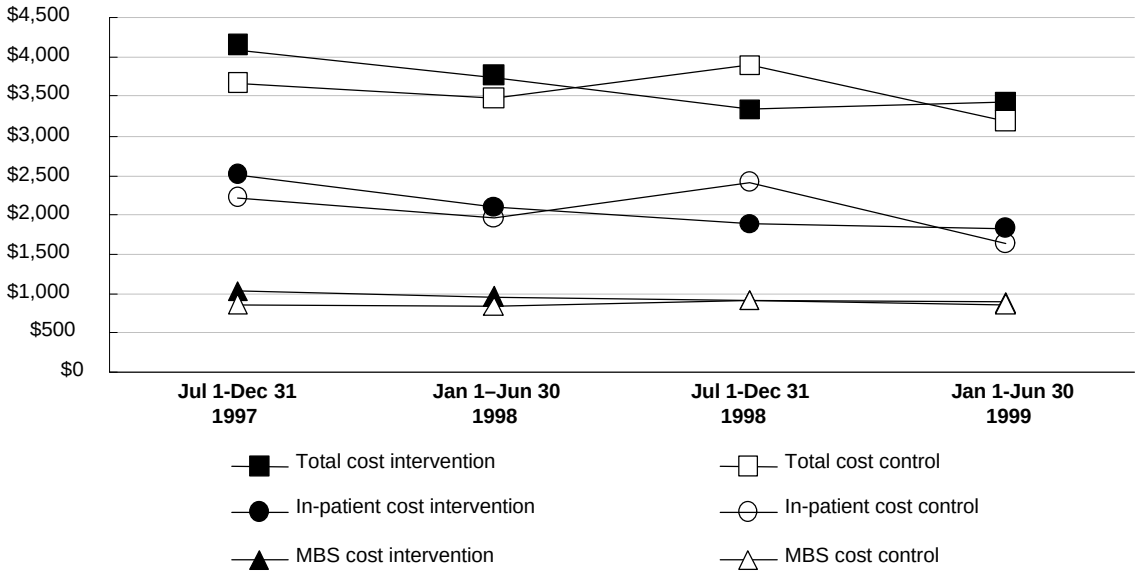


Table 2.6 Mix of service use, control and intervention group to end June 1999

Service type	Intervention Dollars	Control Dollars	Control %	Intervention %	
				(a)	(b)
In-patient - WEIS @ $2200 adjusted for patient LOS	2,043	2,031	57.5%	57.8%	52.2%
Out-patient MMC, DDH (c)	112	90	2.5%	3.3%	2.9%
PBS	486	479	13.6%	13.7%	12.5%
MBS	944	882	26.7%	25.0%	24.2%
Care coordination (GP training, Care plan development & review)	126	0	0.0%	3.6%	3.2%
RDNS	40	50	1.4%	1.1%	1.0%
Case management, Service coordination (d)	164	0	0.0%	4.6%	4.2%
Subtotal	3,915	3,532	100%	110.8%	100%
Trial management (e) **TOTAL**	430 4,345				

Notes:
(a) Health service mix, based on control group total cost
(b) Health service mix based on intervention group total cost

The funds pool – and health service mix

The Funds Pool for the SHCN CCT was financially viable despite the greater use and cost of health services by the intervention group. This has been achieved, because of an over-subscription to the Funds Pool. It highlights the difficulty in predicting service cost of a very disparate participant community on the basis of the observed service use of a sample drawn from the same sample frame (although different cohort). Furthermore because of the Trial eligibility criteria, based on previous high use of acute services, prediction of acute services on the basis of past use is likely to be unsound. This proved to be the case. (The Funds Pool is considered in more detail in Chapter 8).

What is more relevant to the primary hypothesis is whether there was a shift in the health service mix, the mechanism by which improved outcomes were expected to be achieved, within current resourcing. Ascertaining the shift in the mix of health services is complicated by the lack of a constant base. There has been a 19% increase in the total costs of the intervention group, or a 10% increase excluding the costs of on-going management. Taking control group total cost as the base line, there has been an increase across all activities except RDNS. Considering just the allocation of resources for the intervention group, (excluding management costs), there has been a sizable shift to private clinical care and care provided by the care coordination activities. Private medical care increased from 25% (MBS share of control group costs), to 27% (which includes MBS, plus care planning). A new category for direct patient support through case management/service coordination services accounts for 4.2% of costs. In-patient costs fell from 57.5% for the control group costs to 52.4% in the intervention group, achieved largely through an increase in other costs, while in-patient cost remained relatively stable. (See Table 2.6)

It is not clear that the Funds Pool was central to the redirection in the mix of services, which has been achieved essentially through a simple addition of resources. This presumably could have been achieved without the pooling of funds. That is the shift has not been achieved through a redirection of resources but rather through the application of additional resources.

2.4 Conclusion

Based on our evaluation of the SHCN CCT it is not possible to conclude that health and wellbeing has been improved within current resourcing. What we can conclude is that health and wellbeing may have improved on average, and has certainly improved for some. It is unlikely that the health of any participant has deteriorated because of coordinated care.

However it is also clear that any improvements were not able to be achieved within current resourcing. The use and cost of mainstream health services is, in statistical terms, equivalent between the control and intervention group, but with a tendency for medical and outpatient costs to be higher in the intervention group and RDNS costs to be lower. Use and cost of in-patient services and PBS were identical, but in-patient costs were tending to reduce relative to control clients over the two years of the Trial.

Coordinated care also carried additional costs not incurred under usual care. Notably the direct costs of care coordination for, the development of the care plan, training of GPs and the peer review process, and for service coordination and case management services. This amounted to an estimated $290/participant year or 8.2% on top of the cost of mainstream services. Management costs are extra, and in the context of on-going delivery of care coordination with funds pooling, (that is excluding costs specifically related to a trial) are estimated at another 8.5%. If establishment costs are also apportioned to the Trial (at only one third of those that would be required if the model were replicated elsewhere) a further $130 is added. Total costs in the intervention group, are thus substantially higher than for the control group, estimated to be some 23% higher, counting also the small increase in the cost of mainstream services. This calculation is based on a full costing of in-patient services @$2200/WEIS. If in-patient services are valued at cost to the Pool, which was $1275/WEIS, the percentage increase in cost is even greater at 29%.

Whether health gains achieved justify the additional costs of $813 per person year equivalent, or ~$2.3 million over two years of the Trial (based on 2,837 equivalent person years), has not been established. Taking the mean reduction in death rate (which may/may not be attributable to the Trial), over the 28 month follow-up of ~ 18 person years, the additional cost is equivalent to $128,000 per life year gained. This is relatively high in terms of health service cost-effectiveness ratios. The undoubted improvement in quality of life for at least some participants, may well justify some additional cost.

The shortness of the follow-up period is a major problem in considering these results. In relation to chronic disease management, at least a five-year follow-up period is preferable. (The major trials of diabetes management have had at least eight years follow-up, with little improvement in outcomes within the first two years, even where there were strong results at eight years.) It is also probable that the observed health service cost differential would reduce over time. Thus with a longer time frame the cost difference may be less.

It can also be noted, that if the Trial had met the requirement for budget neutrality, a large reduction in the use of mainstream services, by some 29% would have had to occur. It is most unlikely that this could have been achieved without some loss in health and wellbeing.

Annexure to Chapter 2

Table A.2 Change in quality of life score (a)

Quality of life measure		Intervention	Control	Difference, intervention-control mean and confidence limits					
		mean	mean	score			%		
AQoL score		+ 0.02	+ 0.01		+0.012			+1.9	
	panel	- 0.01	- 0.01	-0.0014	+0.0083	+0.029	-2.1	+1.3	+4.4
SF36									
physical component score	all	+ 0.28	+ 1.36		-1.08			- 2.5	
	panel	+ 0.11	+0.45	-1.45	-0.34	+0.772	-3.4	- 0.8	+1.8
mental component score	all	+ 0.77	- 0.05		+0.82			+1.8	
	panel	+ 0.28	- 0.57	-0.429	+0.85	+2.142	-0.9	+ 1.9	+4.6

Notes:
(a) Trial end less Trial start

Chapter 3

Quality of life: survival analysis, SF36 and AQoL

3.1 Introduction

In this chapter, survival during the Southern Health Care Network Coordinated Care Trial (Trial) period in the intervention and control groups as they existed at the start of the Trial (ie after consent and randomisation) is first compared. The intention to treat principle is thus observed. Changes in health-related quality of life across the trial period in the intervention and control groups are then studied so as to address the first part of the primary hypothesis: does the coordination of care for people with multiple service needs result in improved individual client health and well-being?

3.2 Survival analysis

One hundred and eight of 2,074 clients (5.2%) in the intervention group and 40 of 668 (6.0%) clients in the control group died between the date of randomisation and December 31 1999. Survival in the intervention group was enhanced in comparison to the control group, although this did not reach statistical significance (see Table 3.1 and Figure 3.1). When only activated clients (ie those in receipt of a care plan) in the intervention group were considered, the mortality rate was further enhanced. However, this latter comparison could possibly be the result of bias due to exclusion from the intervention of those who might be especially likely to die: there were 30 deaths in the 325 (9.2%) intervention group clients not activated.

Table 3.1 Survival analysis in intervention and control groups

	N	Deaths		Cox Hazard Ratio* Intervention v Control**	p Value	95% Confidence Intervals	
		Intervention	Control			Lower	Upper
All Subjects							
Intention-to-treat	2742	108 / 2074	40 / 668	0.853	0.391	0.592	1.228
Trial entry	2417	78 / 1749	40 / 668	0.714	0.085	0.487	1.048
Respiratory							
No Disease	2265	84 / 1747	20 / 518	1.263	0.350	0.774	2.061
Disease	477	24 / 327	20 / 150	0.457	0.012	0.248	0.839
Respiratory Disease							
Over 50 years	240	12 / 163	12 / 77	0.434	0.042	0.194	0.971
Under 50 years	237	12 / 164	8 / 73	0.501	0.147	0.197	1.275

Notes:

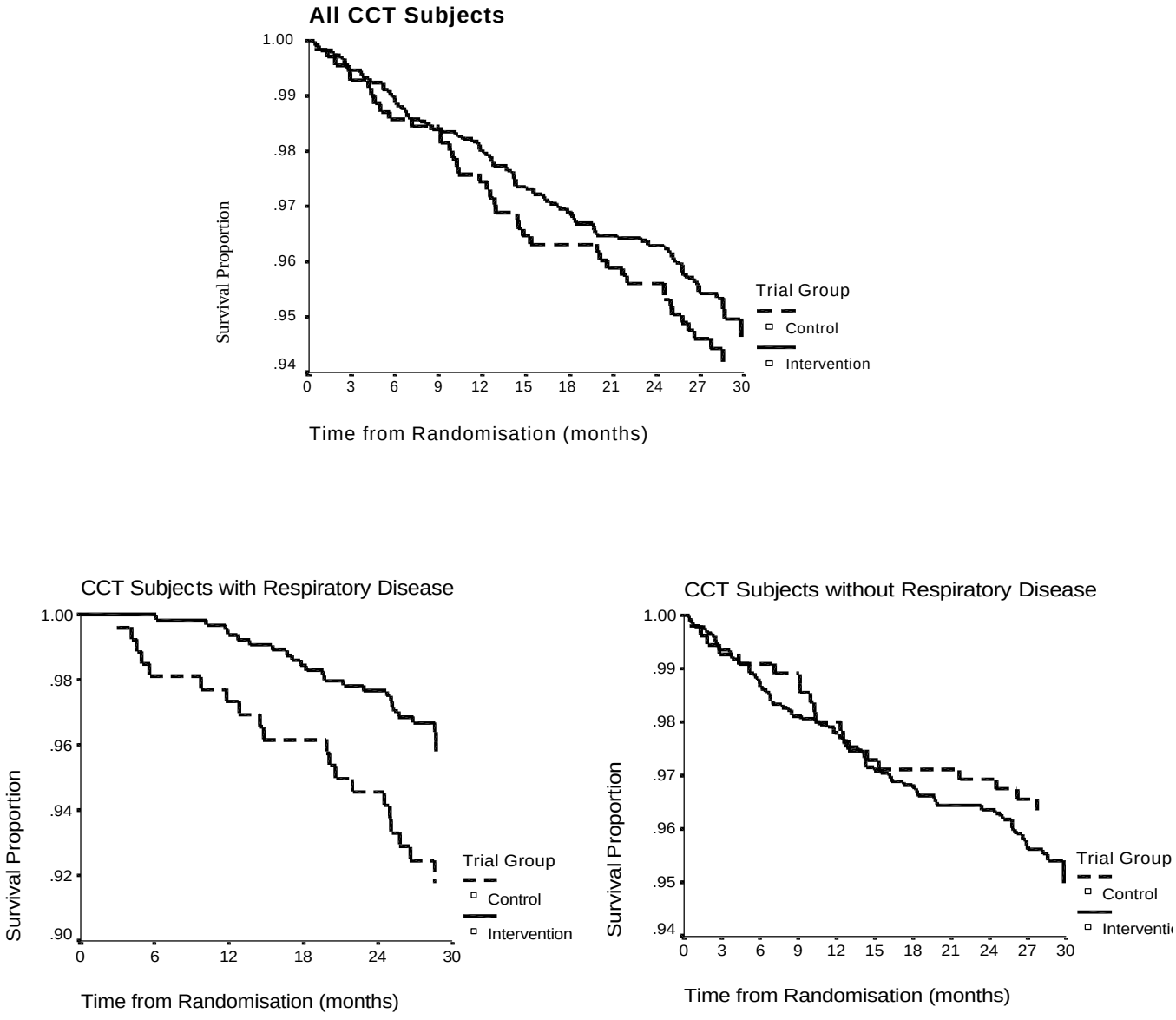
* Cost Hazard Ratio was adjusted for 10 year age group in each case.

** A hazard ratio of 1.0 indicates no difference in survival; a reduced hazard ratio (<1.0) indicates enhanced survival in the intervention group.

Survival analysis was conducted in the clients with respiratory disease, identified from PBS data of use of respiratory drugs (inhaled steroids, beta2-stimulants, mast-cell stabiliser inhalants and theophyllines) (see also Table 3.1 and Figure 3.2). Survival was greatly enhanced in the intervention group, and this was a statistically significant difference. The difference was similar in those older and younger than 50 years of age. This difference was not seen in the remainder of the Trial clients. This large difference may have resulted partly from biased Trial entry. Identification of clients as having respiratory disease depended on collection of prescription details which only occurred after trial activation, and non-activated clients might have included a high proportion of very sick people with respiratory disease suffering a high subsequent mortality who chose not to, or were unable to, undergo care planning. However, if all the deaths in the non-activated group had occurred in people with respiratory disease (ie performing the maximum possible correction for this bias), only half of the mortality rate difference would be explained. So we cannot exclude a true mortality difference being present as a result of the intervention.

Figure 3.1 Survival during the Trial period in intervention and control group subjects

Figure 3.2 Survival during the Trial period in intervention and control group subjects with and without respiratory disease



The Trial was not designed to identify mortality rate differences. Sample size calculation indicates that the Trial would require 8 to 10 times the numbers of subjects in order to exclude a 15% mortality rate reduction. Thus the observed mortality rate reduction in the intervention group in patients with respiratory disease (the majority of this group will have chronic obstructive pulmonary disease) raises the possibility that focussing on this group of high risk patients might lead to an improvement in health care delivery that might reduce the high rate of mortality. The results fall short of definitive proof, and would require to be repeated in a trial of adequate size in order to be confirmed. However, it is also not possible to exclude such a mortality benefit without a repeated trial, and such a trial may be difficult to repeat in exactly the same form, since the repeated trial would have to have as its primary hypothesis that the coordinated care intervention would improve the care over standard community care, and it might be impossible to ensure that standard care would not improve as a result of its inclusion in the repeat trial. Nevertheless, it might be possible to estimate the magnitude of this 'beneficial effect of trial inclusion' by contemporary and historical comparison of mortality rates in matched populations of other subjects with respiratory disease using the same selection criteria.

It was not possible to estimate the separate effect of the Respiratory Care Panel intervention due to our inability to identify an appropriate control group. Ninety-two of the 477 clients with respiratory disease were included in the Care Panel intervention that commenced approximately 18 months after the start of the Trial. Mortality in this component of the intervention group was twice as high as the rest of the intervention group, but this cannot easily be interpreted, since the clients selected may appropriately have been those at highest risk, and mortality might otherwise have been even higher. However, there was no apparent change in survival curves later in the trial, and intervention group benefits in the respiratory disease group appeared to have occurred from the early months of the Trial.

A separate issue that would need to be addressed, if the mortality reduction were to be confirmed, would be whether the quality of life that resulted from the increased survival was felt by the people involved to have any value. People with end-stage respiratory disease, such as the trial respiratory disease control group subjects who had an annual mortality of about 6%, live in considerable distress. It is possible that prolonging that distress might not be felt by the subjects to be worth the effort. We do not believe that this would be found to be the case, but should be part of any future evaluation of such interventions.

3.3 SF36 and AQoL

This section reports results from the first (wave 1), second (wave 2) and third (wave 3) administrations of a quality of life mail questionnaire[15] to participants in the SHCN CCT aged 12 years and over. The questionnaire included two separate instruments: the SF36 and the Assessment of Quality of Life (AQoL). Use of the SF36 to measure quality of life was mandated by the National Evaluator but it was considered desirable to select an additional quality of life instrument to increase the chance of observing a Trial effect if there was one. Normally a disease-specific or age-specific instrument might be used, as it would tend to be more sensitive, but such instruments were precluded by the diversity of the Trial population.

15 A small number of interviews were conducted to collect the data from those participants who had difficulty completing the questionnaire. For those interviews conducted with people from a NESB, interviewers who were fluent in both English and the respondents' preferred language were used.

The multi-attribute utility instrument AQoL (Assessment of Quality of Life, Hawthorne *et al* 1997) was selected because:

- of its capacity to generate a single utility score that could be used to conduct a cost utility analysis of the Trial,
- it was developed in Australia and the scoring system has been calibrated with an Australian sample, and
- it covers domains not well captured by the SF36 so that the instruments are quite complementary.

3.3.1 Response rates

From an evaluation point of view, response rates are calculated using the entire body of 2,742 consented and randomized clients (see Table 1.6 in Chapter 1), however from the perspective of field operations, those who withdrew from the Trial were no longer available to participate in the surveys. A more realistic assessment of the 'success' of the field operations can be made using non-withdrawn clients as the percentage base. In this Trial calculation of the response rates for this purpose is difficult because of the steady attrition of potential respondents from the study population for a variety of reasons. Notwithstanding this, the response rates calculations which take withdrawal from the Trial into account are shown in Table 3.2 below and the response rates calculated in this way are considerably higher than those shown in Table 1.6. This indicates that the response rates in the latter table are strongly depressed by attrition.

As shown in Table 3.2, response rates of over 90% were achieved in the first two waves of the survey. The response rate to the final wave was depressed by the high proportion of non-reconsenting clients who failed to return completed questionnaires. As is also shown in Table 3.2 there are no statistically significant differences between the control and intervention groups in the numbers responding. A similar analysis was conducted to check the possibility that differences in response rate between intervention clients of different risk levels challenged the validity of the Trial. Similar to the finding with respect to control and intervention groups, apparent differences in response rate between clients receiving different levels of the intervention disappeared when differences in withdrawal rate were included in the analysis.

3.3.2 The respondents

A comparison of the intervention and control group respondents' socio-demographic characteristics for each wave of the survey was conducted[16]. There was only one statistically significant difference between the two groups over all the waves (living arrangements in wave 3). Table 3.3 shows a comparison of the socio-demographic characteristics for the intervention and control group respondents who responded to all three waves of the survey. Only one (health insurance status) was statistically significant in the panel (proportion English spoken at home and living arrangements marginally so).

The differences between intervention and control group that have emerged are not numerous indicating that the comparability between the study groups achieved by randomisation has not been greatly disturbed by withdrawal or other factors.

16 These comparisons are shown in Tables 3A.1, 3A.2, 3A.3 in the annex to this chapter.

Table 3.2 Response rates adjusted for withdrawals

	Intervention group	Control group	Total	c^2 *p* value
a. Randomized	1749	592	2341	
WAVE 1				
b. W/drawn by end W1 fieldwork	124	16	140	
c. Inscope at end of fieldwork (a-b)	1625	576	2201	
d. Returned questionnaire	1548	537	2085	
RESPONSE RATE W1 (d/c)	**95.3%**	**93.2%**	**94.7%**	**0.06**
WAVE 2				
f. W/drawn by end W2 fieldwork	389	59	448	
g. Inscope at end of fieldwork (a-f)	1360	533	1893	
h. Returned questionnaire	1261	493	1754	
RESPONSE RATE W2 (h/g)	**92.7%**	**92.5%**	**92.7%**	**0.85**
WAVE 3				
j. W/drawn by end W3 fieldwork	467	90	557	
k. Inscope at end of fieldwork (a-j)	1282	502	1784	
l. Returned questionnaire	1015	405	1420	
RESPONSE RATE W3 (l/k)	**79.2%**	**80.7%**	**79.6%**	**0.48**

Table 3.3 Socio-demographic characteristics of subjects completing all three questionnaires

	Intervention		Control N		Significance (p)
	Mean	SD	Mean	SD	t-test (groups)
Age	49.8	21.0	48.7	21.6	0.389
	N	Percent	N	Percent	χ^2
Sex –female	592	57.3%	241	57.7%	0.904
Born in Australia	575	59.2%	251	62.6%	0.237
ATSIC	2	0.2%	0	0.0%	n/a
English spoken at home	959	94.2%	393	96.6%	0.070
Marital Status					0.275
married	726	70.3%	278	66.5%	
widowed	96	9.3%	37	8.9%	
divorced	73	7.1%	29	6.9%	
never married	137	13.3%	74	17.7%	
Employment Status					0.313
employed FT or PT	324	32.1%	126	30.9%	
home duties	239	23.7%	99	24.3%	
retired	328	32.5%	121	29.7%	
Live in house unit or flat	990	97.3%	392	95.4%	0.057
DVA	25	2.6%	8	2.1%	0.600
Receive a pension	599	62.5%	232	61.5%	0.754
No private health ins.	845	86.3%	71	81.5%	0.026

3.3.3 Change in quality of life within the intervention and control groups

The SF36 provides two summary scores: Physical Component Score and Mental Component Score. Each is scaled to have a mean of 50 and standard deviation of 10. The distributions for scores for the Physical Component for Wave 1, Wave 2 and Wave 3 are shown for the intervention and control groups in Figure A.3.1 in the annex to this chapter. These figures reveal distributions of scores that are almost identical for the three waves of the study for both the intervention and control groups. Again distributional statistics, not cited in detail here, show close similarities in median, skew and kurtosis for the three waves within each group. A similar result emerges from an examination of the Mental Component Scores (see Figure A.3.2 in the Annex).

The AQoL instrument provides an utility index, ranging from -.04 for the worst possible health state, through 0 for death, to 1.0 for perfect health. The distributions for the Wave 1, Wave 2 and Wave 3 results are shown separately for the control and intervention groups in Figure A.3.3 in the Annex. There is no significant change in the scores of either group: means are within .02 across all three observations for both intervention and control groups, the standard deviations very close to identical and the shape of the distributions very similar. Although not reported in detail here, measures of distributional characteristics are also very similar: skewness, kurtosis, median, interquartile ranges being within 0.1 measurement units.

Change in these quality of life measures can also be examined at individual level: that is to say, the Wave 1 and Wave 3 scores for individuals compared and the significance of any change assessed. Using the pairwise t-test for individual differences, the results are insignificant for all quality of life summary indicators for the respondents as a whole and for both the intervention and control groups separately. The result closest to significance using the entire sample for the AQoL shows a mean difference between Wave 1 and Wave 3 of 0.0090 ($t=1.79$, 1429 DF, $p = 0.074$). This result suggests that all participants generally got slightly sicker with the passage of time. When the same test is conducted for the intervention and control groups separately, the differences are even less significant statistically ($p=0.246$ and $p=0.135$ for intervention and control groups respectively).

In brief, both the overall mean AQoL utility score for quality of life and the two summary SF36 scores for physical and mental components show no significant change during the course of the intervention for either the intervention or control groups. Moreover the overall distributions change little between the three waves for either the control or intervention groups in any of the three general indicators examined. These findings suggest a high level of stability in the overall quality of life of the trial participants, regardless of whether they are in control or intervention groups and there is no evidence here to suggest that participation in the intervention has changed overall quality of life.

3.3.4 Change in quality of life between intervention and control group

Although the change manifested within the control or within the intervention may not be significant, there is a possibility that two small changes in opposite directions could represent a difference between the control and intervention groups that was significant. In order to test for this type of change, "turnover indicators" or "change indicators" were constructed for each dimension. This was done by subtracting the value of the indicator at Wave 1 from the value computed for Wave 3. Thus a value of zero indicates no change, a positive number shows an increase and a negative number a decrease in that particular aspect of quality-of-life. If the value of the turnover variable is significantly different from zero, there has been change within the group. If a significant difference were found in the value of the turnover variables between intervention and control groups, this would be evidence to support the proposition that the intervention had had an effect. In no instance of the three general quality of life measures did the difference in turnover between control and experimental groups approach significance. (See Table 3.4)

Table 3.4 T-Test for difference of mean turnover QoL scores Intervention vs Control

	t-test for Equality of Means						
	t	Df	Sig (2-tailed)	Mean Difference	Std Error Difference	95% Confidence interval of the Difference	
						Lower	Upper
SF36 Phys Comp. Score (W3-W1)	-.602	1266	.548	-.3403	.5667	-1.4522	.7715
SF36 Mental Comp. Score (W3-W1)	1.307	1277	.191	.8563	.6551	-.4290	
AQoL3 (4 dim utility score) (W3-W1)	.679	1428	.498	7.569E-03	1.115E-03	-1.43E-02	

An examination of the distribution of turnover scores is instructive (see Figures 3.3 and 3.4). Although the net mean change is negligible for the AQoL and the SF36 PCS, there is a great deal of gross change as shown by the bars at the extremities of each distribution. This gross change is comprised of both increases and decreases in quality of life, and is largely self-cancelling, resulting in negligible change overall.

Figure 3.3 Distribution of AQoL turnover scores respondents completing W1 & W3
0=no change, +1 = maximum improvement, -1 = maximum deterioration

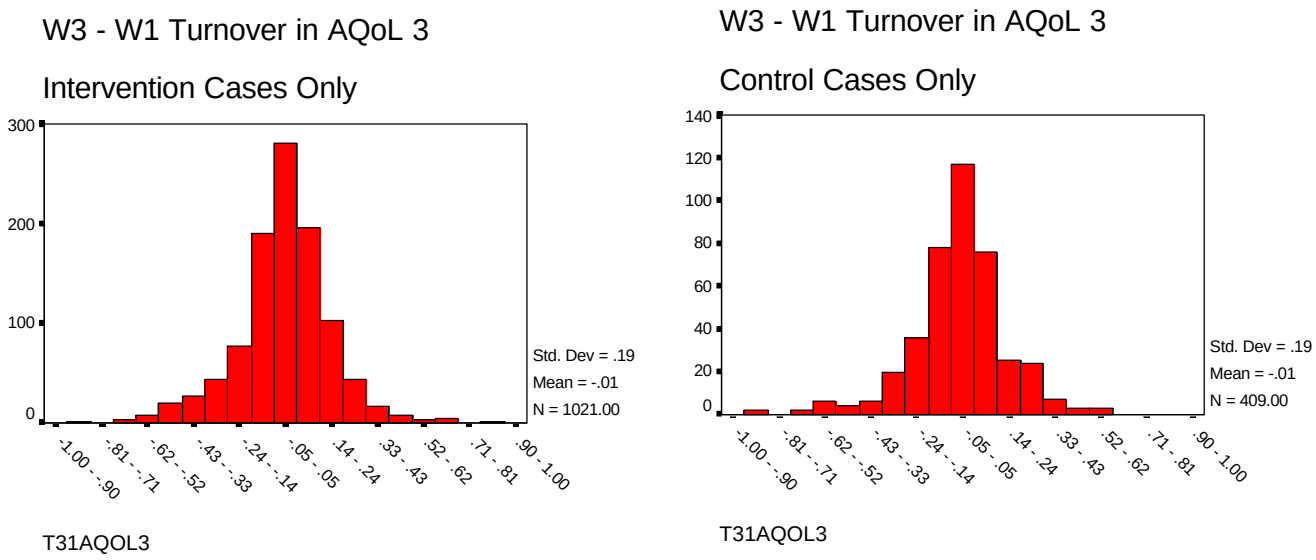
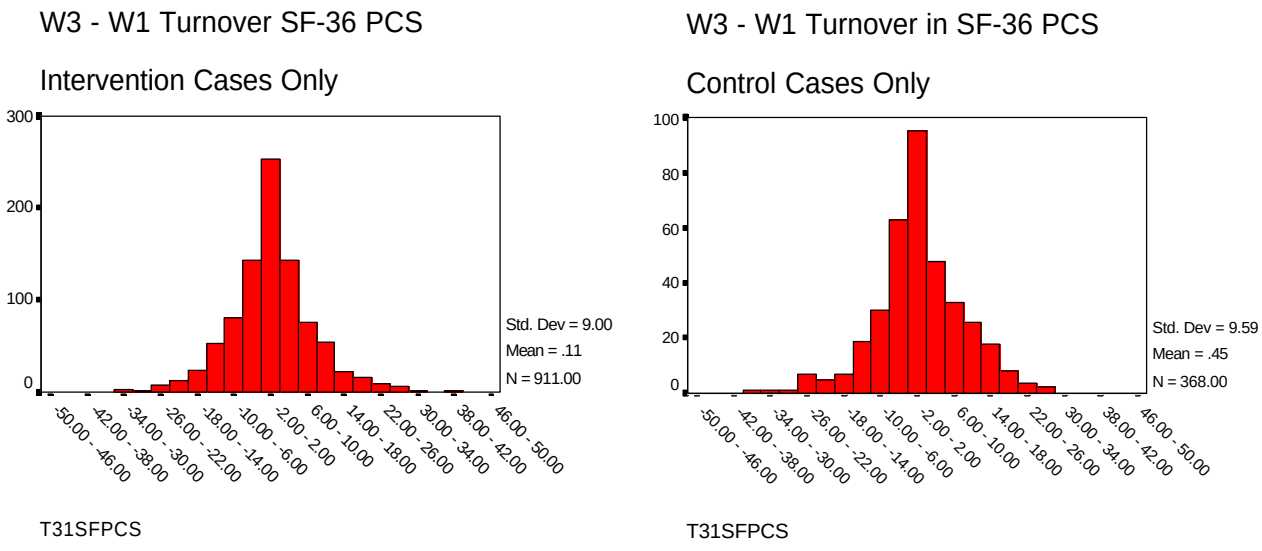
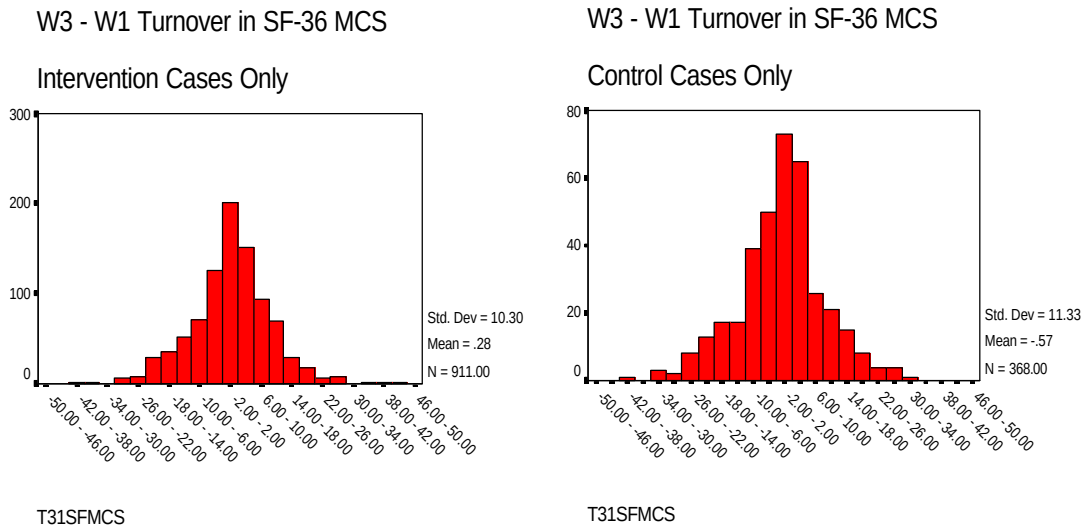


Figure 3.4 Distribution of SF36 PCS Turnover scores: Intervention vs Control
0=no change, +100 = maximum improvement, -100 = maximum deterioration



In Figure 3.5 the turnover is shown for the Mental Component Score. This shows a decline for the control group (mean –0.57), and a small gain for the intervention group (mean +0.28). However, despite the magnitude of the differences, the variances of the two distributions are high (10.3 and 11.3 for the intervention and control respectively) and the t-test for the difference in mean turnover between intervention and control is not statistically significant: (p=0.191).

Figure 3.5 Distribution of SF36 MCS turnover scores: intervention vs control
0=no change, +100 = maximum improvement, -100 = maximum deterioration



3.3.5 Change in quality of life and intensity of the intervention

As part of the care planning procedure, intervention group clients were assigned to one of three risk levels using a specially designed risk assessment tool (RAT). Intervention clients' risk level determined the intensity of the intervention they received – the higher the risk level the more intense the intervention. Because clients' RAT scores for intervention clients could, and did, change over the course of the Trial, the intervention clients have been divided into 4 groups:

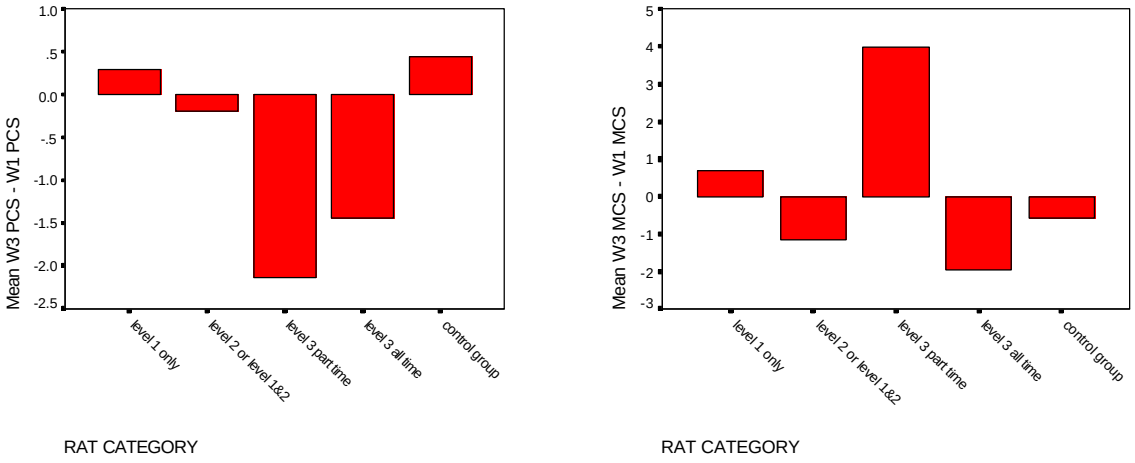
- RAT level 1 score only (N = 1195)
- RAT level 2 or level 1 and 2 (N = 454)
- RAT level 3 part of the time (N = 55)
- RAT level 3 all the time (N 85)

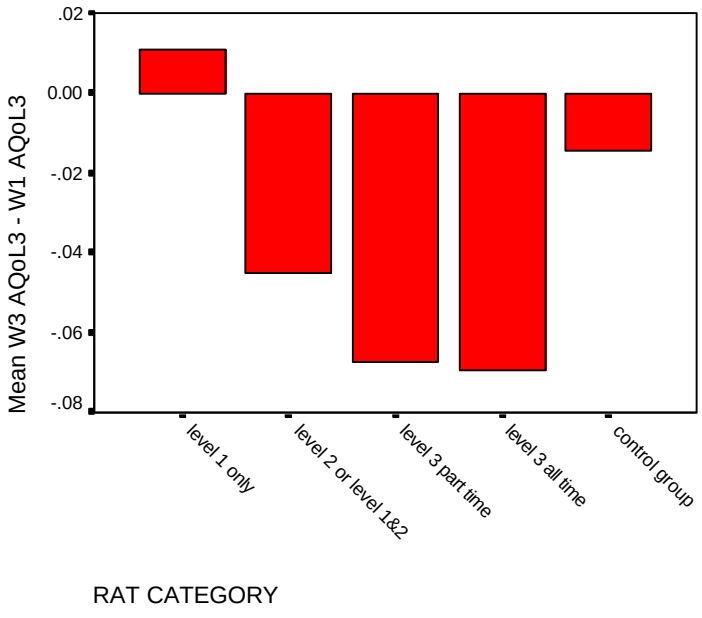
All the quality of life scale results suggest a strong relationship between RAT level and quality of life (see Chapter 2 and Executive Summary). Figures 3.6 to 3.7 show changes in the SF36 physical component score and mental component score and the AQoL utility score for each category of intervention client. Across all three scales level 1 intervention the change in the scores indicates an increase in physical and mental health but the increase in small. As might be expected, the physical component score and AQoL show a decline in physical health over time with increasing RAT level.

Interestingly, those intervention clients who were level 3 part of the time show the largest decrease in physical health between Wave 1 and Wave 3 but, at the same time, show a strong increase in mental health as measured by the SF36. Reasons as to why this might have occurred can be hypothesised: for example, as their physical health deteriorated, these clients received more intense levels of the intervention which improved their mental health. But there are only a small number of clients in this group which makes further analysis difficult.

Figure 3.6 Change in SF36 PCS and MCS (W3 - W1) by RAT level

Figure 3.7 Change in AQoL (W3-W1) by RAT level





Annexure to Chapter 3

Table A.3.1 Wave 1 socio-demographic characteristics of respondents 12 years of age and over

Characteristic	Total records	Coordinated care (N =1471)		Control (N = 565)		Significance level
Age[(a)] (Mean)	2085(a)	52.3		53.0		0.39**
(SD)		18.2		18.1		95% CI 2.6,1.0
Gender[(a)] (Male)	2085(a)	616	39.8%	213	39.7%	0.96
Country of Birth[(a)(b] (Australia)	2080	851	55.1%	315	58.8%	0.14
Aboriginal/TSI[(a)(b)] (Yes)	2060	4	0.3%	0	0.0%	
Language spoken at home[(a)(b)] (English)	2043	1339	88.2%	465	88.7%	0.72
Marital Status[(a)]	2028					0.79
Never married		140	9.3%	54	10.3%	
Widowed		153	10.2$	56	10.6%	
Divorced		74	4.9%	24	4.6%	
Separated		24	1.6%	12	2.3%	
Married		1111	74.0%	380	72.2%	
Living arrangements[(b)] (House unit or flat)	2040	1463	96.5%	497	94.8%	0.092
Employment Status[(b)]	2018					0.63
Child/Student(<12)		56	3.7%	16	3.1%	
Employed FT		258	17.2%	83	16.0%	
Employed PT		181	12.1%	64	12.3%	
Unemployed		55	3.7%	13	2.5%	
Home duties		336	22.4%	119	22.9%	
Retired		499	33.3%	174	33.5%	
DVA status[(b)#] (Yes)	1876	42	3.0%	10	2.1%	0.29
Pension/benefits status[(b)#] (Yes)	1918	524	36.7%	169	34.6%	0.40
Health insurance status[(b)#] (Yes)	1956	189	13.0%	74	14.8%	0.29
Educational status (TAFE college/Uni)[(b)]	1883	260	18.6%	78	16.1%	0.11

Notes:

** 2-sample t-test - all other tests are χ^2 tests
(a) SHC Network records
(b) Socio-demographic mail questionnaire
Voluntary question in questionnaire

Table A.3.2 Wave 2 socio-demographic characteristics of respondents 12 years of age and over

Characteristic	Total records	Coordinated care (N =1471)		Control (N = 565)		Significance level
Age[(a)] (Mean) (SD)	1754	52.0 17.9		52.6 18.0		0.56** 95% CI –2.4,1.3
Gender[(a)](Male)	1754	512	40.6%	196	39.8%	0.75
Country of Birth[(a)(b)] (Australia)	1750	700	55.6%	288	58.5%	0.27
Aboriginal/TSI[(a)(b)] (Yes)	1730	2	0.2%	0	0.0%	
Language spoken at home[(a)(b)] (English)	1704	1098	89.3%	426	89.9%	0.72
Marital Status[(a)]	1708					0.94
Never married		113	9.2%	50	10.4%	
Widowed		121	9.9%	46	9.5%	
Divorced		57	4.7%	22	4.6%	
Separated		19	1.6%	9	1.9%	
Married		915	74.7%	356	73.7%	
Living arrangements[(b)] (House unit or flat)	1669	1164	96.8%	443	94.9%	0.06
Employment Status[(b)]	1656					0.49
Child/Student(<12)		41	3.4%	14	3.0%	
Employed FT		201	16.8%	80	17.3%	
Employed PT		149	12.5%	58	12.5%	
Unemployed		44	3.7%	12	2.6%	
Home duties		274	23.0%	108	23.3%	
Retired		400	33.5%	145	31.3%	
DVA status[(b)#] (Yes)	1530	32	2.9%	9	2.1%	0.39
Pension/benefits status[(b)#] (Yes)	1561	411	36.4%	156	36.1%	0.91
Health insurance status[(b)#] Yes)	1595	143	12.4%	69	15.6%	0.09
Educational status (TAFE college/Uni)[(b)]	1550	207	18.6%	72	16.5%	0.26

Notes:

** 2-sample t-test - all other tests are χ^2 tests
(a) SHC Network records
(b) Socio-demographic mail questionnaire
Voluntary question in questionnaire

Table A.3.3 Wave 3 socio-demographic characteristics of respondents 12 years of age and over

Characteristic	Total records	Coordinated care (N =1471)		Control (N = 565)		Significance level
Age[(a)] (Mean) (SD)	1420					
Gender[(a)](Male)	1420	421	41.5%	165	40.7%	0.80
Country of Birth[(a)(b)] (Australia)	1416	558	55.1%	240	59.4%	0.14
Aboriginal/TSI[(a)(b)] (Yes)	1401	2	0.2%	0	0.0%	
Language spoken at home[(a)(b)] (English)	1387	892	89.6%	355	90.6%	0.61
Marital Status[(a)]	1379					0.10
Never married		76	7.7%	43	10.8%	
Widowed		98	10.0%	42	10.6%	
Divorced		51	5.2%	14	3.5%	
Separated		11	1.1%	9	2.3%	
Married		746	76.0%	289	72.8%	
Living arrangements[(b)] (House unit or flat)	1358	945	97.2%	366	94.8%	0.03
Employment Status[(b)]	1348					0.14
Child/Student(<12)		22	2.3%	14	3.7%	
Employed FT		173	17.9%	69	18.1%	
Employed PT		122	12.6%	48	12.6%	
Unemployed		35	3.6%	9	2.4%	
Home duties		222	23.0%	81	21.2%	
Retired		331	34.3%	122	31.9%	
DVA status[(b)#] (Yes)	1252	25	2.8%	8	2.3%	0.62
Pension/benefits status[(b)#] (Yes)	1273	333	36.3%	134	37.6%	0.66
Health insurance status[(b)#] (Yes)	1297	122	13.1%	61	16.8%	0.08
Educational status (TAFE college/Uni)[(b)]	1258	169	18.8%	62	17.2%	0.32

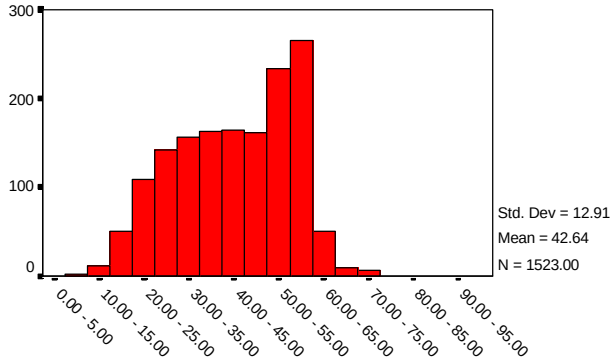
Notes:

** 2-sample t-test - all other tests are χ^2 tests
(a) SHC Network records
(b) Socio-demographic mail questionnaire
Voluntary question in questionnaire

Figure A.3.1 Distribution of scores for SF36, Physical Component Score, Waves 1,2,3: intervention vs control

Wave 1 SF-36 Phys Comp Score

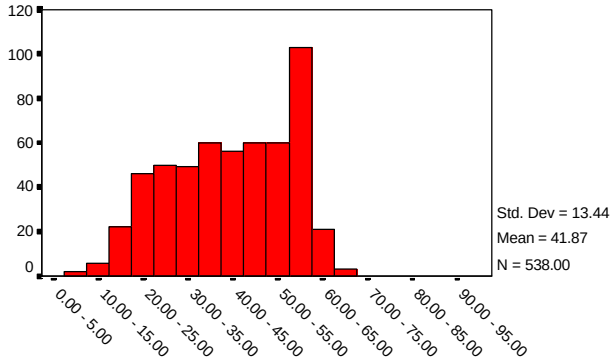
Intervention Cases Only



SFPCS50

Wave 1 SF-36 Phys Comp Score

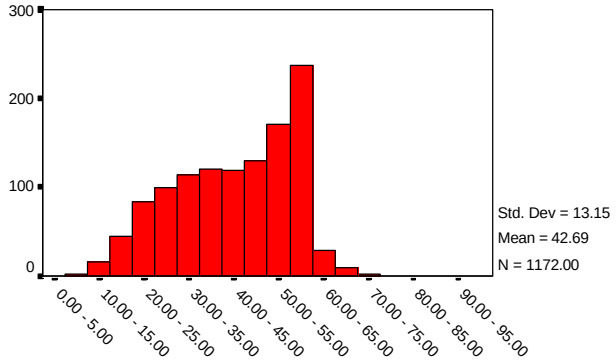
Control Cases Only



SFPCS50

Wave 2 SF-36 Phys Comp Score

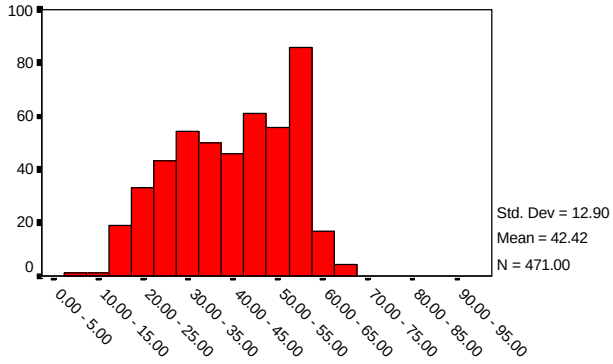
Intervention Cases Only



SF2PCS50

Wave 2 SF-36 Phys Comp Score

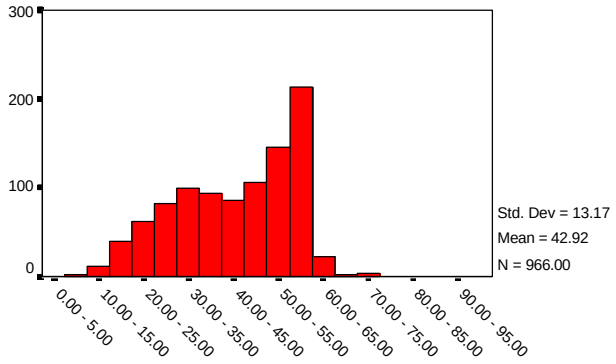
Control Cases Only



SF2PCS50

Wave 3 SF-36 Phys Comp Score

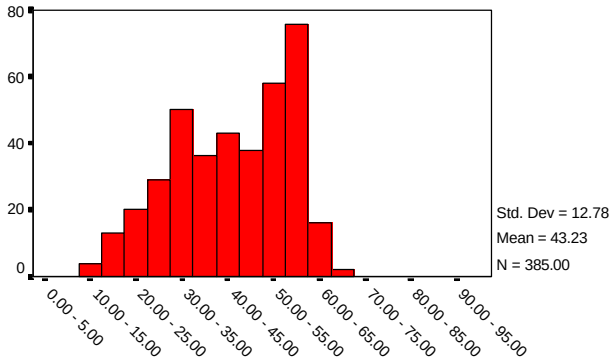
Intervention Cases Only



SF3PCS50

Wave3 SF-36 Phys Comp Score

Control Cases Only

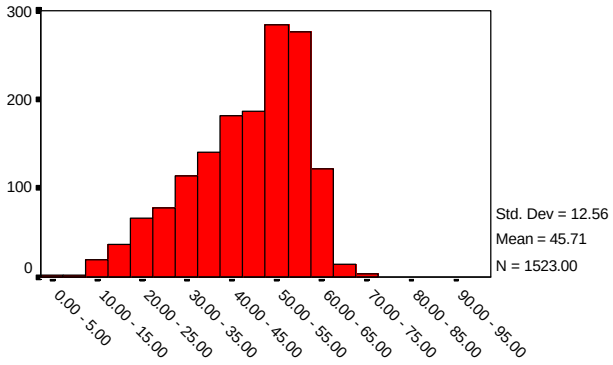


SF3PCS50

Figure A.3.2 Distribution of SF36, Mental Component Score: Waves 1,2,3

Wave 1 SF-36 Mental Comp Score

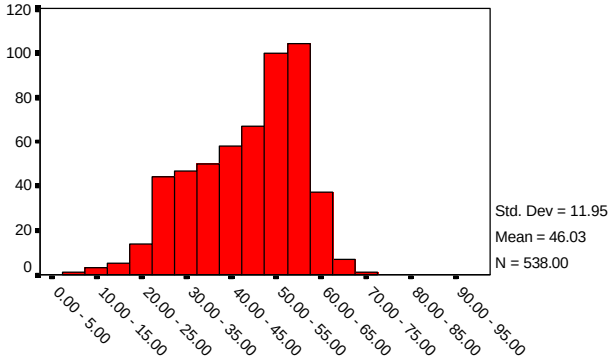
Intervention Cases Only



SFMCS50

Wave 1 SF-36 Mental Comp Score

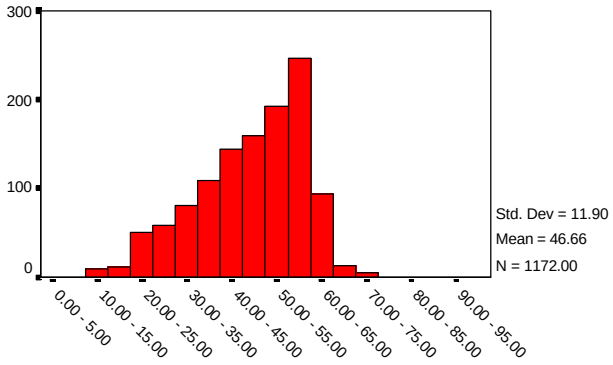
Control Cases Only



SFMCS50

Wave 2 SF-36 Mental Comp Score

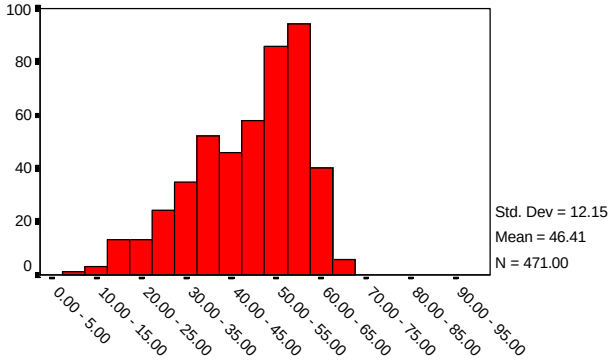
Intervention Cases Only



SF2MCS50

Wave 2 SF-36 Mental Comp Score

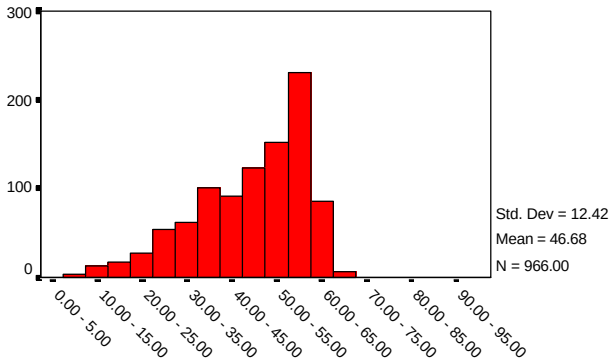
Control Cases Only



SF2MCS50

Wave 3 SF-36 Mental Comp Score

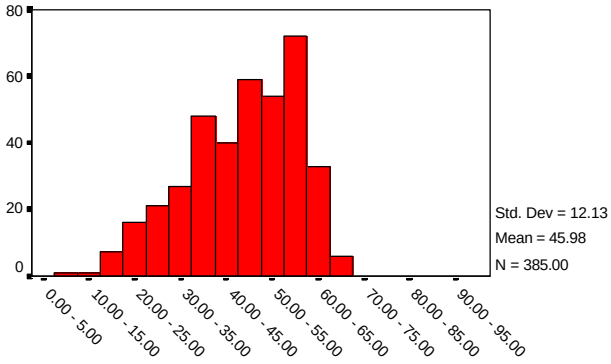
Intervention Cases Only



SF3MCS50

Wave 3 SF-36 Mental Comp Score

Control Cases Only



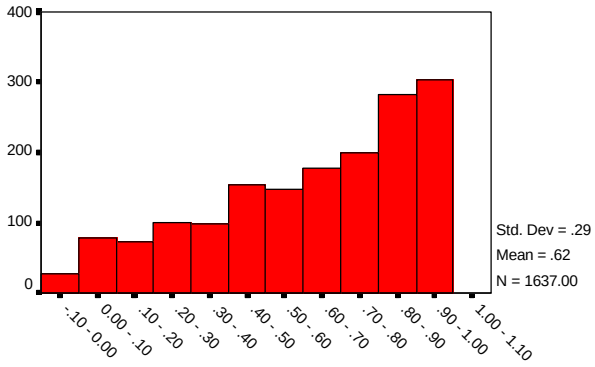
SF3MCS50

Figure A.3.3 Distribution of AQoL scores: Waves 1,2,3

Chapter 4

Wave 1 AQoL3 (4 dimension)

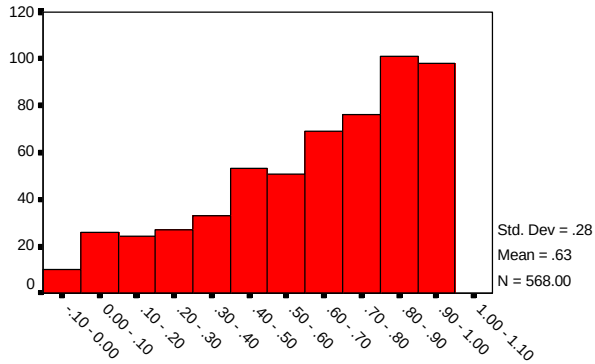
Intervention Cases Only



AQOL3

Wave 1 AQoL3 (4 dimension)

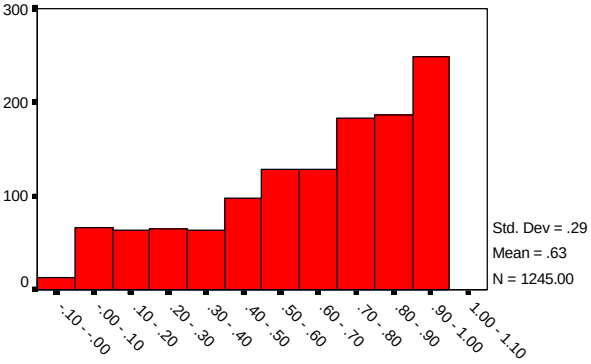
Control Cases Only



AQOL3

Wave 2 AQoL3 (4 dimension)

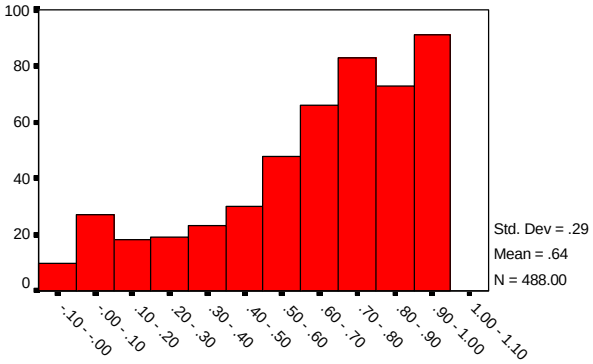
Intervention Cases Only



W2AQOL3

Wave 2 AQoL3 (4 dimension)

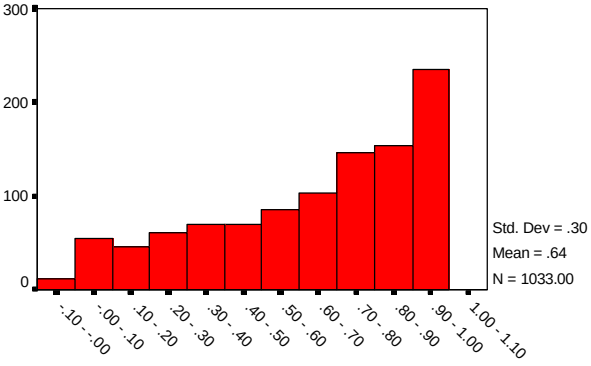
Control Cases Only



W2AQOL3

Wave 3 AQoL3 (4 dimension)

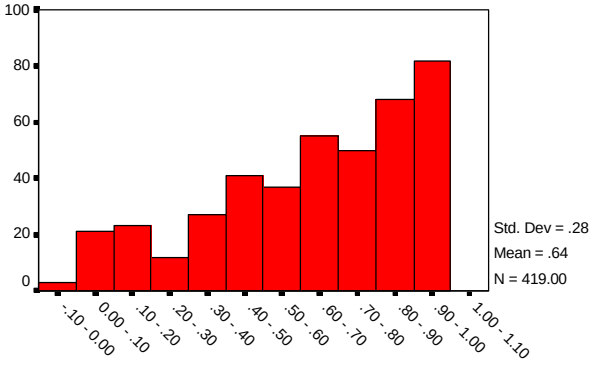
Intervention Cases Only



W3AQOL3

Wave3 AQoL3 (4 dimension)

Control Cases Only



W3AQOL3

Quality of life: patients' perceptions

4.1 Introduction

This chapter presents the qualitative and quantitative data obtained in a survey using the patient perception questions attached to the wave 2 and wave 3 mailed SF36 and AQoL questionnaires. The patient perception questions were developed from the responses to questions contained in the patients diary (see Chapter 6) and the qualitative data obtained in the interviews with patients and their families[17]. These data indicated that, for some patients, the Trial had a positive, and sometimes quite significant, impact on their quality of life. Yet the mid-term SF36 and AQoL results did not detect any change either within and between groups (see Chapter 3). The questions and the analysis contained in this chapter were designed to try to reconcile those different results. They looked at quality of life from the point of view of the participants in the Southern Health Care Network Coordinated Care Trial (SHCN CCT) and the perceived impact of the Trial participants' quality of life.

4.2 Survey methodology

The patient perception questions were appended to the SF36 and AQoL questionnaires which were administered in 1998 and 1999. Set out in Table 4.1 are the response rates for those questionnaires for the principal carer of children under 5 years of age and respondents 12 years of age and over. In both waves of the survey the response rate for carers is less than that for the respondents aged 12 years and over and response rates declined for both groups in the 1999 survey. As shown in Table 4.2, intervention group respondents were under-represented in the two waves of the survey in comparison with the initial randomisation.

Table 4.1 Response rates to empowerment questions

	Carers of participants less than 5 years of age		**Participants 12 years of age and over**		**Total**	
	Number	Percent	Number	Percent	Number	Percent
1998: Mailed	211	10%	1930	98%	2141	100%
1998: Respondents	165	9%	1754	91%	1919	100%
1998: Response Rates	**78%**		**91%**		**90%**	
1999: Mailed	160	9%	1639	91%	1799	100%
1999: Respondents	122	8%	1420	92%	1542	100%
1999: Response Rates	**76%**		**87%**		**86%**	

[17] These data are contained in a confidential report to the Local Evaluation Team.

Table 4.2 Intervention and control group respondents in 1998 and 1999

	Intervention Group		Control Group		Total	
	Number	Percent	Number	Percent	Number	Percent
Consented clients at start[18]	2018	76%	651	24%	2669*	100%
1998 respondents	1383	72%	536	28%	1919	100%
1999 respondents*	1100	71%	441	29%	1542	100%

Notes:

* Group data missing for one respondent who removed the id from the returned questionnaire

The socio-demographic characteristics of the groups are compared in Tables A4.1 and A4.2 in the annex to this chapter. These comparisons show that the only statistically significant differences between the two groups of respondents are health insurance status in waves 2 and 3 (higher proportion of control clients have private health insurance) and living arrangements in wave 3 (higher proportion of intervention group respondents listed their living arrangements as 'home, unit or flat').

4.3 Clients' expectations

Interviews conducted with clients and carers indicated a variety of reasons for taking up the offer to participate in the Trial. The reasons involved perceptions of the extrinsic and intrinsic rewards that would come from participating. Extrinsic rewards involved the expectation of tangible benefits to help the cope with health-related problems. Intrinsic rewards involved the expectation that participation would help others through improvements in the health care system. Sometimes this altruism was a way of saying 'thank you'.

> *I am lucky to have had a kidney transplant. It saved my life. So I support any attempt to improve the health care network.* (Ware 3 Control Group Respondents Id 2595)

This meant that participants and their families entered into the Trial process with different expectations which may or may not have been met during the course of the Trial. Sometimes it was the design of the Trial which confounded those expectations. Those who entered the process with some expectation of extrinsic rewards would have been disappointed in those expectations due to randomization to the control group. In the 1999 survey, 26 control respondents (6%) indicated in the open-ended questions that their expectations had not been met - they did not get what they hoped for from the Trial.

> *My doctor has never been involved in my care plan, this means I feel I do not receive the care I require in managing the arthritic pain in my knees and back. Council in Casey says no funds are available, I now have to pay for private home care out of my pension. I don't feel I have been involved. I am disappointed.* (Control Group Id 1286)
> *I was invited to joint the Trial, presumably because I had been a patient at Monash Medical Centre. However, I personally feel that the Trial was not relevant to my situation and, unfortunately, don't feel that I've gained anything at all from my participation.* (Control Group Id 264)

But even those who anticipated less tangible benefits were disappointed by assignment to the control group.

> *I would have liked to be an active participant as I believe my history of ill health and very frequent stays in hospital for surgery or management has given me a greater understanding of the public health and hospital system which would have been very helpful to the Trial.* (Control Id 1703)

However, some control group participants had managed to benefit from their participation:

[18]

Age of all consented clients	Number	Percent
Less than 5 years of age	248	9%
5 and up to 12 years	73	3%
12 years and over	2421	88%
Total	2742	100%

The Trial has made me learn to take more of an active role in my health care and to find out that there is help out there for many different needs. I now make sure that I get the answers and care that I should from my GP. (Control Group Id 2153)

4.4 The effect of assignment to the intervention group[19]

The potential impact of assignment to the intervention group on the quality of life of is illustrated in the comments written on the questionnaires.

The Southern Health Care Network saved my life. Their continence sister detected very high blood pressure which she reported to my former GP, who denied it to me. I consulted another doctor who confirmed the seriousness of my high blood pressure and has subsequently treated me satisfactorily. (Intervention Group Id 2540)

Even some intervention group participants whose only contact with the Trial was visiting their care coordinator (GP) for their care plan development and 12-monthly review found the intervention was helpful.

I have been able to go to my GP for Trial related check-ups and to see how my health is. Whereas I most likely would not have gone. It has made me feel better in myself knowing that any problems that I may have would be quickly rectified. (Intervention Group Id 753)

As my health is stable I don't see my GP too often. Doing this Trial has kept me in more regular contact with my GP so I have been able to talk about problems that I have been having at home that I would not have discussed with him normally. (Intervention Group Id 1811)

19 The names of the service coordinators and case managers have been retained with their permission.

To reconcile these apparent benefits from participation in the Trial with no apparent impact on the quality of life as measured by the SF36 and AQoL, the 1999 survey contained the question: 'Has your participation in the Coordinated Care Trial affected your quality of life?' Respondents were asked to tick on of the following boxes and comment on their answer:

- ☐ yes, improved it a lot,
- ☐ yes, improved it a little,
- ☐ yes, made it a little worse,
- ☐ yes made it a lot worse,
- ☐ no, it has not changed.

As shown in Table 4.3, intervention group respondents were more likely than control group respondents to say that their participation in had improved their quality of life and the difference between the two groups was statistically significant. The major difference was that, 17% of intervention but only 8% of control group respondents indicated that their life had 'improved a little'. Seven percent of each group indicated that their quality of life had 'improved a lot'.

Table 4.3 Changes in intervention and control group respondents' quality of life

	Intervention Group		**Control Group**		**Total**	
	Number	Percent	Number	Percent	Number	Percent
Improved a lot	78	7%	33	8%	111	7%
Improved a little	180	17%	37	8%	217	15%
No change	807	75%	356	83%	1163	78%
Worsened	5	1%	3	1%	8	<1%
Total	1070	100%	429	100%	1499	100%

Notes: $\chi^2 = 10.886$, $df = 2$, $p = .001$ (for the purposes of this test the 'no change' and 'worsened' were combined into 'did not improve' category)

One hundred and fifty-four (47%) of the 328 people who indicated that their participation in the Trial improved their quality of life wrote specific positive comments on their questionnaires relating to their participation in the Trial. An analysis of these comments is shown in Table 4.4. Over 20% of those 154 respondents made comments relating to increased understanding and management of their own health. The major areas of difference between the intervention and control groups were in relation to:

- assistance with access to services (63% compared to 37%),
- appreciation of concern shown and having someone to talk to (31% compared to 22%), and
- improvements in GP management and liaison between service providers (17% compared to 7%).

Table 4.4 Positive comments of respondents who indicated their participation in the Trial had improved their quality of life

	Intervention Group (N = 127)		Control Group (N = 27)	
	Number	Percent	Number	Percent
Assisted with access to services	81	63%	10	37%
Appreciated concern shown and having someone to talk to	39	31%	6	22%
Increased understanding and management of own health	27	21%	6	22%
GP management or liaison between service providers improved	21	17%	2	7%
Increased awareness and reassurance	18	14%	4	15%
Provided extra knowledge about services	10	8%	3	11%
Helping others	9	7%	3	11%
Liked newsletter	8	6%	2	7%

4.5 The effect of assignment to a risk level

Just as assignment to the control group may have confounded expectations, assignment to the intervention group did not necessarily ensure that client's expectations would be met. Six percent of intervention group respondents also indicated their expectations had not been fulfilled.

> *My son needs access to specialised mental health professionals that are not readily accessible. I felt it [the Trial] was pointless as it was unable to improve the situation.*
> (Level 2 Id 2267)

Even intervention clients who were helped by the Trial did not have all their expectations (or needs) met. One respondent indicated that the Trial had helped him to obtain an optihaler but had not been able to help him obtain physiotherapy, a carer's pension or a taxi card. A level 2 client wrote:

> *When my granddaughter's car was stolen my disability card also was taken. They [the Trial] helped me so much in getting my new one. The Trial got the Council to put in a rail at the front door so I'm now able to use the steps and helped me get my PACS alarm system installed. But I cannot afford the $500 it costs for dentures.* (Id 229)

The primary intervention in the Trial consisted of:

- the development of care plans by the care coordinators (GPs) in conjunction with the clients or the clients and their families;
- classifying clients into one of three risk levels using the Risk Assessment Tool (RAT); and
- implementation of the care plan according to risk level.

This meant that intervention clients were exposed to different intensities of the intervention depending on their RAT score and their RAT score could change during the course of the Trial.

To account for this variability in intervention intensity in the analysis, intervention clients were divided into three groups according to their highest RAT score during the Trial. In wave 3 of the questionnaires, there were 57 intervention respondents whose highest RAT score was 3 (highest level of intervention intensity), 267 whose highest score was 2 medium level of intervention intensity) and 746 whose highest RAT score was 1 (lowest level of intervention intensity). As shown in Table 4.5, intervention group respondents who were exposed to a more intense level of intervention and were more likely to say that their quality of life had 'improved a lot' or 'improved a little' than those exposed to lower levels, and the difference was statistically significant.

Table 4.5 Differences in quality of life according to RAT score

	RAT Score (Intensity of Intervention)					
	Level 3 (Highest)		**Level 2 (Medium)**		**Level 1 (Lowest)**	
	Number	Percent	Number	Percent	Number	Percent
Improved a lot	16	28%	34	13%	28	4%
Improved a little	22	39%	77	29%	81	11%
Did not improve*	19	33%	156	58%	637	85%
Total	57	100%	267	100%	746	100%

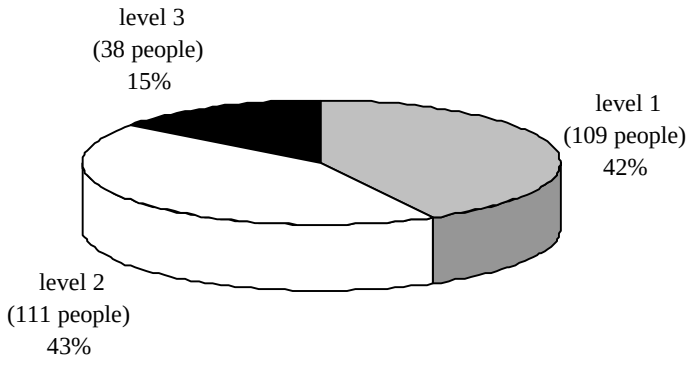
Notes:

$\chi^2 = 145.381$, $df = 4$, $p = .000$

* Included 807 intervention respondents who said their quality of life 'did not change' and 5 who said it 'worsened'

As shown in Figure 4.1, of the 258 people who indicated that the quality of their life had been improved by their participation in the Trial 109 (42%) were level 1, 111 (43%) level 2 and 38 (15%) level 3.

Figure 4.1 Respondents reporting improvements in their quality of life



4.6 The impact of case management and service coordination

Case management was offered to intervention clients classified as level 3 and service coordination to those classified as level 2 at any time during the Trial. The qualitative data indicate that case managers and service coordinators were active in those areas, which appear to be associated with improvements in client's quality of life. They:

i) helped clients and their families gain access to services,
ii) provided psychological support for clients and their families,
iii) played an educative role in helping clients understand issues relating to their own health and how to manage their own health needs, and
iv) helped negotiate changes in GP management and coordination of service providers.

In the 1999 survey, 326 intervention group (30%) and 125 control group respondents (28%) indicated that they had needed services over the last 2 years but had not been able to get them. In the same survey, 11% of the intervention group and 3% of control group respondents indicated that the Trial had helped them gain access to health related services.

For both the intervention and the control group, the highest areas of need were for dental services, allied health services, personal items such as spectacles, hearing aids and personal alarms and financial help such as health care card or carer's pension (see Table 4.6 and Table 4.7).

A comparison of those tables reveals that, in the area of highest need (dental services), 7% of intervention group and none of the control group respondents who indicated that they needed but had not been able to get the services, indicated that the Trial had helped them to get the dental services. Compared to the control group respondents, the Trial was more effective in helping needy intervention group respondents to get:

- other services (such as being placed on waiting lists, transport, help for carers and case management services outside the Trial),
- personal help,
- allied health services (such as podiatry, dietitian and hydrotherapy),
- personal items (such as personal alarms, special stockings and footwear and special equipment for the bathroom) and home maintenance and modifications (see Tables 4.6 and 4.7).

Table 4.6 Intervention group respondents' access to services

Intervention group respondents (N = 1100)	**Needed services (a)** Number	**Was able to access services (b)** Number	**Proportion helped (b) / (a)** Percent
Other*	56	21	38%
Personal help (eg home help, RDNS)	84	28	33%
Allied health services	148	43	29%
Personal items (eg spectacles, personal alarm)	126	37	27%
Home maintenance and modifications	61	14	23%
Financial help (eg carer's pension, health care card)	94	10	11%
Dental services including dentures	144	10	7%

Notes *Includes surgery, placement on waiting lists for surgery, transport, help for carers, case management services

Table 4.7 Control group respondents' access to services

Control group respondents (N = 441)	Needed services (a) Number	Was able to access services (b) Number	Proportion helped (b) / (a) Percent
Home maintenance and modifications	16	3	19%
Personal help (eg home help, RDNS)	24	4	17%
Personal items (eg spectacles, personal alarm)	33	5	15%
Allied health services	59	6	10%
Other*	13	1	8%
Dental services including dentures	61	0	0%
Financial help (eg carer's pension, health care card)	28	0	0%

Notes: *Includes surgery, placement on waiting lists for surgery, transport, help for carers, case management services

4.7 The impact of care planning

All interventions client respondents received access to some level 'care planning' as part of their participation in the Trial. This involved the initial development of the plan and regular reviews depending on risk level. In the 1999 survey, 742 intervention group respondents (68%) were sure that their GP had reviewed their care plan with them. Of those 742, two-thirds (66%) said that they felt 'totally' or 'very involved' in the review, 20% felt 'moderately involved' and 12% 'slightly' or 'not at all involved'. There were no statistically significant differences in the level of involvement felt by level 1, 2 and 3 respondents.

Because the intervention for level 2 and 3 respondents involved service coordination or case management as well as care planning it is not possible to discern the effect of care planning only on quality of life for these clients. However, because the only intervention to which respondents with a maximum RAT score of level 1 were exposed was the development, and 12 monthly review, of the care plan, examining the perceptions of these clients, means it is possible to isolate the effect of the care planning process from contamination by other elements of the intervention.

In the 1999 survey, level 1 respondents were more likely to say their quality of life had improved if they were sure their GP had reviewed their care plan with them and they found the care plan to be very useful. These differences were statistically significant (see Tables 4.11 and 4.12).

Table 4.8 Impact of care plan review for level 1 respondents' quality of life

Quality of Life	GP reviewed care plan with respondent					
	Yes		Not sure		No/no plan	
	Number	Percent	Number	Percent	Number	Percent
Improved	92	19%	8	10%	8	5%
Did not improve	389	81%	69	90%	167	95%
Total	481	100%	77	100%	175	100%

Notes: $c^2 = 22.931$, $df = 2$, $p = .000$

Table 4.9 Impact of the usefulness of the care plan for level 1 respondents' quality of life (N=481)

Quality of Life	Usefulness of the care plan					
	Very		Moderately		Little/No use	
	Number	Percent	Number	Percent	Number	Percent
Improved	50	46%	39	29%	1	1%
Did not improve	59	54%	97	71%	155	99%
Total*	109	100%	136	100%	156	100%

Notes:

$c^2 = 80.007$, $df = 2$, $p = .000$
* Missing data means total ≠ 481

Level 1 intervention group respondents were more likely to say their quality of life had not improved if they felt only slightly or not at all involved in the review of the care plan and if their GP seldom or never referred to it. These differences were statistically significant (see Tables 4.12 and 4.13).

Table 4.10 Impact of involvement in the care plan review on level 1 respondents' quality of life

Quality of Life	Respondents' level of involvement					
	Totally/Very		Moderately		Slightly/Not at all	
	Number	Percent	Number	Percent	Number	Percent
Improved	67	21%	22	25%	1	2%
Did not improve	253	79%	65	75%	57	98%
Total*	320	100%	87	100%	58	100%

Notes:

$c^2 = 14.026$, $df = 2$, $p = .001$
* Missing data means total ≠ 481

Table 4.11 Impact of GP referring to the care plan on level 1 respondents' quality of life

Quality of Life	How Often the GP Referred to the Care Plan					
	Always		Mostly		Seldom/Never	
	Number	Percent	Number	Percent	Number	Percent
Improved	19	31%	26	33%	7	5%
Did not improve	43	69%	52	67%	135	95%
Total*	62	100%	78	100%	142	100%

Notes:

$c^2 = 34.879$, $df = 2$, $p = .000$
* Missing data means total ≠ 481

Annexure to Chapter 4

Table A4.1 Wave 2 socio-demographic characteristics of respondents 12 years of age and over and carers of children under 5

Characteristic	Total records	Data source	Coordinated care (N = 1383) N	%	Control (N = 536) N	%	Significance level
Age (Mean) (SD)	1919	(a)	47.6 22.2		48.5 22.1		(95% CI –3.1,1.3
Gender (Male)	1919	(a)	580	41.9	217	40.5	
Country of Birth (Australia)	1915	(a)(b)	793	57.5	318	59.4	
Aboriginal/TSI (Yes)	1888	(a)(b)	2	0.1	0	0.0	
Language spoken at home (English)	1854	(a)(b)	1200	89.4	461	90.0	
Marital Status Never married Widowed Divorced Separated Married	1873	(a)	 234 121 58 19 915	 17.4 9.0 4.3 1.4 67.9	 93 46 22 9 356	 17.7 8.7 4.2 1.7 67.7	
Living arrangements (House unit or flat)	1810	(a)	1266	97.1	482	95.3	
Employment Status Child/Student(<12) Employed FT Employed PT Unemployed Home duties Retired	1821	(a)	 163 201 149 44 274 400	 12.4 15.3 11.3 3.3 20.8 30.4	 57 80 58 12 108 145	 11.3 15.8 11.5 2.4 21.3 28.7	
Income status[+ #] (< $20,000)							
DVA status[#] (Yes)	1664	(a)	32	2.7	9	1.9	
Pension/benefits status[#] (Yes)	1693	(a)	466	38.0	176	37.6	
Health insurance status[#] (Yes)	1730	(a)	162	12.9	81	16.9	

Educational status (TAFE college/Uni)+	1685	(a)	246 20.3	86 18.2	

Notes:

**	2-sample t-test - all other tests are χ^2 tests
(a)	SHCN records
(b)	Socio-demographic mail questionnaire
#	Voluntary question in questionnaire
+	Parent characteristic if subject aged 12 or under

Table A4.2 Wave 3 socio-demographic characteristics of respondents 12 years of age and over and carers of children under 5

Characteristic	Total records	Data source	Coordinated care (N =1100) N	%	Control (N = 441) N	%	Significance level
Age (Mean)	1541	(a)	48.7		48.6		
(SD)			21.5		22.1		
Gender (Male)	1541	(a)	467	42.5	184	41.7	
Country of Birth (Australia)	1537	(a)(b)	624	56.9	266	60.5	
Aboriginal/TSI (Yes)	1519	(a)(b)	2	0.2	0	0.0	
Language spoken at home (English)	1502	(a)(b)	968	90.0	386	90.6	
Marital Status	1500	(a)					
Never married			160		79		
Widowed			98	15.0	42	18.2	
Divorced			52		14		
Separated			11	9.2	9	9.7	
Married			746		289		
				4.9		3.2	
				1.0		2.1	
				69.9		66.7	
Living arrangements (House unit or flat)	1468	(a)	1020	97.4	401	95.2	
Employment Status	1469	(a)					
Child/Student(<12)			107		50		
Employed FT			173	10.2	69	12.0	
Employed PT			122		48		
Unemployed			35	16.5	9	16.5	
Home duties			222		81		
Retired			331	11.6	122	11.5	
				3.3		2.2	
				21.1		19.4	
				31.5		29.2	
Income status[+ #] (< $20,000)		(a)					
DVA status[#] (Yes)	1356	(a)	25	2.6	8	2.1	
Pension/benefits status[#] (Yes)	1374	(a)	375	38.0	147	38.1	
Health insurance status[#] (Yes)	1401	(a)	138	13.7	71	18.1	
Educational status (TAFE college/Uni)[+]	1363	(a)	201	20.7	75	19.1	

Notes:

** 2-sample t-test - all other tests are χ^2 tests
(a) SHCN records
(b) Socio-demographic mail questionnaire
Voluntary question in questionnaire
+ Parent characteristic if subject aged 12 or under

Chapter 5

Resource use and cost

5.1 Concepts

Resource use is interpreted from the community perspective and based on the concept of economic cost, or opportunity cost - the lost opportunity for achieving benefits elsewhere. This is best approximated by full (long run) average cost of services used by Trial participants. The key matter to be explored relates to the cost of providing care under the alternative funding and delivery model that is coordinated care, in comparison with usual care. Of interest are both total resource use and the health service mix.

Because of the decision to conduct the evaluation of the SHCN CCT through the randomised control design, and the success of the randomisation process, the cost of usual care can be derived from the control group experience. Resource use of the intervention group can then be compared with the control group to establish the impact of the Trial on total health service use, (or at least on that which is captured by the Trial).

Because eligibility for the SHCN CCT was based on high use of in-patient services over a 2-year period, use of historic costs to determine 'current resources' or expected service use is problematic. Historic costs would include the period of high in-patient use, which might not be typical. The failure of the Funds Pool calculation to provide a reasonable estimate of expected service use, especially in relation to in-patient services justifies this concern. (The failure is demonstrated by the comparison between the Funds Pool contributions and the experience of both control and intervention group participants, as reported in Chapter 8).

To establish the impact of the Trial on resource use, the ideal would be to:

i) include all health services, and possibly other services (such as community and welfare services) which may be affected by the CCT;
ii) include government contributions as well as the financial contributions of patients and the direct care activities of patients' families and other unpaid carers; and
iii) cost health services at full (long run) average cost, that is, preferably incorporating the cost of capital. This is not necessarily the same as the price paid.

5.2 Unit cost

Where available, long run average cost has been used to calculate the net impact on resource use, even where this differs from the price negotiated. For the SHCN CCT the negotiated Funds Pool price, (the rate at which contributions are determined and services paid for), differs from full average cost for each service category.

For MBS and PBS the HIC contribution to the Pool was based on expected service use at the cost to government. In calculating the cost of medical services and pharmaceuticals used by trial participants, the evaluation team in analysing data supplied by the HIC has collated information on total service cost, including both the government contribution and patient co-payment. This will provide a good measure of the true economic cost.

In relation to in-patient services, the SHCN has contributed to the Pool on the basis of expected use of acute service expressed as number of WEIS (weighted inlier separation) per equivalent participant month, multiplied by the rate negotiated of $1275/WEIS.

This represents the 'variable' (or direct) component of Victoria's in-patient funding formula and is the basis for contributions to the Funds Pool and payment to the SHCN for in-patient admissions. This is substantially below the full (current) average cost of an inpatient admission, reported to be $2200[1]. This latter WEIS rate has been used to determine the resource impact of inpatient services. It still covers only operating costs, as the costs of capital are excluded from the patient level costing studies and the WEIS based funding formula. Full (long run) average cost of inpatient care is probably 10-15% higher again. At the marginal WEIS rate of $1275, in-patient services are costs at only some 50% of long run average cost.

Preferable still would be to cost patient admission at the actual cost incurred for each individual patient. It is possible that coordinated care may change not just the pattern of hospital admissions, but also the severity level at which someone is admitted (which is only captured in some DRG classes and in any case not perfectly). People may be admitted sooner, or they may be able to be discharged sooner eg where a case manager or service coordinator is able to assist in setting up home based support. The only way to capture this effect is though patient level costing. The introduction of patient level costing systems at most major Victorian Hospitals should have meant this would be possible. Unfortunately due to problems with the collection of patient level data at MMC and DDH during the period of the Trial, it was not possible to collect patient level data. In its absence we have developed a surrogate patient level costing for inliers by adjusting the DRG cost for patient LOS (length of stay). For instance if the mean LOS for a particular DRG were 4 days, but the patient actually stayed for 5 days the surrogate patient level cost would be 1.25 x the DRG value, or a 3 day stay would be costed at 75%. This approach is supported by research, which demonstrates that LOS typically describes 80% of cost difference in relation to in-patient admissions.

In quoting cost of health services included in the pool three costing options have been reported; $\mathbf{c_1}$ cost of in-patient services @$2200/WEIS and based on DRG cost, $\mathbf{c_2}$ cost of in-patient services @$2200/WEIS but adjusted for patient LOS, with outliers included as costed, and $\mathbf{c_3}$ in-patient admissions costed at price paid @ $1275/WEIS.

5.3 Time frame

Use and cost of MBS services, hospital in-patient and outpatient services, pharmaceuticals on the PBS, and RDNS have been collated and analysed, by patient month for the period from Trial commencement to June 30th 1999. While the Trial continued to December 31 1999, there was a major discontinuation at June 30 1999. This occurred because re-consent of all participants was required to continue their involvement in the Trial and in the evaluation beyond June 30 1999, the original Trial completion date. This created a problem both by virtue of the smaller numbers, increasing the influence of random variation, but also posed a threat to the integrity of the randomisation as the failure to re-consent was not consistent across all participant groups.

As shown in Table 5.1, re-consent was far lower in level 1 intervention clients, those who receive less intensive support and are generally in better health, at 55%, compared with a re-consent rate of 88% in level 3 intervention clients. The sicker level 3 clients receive direct support of case managers and thus have an incentive to stay with the Trial, otherwise this support would not be available to them. However the sicker clients in the control group have no such incentive to re-consent. It must therefore be presumed that the randomisation has been invalidated.

The view of the evaluation team is, that any comparison between control and intervention group clients beyond June 30 would be invalid as a basis for establishing the effect of the Trial on resource use. Similarly any trend analysis could not be interpreted. By conducting the costing analysis only to June 30 1999 the integrity of the RCT evaluation design has been retained.

Table 5.1 Continuation of participation in Trial June 30 1999 to December 31 1999 by participant type

Participant type	Total randomised number	Still involved at June 30 1999 number	Reconsent: continue beyond June 30 1999 number	%
Control group	667	592	388	66%
Intervention group				
• RAT 1 only	1194	1076	594	55%
• RAT 2 or 1 & 2	453	378	288	76%
• RAT 3 and 3	55	41	37	90%
• RAT 3 only	82	49	43	88%

Notes:

* Excluding those for whom no RATSCore available
# Of those still involved at SHAC 30 1999

5.4 Scope of coverage and methods

Health services on which information on service use and cost has been gathered throughout the Trial period has been limited to; in-patient services across Victoria, outpatient services provided through MMC and DDH, medical services covered by the CMBS, pharmaceuticals recorded by the HIC and RDNS. Most of the data relates to services that have been included in the funds pool. The only exception relates to in-patient admissions to hospitals across Victoria, Public and private, that is not just to MMC and DDH. This wider source of hospital data is available through access to the Victorian Minimum In-patient Data set (although only partial capture is possible). This is likely to be quantitatively important and may differ between control and intervention group clients. The process is described below in relation to each major service type.

Hospital in-patient data

To assess the impact on use of acute services, hospital in-patient data were obtained to cover all admissions to private and public hospitals in Victoria by Trial participants. In relation to admissions to Monash Medical Centre (MMC) and Dandenong and District Hospital (DDH), the public hospitals within the SHCN region, patient admissions have been identified through a careful tracking of all SHCN CCT participants. In relation to renal services, the allocation per renal patient, which is additional to the payment/cost per admission was captured in an earlier data set, but not the final patient level data set. As this grant is purely dependent on the number of renal patients it seems inappropriate to include it as a cost that may be influenced by the Coordinated Care Model. Any difference between control and intervention group costs will certainly reflect the result of the randomisation process. However, as the renal grant is included in the contribution rate, its exclusion from the costing data will distort the analysis of the Funds Pool. (This is further discussed in chapter 7.)

Admissions to other hospitals, in Victoria both public and private, have been derived from the Victorian minimum in-patient data base. The matching process is thought to track ~ 60% of these admissions. Any loss of capture should be similar between control and intervention group participants.

Medical services

Medical services analysed cover only those paid for by the HIC. This includes all medical services identified under the Commonwealth Medical Benefits Schedule, (consultations, pathology, imaging, optometry). It does not include medical services funded directly by Veterans Affairs, Transport Accident or Workcover. Also excluded are services paid entirely by the client (for example specialist visits for which a referral has not been made). This will involve a small underestimation of medical services and costs. But given the client group of the SHCN CCT, this loss is not expected to be substantial. More importantly any loss should be broadly equivalent between the control and intervention group clients.

Data has been collected and provided as individual patient service, recording patient ID, item number, date of delivery of service, cost to government and total cost. Item numbers have been collated to provide information on medical services by major sub-category, notably GP services, specialist/consultant visits, pathology, imaging, and other tests.

Pharmaceutical

Pharmaceutical data covers that provided by the HIC, which only relates to drugs listed on the Pharmaceutical Benefits Schedule. Even then capture is incomplete. Missing are drugs for which the price is less than the co-payment level, or for scripts filled after the safety net has been reached, when individual level data is no longer available. It also excludes drugs not on the PBS.

A limited amount of additional information on the use of drugs and other health care products not captured in the HIC data-base, was obtained through a patient diary.

This was completed for 1 month, twelve months into the Trial by over 400 intervention and control group participants. This has been reported in Chapter 6.

Community and home based services

Use and cost of RDNS (Royal District Nursing Services) have been collated and analysed, for control and intervention group clients from Trial commencement to June 30th 1999.

No other home based services have been captured as part of the Trial data base. For the evaluation the participant diary provided sample data on the use and cost of clinical and other health services not covered through the MBS, such as allied health services, personal care services, paid and un-paid carer support, home modifications etc. These results are reported in Chapter 6. The diary was a one-off survey and applied to a sample only of participants. Repeat implementation was beyond the resources of the evaluation. This means that if the Trial has resulted in an increase (or reduction) in community based services other than RDNS, the evaluation team has no capacity to capture this.

Data on use of services provided through community health centres and their costs, was not provided to the evaluation team, and is not therefore included in our patient level costing data set. We have limited information on the use of community health centres through the Patient Diary.

Out-patient visits

Out-patient visits have been collected in relation to Monash Medical Centre (MMC) and Dandenong and District Hospital (DDH). The extent of capture is not certain, but it is known to exclude out-patient services that do not represent formal clinics. Activities of community health centres have not been captured by either the Trial or the evaluation team, except through the Patient Diary. The loss of capture should be similar between control and intervention group clients.

Care coordination services

Intervention group participants had access to a range of care coordination activities that need to be captured in the Trial costs. The primary care coordination activities were:

i) *Care planning* and associated activities; including development of the care plan, conduct of care plan reviews, case conferences, GP training and the peer review role of the Division of GP. This is captured in payments to GPs for care planning which is clearly itemised showing initial care plans and care plan reviews completed and their cost. The GP Division had several roles, only part of which related to care planning. They also had a broader management role, as one of the auspice agencies for the Trial, appearing on various working groups, attending management team meetings, managing the GP reference group etc. A $150,000 payment to the Division of GP was made, which has arbitrarily been allocated as 50% to management (eg to support the involvement of the Division in the SHCN CCT management team), and 50% to care planning.

ii) *Service coordination:* the service coordinators provided were primarily the support to patients and GPs in gaining access to services required by level 2 participants. As part of this tasks a service directory was compiled. The cost of service coordination is fully captured in the payments made to the service coordinators and to the care coordination manager, (a member of the trial management team). It is not clear however that non wage costs are captured in these payments, in which case the payments for service coordination (and case management) might understate the cost of this service.

iii) *The case managers* provided direct care and support to level 3 clients. Their cost is fully captured in the payments made to the case mangers and the care coordination manager (noted above). Whether non-wage costs and other attributable costs (such as consumables, office costs etc.), are captured in the payments to case managers is not certain. This cost category might also be under-estimated.

Management

In analysing Trial management costs, the aim is to separate out those management costs which are integral to the care coordination model and would be incurred in an on-going delivery setting, from costs which are particular to the evaluation, or the fact that it is a pilot. The latter should be excluded. In relation to establishment costs, as any application of coordinated care would involve establishment costs these should be included unless they relate only to the pilot or evaluation aspect. It might however be appropriate to spread the establishment costs over more than the two year period of the Trial. The attribution of management and establishment costs has been approached by careful review of Trial financial records with the Trial accountant. Management and administrative costs have been allocated to the coordinated care model, or to the pilot/evaluation, based on the description of each cost entry.

Comment

Important gaps remain in health services covered by the data collection activities of the Trial and the evaluation team. This reflects in part the relatively narrow base of the Funds Pool. (See Chapter 7.) Activities that have been entirely excluded are residential care services (hostel, nursing home etc.) and disability services, while the capture of community based services is very incomplete.

Health service use and cost data has been analysed in terms of equivalent participant years based on 365.25 participant days from trial commencement to June 30 1999. Data is reported by month, 6 monthly and for the entire 2 year period, for control and intervention group participants, which are compared. Results are also presented for selected disease groups (diabetes and cardiovascular disease), and by three categories of participant status and at Trial completion, namely; still in trial, exited due to death, exited trial for other reason.

5.5 Results

Total resource use

Total service use and cost for control and intervention clients, excluding care coordination services, is in statistical terms equivalent. Observed values were $3,610 for intervention clients and $3,558 for control clients per equivalent participant year, (in-patient services priced at full average operating cost, WEIS $2200). Based on the price paid for in-patient services, the mean total cost per equivalent participant year was $2,758 for intervention clients and $2,695 for control clients. (This data is reported in Table 5.2.)

The largest observed difference between control and intervention group clients is for out-patient services and medical services, both of which were more costly in the intervention group. Expenditure on RDNS is the only service category for which the control group cost is higher. Use and cost of in-patient services and PBS by intervention and control clients is equivalent, as is the use and cost of hospital in-patient services. Although, as noted later the equivalence in in-patient costs reflects higher costs in the first year followed by lower costs in the second year. The net equivalence also masks a difference in experience at Monash Medical Centre and Dandenong District Hospital (in the SHCN), with a lower in-patient cost observed in intervention group participants, (7.5% lower), in contrast with a mean increase in-patient costs at hospitals outside the SHCN (15% higher). For those who have died, in-patient costs are both considerably higher (by 5 to 8 fold) than for those remaining in the Trial, but also consistently higher in the intervention group (see Table 5. 5). The impact on number of services is summarised in table A.5 (Annexure to Chapter 5).

To determine the overall impact on resource use, the costs of care coordination services plus trial management must also be included. Care coordination activities include the care planning by general practitioners, and the activities of service coordination and case management. In relation to management, the aim is to identify those management and administration costs that would be incurred if the pilot health service model were to be continued.

The cost of care coordination services associated with care planning have been estimated at $358,000 until June 30 1999. This includes payments of $283,000 to GPs for care planning plus case conferencing plus we have allocated 50% of $150,000 paid to the Division of GP which has covered training of GPs assistance with development of care planning form, receipt and peer review of care plans. The remaining allocation to the Division of GP is allocated to management. The evaluation team has estimated the number of equivalent participant years to June 30 1999 in the intervention group at 2,837 equivalent participant years, (an average 1418 persons per year over 2 years). Care planning cost per participant year is thus calculated at $126 ($358,000/2837).

Table 5.2 Average service use and cost per equivalent participant year(a) Control and intervention group clients, July 1st 1997 to June 30th 1999 (b)

Type of service	Intervention	Control	Difference		p
			dollars	%	value
In-patient					
@ $2200/WEIS	2,028	2,057	-29	-1.4	0.92
@ $2200/WEIS adj. for patient LOS	2,043	2,031	+12	+0.6	0.97
@ $1275/WEIS - all Vic	1,177	1,194	-17	-1.4	0.92
- DDH and MMC only	810	876	-66	-7.5	0.75
PBS (d)	486	479	+ 7	+1.5	0.84
MBS	944	882	+62	+7.0	0.21
Out-patient services DDH & MMC	112	90	+22	+24	0.24
RDNS	40	50	-10	-20	0.61
Sub-total	3,610 (c_1)	3,558 (c_1)	+52	+1.4	0.88
	3,625 (c_2)	3,532 (c_2)	+93	+2.6	0.80
	2,758 (c_3)	2,695 (c_3)	+63	+2.3	0.77
Care planning (e)	126	n a			
Service coord./case management (f)	164	n a			
Management (g)	430				
Total	4 330 (c_1)	3 558 (c_1)	+772	+21.2	
	4 345 (c_2)	3,532 (c_2)	+813	+23.0	
	3 478 (c_3)	2,695 (c_3)	+783	+29.1	

Source: see text

Notes:

a) Annualised patient cost based on mean cost per participant day x 365.25,

b) Health service use and cost data analysed until June 30 the original end date for the Trial.

c) In-patient costs cover all admissions in Victoria.
c_1 - cost of in-patient services based on DRGs priced at full average cost of $2200/WEIS
c_2 - inlier admissions adjusted for patient length of stay, outlier admissions as costed.
c_3 - cost of in-patients at payment rate to Pool, variable WEIS rate of $1275

d) PBS partial data only as captured by the HIC.

e) Cost associated with development of care plans by GPs.

f) Costs of service coordinators and case managers

g) Trial management on-going costs only, plus an apportionment of establishment costs.

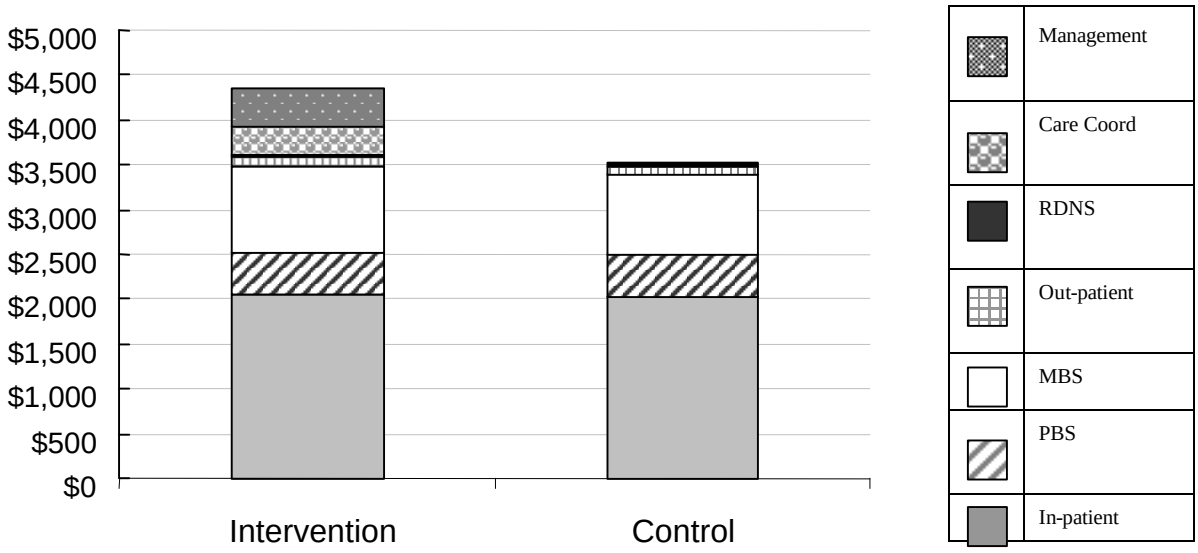
The activities of the service coordinators and the case managers, for the support of the medium and high risk level 2 and 3 clients is costed at $465,000. This covers the salaries and wage on-costs of the case managers, service coordinators and the person on the management team with specific responsibility for these activities. Averaged across the 2837 equivalent participant years in the intervention group this amounts to $164 per participant year.

While a small number of control clients will have had case managers through existing programs (such as Linkages or mental health), the cost of this has not been recorded. Generally such cost will also not have been recorded for intervention group clients.

Trial management and administration to cover just those costs presumed to be required in the context of continuation of this health service funding and delivery model are estimated at $852,000 over 2 years, (not including the costs of care coordination which have been counted separately). To this must be added establishment costs that would need to be incurred if this funding model were replicated elsewhere, (excluding costs associated with the pilot such as evaluation costs). These are costed at 1.12 million, (based on SHCN data set 25/10/1999). Allocated across a 6 year time frame, they are equal to $370,000 over the two years of the SHCN CCT. The attributed costs of establishment, on-going administration and management are thus estimated at $1.22 million over 2 years, which is equivalent to $430 per participant year (averaged across 2837 equivalent participant years). These results are also shown in Table 5.2 and Figure 5.1.

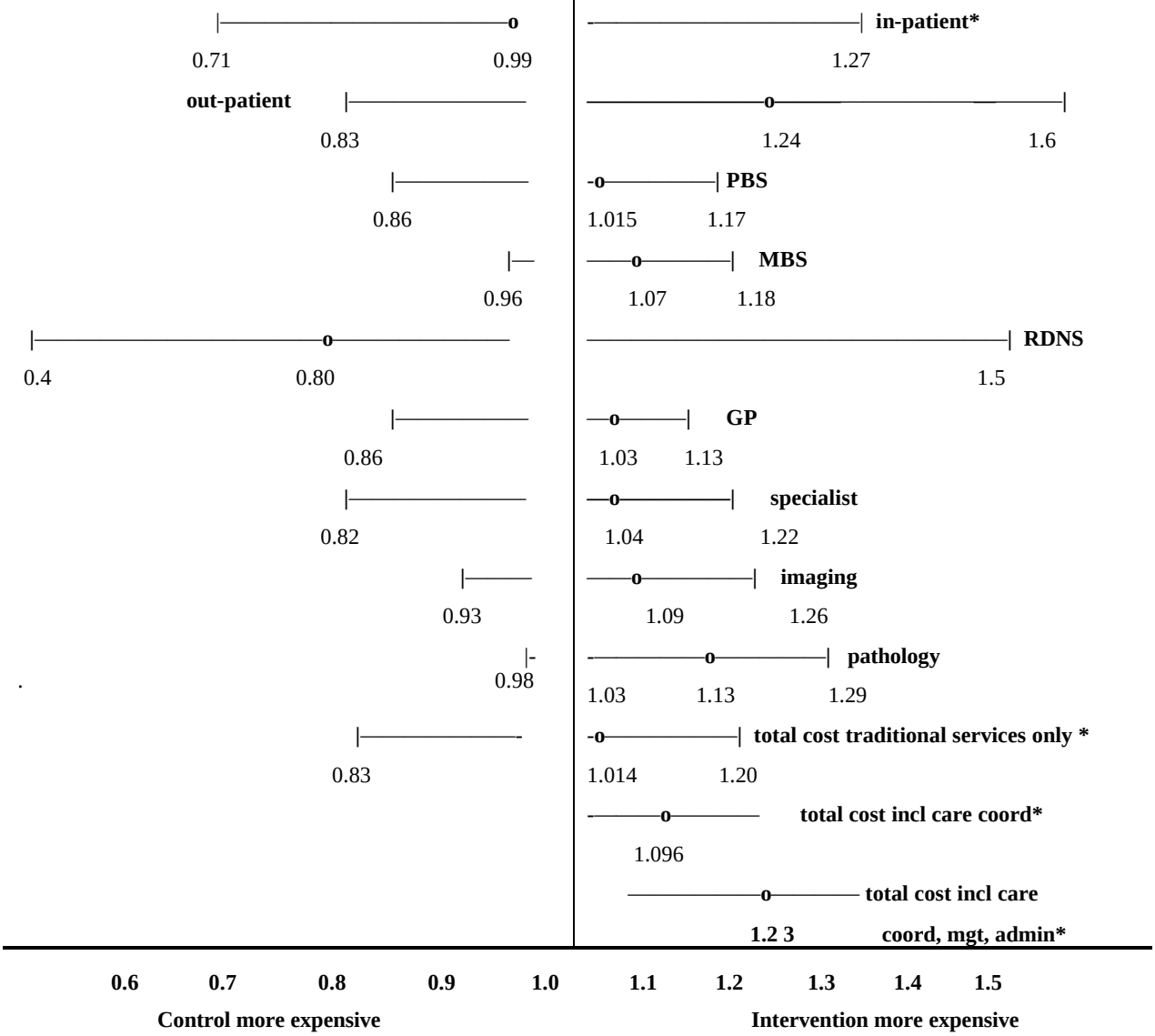
The mean total cost of care for intervention clients is found to be substantially higher than for control clients, largely due to the additional costs of care coordination and for administration and management. The cost difference is a mean $813 per equivalent person year, (in-patient admissions costed at WEIS @$2200 and adjusted by patient LOS). This is equivalent to an extra 23% of the cost of providing care under the standard care delivery model, based just on services included in the Funds pool. If in-patient services are costed at the negotiated price the dollar differential is only slightly less at $783, but this represents a greater cost increase at 29% (due to the lower total cost base). If the alternative health funding and delivery model were implemented more widely there might be savings in other management and administration costs. This possibility has not been allowed for in this calculation.

Figure 5.1 Intervention and control group - mean resource cost
Annualised cost/participant for Trial period, total and by cost category $



The cost of services available under usual care has been expressed in relative terms, as a simple way to compare the experience of control and intervention group clients, by type of service. This is illustrated in Figure 5.2. This shows that the relative mean cost of acute care and PBS for intervention group participants is within 99% and 101.5% respectively compared with control , and 7% higher for intervention group participants relative to control group in relation to medical services. This particularly reflects higher use and therefore costs of specialist consultations, imaging and pathology. Other cost categories are shown to be more different, which may in part reflect the far wider confidence intervals. (At this stage we are not entirely confident that the confidence intervals are correctly drawn in the context of grouped two years of data and advice is to be sought on this matter.)

Figure 5.2 Relative cost (a) control and intervention group clients, total and by service type



Notes:

(a) at 1.0 control and intervention group costs are equivalent, 1.05 would mean intervention group 5% more expensive/client day over course of the trial or 0.8 intervention group 20% less costly.

* WEIS @ $2200

Change in resource use over the two years of the Trial

While the cost of service use by intervention clients is higher over the two year period taken as a whole, there is a clear trend for a reduction in the cost differential. Comparing health service use and cost in the first and second twelve month periods for core health services (in-patient, MBS, PBS, outpatient, RDNS), mean total cost for intervention group participants goes from 9% higher for intervention than control group participants to 9% lower. The main categories to turn around are medical services and in-patient costs. With both categories, control group costs were relatively constant across the two year period while intervention group costs fell substantially. This data is summarised in Table 5.3 and Figure 5.3.

In relation to in-patient costs, using the LOS adjustment, the turn around in cost between the first and second twelve month period is considerable. Mean in-patient cost goes from 15% higher in intervention group participants compared with control group, to 11% lower. As this turnaround is greater than that observed when the LOS adjustment is not used, (which goes from 8% higher to 9% lower,) a reduction in both admissions and length of stay is indicated. Other cost categories are similar across the Trial period. (Concern about the completeness of these data suggest a more detailed analysis across the period is not warranted).

If the observed turnaround is an indication of a real trend this is an important qualification to the view that the Trial has resulted in an increase in the cost and use of health services. Furthermore, the high initial cost of medical services is entirely consistent with the objectives of the Trial, of encouraging the adoption of best practice care. It would be expected that this might involve GPs in a higher rate of referral to specialists and for tests. What is encouraging, is to see a fall back in these activities to control group levels in the second twelve months, and also a reduction in in-patient costs, the hoped for consequence of more proactive care. In order to be confident that this represents a true result of care coordination, a longer follow-up period would be desirable, or corroboration from other Trials.

Table 5.3 Mean cost of health services: first and second twelve months Intervention group participants $, and comparison with control

Cost category	July 1 to June 30 1997-8		July 1 to June 30 1998-9	
	$ (a)	relative to control (b)	$	relative to control (b)
in-patient (c_1)	2,241	1.08	1,863	0.91
in-patient (c_2)	2,370	1.15	1,792	0.89
in-patient (c_3)	1,298	1.09	1,081	0.91
MBS	997	1.15	903	1.00
other costs (d)	654	1.03	623	1.02
Total	3,883	1.09	3,390	0.91

Notes:

a) mean cost for intervention group participants, per equivalent participant year

b) mean value for intervention group participant compared with control group, for instance at 1.09 intervention group 9% more expensive, or at 0.91 intervention group 9% less expensive than control.

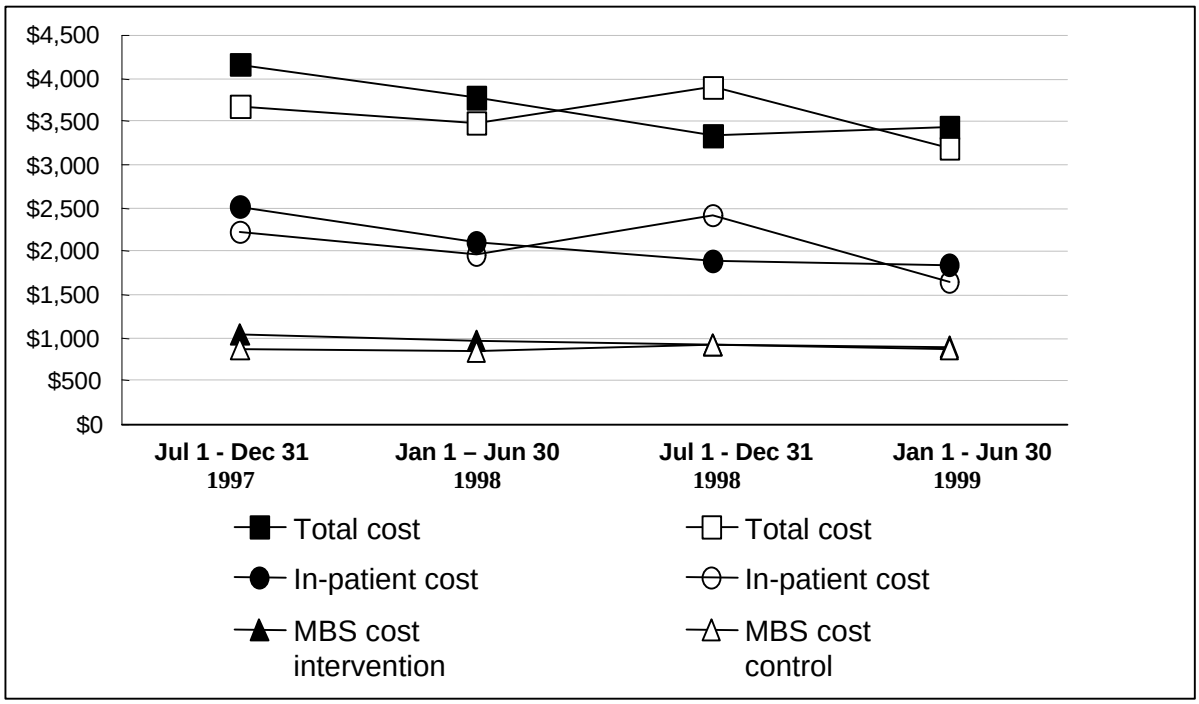
c_1) based on WEIS at $2200 (average operating cost)

c_2) based on WEIS @ $2200 adjusted for patient length of stay

d) PBS, RDNS, out-patient

c_3) based on WEIS @ $1275

Figure 5.3 Costs over the Trial period, total cost, in-patient cost and MBS.



5.5.1 The health service mix

Central to the primary hypothesis is whether there was a shift in the health service mix, the mechanism by which improved outcomes are expected to be achieved within current resourcing. Ascertaining whether there has been a shift in the mix of health services is complicated by the lack of a constant base. There has been a 23% increase in the total costs of the intervention group, or a 10% increase, excluding management costs. If control group total cost of standard care (represented by the control group) is taken as the base line, there has been an increase across all activities except RDNS. If intervention group costs are taken as the base line, (excluding management costs), a shift to community based care through private clinical care and care coordination activities is observed. Private medical care is seen to have increased from 25% (MBS share of control group costs), to 27% (for MBS plus care planning).

The new category of case management/service coordination services accounts for 4.2% of costs, a 6.2% greater share for community based services. The share of in-patient costs has fallen from 57.5% for the control group to 52.4% in the intervention group. This has been achieved largely through an increase in other costs, with in-patient costs remaining relatively static (over the two years of the Trial). These results are presented in Table 5.4.

While a shift in health service mix has occurred, it is not clear, however, that the funds pool is central to this redirection in the mix of services. It has been achieved essentially through the addition of resources. It is feasible therefore that a shift in the health service mix could have been achieved simply by applying additional resources to community based services, without the pooling of funds. At least at this stage, the shift in health service mix has been achieved not so much through a redirection of resources but rather through the application of additional resources. However, the comparison between the first and second 12 month period suggests that this might be changing.

Table 5.4 Mix of service use, control and intervention group* to end June 1999

Service type	$		%		
	Intervention	Control	Control %	Intervention % (a)	(b)
In-patient					
- WEIS=$2200 patient LOS	2,043	2,031	57.5	57.8	52.2
Out-patient MMC, DDH (c)	112	90	2.5	3.3	2.9
PBS	486	479	13.6	13.7	12.5
MBS	944	882	26.7	25.0	24.2
Care coordination (GP training, Care plan development & review)	126	0	0	3.6	3.2
RDNS	40	50	1.4	1.1	1.0
Case management Service coordination (d)	164	0	0	4.6	4.2
Subtotal	3,915	3,532	100%	110.8%	100%
Trial management (e)	430				
Total	4,345				

Notes:
(a) Health service mix, based on control group total cost
(b) Health service mix based on intervention group total cost

The shift in use and cost of medical services may reflect random variation, but is more likely to reflect a response to the care planning process. As care plans are developed and reviewed by the GP, it appears that additional tests are ordered, specialist referrals made, or more regular visits to the GP suggested. In some cases a claim is made on the HIC at the time of the care plan visit. This conclusion is supported by the more detailed analysis of this data, which demonstrates a cost differential in relation to GP services, specialist services and investigations, but with the greatest difference, (in terms of statistical significance) in pathology. Furthermore, over the course of the trial the cost difference tends to disappear, supporting the proposition that the cost shift is real and reflects a response to the care planning process.

Cost by category of participant

The difference in cost between control and intervention clients is most apparent in the patients who died during the trial. This is demonstrated in Figure 5.4 and Table 5.5 which maps mean annualised cost for control and intervention group clients, for total cost, in-patient costs and MBS, for patients who remained in the trial and those who died. In Figure 5.4 in-patient admissions are costed at $1275/WEIS (because of scale problems if the higher WEIS rate is used). Data are also summarised for those who exit alive. The experience of this group is similar to the results for those remaining in the Trial, except for the small number who exited to nursing homes. This group has a similar experience to patients who died during the Trial.

Persons who die are seen to have incurred far higher costs. For instance, the mean annualised cost for intervention group participants who died during the Trial was $26,155 (@$2200/WEIS and LOS adjusted), compared with $3,625 for those who remain in the Trial. There is also a greater resource use differential between intervention and control clients in this group, with total cost 55% to 63% higher, compared with equivalent costs for those who remain in the Trial. For those who exited alive the cost differential is between these two groups, in part because of the influence of the patients who exit to nursing homes.

This analysis also suggests that coordinated care seems to increase the resources applied to the sickest patients, but does not in overall terms alter health care applied to others. (This analysis excludes the costs of care coordination and management).

Figure 5.4 Mean annualised cost per participant.
Total cost, In-patient and MBS for Intervention group and control group for persons remaining in the trial and for persons who died.

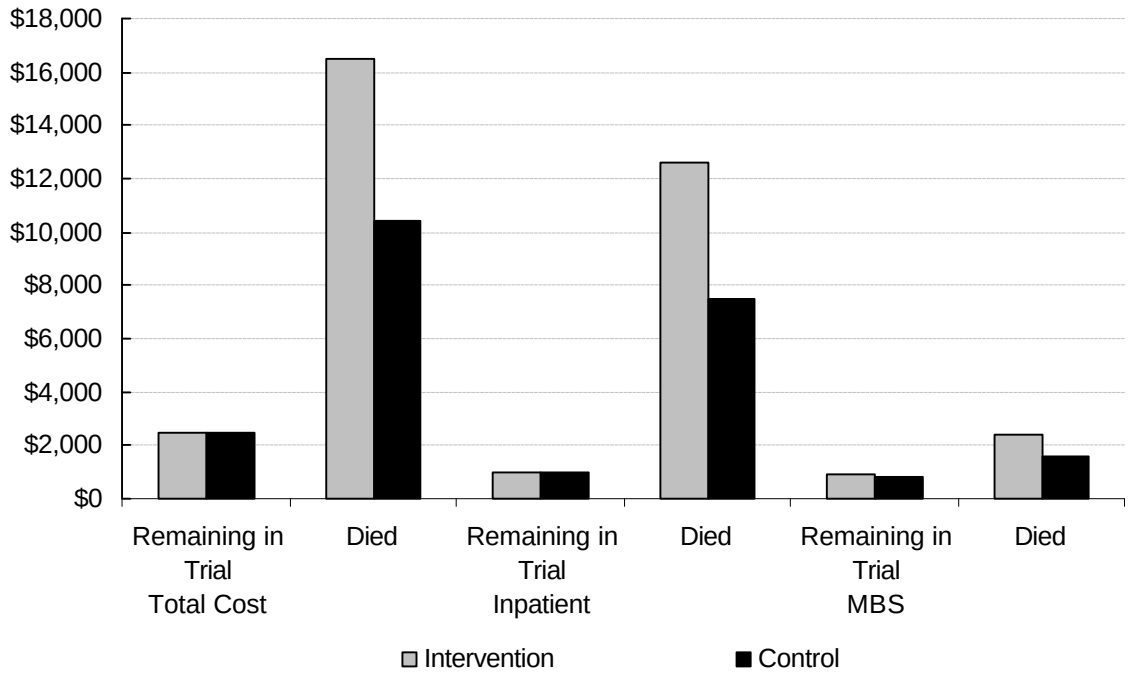


Table 5.5 Total cost health service by participant characteristic, (excluding costs of care coordination and management)

Participant characteristic	Intervention group		Control group
	$	relative to control	$
All trial participants:			
in-patient @ $1275/Weis	2,758	1.02	$ 2,695
in-patient @$2200/WEIS	3,609	1.01	$ 3,558
in-patient @$2200/weis, LOS adjusted	3,625	1.03	$ 3,532
Subjects remaining in the trial:			
in-patient @ $1275/Weis	2,490	1.01	$ 2,457
in-patient @$2200/WEIS	3,170	0.99	$ 3,187
in-patient @$2200/WEIS, LOS adjusted	3,157	1.01	$ 3,139
Subjects who died whilst in the trial			
in-patient @ $1275/Weis	16,777	1.59	$10,545
in-patient @$2200/WEIS	25,916	1.63	$15,942
in-patient @$2200/WEIS, LOS adjusted	26,155	1.55	$16,891
Subjects who exited alive prior to June 30 1999			
in-patient @ $1275/Weis	2,625	1.05	$2,502
in-patient @$2200/WEIS	3,514	1.10	$3,209
in-patient @$2200/WEIS, LOS adjusted	3,779	1.23	$3,078

5.6 Overall impact on resource use

The use and cost of mainstream health services is in statistical terms equivalent between the control and intervention group, but with a tendency for medical and outpatient costs to be higher in the intervention group and RDNS costs to be lower. Use and cost of in-patient and PBS were identical, but in-patient costs were tending to fall relative to control clients over the two years of the Trial.

Coordinated care also carried additional costs not incurred under usual care. Notably the direct costs of care coordination for the development of the care plan, training of GPs and the peer review process, and for service coordination and case management services. This amounted to an estimated $290/participant year or 8.2% on top of the cost of mainstream services. Management costs are extra, and in the context of on-going delivery of care coordination with Funds pooling, (that is excluding costs specifically related to a trial) are estimated at another 12.5%. Total costs in the intervention group, were thus estimated to be some 21% higher in the intervention group than the control group, counting also the small increase in the cost of mainstream services. This calculation is based on a full costing of in-patient services @$2200/WEIS. If in-patient services are valued at cost to the Pool, which was only $1275/WEIS, the percentage increase in cost is greater at 29%.

The shortness of the follow-up period is a major problem in considering these results. In relation to chronic disease management, at least a five-year follow-up period is preferable. (The major trials of diabetes management have had at least eight years follow-up, with little improvement in outcomes or resource savings within the first two years). It is probable that the observed health service cost differential would reduce over time.

Annexure to Chapter 5

Table A.5 Average service use per equivalent participant year(a) control and intervention group clients : services available under usual care July 1st 1997 to June 30th 1999 (b)

Type of service	Number of services per participant year		
	Intervention	Control	p
In-patient admissions (d) - mean admissions/persons/yr - mean LOS/admission - mean bed days/person/yr (e)	3.81(d_1)	3.96(d_1)	0.8
PBS (f)	18.6	19.4	0.5
MBS	27.6	26.4	0.3
Pathology services	9	8.2	0.2
Out-patient services DDH & MMC	0.7	0.65	0.3
RDNS	1.5	1.45	0.9
Total	49.6	49.0	0.8

Notes:

a) Annualised patient cost based on mean cost per participant day x 365.25

g) Health service use and cost data analysed until June 30 the original end date for the Trial, (see text for explanation).
c_1 - cost of in-patient services based on DRGs at price paid into and charged to the pool of $1275/WEIS
c_2 - cost of in-patient services based on DRGs priced at full average cost of $2200/WEIS
c_3 - with inlier admissions adjusted on the basis of patient length of stay, outlier admissions as costed.

i) in-patient services/costs, all admissions in Victoria; for MMC and DDH based on tracking of all SHCN CT participants, admissions to other hospitals in Victoria derived from the Victorian minimum in-patient data base.
The matching is thought to track ~ 60% of these admissions. Any loss of capture should be similar between control and intervention group clients.

j) PBS partial data only as captured by the HIC.

Chapter 6

Resource use and costs: the patients' diaries

6.1 Introduction

This chapter reports on the data contained in the diaries that Southern Health Care Network Coordinated Care Trial (SHCN CCT) clients kept for one month at the mid-point of the Trial. The diary was developed primarily to extend the data collection to include health-related products and services used by Trial participants for which no information was readily available from other sources. These data related to information about medicines and health care products not captured in the PBS data, community-based health services and the role of families and others in providing health care support.

The original intention was to implement two waves of the diary, one in 1998 and the other towards the end of the Trial in 1999. However, the burden on respondents of keeping the diary, the high cost of implementing it in a way that would ensure an adequate response rate and the research burden in terms of coding, data entry and analysis led to a decision not to implement the second wave. The diary data and analysis therefore cannot be used to look at the impact of the SHCN CCT interventions on clients' resource use and costs, but it does provide descriptive data relating to resource use and costs at the Trial mid-point for both intervention and control group respondents.

6.2 Methodology

The diary contained one page for each day of the data collection period and each page was divided into three sections, one for each of the broad categories of information sought. The data related to:

i) health care products: prescription and non-prescriptions medicines and health care products and equipment that the respondents had bought or hired during the diary period;
ii) formal services: health and community services that respondents used during the period;
iii) informal services: care and support services provided by family and friends because of the respondent's ill-health during the period.

A brightly coloured loose-leaf insert was included in the diary with instructions on what was to be included in each section.

In recognition of the respondent and research burden, it was decided to distribute the diary to a sample of participants. A stratified random sampling procedure was used to ensure adequate numbers of high-service users. Expectation of high service use was measured by the number of MBS services used during a specified period. Fifty percent of the sample was drawn from those with 13 services or more (a 2.5 times over-representation) and 50% with less than 13 services (38% under-sampling). Equal numbers were drawn from the intervention and control groups (an over-sampling of the control group).

The data collection period was August 1998 and in July a sample of 678 participants was sent a letter from the Trial over the signature of the Project Manager, informing them that they had been chosen at random to participate in the diary and offering them the option to decline. Through this process, 48 participants indicated their preference not to receive a diary. Subsequently 630 diaries were mailed to participants.

Included in the mail-out was the diary, a covering letter from the evaluation team, a booklet of 10 stamps and a stamp addressed return envelope. The letter from the evaluation team stressed the importance of participation by all, including those in good health who had little or nothing to enter in the diary. The booklet of stamps was designed to cover the cost of any calls made to the evaluation team about the diary, and as a token of appreciation for their participation. In the first two weeks of August, calls were made to most participants, to confirm that the diary had been received, to offer any assistance if needed and to encourage participants to complete and return the diary at the end of the month. Participants who said that they had not received the diary were sent a replacement. During the third and fourth weeks of September, attempts were made to telephone all those participants whose diary had not been received, as a reminder to return the diary.

Four hundred and eighteen completed diaries were returned, which represented rate of 62% of the sample (raw response rate) and 65% of mailed diaries (adjusted response rate).

6.3 The respondents

As shown in Table 6.1, there were no statistically significant differences between the respondents and non-respondents in terms of their gender or the group to which they were randomized. There were statistically significant differences with respect to marital status and age. Respondents were more likely to describe their marital status as 'married' (73% compared to 61%) and were, on average, older than non-respondents (54 years compared to 46 years). This means that care needs to be taken in making any assumptions about the generalizability of the diary results to the rest of the Trial study population.

Table 6.1 Comparison of respondents and non-respondents

	Total	**Non-Respondents**		**Respondents**		***p* value**
	**	Number	Percent	Number	Percent	χ^2
Intervention group	678	124	48%	215	51%	0.34
Gender (Female)	678	155	60%	235	56%	0.38
Marital status	665					0.00
Never married		46	18%	47	12%	
Married		157	61%	297	73%	
Other*		55	21%	63	16%	
		Mean	SD	Mean	SD	t-test
Age	678	46 yrs	22	54 yrs	19	0.00

Notes:

* Other includes widowed, separated, divorced

** Missing data means Total ≠ 678

Table 6.2 shows a comparison of the intervention and control group respondents. There are no statistically significant differences between the two groups in terms of age, gender, marital status, health care cards, safety net provisions and hospital admissions.

Table 6.2 Intervention and control group characteristics

	Total ***	Intervention group Number	Intervention group Percent	Control group Number	Control group Percent	p value χ^2
Health Care Card (Yes)	418	130	61%	123	61%	0.91
Safety Net (Yes)*	81	43	n/a	38	n/a	n/a
Hospital Admissions (Yes)**	253	14	11%	6	5%	0.21
Gender (Female)	418	119	55%	116	57%	0.71
Marital status	413					0.77
Never married		22	10%	25	12%	
Married		31	15%	32	16%	
Other*		155	73%	142	71%	
		Mean	SD	Mean	SD	t-test
Age	418	53 yrs	19	54 yrs	20	0.94

Notes:
* Before the end of August 1998
** Includes same day admissions
*** Missing data means Total ≠ 418

6.4 Health care products

Health care products have been divided into four groups: items bought on prescription, non-prescription medicines and items, equipment (including personal items such as spectacles) and dressings.

Overall, a total of 2,469 products were purchased or hired by the 418 respondents during the diary period. Three hundred and twenty-nine respondents (79%) recorded items, only 89 (21%) did not. The maximum number of products recorded by any one participant was 48, the average number per respondent was 6 and the median was 5 for the intervention group and 4 for the control group (see Table 6.3).

Table 6.3 Health care products purchased or hired by intervention and control group respondents during the month

	Number of health care products / respondent					
			Percentile of respondents			
	Total	Mean	25th	50th	75th	Maximum
Intervention (N=215)	1,320	6	1	5	10	39
Control (N=203)	1,149	6	1	4	8	48
Total (N=418)	2,469	6	1	5	8	48

Notes: *Mann-Whitney: Z* = -.537, *p* = .591

As shown in Table 6.4, the total out-of-pocket expenditure, summed across all intervention and control group respondents was $14,362. One quarter of respondents had no out-of-pocket expenditure, half $18 or less, one quarter more than $44. The highest level of expenditure by an intervention group respondent was $489 and included $476 for a spectacles which were collected during the period. The highest level of expenditure for a control group respondent was $545. This was for a male participant aged 7 years and Figure 6.1 shows the expenditure recorded for a typical Saturday during the diary period.

Table 6.4 Out-of-pocket expenditure on health care products per respondent for the month of August 1999

	Total	**Respondents**	**Out-of-Pocket Expenditure / Respondent**				
	Expenditure	Number	Mean	25th Percentile	50th Percentile	75th Percentile	Maximum
Intervention	$8,277	215	$38	$0	$17	$53	$489
Control	$6,085	203	$30	$0	$18	$35	$545
TOTAL	$14,362	418	$34	$0	$18	$44	$545

Notes: *Mann-Whitney: Z* = -.935, *p* = .350

Figure 6.1 Sample of a day in the diary of the respondent who incurred the maximum expenditure of $545 for the month

What was the item you purchased?	***Was it a prescription?***	***What was it for?***	***How much did you pay?***
1. Fleet bottles 133	*No*	*Wash outs x 14*	*$67.50*
2. New jocks	*No*	*As can't wear nappies at night*	*$15.07*
3. Gauzes 10	*No*	*So catheter stays in*	*$7.10*
4. Catheter 10cc	*No*	*Have to change once a week*	*$22.60*
DAILY TOTAL			*$112.27*

Source: Diary of respondent 477 page for 15th August, 1999

There were no statistically significant differences between the intervention and control groups with respect to the number of respondents reporting the purchase or hire or health care products, the number of products or the level of expenditure. As shown in Table 6.5, the most frequently purchased items were prescriptions (74% of respondents, 67% of items) and attracted the highest level of expenditure (48%). Dressings were the least purchased items (7% of respondents, 2% of items) and attracted the lowest level of expenditure (3%).

Table 6.5 Health care products: buyers, items and out-of-pocket expenditure for the month of August 1999

Product group	**Respondents**		**Items**		**Expenditure**	
	Buyers	Percent	Number	Percent	Dollars	Percent
Prescriptions	310	74%	1,664	67%	$6,838	48%
Non-prescriptions	174	42%	658	26%	$4,396	31%
Equipment	54	13%	99	4%	$2,773	19%
Dressings	29	7%	58	2%	$335	3%
TOTAL	418		2,479		$14,342.	

When the 'use of health care products' was measured by the number of intervention and control group respondents recording purchases during the diary period, there were no statistically significant differences between the two groups (see Table 6.6).

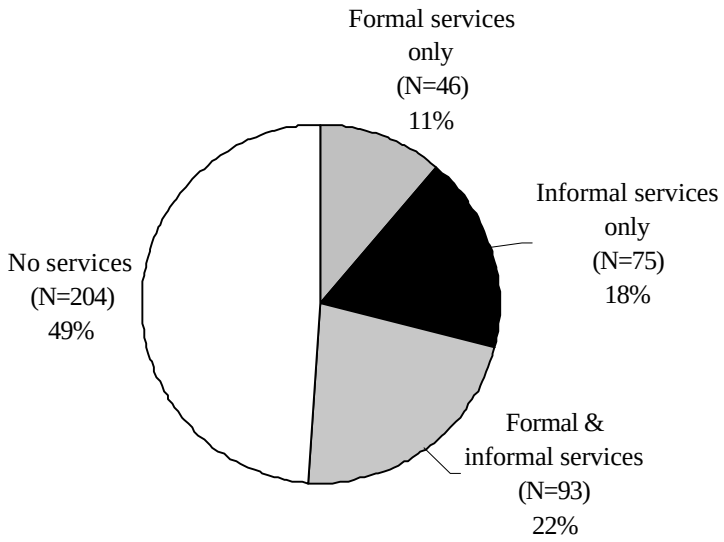
Table 6.6 Buyers of health related products for the month of August 1999

Product group	**Intervention (N=215)**		**Control (N=203)**	
	Buyers	Percent	Buyers	Percent
Prescriptions	165	76%	145	71%
Non-prescriptions	89	41%	85	42%
Equipment	26	12%	28	14%
Dressings	14	7%	6	3%

6.5 Formal and informal services

Of the 418 people who responded to the survey, 204 (49%) did not record any service usage during the month. As shown in Figure 6.2, 22% respondents used both formal and informal services, 18% used informal services only and 11% formal only (see Fig 6.1). There were no statistically significant differences between the intervention and control group respondents
(*chisq* = 4.059, *df* = 3, *p* = 0.255).

Figure 6.2 Number of respondents reporting some form of formal or informal service use during the month of August 1999



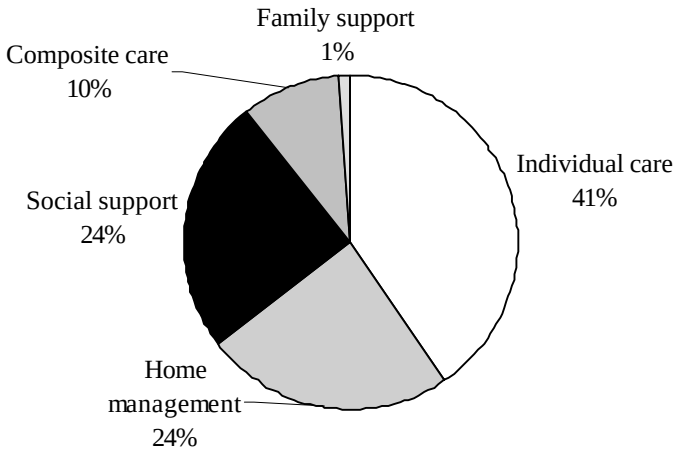
A large variety of formal and informal services were recorded in the diary and, to make the data more amenable to analysis, the services have been group into five categories: individual care, home management, social support, family support and composite care (see Table 6.7).

Table 6.7 Grouping of the formal and informal services included in the diary

Service	Definition	Examples
Individual Care	Aims to maintain the psychological and physical integrity of individuals.	Formal: counselling, personal care, allied health, paramedical services, home nursing Informal: *Making up medication and putting in bottles every morning (wife 30 minutes), hourly medication 17 times a day (wife 5 minutes x 17)* (Respondent Id 176)
Home Management	Aims to maintain the integrity of the individual's home environment.	Formal: home help, meal preparation and delivery, gardening, home repairs, home maintenance Informal: *Mowing lawns (friend 1½ hours), some housework (elderly friend ½ hour)* (Respondent Id 1202)
Social Support	Aims to facilitate individual's interactions outside the home.	Formal: banking, shopping, accompanying clients to appointments with service providers, Informal: *Banking, account paying, shopping (friend 2 ½ hours)* (Respondent Id 2478) *Daughter accompanied me to St Vincent's MRI Department (4 hours)* (Respondent Id 1224)
Family Support	Aims to maintain family functioning.	Formal: respite care, child care, care of family pets Informal: *My mum looked after one 15 month old daughter and my mother-in-law looked after my 3 years old (8 hours each)* (Respondent Id 1159)
Composite Care	Includes elements of individual care, home management, social and family support that could not be disaggregated.	Informal: *Husband helped me get to hospital and stayed all day. Helped me to the toilet then brought me home. Prepared dinner, got me dressed for bed and sorted out the medication for me. (16 hours)* (Respondent 617)

As shown in Figure 6.3, the largest number of service contacts (informal and formal) reported in the diaries related to individual care (41%) and the least related to family support (1%).

Figure 6.3 Types of services reported by respondents during August 1999 (based on number of reported contacts for each service group)



Overall, 81% of the contacts (3,517) related to informal care and support provided by family and friends, only 19% related to formal service provision. Only in the family support service area did formal contacts outnumber the informal (see Table 6.8).

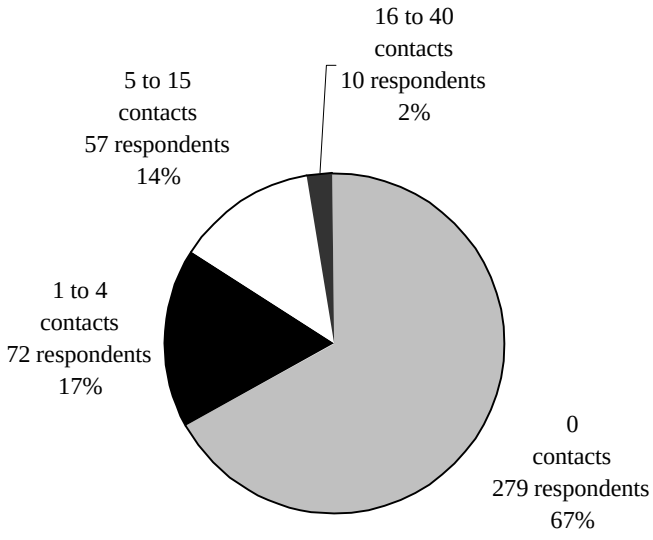
Table 6.8 Number of formal and informal service contacts reported during August 1999

	Formal		Informal		Total	
	Number	Percent	Number	Percent	Number	Percent
Social support	139	13%	914	87%	1053	100%
Composite care	69	16%	351	84%	420	100%
Home management	204	19%	854	81%	1058	100%
Individual care	384	22%	1373	78%	1757	100%
Family support	29	54%	25	46%	54	100%
TOTAL	825	19%	3517	81%	4342	100%

6.5.1 Formal Services

Formal services included services provided by allied health professionals outside the acute (hospital) sector. It did not include medical services provided by GPs or specialists or any services accessed through Monash Medical Centre of Dandenong Hospital. Of the 418 respondents, 279 (67%) had no informal service contacts, 72 (17%) had less than 5 and 167 (16%) had more than 5 (see Figure 6.4). The highest number of formal service contacts reported by a single respondent was 40. This respondent was a 65 year old male who went to hydrotherapy every weekday during the month by public transport (2 contacts per day for 20 days).

Figure 6.4 Number of contacts users had with formal services during August 1999



Formal service usage can be measured in three ways: number of respondents using the service, number of formal service contacts reported and reported out-of-pocket expenditure. As shown in Table 6.9, family support services were the least used service (1% of respondents, 4% of the contacts and 2% of out-of-pocket expenditure) and individual care the most heavily used (23% of respondents, 47% of contacts, 55% of expenditure).

Table 6.9 Formal service use: users, number of contacts and out-of-pocket expenditure for the month

	Respondents		Contacts		Expenditure	
	Users	Percent	Number	Percent	Dollars	Percent
Individual care	96	23%	384	47%	$2,844	55%
Home management	51	12%	204	25%	$1,303	26%
Social support	36	9%	139	17%	$645	13%
Family support	5	1%	29	4%	$100	2%
Composite care	7	2%	69	8%	$215	4%
TOTAL	418		825	100%	$5,107	100%

Overall, a higher proportion of intervention group respondents used formal services than control group respondents but the difference was not statistically significant. However, when the data were disaggregated into the different types of services the difference in individual care service users was statistically significant (see Table 6.10).

Table 6.10 Formal services: intervention and control group users

	Intervention group (N=215)		Control group (N=203)	
	Users	Percent	Users	Percent
Individual care*	58	27%	38	19%
Home management	25	12%	26	13%
Social support	23	11%	13	6%
Family support	3	1%	2	1%
Composite care	3	1%	4	2%

Notes: *C*hisq* = 4.024, *df* = 1, *p* = .045

When the data for individual care are disaggregated the statistically significant differences between the intervention and control group were in relation to:

- hydrotherapy - 12 intervention group respondents (6%) compared to 6 control group respondents (1%) (χ^2 = 6.814, df = 1, p = .009);
- home nursing – 10 intervention group respondents (5%) compared to 1 control group respondent (<1%) (χ^2 = 7.047, df = 1, p = .008);
- psychological/spiritual care – 1 intervention group respondent (<1%) compared to 12 control group respondents (6%) (χ^2 = 10.278, df = 1, p = .001).

In terms of number of contacts per user, there were no statistically significant differences between the intervention and control groups.

The average level of out-of-pocket expenditure per contact was highest for individual care and the highest level of expenditure for any one contact was $280 for an individual care contact (see Table 6.11). This was spent on a visit to the dentist for a 4 year old respondent. The mother of this respondent commented in the diary:

> *You have to wait years to qualify to see a dentist so I went to a private dentist. Lucky I did, her tooth was filled right to the nerves.* (Id 465)

Table 6.11 Out-of-pocket expenditure per formal service contact

	Out-of-Pocket Expenditure / Contact*				
	Mean	25th Percentile	50th Percentile	75th Percentile	Maximum
Individual care	$8.13	$0.00	$3.00	$6.50	$280
Home management	$6.45	$4.50	$4.50	$6.03	$30
Social support	$5.20	$1.40	$3.00	$7.13	$50
Family support	$4.97	$2.50	$6.00	$6.75	$7
Composite care	$3.11	$0.80	$3.53	$5.00	$8

Notes:

* Expenditure data missing for 34 individual care contacts, 2 home management contacts, 15 social support contacts and 9 family support contacts.

Seventy-one percent of respondents (279 non-users and 18 users) did not spend any money at all on formal services. Intervention group respondents recorded an out-of-pocket expenditure of $2,957 and control respondents $2,149 (see Table 6.12). The difference in the expenditure between the intervention and control groups was not statistically significant.

Table 6.12 Respondents' out-of-pocket expenditure on formal services for the month

	Intervention Group (N = 215)	Control Group (N=203)	Total (N=418)
Mean	$14	$11	$13
Median	$0	$0	$0
Percentile 75	$12	$4	n.a.
Percentile 95	$84	$59	n.a.
Maximum	$240	$350	$350
TOTAL	$2,957	$2,149	$5,106

Notes: *Mann Whitney: Z = -1.502, df = .133*

As shown in Table 6.13, users' average out-of-pocket expenditure was greatest for individual care and composite care and least for social support. However, in terms of users' median expenditure the greatest level of out-of-pocket expenditure was for home management services but the least was still for social support. Among the users of formal service the most common out-of-pocket expenditure for social support was zero dollars. The maximum level of expenditure on formal services was incurred for

Table 6.13 Users' out-of-pocket expenditure on formal services for the month (N=139)

	Users	**Out-of-pocket expenditure / user of formal services**				
	Number	Mean	Median	Mode	Min	Max
Home management	51	$26	$19	$12	$4	$99
Individual care	96	$31	$18	$0	$0	$350
Family support	5	$25	$17	$14	$14	$53
Composite care	7	$31	$16	$0	$0	$130
Social support	36	$21	$11	$0	$0	$99

Users' out-of-pocket expenditure was affected by whether or not they used subsidised services. For example, the average out-of-pocket expenditure per contact for home help accessed through private arrangements is over twice that accessed through providers such as local councils. Visits to the podiatrist attract over 4 times as much when they are access privately than when they are accessed through, say, a community health centre (see Table 6.13).

Table 6.14 Examples of the effect of use of subsidised services on users' out-of-pocket expenditure

	Contacts		**Out-of-Pocket Expenditure / Contact**			
	Number	Percent	Mean	Median	Sum	Percent
Home Help (Home Maintenance)						
Private	11	9%	$14	$14	$124	19%
Subsidised (eg council)	114	91%	$6	$6	$663	81%
Podiatry (Individual Care)						
Home or provider' rooms	6	33%	$27	$31	$163	69%
Subsidised (eg Community Cntr.)	12	67%	$6	$7	$74	31%

6.5.2 Informal services

Of the 418 respondents 250 (60%) had no informal services contacts, 48 (11%) had an average of less than 4 contacts and 46 (11%) had 31 or more. The highest number of contacts reported by a respondent was 150 (see Figure 6.5). This respondent was a 66-year-old male and Figure 6.6 shows the entries for a typical day in this respondent's diary.

Figure 6.5 Number of contacts by users of informal support services

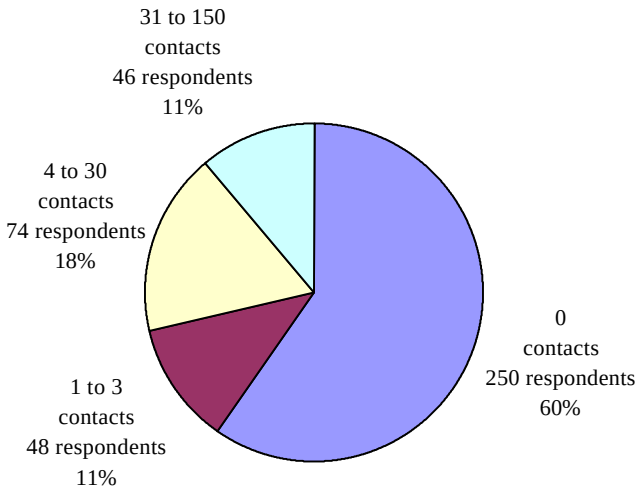


Figure 6.6 Example of a day in the diary of the respondent who recorded the highest level of informal service provision during the month

What type of care and support was it?	*Who provided the care and support?*	*How long did it take?*
1. Assisted with washing, personal hygiene & dressing	*Wife*	*1 hour*
2. Given medication x 3 times a day	*Wife*	*15 mins*
3. Preparing nebuliser machine x 7 times a day	*Wife*	*35 minutes*
4. Preparing meals, cups of tea, etc. x 3 times a day	*Wife*	*3 hours*
5. Emptying & cleaning urine bottle x 6 times a day	*Wife*	*20 minutes*
6. Household tasks	*Wife*	*1 ½ hours*
7. Being there, given reassurance when necessary	*Wife*	*2 hours*

Source: Diary of respondent 1282 Monday 17th August 1999

Informal service usage can be measured in three ways: number of users, number of contacts and time. Across all these 3 measures family support services were the least used service (2% of respondents, 1% of contacts and 2% of the total time). Use of social support services was reported by the highest number of respondents (32%), individual care accounted for the highest number of contacts (39%) and composite care accounted for the greatest amount of time (30%) (see Table 6.15).

Table 6.15 Informal service use: users, contacts and time recorded for the month

	Respondents		Contacts		Time	
	Users	Percent	Number	Percent	Hours	Percent
Individual care	75	18%	1,373	39%	1,237	21%
Home management	76	18%	854	24%	1,285	22%
Social support	132	32%	914	26%	1,527	26%
Family support	9	2%	25	1%	145	2%
Composite care	25	6%	351	10%	1,783	30%
TOTAL	418		3,517	100%	5,977	100%

When informal service usage is measured by the number of users, there are no statistically significant differences between the intervention and control groups (see Table 6.16). Measured in terms of the number of contacts per user the only statistically significant differences between the two groups was for individual care services (see Table 6.17).

Table 6.16 Number of users of informal services during the month

	Intervention (N=215)		Control (N=203)	
	Users	Percent	Users	Percent
Individual care	38	18%	37	18%
Home management	39	18%	37	18%
Social support	75	35%	57	28%
Family support	4	2%	5	2%
Composite care	12	6%	13	6%

Table 6.17 Number of informal individual care contacts per user for the month

	Contacts	Users	Number of Informal Service Contacts / User				
	Number	Number	Mean	25th Percentile	50th Percentile	75th Percentile	Maximum
Intervention Group	912	38	24	4	26	32	65
Control Group	461	37	12	1	3	15	84

**Mann-Whitney: $Z = -3.150$, $p = .002$*

Individual care contacts consisted of: personal care contacts, allied health contacts and nursing contacts. The only statistically significant difference between the intervention and control group users was for personal care. Intervention group users recorded more personal care contacts per user than the control group (21 per intervention group user vs 9 per control group user). (See Table 6.18) Personal care consists of services such as showering, dressing, toileting and feeding provided by family members, other relatives and friends:

> *Showering and dressing (1 hour husband), toileting (10 minutes 5 times husband), getting to bed (1/4 hour husband).* (Respondent 788)

Table 6.18 Number of informal personal care contacts per user for the month

	Contacts	Users	Number of personal care contacts / user				
	Number	Number	Mean	25th Percentile	50th Percentile	75th Percentile	Maximum
Intervention Group	586	28	21	5	28	31	46
Control Group	148	16	9	2	3	10	42

* *Mann-Whitney: Z* = -2.294, *p* = .022

The similar result was obtained when informal service use was measured in terms of time. Intervention group users recorded a total of 3,298 hours of informal service use and control group users 2,735 hours, but the only statistically significant difference between the groups was in the area of individual care. On average, intervention users recorded just over twice as much time being spent on the provision this service than the control users (see Table 6.19).

Table 6.19 Hours of informal individual care per intervention and control group user for the month

	Hours	Users	Hours of informal individual care / user				
	Total	Number	Mean	25th Percentile	50th Percentile	75th Percentile	Maximum
Intervention Group	844	38	22.2	1.5	8.3	32.6	161
Control Group	393	37	10.6	0.29	1.08	4.4	109

* *Mann-Whitney U* = 49.000, *Z* = -3.116, *p* = .002
**Data missing for 154 contacts

When the data for the individual care contacts were disaggregated the only statistically significant difference is for personal care: on average intervention users reported a higher level of personal care support than control group users (see Table 6.20).

Table 6.20 Hours of informal personal care per intervention and control group user for the month

	Hours	Users	Hours of informal personal care / user				
	Total	Number	Mean	25th Percentile	50th Percentile	75th Percentile	Maximum
Intervention Group	483	28	17.2	2.8	9.6	27.7	65
Control Group	200	16	12.5	0.4	1.4	4.5	96

* *Mann-Whitney: Z* = -2.062, *p* = .039

Family members (including relatives) accounted for 93% of the informal service contacts and 94% of the time spent providing informal services (see Table 6.21). Non-family members were most active in the area of informal social support (19% of contacts) and least active in the area of informal composite care (1% of contacts) (see Table 6.22).

Table 6.21 Providers of informal services during the month

	Contacts		Hours	
	Number	Percent	Number	Percent
Family members	3,270	93%	5,606	94%
Non-family members	244	7%	370	6%
Total	**3514***	**100%**	**5,976****	**100%**

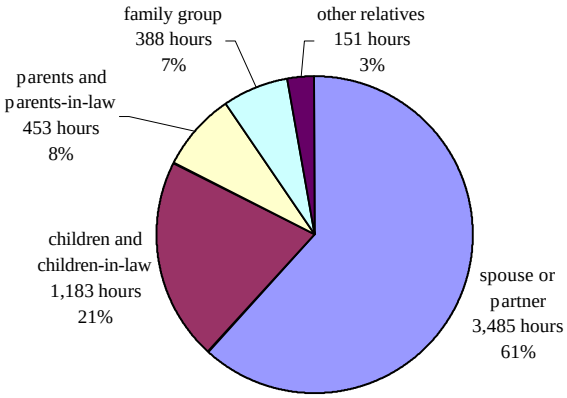
Notes:
* Data missing for 3 contacts
** Data missing for 156 contacts

Table 6.22 Hours of informal service support provided by family and non-family members during the month

	Family members		Non-family members	
	Hours	Percent	Hours	Percent
Individual care	1,223	99%	15	1%
Home management	1,241	97%	44	3%
Social support	1,230	81%	295	19%
Family support	140	97%	5	3%
Composite care	1,772	99%	12	1%

Within families, spouses and partners provided most of the caregiving (3,430 hours), children 1,181 hours, parents 453 hours and other relatives 151 hours. Three hundred and ninety hours were provided by groups of family members, which it was not possible to allocate to family members (see Figure 6.7).

Figure 6.7 Hours of informal service provided by family members



Section II

Secondary Hypotheses:
Factors Affecting Outcome

Chapter 7

The care coordination model: overview of secondary hypotheses

7.1 The role of care coordination

An important evaluation question for the Trial concerns the care coordination model, particularly the preferred approach to the pooling of funds, criteria for access to health services and the future role and function of the care coordinator. In exploring these issues the evaluation team has taken account of the experience of the SHCN CCT, the proposed changes in the funding and delivery of health care, the existing demands on general practice and the other providers and the wider health system reform and care coordination.

Care coordination does not have a unique description, but rather, it can be thought of as a set of arrangements that will facilitate the coordination of care, especially for those with chronic illness, associated with more complex care needs. Coordinated care need not be restricted to chronic care. It may also relate to once-off acute episodes, and the coordination of services between the acute and community sector (and between provider and patient/family). It can also be relevant at the population level where the focus will be disease prevention and health promotion.

There are several objectives of care coordination, but the primary focus is modification of the health service mix, so that it better meets the needs of the patient/citizen. It is extremely wasteful to provide services that do not well reflect the needs of patients. That is, part of the aim is to empower patients (and family members and citizens), to have a greater role in determining their needs and in being able to access a more optimal mix of services. This is analogous to the economic concept of consumer sovereignty. It has been argued that support of a stronger consumer role with an associated reduction in provider dominance will contribute both to enhanced health outcomes and a more efficient health system. (For a presentation of the arguments see Segal 1998[20]). This might be thought of as a demand side role for coordinated care.

Care coordination also has a supply side role, to assist the various providers to work better together, to improve the quality of care. It is also postulated that there may be some reduction in wastage and duplication on the one hand, and the identification and addressing of gaps in services and eligibility on the other.

Coordinated care may also provide a means to better target services so that those in greatest need (however defined) might obtain preferential access. This can be seen to have both an efficiency and an equity objective.

20 Segal L., 'The importance of patient empowerment in health system reform', *Health Policy*, 1998 vol. 44 (1), pp 31-44

Various players in the system will have their own views about what they expect coordinated care to deliver. General practitioners may hope for a resource to assist them in the management of chronically ill patients, whose needs for health services are high. They may particularly seek support in relation to the non-medical components of care. Patients and families may seek direct support for a more effective involvement in their health care decisions, and in access to services. Governments may seek a more efficient approach to health care that can deliver improved outcomes within existing resourcing.

7.2 Typical elements of care coordination

In Table 7.2 the key elements of the SHCN CCT are summarised and comments on performance made. What is clear from this table, in which ten major care coordination elements are identified, is that the description of a care coordination model is likely to be complex, with the possible variations immense. There are literally hundreds (thousands) of different programs which have an element of care coordination, from small (or large) case management programs to the all encompassing managed care and GP budget holder models.

Key descriptors for the care coordination model will revolve around:

i) **Eligibility**: the care coordination model can have a population (usually regional) base where all in a nominated geographic area (or with a particular employer) are covered, or it can be exclusive and focused on a high risk sub-population. If it is to target high risk groups, this may be defined by disease/health problem status, or current high level use of health and community based services, or a specific measure of vulnerability and need for support.

ii) **Enrolment method**: the enrolment method may be inclusive as in the population based models, or exclusive as in the high risk models. Decisions about opting in or opting out may be made by the patient/citizen or provider or funder.

iii) **Recognition of levels of need***:* the model may incorporate single or multiple program levels. Under the latter there may be a defined set of components to be accessed differentially depending on the application of a risk assessment tool which is designed to discriminate by level of need, (for care coordination and/or services).

iv) **Services offered**: the Care coordination model may incorporate a range of services such as care planning, assistance in access to services, quality assurance, direct care and support eg, patient advocacy, family support, program/service development.

v) **Allocation of roles***:* the key activities/services can be undertaken by alternative professional groups and as a specialist role or part of other functions. For example care planning can be undertaken as part of a mainstream provider role (eg by GP), or as a specialist task by a ‘care planner’.

vi) **Relationship between tasks and players**: these need to be specified as a potential mechanism for achieving supply side change. For instance the tasks of preparing the care plan can be delegated to a single person or a team, and in either case protocols for liaison with other players need to be specified.

vii) **Involvement of patients**/clients and their families, in care planning, in the choice of services. The model may be designed to empower patients and redress provider dominance, or alternatively to support provider based decision making, or give greater power to the funder. Depending on the focus, supports can be introduced to assist patients to take a more proactive role in understanding their care needs and the service options available to take greater control over their health.

In response to the questions in the SHCN CCT patient survey, regarding who should make decisions about their health care, participants (both control and intervention group) were overwhelmingly in favour of making those decisions themselves, albeit sometimes with their families and with access to the advice of their GP. Only 14% suggested that the doctor should make the decisions about their care, even in consultation with them.

viii) **Service development role**: there may be a focus on the direct development of services, an advocacy role to encourage other agencies in service development, a support role to other agencies to assist them to take on different activities etc. This may be central to achieving a shift in the health service mix, by ensuring there are the services on the ground to better meet the need of the client group.

ix) **Access to discretionary funds***:* care coordination models differ in their access to discretionary funds and, if they are available, on what basis. Options include a per capita allowance (eg. adjusted to reflect level of need) up to a limit per individual or per 'group', through application to a regional/program pool of funds according to nominated criteria. Access may be through patients/families or the 'care coordinator,' etc. The amount accessible as discretionary funds varies considerably.

x) **Quality assurance***:* are there to be processes to review care planning activity to monitor quality of care?

xi) **Basis for access to services**: is to be according to standard eligibility, is care coordinator to be budget holder, who is responsible for monitoring cost of care etc.?

xii) **Single/multiple point of entry**: the care coordination model may represent just one extra program, or it may endeavour to provide a coherent vehicle for bringing together a range of services, and provide, for instance, a single access point for access to all case management services.

xii) **Funds holding/funds pooling**: care coordination can occur as a separate program with its defined budget, or it can act as a means to pool funds and be funded out of the budget of existing services, usually with some additional direct funding for administration (eg the UK GP budget holding model).

7.3 The SHCN care coordination model

Philosophy

The model of care co-ordination devised for the SHCN CCT, reflects an interest in combining a regional focus with a high risk group. The Trial was to be aimed at a broad client base drawn from a region, not according to disease grouping or complexity of care requirements, but on the basis of high use of acute services. The Trial was exploring the issue of who might benefit from coordinated care and how this group could be defined, as much as whether coordinated care works. The proponents of the Model argue that it was a population based model, although as less than 2% of residents of the SHCN met the eligibility criteria the integrity of this proposition is difficult to sustain. Little was known in advance about the nature of this group of high cost users of acute care, except that they would be drawn from all age groups and health problems, and with little knowledge of the complexity of their health service needs.

It was apparent that there would be great diversity in complexity of care needs and risk of hospitalisation, and need for care coordination support. For this reason it was decided that there would need to be various intensities of care coordination support able to be offered, to reflect differing levels of need.

The use of a Risk Assessment Tool

Those identified as low risk were to be offered care planning, those at medium risk were to have access to care planning plus a service coordinator - a phone based service to assist the patient (or GP for the patient) to access services identified in a care plan; those with highly complex care needs and at high risk of hospitalisation were to be offered care planning plus intensive case management support. A risk assessment tool, (RAT) was devised specifically for the Trial to allocate all intervention participants into the three care coordination levels. The risk assessment tool had 9 questions covering current/expected use of services and capacity to self manage. A copy of the RAT is attached at Annex to Chapter 10.

All participants were scored from 1 (lowest service use/need for care support) to 3, yielding total possible scores of between 9 and 27. The risk tool was implemented by the GP, with those scoring between 9 and 13 allocated a low risk (level 1), a score of 14-21 medium risk (level 2) and a score of 22+ denoting high risk (level 3). The vast majority (70%) of clients were allocated to risk level 1, a further 25% were identified as medium risk clients and allocated to level 2, while only 5% were identified as high risk and allocated to level 3. This distribution was quite different to that expected by Trial management, who had presumed level 2 would be most common with 60% of participants, with 20% allocated to levels 1 and level 3.

Each participant regardless of risk level was asked to nominate a GP to act as their care coordinator. The GP was notified about taking on this role, and if they accepted the role, they took on responsibility for development of the care plan, and for periodic review, depending on client risk level. Those in level 2 were allocated a service coordinator, who had a case load of 200-250 patients, and who undertook the task of assisting patients to access services nominated in their care plans. The service coordinator could also liaise with the GP concerning the content of a care plan. The GP however had sole responsibility for development of the care plan. The case manager had a case load of 35 to 40 clients and a brief to provide intensive individualised support and advocacy. Again the GP had responsibility for care plan development and review, but the case manager would often contribute to this process, with greater willingness from GPs as the Trial matured and respect for each others contribution was gained. The arrangement was not easy for the service coordinators or case managers, but did have the potential to ensure that GPs became better informed about a broader range of issues in the management of their more complex patients. Some development of the service coordinator and case manager roles occurred over the course of the Trial, for instance to give the service coordinators an opportunity to contribute to the care plan review for the more complex clients.

A standard care plan form was developed for completion by the GP with the patient. A copy of the Plan was sent to the Dandenong Division of GP for peer review. The Division also provided training for GPs in their role as care coordinator.

7.4 Performance of the SHCN care coordination model

Our conclusions about the success of the care coordination model are based on various research tasks, namely:

- a review of the health system reform literature including that relating to care coordination, managed care and case management models;
- in-depth interviews with GP care coordinators, service coordinators, case managers and Trial management; and
- a comprehensive survey completed by 330 GP care coordinators at 12 months into the trial and again at 24 months, in which their views about the care coordination model was elicited.

For patients in the medium and high risk groups, the role of care coordination in the form of care planning and access to the services of the case manager or service coordinator was a clearly identifiable activity for both the patient and the patient's family, and the general practitioner and was generally well regarded.

The purpose of care coordination for low risk patients is less apparent to both the care coordinator and the client and the response is far less positive. While including low risk participants was useful in defining the boundaries around who would benefit from coordinated care, and to gain insights into the service use of participants with more and less intensive health problems, the offering of care planning for those at very low risk, may offer little benefit.

View of general practitioners

The GPs, as care coordinators, played a central role in the SHCN CCT model. At the commencement of the Trial, there was substantial scepticism from GPs about coordinated care. GPs did not volunteer to participate in the Trial, but rather were brought in by their patients, in a way that made it difficult to refuse. Furthermore the Trial was not offering discretionary funds with which GPs could purchase services for their patients. Despite what might be considered a difficult start, the cooperation from GPs was encouraging. The response rate to the first and second GP questionnaires was 76% (1998) and 70% (1999), both exceptional. Results of the questionnaire are summarised in Table 7.1.

In relation to medium and high risk clients, approximately half the GPs responding, reported that the Trial assisted in the identification of medical or other needs and other health professionals. Less then 20% found it useful in this regard for low risk patients. The responses were similar in terms of organising and ensuring access to necessary services. Fewer GPs, but still around one third, thought it useful in reducing unnecessary duplication or inappropriate care, for medium and high risk patients, and around 20% for low risk patients.

Table 7.1 View of GPs of coordinated care: percent said helped in relation to nominated attribute

Attribute	GPs with only medium and high risk patients n=30		GPs with medium, high and low risk patients n=114		GPs with just low risk patients n=62	
	1998	1999	1998	1999	1998	1999
Identify medical needs	38%	52%	52%	48%	33%	15%
Identify services to meet medical needs	48%	48%	48%	46%	25%	16%
Identify other needs	41%	44%	36%	42%	19%	12%
Identify allied health services	41%	52%	47%	54%	19%	7%
Organise social and welfare services	50%	52%	44%	52%	17%	7%
Organise medical services	49%	56%	47%	49%	25%	21%
Make sure patients get services	41%	56%	44%	45%	27%	19%
Reduce unnecessary duplication	34%	48%	28%	3%	25%	23%
End inappropriate care	28%	32%	17%	24%	25%	16%

Almost all responses were slightly more supportive in the second than the first survey. This is extremely encouraging as it suggests a quite significant culture change in just the two year time frame of the Trial. The change in support over the course of the trial depended on the GPs mix of patients of the GP. Increased support was most apparent for those with only medium and high risk patents, and a fall in support for those with only low risk patients.

Value of various elements of the SHCN CCT model

Based on the various sources of information an overall view of the performance of the major elements of the coordinated care model are summarised in Table 7.2. Each of the key components of the SHCN CCT is described together with the assessment of the value of each component by the evaluation team and by GPs.

Broadly the activities that worked best were the classification of participants into risk levels and the three levels of care coordination support offered. While the initial cut-off points were not always appropriate at the individual level, it provided a useful initial allocation and there was sufficient flexibility for changes to risk level to be made during the Trial. This is appropriate. Further, at each level the intensity of support provided to each client varied, which is also desirable.

As noted, it is now clear that those who had no elevated risk, scoring a 9, do not in general need coordinated care and would be better excluded. However, including them in this Trial enabled data to be gathered concerning health service use and cost, which means this conclusion can now be drawn based on objective evidence.

The role of the GP as care coordinator is more complex. Clearly this is strongly supported by GPs and was probably central to the quite high acceptance of care coordination amongst GPs. It also was a means for engaging GPs in the process and a greater understanding of the needs of their complex clients. However, as this Trial did not implement any alternative model it is not possible to determine whether an alternative approach would have worked better. certainly the training of GPs in the care planning activity was extremely limited and probably inadequate. Also the care planning form did not encourage a social assessment, and the focus tended still to be essentially medical. Thus if the GP was to retain the role as care coordinator, greater attention to training is warranted, and probably a review of the care plan form. Further consideration needs to be given about whether the empowerment of patients is to be a central theme of care coordination, and if so this would need to be more directly brought into the care planing activity.

As discussed in Chapter 8, the approach to funds pooling was not seen to be successful and some suggestions are made later about alternative models that could be adopted. The lack of discretionary funds was a source of frustration for the GP, the service coordinators and case managers. While, it can have the advantage of encouraging an aggressive advocacy role and pushing the service system to achieve broader system change, it can also be very inefficient, if substantial time is spent trying to access critically needed services which would be far simpler to purchase.

In relation to discretionary funds, one option is for an amount of discretionary funds to be set aside for access by GPs patients, service coordinators and case managers, for services identified in care plans, which cannot be accessed in other ways, and where benefits can be documented. The alternative is simply to allocate up to $x per client, as occurs with many disability services programs.

Discussion about the possible desirable features of a coordinated care model for wider adopted throughout Australia, concludes this Chapter.

Table 7.2 Elements of care coordination model

Care coordination element	Performance	Views of GPs
Enrolment method: postal, client driven	Very effective and efficient, ensured involvement of large number of GPs and patients.	Many GPs had only 1 or 2 clients in CCT. This presents difficulties.
Eligibility for trial >$4,000 in-patient admission over 2 year period and location within selected postcodes	Ensured complex patients identified, but also many who did not need care coordination. Provided the research base to refine target.	Eligibility criteria were considered too broad. GPs thought coordinated care should only be offered to medium and high risk patients.
Use of risk assessment tool (RAT)	Effective, in identifying those in need of more intensive care coordination support, and service use. Capacity to move between levels important, to reflect either changing circumstance, or initial incorrect allocation.	GPs were generally supportive of the RAT: 58% of respondents considered its retention important while only 6% considered it unimportant.
GP as care coordinator	Mixed capacity to undertake care planning, training limited and only attended by about 50% GPs, but ensured liaison with GP by other service providers. Conduct of role variable, from dismissive to thorough.	GPs strongly supported their role as care coordinator: 86% of respondents considered this important.
Care plan/Care Plan proforma	Developed in short time frame. Adequate but possibly too narrowly focused in medical care. Quality of care plans very mixed.	Most (86%) of GPs considered the fee for care panning important.
GP Division audit of care plan	Provides a peer review process, useful but relatively uncritical.	Least well supported component of the care coordination model. But still 39% of GPs nominated this as important, while 16% considered it unimportant.
Care panels	Difficult task to develop strategies in time frame of the trial. Some success with respiratory panel, and mental health. Bringing together a group of experts as part of the panel was valuable. May contribute to adoption of better quality care in some areas.	Those GPs who engaged with the care panels found to be of some use. Many had little or no involvement.
Case managers	Valuable support to high needs clients. Some tension in relationship with GP, but model ensured some dialogue took place. Lack of capacity to purchase services made role more difficult, with a strong advocacy element.	GPs valued support provided by case managers for high needs patients. Respect for their role increased over time: 75% of GPs considered this role important.
Brokerage /discretionary funds	Brokerage funds were not available, which helped keep costs down. Intervention clients still obtained slightly better access to services. Access to a limited pool of discretionary funds, may have improved the responsiveness to individual circumstances, at relatively low cost.	GPs and service coordinators and case managers disappointed at lack of brokerage.
Service coordinators	Unlike case management, little precedent for this role as a purely telephone based service. Is a mechanism for identifying who might need case management assistance.	The knowledge of services was found to be valuable. 80% of GPs considered retention of this role important.

Management and administrative arrangements

There are major challenges in the implementation of coordinated care, in encouraging various health professionals to work in a more collaborative way, to get agencies to contribute to a funds pool, at some risk to their own financial viability, to achieve a more responsive service system. It will not always be possible to develop common goals, and it is not always possible to allocate the time for development that might be desirable.

However, a number of attributes that seem to be central to an effective development and implementation process have been confirmed by our evaluation of the SHCN CCT, (some through example and some through failure).

Key requirements would seem to be:

- strong and inspiring leadership, combined with a capacity to be inclusive and involve the management team and other players in key decisions and implementation arrangements, where possible;
- skilled staff, in the elements of coordinated care, and some understanding of principles of evidenced based research;
- a primary focus on enhanced care and client outcomes, rather than cost. (If the model is valid the improved care will result in a better financial outcome. If it is not, a direct focus on cost may well be self defeating if it prevents access to precisely those services that may allow downstream cost savings);
- an adequate time frame for the trial to be able to test the research principles is clearly desirable - this would suggest at least a 5 year time frame. (In relation to chronic disease management, studies of shorter duration are often inconclusive, especially if cost savings are to be identified from a reduction in the rate of disease progression);
- adequate time for the establishment of the program to set up processes and to engage key players, normally at least 12 months would be required for this task; and
- a management structure that allows the key participants to input into the decision making process, but still allows the Trial manager to make executive decisions when necessary.

7.5 Future of care coordination: an alternative model?

Care coordination has some strengths. It is able to deliver significant benefits, to at least some participants, and contribute to the adoption of best practice care by general practice, which over time will tend to extend the benefits to many in the community. That benefits are achievable within current resources has not been established, nor that a shift in the health service mix has been facilitated, other than through additional funds.

Whether an alternative model would be able to achieve the enhanced outcomes, within current resourcing, or the current model if continued for longer could do this, is debatable. Perhaps elements of the model, most central to observed gains could be retained and other elements refocused. That funds pooling can fulfil the designated role of breaking down program boundaries to allow resource shifts has not been established, and given the significant administration costs of this activity, exploration of the possibility of other arrangements is desirable.

The fact of implementing the trials and gathering a wide range of quantitative and qualitative data has, regardless of performance in the narrow sense, added immeasurably to the state of knowledge of alternative health planning and delivery arrangements, and the capacity to Trial health system reform.

Some thoughts about the possible future direction for coordinated care, based on our evaluation and other research into health system reform issues concludes this chapter.

A model that would offer the benefits of coordinated care, but obviate the need for negotiation of a funds pool with individual providers may be the way to proceed. This, we suggest, may be achieved through the application of care coordination in a regional context, taking a whole of population model.

Possible elements would involve:

- **Population coverage**: A regional boundary, within which the entire community is to be covered by the new health funding and delivery arrangement.

- **Enrolment/Assessment** of the public for access to specific care coordination services via completion of a risk assessment tool (similar to that used in the SHCN CCT). A single risk tool would be developed and applied by a GP or other primary care provider. Only those seeking access to special care coordination services, (beyond the care planning item on the Medicare Schedule would complete the risk tool. A means for training and providing a peer review process for GP care planning would be introduced.

- **Care coordination services**: On the basis of the results of the risk assessment tool, individuals would be allocated to 3 levels for care coordination, level 1 - no care coordination service, level 2 - a largely phone based service similar to the service coordination offered by the SHCN CCT, and level 3 case management. The case management and service coordination service would be offered across the region, and ideally all existing case management services would come under the umbrella of the regional model. Once an individual was identified as probably suitable for case management a more thorough assessment would be completed, after which the individual would be allocated a suitable case manager. Whether all the existing case management programs would continue or could become part of a single regional case management service with distinct specialty groups (such as for the frail elderly, for children with special needs, for persons with acquired head injury, for families at risk etc).

- **Funding**: In relation to funding there seem to be a few broad options. Fund according to recent health services experience of the entire region, or fund for individuals within the region based on a risk tool. The logical approach is to develop a regional funding formula, based on pertinent population characteristics, and adjusting for supply side variables. This would enable greater equity to be achieved, in that access to services could better reflect need, as well as contribute to efficiency objectives. Funds would need to be contributed by the Commonwealth and State Government, with agencies receiving their funds through the region, rather than through State or Commonwealth programs.

- **Regional health planning/Access to services**: A strong focus on regional health planning would support the model. Planning would focus on determining need for services, as a function of the population profile of the region, and incorporating approaches to priority setting to ascertain the services that should be expanded and those which should be contracted. Services could be accessed according to pertinent eligibility criteria but with a planning element underpinning supply, to ensure a better match between services on the ground and the needs of the community. A population focus would enable greater attention to public health interventions, health promotion and disease prevention strategies.

- **Disease based initiatives**: Specific disease based initiatives to promote best practice care would also be desirable.

A regional based model as outlined above, provides an alternative means to break down program boundaries and allow funding for regions to be more equitable and promote efficiency by facilitating resource shifts, but in a way that can still encourage the adoption of best practice care. What is also a challenge is to develop a model and implementation arrangements that will simultaneously contribute not only to supply side reform and to improve quality of care, service coordination, avoidance of duplication and gaps, but also demand side reform and encourage the active involvement of patients and their families in health care decisions, to which providers respond.

The next round of trials, informed by the implementation and results of the initial round of trials should add considerably to our understanding of models of coordinated care. An important observation of the evaluation team is that the use of the randomised control, while potentially problematic in the context of a broad based and complex intervention, has proved invaluable in demonstrating the impact of the trial on health service use and cost, on quality of life and survival. The insights gained just could not have been obtained in the absence of the randomised control. This creates a major dilemma for a regional based model as the RCT is not a viable means for assessing performance.

Chapter 8

Funds Pool

8.1 Introduction

The creation of a Funds Pool from which to pay for the health services used by Trial participants represents a central element of the alternative funding and health delivery model that is the National Coordinated Care Trials. This chapter covers a number of issues to do with the Funds Pool, notably:

- *the basis for calculation of the Pool* – covering the conceptual or theoretical framework, services included, the basis for determining expected volumes, unit rate of payment;
- *protocols for service assessment* and mechanisms for adjustment in response to the status of the Pool;
- *the financial viability of the Pool:* including a brief consideration of factors that impinge on the capacity to predict service use and cost.

The chapter concludes with some observations about the importance of the Funds Pool concept, and the extent to which Funds Pooling is central to the health system reform agenda. It seeks to address the question of whether funds pooling is required to address allocative efficiency, and if so is a model based on recent service use the best way to proceed?

8.2 The role of the funds pool

Conceptual framework

The Framework for the National Coordinated Care trials, required the establishment of a Funds Pool that would bring together, into a single budget, all the sources of funds for health services for clients enrolled in the Trial. The principle underpinning the Pool is that of providing maximum flexibility in the services that could be accessed by persons with complex chronic conditions. The aim is to break down the current program boundaries in the funding of, and access to, health services. Current arrangements limit access to individual services according to eligibility criteria defined by each service in isolation. This has the effect of creating anomalies in access to services between different types of patients, with access based not on need but on meeting some defined eligibility criteria. This often leaves gaps whereby some patient groups miss out altogether, whereas others are able to access several alternative programs.

Current arrangements also restrict the capacity for resources to flow to those services most able to meet the needs of patients from those that are less effective and less cost-effective. In short, the aim of the Funds Pool is to facilitate resource shifts between services and to make services more responsive to the need of clients and less driven by the objectives of providers.

For the Funds Pool to be effective it would need to result in a different service mix, with some services expanded at the expense of others. Herein lies the inherent contradiction and challenge in making the Funds Pool model work on the ground. Trial management must be able to convince agencies to contribute, to the Pool, a share of their current budget, knowing that the objective is to purchase back more of those services found to be most valuable to clients but less of others.

Agencies must be prepared to lose some control over their budgets, to modify eligibility criteria as required by Trial management, and risk a reduction in their total budget. Even though this would be associated with a reduction in service provision it may be difficult for agencies to scale down costs in the short term in response to a reduction in demand, and agencies may not in any case wish to downsize. Agencies that expect to gain clients and additional income may be more willing to participate than those that may expect to lose clients and budgets. Further, agencies will endeavour to limit their financial exposure by insisting on an agreed 'buy back' of services or contribution to the Pool at only short run marginal cost.

Because additional services (such as care coordination and care planning) as well as administrative costs not currently provided for, are to be provided from Funds Pool budgets, even those agencies that in relative terms might expect to gain a greater share of the budget, may experience a reduction in total demand for their services (unless they provide care coordination services directly to the Pool).

Completing the negotiations required to set up a Funds Pool capable of generating flexibility in service access and use, will be extraordinarily difficult, particularly in the context of no net increase in resources to the client group. This issue has the capacity to undermine, entirely, the Funds Pool model. Other ways of bringing together the funds spent on health for a client group may then need to be explored.

While pooling of funds is widely practiced, a model which requires negotiated contributions from providers is uncommon. Alternative models are more typical, particularly:

i A regional population based weighted capitation model; whereby all funds are allocated at the regional level based on a risk or needs adjusted population formula, but where this occurs not through negotiation with individual agencies, but through direct funding from the central and/or regional government.

ii The risk adjustment model used by HMO where capitation payments are received from individuals (either paid by themselves as an insurance premium or through government or third party payers – employers, work cover, transport accident), with the Fund having complete responsibility for the purchases of services from providers. Contribution by individual agencies is again circumvented.

Given the Funds Pool model nominated for the National CCTs, performance of the SHCN CCT can be assessed in terms of defined criteria. If the Funds Pool is to facilitate resource shifts, several requirements should be met. In particular that:

- the range and scope of services that are included in the Pool is maximised;
- the Trial management has the capacity to determine eligibility criteria for access to services and to adjust access to services according to the state of the funds pool;
- it is possible to achieve financial viability. (For this to be sustainable, in the context of a fixed budget, it would need to be underpinned by zero growth in real resource use.);
- there are agreed tools to determine the total size of the Pool and a fair contribution from each agency can be determined. (The guiding principle defined by the Commonwealth is that the Pool should approximate the costs of `usual care'- the expected resources that would be allocated to the Trial population under the pre-existing health funding and delivery arrangements.)

It is important to recognise that financial viability of the Pool over a two year period, is a minimum criteria for success.

Short term financial viability will tend to reflect on the accuracy of the Pool calculation, the negotiating capacity of the trial management and the basis for access to services. (If the pool is over-estimated, financial viability will be far easier to achieve, than if it is correctly estimated or under-estimated.), short term financial viability, does not guarantee that this situation can be maintained, or that the Pool is able to facilitate resource shifts, beyond those associated with an injection of additional funds. That is, in reviewing the performance of the pool, it is necessary to look beyond simple financial viability.

8.3 Performance of SHCN CCT funds pool – basic criteria

The SHCN Funds pooling arrangement is thus considered against each of the requirements for a successful funds pool.

Scope

The scope of services included in the SHCN CCT Funds Pool is relatively narrow. The Trial management decided to focus entirely on the 'major' health services for inclusion in the Funds Pool. This reflected in part the tight time frame for setting up the trials, and the complexity of negotiations with potential contributors to obtain agreement concerning the volume and rate for the contributions to the Funds Pool. There can be forty or more HACC providers in a region, plus several community health centres, and numerable not for profit agencies, all of whom could potentially be approached to contribute to the Pool. For these providers, while their potential contribution may be small relative to the Pool, relative to their own organisation any financial exposure might be considerable. While negotiations were commenced with many agencies, (as reported in the SHCN CCT Revised Funds Pool document, May 1998 p21), RDNS was the only community based agency to be included in the Funds Pool, (and that after 12 months).

The Funds Pool initially included only in-patient admissions to MMC and DDH (including renal patients), out-patient services at MMC and DDH, HIC funded medical services and pharmaceuticals. Part way through the trial RDNS also became a contributor to the Pool. Residential care was explicitly excluded from the Pool, as were other aged care services and disability services. This contrasts with other Trials which succeeded in negotiating with a far wider range of contributors.

In terms of the objective of the Funds Pool in bringing together the entire health budget of the client group, the SHCN CCT Pool is limited. This represents a compromise to the Coordinated Care Model, but one that substantially simplified the management task, and explains in part why the Trial was able to 'go live' on July 1 1997. Even bringing together HIC funded MBS and PBS with hospital services represents a gain. In the context of an on-going health system reform it would be possible to, over time, extend the scope of services and providers included.

Basis of contribution to the pool by participating agencies

The Trial negotiated the contribution rate for each agency/provider, based on expected service utilisation and an agreed unit price. The unit price was to represent both the unit contribution rate and the fee for services purchased from the agency, for persons enrolled in the Trial (intervention group participants only).

In-patient services were contributed to the Pool, and paid for on the basis of discharge DRG, at the mean variable funding WEIS rate for MMC and DDH for 1997/8 of $1275. This was related to the estimate of expected WEIS for the participant population to determine a monthly contribution per participant. A contribution for mental health services and for renal patients (the program grant element) were negotiated separately with the SHCN.

In relation to MBS and PBS, expected use was estimated from recent experience of the eligible cohort. Unit cost reflects the government contribution to private providers based on the MBS and PBS schedules, which excludes private contributions, (made by individuals to the medical practitioner or pharmacy). Expected cost of MBS and PBS services for the enrolled population, in the absence of coordinated care was expected to equal previous experience. This was translated into an expected monthly rate per participant to define the HIC (Commonwealth Government) contribution.

In order to maximise opportunities for resource shifts, agencies should contribute to the Funds Pool on the basis of full (long run) average cost. This will ensure that the impact on the funds pool of a particular choice of services is equal to the real resource impact. It is also desirable that all agencies contribute to the Pool on the same costing basis as each other. Otherwise there will be an incentive to use those services that can be purchased at less than full average cost compared with other services which are charged at full cost. But this requirement will contradict with the objective of an agency in seeking to minimise its financial exposure, and thus contribute to the Pool at less than full average cost, preferably, at no more than short run marginal cost.

None of the main contributors to the SHCN Pool agreed to contribute at full long run average cost. Hospital contribution at the variable WEIS rate of $1275, excludes both indirect patient costs, which brings the WEIS rate to ~$2200, as well as any contribution to capital. Thus the in-patient contribution rate is only about 50% of full average cost. With MBS and PBS while the buy in rate represents the full cost to government, this represents 89%* of MBS costs (11% of payments by individuals, but 82% of all medical costs taking account also of payments by insurers and other third party payers). In relation to pharmaceuticals, government expenditure represents 83% of the cost of items on the PBS, but only 54%* of all pharmaceuticals (including also over the counter scripts). Thus MBS and PBS are paid for at less than full average cost. For MBS the discrepancy is less than with in-patient services.

Finally the less the contribution rate, the smaller the Pool and the less the opportunity for resource shifts. It also reduces the attractiveness of new services, including care planning and case management, if they have to be purchased at full average costs, while other services are effectively purchased at less than full cost. If agencies impose limits in terms of minimum buy back requirements that further limits the flexibility of the Pool. That did not occur with the SHCN CCT.

Determination of the volume of services, to which unit costs are to be applied has been a major challenge in implementing the CCTs. There are several possible approaches to estimating health service demand:

i) extrapolation: simple extrapolation from past service use, perhaps adjusting for age, disease progression (or cure), and to incorporate the effects of external influences (health technology etc.) (Such an estimate will be specific to population on whom the calculation is based);

ii) modelling of influences on health service use and cost to establish a risk/needs adjusted formula, applicable to any population – to achieve horizontal equity (that is to match service use to need, as determined by service use across a large population);

iii) a weighted capitation formula to reflect current service use as a function of patient level and regional characteristics, (as above), but also incorporating a vertical equity objective. This involves specific adjustments to take account of anomalies in service provision that have unduly restricted access to services for certain patient groups, (or made very generous provision to other groups);

iv) estimation of service needs on the basis of clinical protocols, or defined care pathways.

Any of the above approaches could be consistent with an objective of resource neutrality across the health system. The concept of resource neutrality or expected health service use can take on various meanings. In relation to the CCTs there was a strong expectation that an actuarial approach would be taken, that reflected a simple or perhaps even sophisticated extrapolation of recent past experience.

* AIHW *Health expenditure bulletin*, no 15 1997-1998 (Table 25), June 1999

The SHCN CCT employed Trowbridge consultants to undertake an actuarial analysis to determine the Pool for the SHCN CCT, and the appropriate contribution rate of the key service providers. The aim was to determine the level of health services use and cost, if coordinated care had not been introduced.

For the initial Pool calculation, use of in-patient services was analysed for 7,800 patients who met the eligibility criteria for the SHCN CCT, (more than $4,000 of in-patient admissions to MMC and/or DDH over a 24 month period). The expected future service use was based on an extrapolation from this data using a 'modified chain ladder method' in which future experience is a reflection of past experience but with projected service use reducing after an initial episode. The model takes no account of individual patient characteristics, and did not employ an econometric analysis. It seems to have inadequately adjusted for the bias associated with selecting a patient group due to their high use of in-patient services, such that the regression to the mean would be expected to be substantial in such circumstances.

Separate contributions were fixed for mental health, which was based on a daily bed day rate ($291/day), to reflect, in the first instance, the expected number of psychiatric patients and assuming a mean 15 bed days per client over a 2 year period. For renal patients an extra payment was made to cover the 'fixed program component' cost of renal services of $27,000 per patient year. Variable in-patient costs for renal patients were captured through the WEIS data.

MBS and PBS services were tracked for 2 years for 590 persons drawn from the 7,800 patients for whom in-patient data were collected, and who gave their permission to access their use of HIC funded MBS and PBS services. The pattern of use of these services was seen to be relatively regular and was simply extrapolated into the future. That is past expenditure was expected to continue unchanged.

Non-admitted services at DDH and MMC and RDNS were added later to the Pool. They represented relatively minor contributions to the total Pool. While discussions were held with a range of HACC providers concerning their participation in the Pool, no agreement was reached to pool funds for any agencies other than RDNS.

Monthly and daily Pool contribution rates were calculated and translated into total Funds Pool estimates over 2 years (the initial time-frame for the Trial), multiplying by the expected number of intervention group participants, (initially assumed to be 2000), and adjusting for a presumed attrition rate, of 30% over two years or 1.25% per month. Further adjustment was then made for actual client numbers.

In sum the Funds Pool calculation reflected the proposition that recent service use would provide a simple basis for determining future service use. The robustness of the estimates has been investigated by comparing the pool calculations with the experience of the control group participants, who approximate 'usual care'. This is shown below in Table 8.1.

Firstly the agreed contribution rates for the major health service categories included in the Pool are summarised in Table 8.1 (and compared with the actual experience). Actual contribution by the SHCN was substantially lower than provided for in both the initial and revised Funds Pool estimates. This reflects a later adjustment made some 18 months into the trial, when it became apparent that the initial funds pool contribution in relation to in-patient services was excessive, given the control group experience. Although as noted below in Section 8.3, the PBS contribution seems to have been revised down too far. (See discussion below.)

Eligibility for access to services/adjustment to access according to status of Pool

Only those services that contributed to the Pool were to be paid for from the Pool. Given the limited scope of services in this Pool, this presented a severe restriction on the possibilities for substitution. Furthermore, intervention group participants were required to access services according to pre-existing eligibility criteria. There were no discretionary funds available to GPs, Service Coordinators or Care managers to purchase services for their patients, even where these appeared on approved Care Plans and were considered integral to a patient's care. The only services purchased through the funds pool other than in-patient services, HIC funded MBS and PBS and RDNS were care planning by the GP, the service coordination and case management services offered to those in RAT level 2 and 3.

Through the Care Panels GPs were able to access support and training in the management of their cardiac, respiratory and mental health clients, or a pharmacy review of a patient's medication. For participants the only additional service was that of a respiratory nurse educator, who was difficult to access.

In short the Trial did not facilitate, through the Funds Pool, access to alternative services. There was no mechanism for adjusting the health service mix, other than through the direct activities of those involved in care coordination; the GP, the case managers and the service coordinators. This could equally have been achieved through an investment in those services, without the effort of setting up a Funds Pool.

Retaining the pre-existing basis for access to services through the Funds Pool does not support the redirection of the service mix. If changes have occurred, they are likely to reflect the activities directed at improving the quality of care through the Care Panels. The Funds Pool has not addressed the issue of program boundaries and the narrow eligibility criteria employed by programs, and of course had no capacity to influence the open-ended nature of access to Medicare services.

Table 8.1 Funds pool contribution rates for key contributors, $'000 over 2 years

Contributor	To June 30 1999			To end Trial, Dec 31 1999	
	Proposed contribution		Actual payments	Proposed contribution	Actual payments
	Initial Estimate	Revised Jan '98[2]		As revised Jan 98[3]	
SHCN					
- general inpatient [1]	$ 6,156 (a)	$ 5,215 (b)			
- renal[4]	$ 1,620 (e)	$ 413 (e)			
- outpatient	$ 721 (c)	$ 1,220 (d)			
- psych services	$ 705 (f)	$ 353 (f)			
Total SHCN	**$ 7,995**	**$ 7,553**	**$ 3,801**	**$ 6,684**	**$ 4,667**
Revised May 1998		**$ 5,366[3]**			
MBS	**$ 4,609 (g)**	**$ 4,073 (h)**	**$ 2,521**	**$ 3,630**	**$ 3,067**
PBS	**$ 2,000 (g)**	**$ 2,029 (h)**	**$ 1,188**	**$ 1,808**	**$ 1,427**

Source:
SHCN CCT Fund Pool Revision, 26.5.98, prepared by Trowbridge consultants,
a) Table 2 p 6, b) Table 3 p 7, c) Table 4 p 8,
d) Table 5, p 8 e) text p 8, 9, f) text and Table 6 p 9
g) Table 8 p 10, h) Table 19 p 22. i) Table 21 p23, based on actual enrolments

Notes:
1) based on $1275/WEIS
2) revised at Jan 1998 based on 2,000 intervention group participants,
3) revised May 1998, to take account of enrolments to April 1998, and applying an attrition rate of 1.25% per month.
4) program contribution

8.4 Financial viability of the Pool

Financial viability and genuine resource neutrality
In assessing the performance of the Funds Pool in terms of financial viability the question is not simply did the Funds Pool break even, but was financial viability if achieved, underpinned by genuine resource neutrality. If not, the financial viability will be a short lived phenomenon unable to be maintained.

Contribution rate and expenditure on pooled services
Contribution rates have been revised twice, initially on the basis of revised data on intervention group participants, and then some 18 months into the Trial based also on a comparison with control group experience. The revision was necessary in light of what was found to be a substantial over-estimate of the in-patient contribution rate. This final revision was possible because of the existence of a randomised control group. Even with the final revision, contribution from the SHCN is substantially, at 25% and $755,000, in excess of expenditure from the Pool on intervention group participants. (See Tables 8.2 and 8.3). It is clear from control group experience that the surplus almost certainly reflects an overestimate of the contribution rate by the SHCN, rather than a savings in acute care costs.

Table 8.2 Comparison of contribution rate and expenditure on intervention group participants; in-patient services, MBS and PBS to June 30 '99 $'000

Service type	Funds Pool Contributions Projected (a)	Funds Pool Contributions Actual (b)	Expenditure on intervention group (b)
SHCN in-patient and out-patient services	5,366	3,802	3,047
MBS	2,924	2,521	2,459
PBS	1,381	1,189	1,250

Source:

(a) Funds Pool Revisions SHCN CCT Table 21 p 23 total estimated Pool contribution July 1997 to June 1999

(b) SHCN Trial Data to end June 1999

Contributions to the Pool have more than covered mainstream health service expenditures, as is reported in Table 8.4. But, this undoubtedly reflects the excess contribution rate by the SHCN, in relation to both acute and outpatient services (based on estimated expenditure under usual care, as defined by control group experience) and a lesser over-contribution by the HIC. This is seen in the comparison between control group costs and contribution rates reported in Table 8.3. Under the 'revised estimate' (May 1998) SHCN contribution rate was 94% above the control group, (nearly double what it should have been). This was however further modified based on control group experience, so that actual contribution based on income received by the Trial, was 38% above the control group costs to the SHCN.[21]

This comparison was based on admissions by the control group to MMC and DDH, costed at $1275 per WEIS. (Elsewhere in-patient costs are reported for admissions across Victoria and costed at $2200/WEIS). Out-patient costs are included at price charged. In relation to MBS contribution rates under the 'revised' estimate were set at 24% above control group values, but actual contribution rates seem to be only just above control group costs (+2.5%). Unlike other estimates of MBS and PBS costs, the calculations for the comparison between funds pool contribution and control group experience includes cost to government only not also the patient contribution, as the basis on which the Funds Pool contributions were determined. In relation to PBS, the 'revised estimate' is an estimated 20% above control group costs while the actual contribution rate, adjusted in response to information on control group expenditure, is also just above the cost of usual care, (4.5%). While the RDNS recommended 'revised contribution rate' is equal to control group experience, the actual contribution rate was less, resulting in a contribution 35% below control group experience.

[21] It is not certain that fixed program funds in relation to renal patients have been handled equivalently in relation to expenditure from the pool and payments into the Pool. These payments do not appear in the cost data, so are not in control or intervention group expenditure. Whether they appear in the contribution by SHCN, or in payments actually made from the Pool, in relation to renal patients has not been established. This may alter the conclusion about the relationship between contribution and expected cost of care. Payments under the renal program are not insubstantial even for small numbers of clients as the rate is $27,000 /patient on renal dialysis per year.

Table 8.3 Contribution to and expenditure from funds pool per participant day

Cost category	Contribution $			Expenditure $			Difference % (g) between contribtn and exp on control	
	Initial estimate (a)	Revised est. May '98 (b)	Actual contribution (c)	Control	Intervention (e_p)	Intervention (e*)	Revised	Actual
SHCN								
. in-patient (d)	4.98	4.30	}3.67	2.40	}2.94	2.22	+ 79	} + 38
. out-patient	0.49	0.84	}	0.25	}	0.31	+336	}
MBS	3.16	2.79	2.43	2.25	2.37	2.38	+ 24	+ 2.5
PBS	1.37	1.39	1.21	1.16	1.21	1.19	+ 20	+ 4.3
RDNS (f)		0.14	0.09	0.14	0.08	0.09	0	- 36
TOTAL		**9.46**	**7.40**	**6.51**	**6.60**	**6.53**		

Source/Notes:

a) Fund Pool Revision SHNC CCT May 1998, Table 9, p 10,

b) ibid Table 20 p 22, or Table 21 p23 / based on an assumed 43,020 participant months to

c) based on SHCN CCT Financial Report-Income from Pooled Services total to June 30 '99, as revised to reflect the apparent over estimation of the Funds Pool contribution rate (based on control group experience); for SHCN $3.8 million, divided by 1,036,234 equivalent participant days (2,836 equivalent participant years for the intervention group), MBS, $2.52 million/1,036,234; PBS $1.25 million/1,036,234.

d) based on $1275 per WEIS and admissions to DDH and MMC only

e) e_p) SHCN Financial Report, Expenditure to June 30 1999 divided by 1,036,234 equivalent participant days (derived by the evaluation team); SHCN of $3.05 million, MBS $2.46 million, PBS $1.25 million. But not certain expenditure related to services incurred to June 30 are fully captured.
e*) estimate derived from evaluation team calculations from data provided by SHCN to June 30 1999, in-patient costs taken at $1275/WEIS and for DDH and MMC only. For MBS and PBS costs taken at government contribution only, that is excluding patient contribution.

f) RDNS pooled from July 1998; contribution rate = pooled income of $48,858/585,806 participant days from July 1998 to end June 1999. But additional $20,000 expenditure to Dec 1999, but no extra income to Pool?

g) A positive sign means the funder has contributed in excess of control group costs. So +38% means SHCN contributed 38% more than control group costs (what they might otherwise have spent on participant group), while -8% means HIC contributed 8% less than control group costs, suggesting an under-contribution to the Pool.

Statement of funds received and expenditure incurred total service plus infrastructure

Source and allocation of funds in relation to the SHCN CCT are in balance. That is incomes received from all sources - the infrastructure budget plus pooled incomes, is equal to outgoings for project development and expenditure on services. The financial result for the SHCN CCT is reported in Table 8.4. Establishment costs at $3.3 million are seen to represent roughly 25% of the total income and expenditure of the budget of the SHCN CCT.

Table 8.4 Financial outcome SHCN CCT $'000 to Trial end Dec. 1999

Cost category	Income	Expenditure	Difference: income less expenditure $	%	% (c)
I Establishment and management					
recruitment		754.1			
division of GP		150.0			
evaluation		491.5			
general trial management		1,550.1			
trial infrastructure		431.7			
sub total	**3,584.0**	**3,377.3**	**+ 206.6***		
II Pooled services					
SHCN	4,667.3	3,906.5	+ 760.8	+19%	+ 12% (c)
MBS	3,067.4	2,941.6			+ 11% (c)
PBS	1,426.7	1,501.0	+ 125.8	+ 4%	- 4% (c)
RDNS	na	na	- 74.3	- 5%	
Care planning		267.1	na		
Service coordination and case management		571.2			
sub total	**9,210.4**	**9,299.2#**	- 267.1 - 571.2 **- 26.0***		

Notes:

* wind up costs still to be covered

\# including also $40,000 on misc.

na data not available

c) income relative to costs of control group, which should be equal to the cost of usual care

Income for pooled services covered all health service costs, including care coordination, due to the large excess contribution by the SHCN, and the far smaller excess contribution from the HIC services (by 3.7%). The HIC contribution is virtually equivalent to the expenditure on the intervention group (due to a small increase in MBS and PBS costs relative to the control). In relation to the HIC, the excess contribution relative to the experience of the intervention group is even greater due to a slight reduction in use of SHCN services by intervention group clients relative to the control group.

Over the two year period from July 1 1997 to June 30 1999, the Funds Pool is financially viable, because of the large infrastructure contribution which entirely covered management and establishment cost and the excess contribution by the SHCN. At this stage financial robustness in terms of internal funds is not indicated. As demonstrated in Chapter 5, overall the total cost of mainstream services has been slightly higher in the intervention group, even excluding the costs of care coordination.

There had not been a reduction in the cost of services that could cover the cost of care planning. Although as noted in Chapter 5, a trend was emerging for a reduction in in-patient costs.

Variability of health service use and cost

The capacity to calculate a Funds Pool that will provide a reasonable predictor of health service use and cost depends on both the capacity to develop a robust predictive model, but also the underlying variability of the item being modelled. An analysis of the health service use and cost data for the SHCN CCT provides valuable insight into this question. Figures 8.1 to 8.5 illustrate the far greater variability in monthly compared with 6-monthly data, and by implication 2 yearly data (if more observations were available). This is presented in relation to total cost, in-patient admissions, MBS, PBS and RDNS. The PBS data show a very strong seasonal trend. This reflects in part the loss of capture of data once the safety net is reached, as well as the distorting effect of this on patient behaviour. Otherwise variability is inherently slight as is apparent from the extremely similar results for intervention and control group participants, on a monthly basis. MBS data also exhibits less variability than in-patient services or RDNS.

This suggests that greater robustness in the model can be achieved not just through increase in the patient population, but also by extending the time frame over which financial viability is required. The longer the time frame, the greater the chance for random error to `cancel out'. Thus for a viable Funds Pool, it may be more important to seek robustness over a two or three year period than to include more participants in the Pool. This is illustrated by comparison between the control and intervention group. Even though the control group has only 40% of participant numbers as the control group, with a longer time frame, (say 12 months), the observed variability in the control group is similar to that for the intervention group.

Certainly the idea of monitoring the Pool on say a monthly basis is not reasonable. But what it does mean is that it might take a few years to determine if a Pool is unviable by which time it would be late for taking remedial action. This presents a dilemma for Funds pool management, and is one reason for seeking robustness through an increase in the size of the participants group.

Figure 8.1 Total cost of services (mean annualised) $ for intervention and control group (all subjects), (WEIS $2200, adjusted for patient LOS)

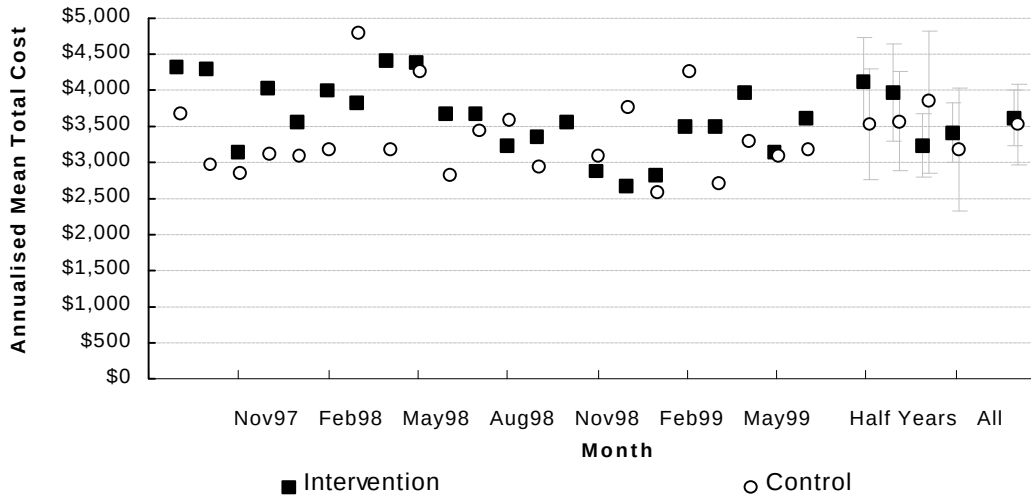


Figure 8.2 In-patient admissions: mean annualised cost $ intervention and control group, (WEIS $2200, adjusted for patient LOS)

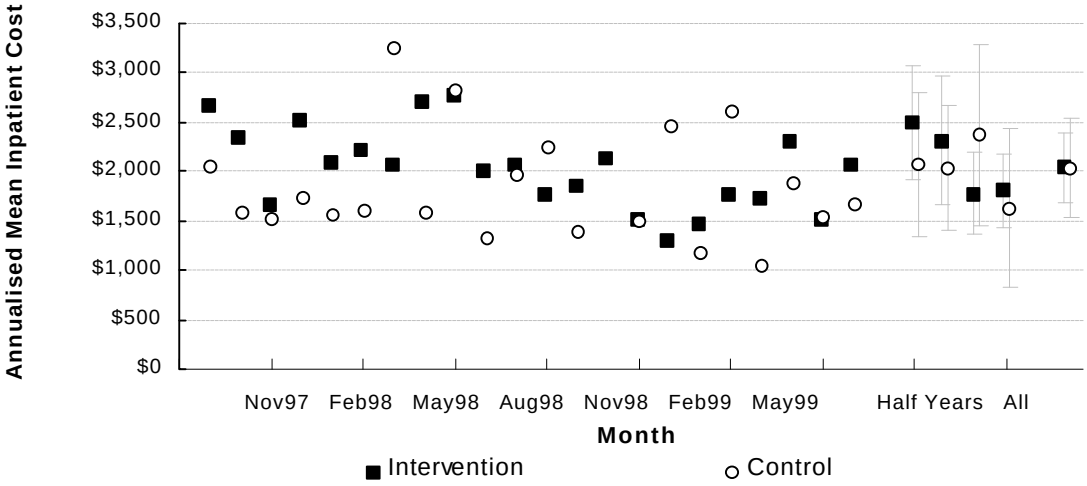
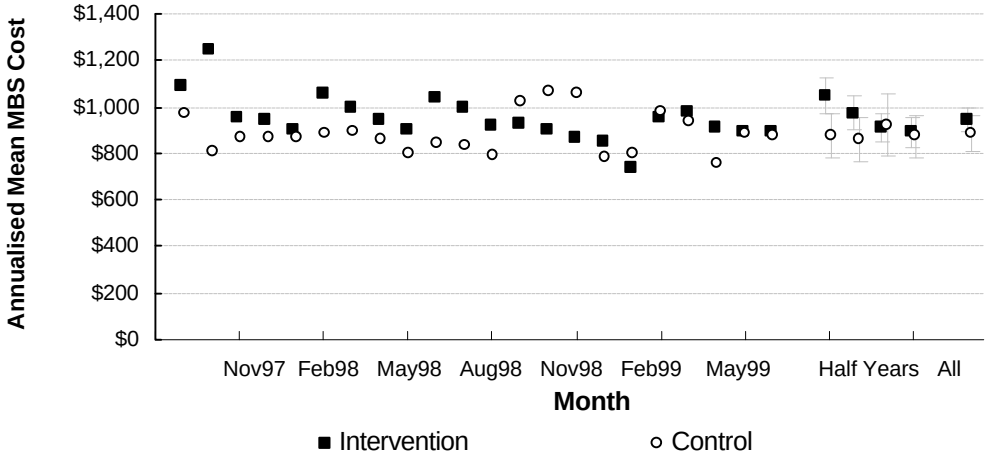


Figure 8.3 MBS admissions: mean annualised cost $ intervention and control



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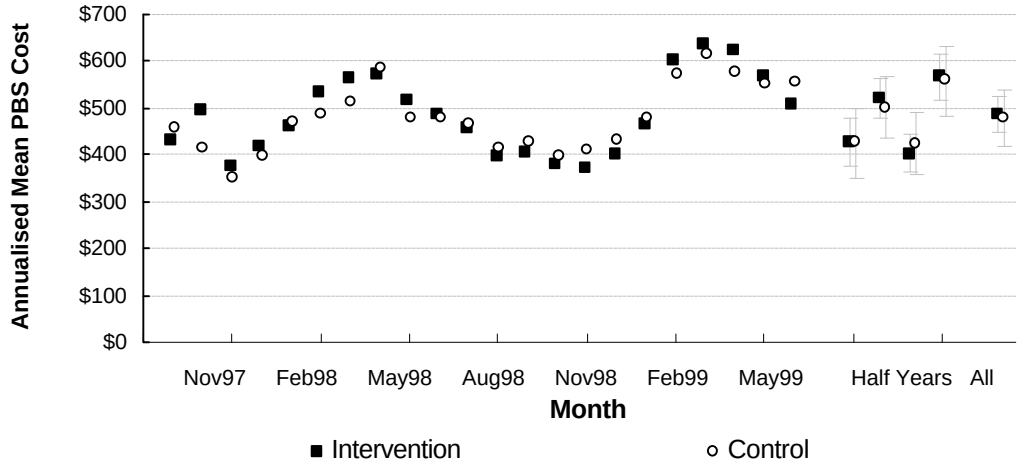
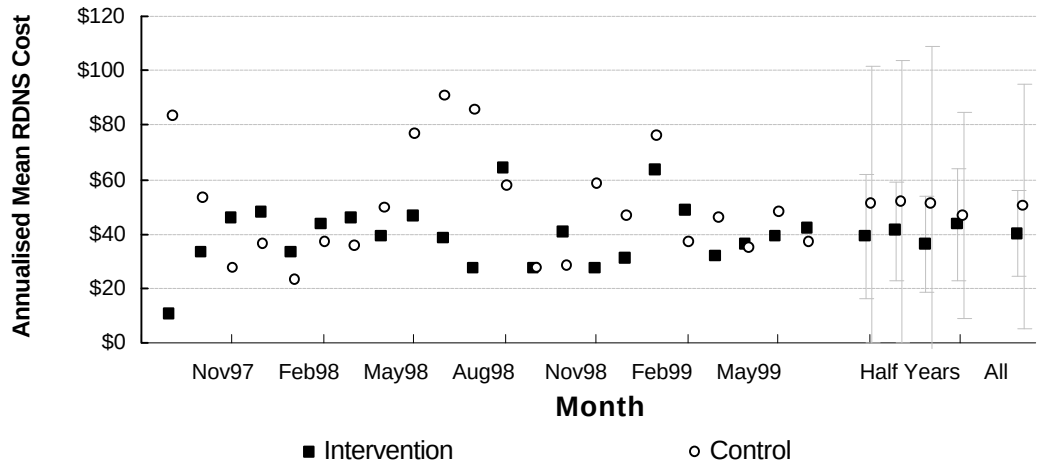


Figure 8.5 RDNS: mean annualised cost $ for intervention and control group,



Concluding observations: the performance of the funds pool component of the CCT model

In theory, greater flexibility in resource shifts should be achieved the broader the set of services included in the Pool. However, what is also critical is the basis on which services can be accessed – the extent to which contributors are prepared to risk their financial returns. The SHCN CCT had a restricted funds pool in terms of contributors, and also an extremely restricted approach to access to services. This severely limited the extent and type of resource shifts that could occur. The only way the trial influenced resource use was through the direct provision of care coordination services, which could have been done, far more simply by a single up-front payment. The funds pool was not used in any way to adjust health service use.

While there has been shift in the mix of health services (as demonstrated in Chapter 6), this has been achieved through the injection of additional money for care coordination, and extra medical services obtained through standard Medicare entitlements as a result of the care planning process. This could be supported only because the original Funds Pool estimate was too high. If a more accurate funds pool calculation had been made, the Trial would have made a substantial loss or been forced to prevent participants' access to medical services, which was not allowable under Medicare entitlements, or refuse admission to hospital for urgent care, again an unacceptable option.

Determination of the Pool on the basis of an actuarial model proved unsatisfactory. While adjustment once patient enrolment was completed improved the accuracy of the contribution estimates, there was still a large discrepancy with the cost of usual care as defined by control group experience, except in relation to PBS services, which seem readily predictable from recent experience. Even MBS is predictable from recent experience, depending on the level of accuracy required. But recent use, certainly in the absence of a sophisticated modelling approach, or without the use of specific predictors, such as the risk assessment tool, which seems to be a reasonable predictor of in-patient costs (see Chapter 11), makes estimation of in-patient cost totally unreliable. Further, without a control group, it is not clear how the validity of the estimated contribution rate can be tested.

A totally separate issue is whether cost neutrality is a reasonable objective, particularly in the context of the funding and provision of services for persons with complex chronic conditions and who are relatively deprived (in terms of socio-economic status). It is a perhaps an insurmountable challenge to improve health outcomes while achieving cost neutrality, with the client population enrolled in the SHCN CCT. There is gathering evidence that lower socio-economic status is associated with reduced access to and use of services relative to need. Added to this, with an expenditure per head in Victoria on public hospitals which is lower than the Australian average, the potential for cost savings might be slight. That is funding on the basis of recent experience might well favour the adoption of coordinated care in geographic areas and in relation to disease groupings that are well funded. That is not necessarily desirable.

If the funds pool is to be based purely on 'expected cost' based on history or the experience of a control group and takes no account of needs, trials in areas which are currently relatively poorly funded will struggle with a requirement for budget neutrality and financial viability.

In conclusion based on our evaluation, in the context of the SHCN CCT, the Funds Pool cannot be deemed to be a successful component of the model, either in the way implemented by the SHCN, or more broadly in terms of whether it is an effective means for contributing to the objectives of coordinated care. While this is not to suggest that the polling of funds is not desirable, other options, notably a regional population based approach is likely to offer any advantages. This options have been discussed further in Chapter 7 on the Care Coordination model.

Chapter 9

Achieving A Better Result The Second Time Around

9.1 Introduction

It is appropriate at the end of the Southern Health Care Network coordinated Carte Trial (SHCN CCT) and the first round of trials more generally, to reflect on its (their) results to inform the design and implementation of the second round of trials. It is also important to assess the significance of these studies' results in terms of new learning and knowledge about coordinated care in the wider academic literature.

In broad terms, while the SHCN CCT had some distinctive features, the results of its evaluation were similar to other trials, at least as provisionally reported in the Major Interim National Evaluation Report. These were that coordinated care led to expenditures above existing resources but with no improvement in individual client health and wellbeing, at least as measured with the SF36. Reckoned this way, the primary hypothesis of the national evaluation was not confirmed (null hypothesis not negated). This has led, not unnaturally, to considerable discussion about the value of coordinated care and its place within wider Australian health service reform and development.

A number of suggestions have emerged from these discussions about the reasons for these results. For example, there has been questioning about the sensitivity of the SF36 to detect program effects on a trial population with such diverse illness and care characteristics. Other suggestions have concerned the artificial nature of the funds pooling arrangements and the nature of the care coordination model. Some others, though, concern the use of coordinated care resources and the need to refocus these. This could involve directing the care effort at sick individuals at an earlier stage of their illness. It has been argued that in the first round of trials, resources were unduly directed at individuals at the end stage of their illness with a downward health trajectory determined largely by their disease rather than coordinated care.

These latter propositions concern secondary hypotheses 3 and 4 - the extent to which the quality of clinical and service delivery protocols and the characteristics of the client population affect the success of coordinated care. These will be considered in turn in this chapter. As will become clear, the two topics are interrelated and it is not really possible to discuss them separately.

9.2 Care coordination, hospitalisation and quality of life

A central proposition about coordinated care (or case management more generally) is that it leads to more appropriate service use - reduction in inpatient hospitalisation and its replacement by care in the community (as well as reduction in pharmaceutical usage and specialist referral by the general practitioner).

A review of the literature concerning case management for the frail aged and patients with severe mental disorders confirms that the institutionalisation rate (for nursing homes and mental health institutions respectively) may be reduced, particularly for those most at risk of this happening (Fine and Thompson, 1994; Marshall and Lockwood, 2000). A number of studies have been published concerning the impact of case management on high-cost, acute sector (hospital) users (eg Smith et al, 1988; Fitzgerald et al, 1994; Weinberger, 1988; Weinberger et al, 1996). The last in this series of studies did not confirm a reduction in readmission rate, but rather an increased rate in patient admission and health service usage with no improvement in health outcome as measured by SF36 levels. The results of the evaluation of the SHCN Trial are consistent with these findings. It may be then that care coordination (or case management) in the acute care sector does not lead to lower institutionalisation rates in that sector as it does in the aged care and mental health sectors.

In terms of the psychometrically validated SF36 and AQoL there was no change in health related quality of life for participants in the SHCN CCT in either the care coordination or control groups. But neither was there any deterioration in the scores. However, there were statistically significant differences between the care coordination group and the control group in terms of their perceptions of the impact of the SHCN CCT on their quality of life. The more favourable perceptions of clients in the coordination group about the Trial and its impacts on their quality of life are similar to the reports of increased patient satisfaction in the Veteran Affairs Trial.

While impacts in the acute care sector (favourable client judgements about coordinated care and its impact on their quality of life) may not be as 'hard' as health outcomes measured by SF36 and AQoL levels, they are nevertheless important. They add another dimension to understanding the impact of such trials upon participants' quality of life. This is particularly so when it is remembered that treatment of chronic illness is not curative and able to produce the major improvements in health outcomes as measured by SF36 scores. In these circumstances, treatment is more palliative in intent.

Nevertheless, if the aim of the coordinated care trials continues to be 'improved health and wellbeing within existing resources', it is unlikely that coordinated care as delivered in the first round of Trials will produce this. This means that to realise the primary hypothesis it will be necessary to vary the model of coordinated care. The coordinated care model can be varied in a variety of ways and these are discussed further in Chapter 11. The intent is the same – to achieve a shift from current clinical practice. This practice can be characterised as being reactive to patient demand and employing clinical processes largely based on the experience of the individual doctor or an authoritative mentor chosen by that doctor. The desired shift (at least for chronic illness) is to proactive care based on patient need and evidence-based clinical processes that are comprehensive, including test ordering, drug prescribing and specialist referring. One way to do this is to more centrally base care plans around clinical protocols.

9.3 Care coordination and the use of clinical protocols

Clinical protocols have been, until recently, consensus-based but, since the establishment of the Cochrane Collaboration, they have been increasingly evidence-based. They are becoming increasingly influential amongst the leaders of the medical profession but still encounter grass roots resistance from doctors who perceive them as intruding on their clinical autonomy and diminishing the value of their clinical experience.

Based on the identification of diagnostic and treatment processes for diseases common in primary care for which strong evidence exist for their effectiveness, there is an argument for their application in primary care. It should be conceded however, using evidence-based criteria, that the evidence for the beneficial impact of these clinical protocols in general practice is not overwhelming. An evidence-based review of the impact of clinical practice guidelines on patient outcomes in primary care by Worrall *et al* (1997) revealed only 13 relevant studies and only five of these showed statistically significant, albeit modest, improvements in outcome and only for some of the patients studied. They concluded that:

> 'there was little evidence that the use of clinical practice guidelines improve patient outcomes in primary medical care but (that) most studies published to date have used older guidelines and methods, which may be insensitive to small changes in outcomes. Research is needed to determine whether the newer, evidenced-based guidelines have an effect on patient outcome'.

An important factor influencing whether guidelines have an impact on general practice is whether they are accompanied by strategies to overcome barriers to their take-up. These strategies include GP education (by e.g. academic detailing), financial incentives, audit and feedback and consumer input. The effectiveness of these strategies to overcome barriers is currently being subjected to a Cochrane Review by Baker *et al* (2000). One important recent randomised control trial of the impact of guidelines accompanied by practice education on the care of diabetes and asthma in general practice in East London indicated that the management of diabetes and possibly asthma was improved (Feder et al, 1995). Another study (on clinical guidelines for patients with low back pain) also demonstrated important improvements in patient outcome (Deane & Crick, 1998).

Other relevant considerations in the use of clinical protocols are the extent to which current clinical practice in general practice already conforms to evidence-based recommendations for diseases that are severe and prevalent in general practice, and to what extent any lack of conformity has important consequences in terms of its impact on patient outcome.

The use of clinical protocols to improve patient outcomes was an option in the first round of trials. A number of factors however limited their application. First, their use was promoted as an innovation alongside service delivery protocols, including ones aimed at protecting the Funds Pool, as a result of which clinical protocols would not have used by some trials. Second, the diversity of the illness experience of the client populations in the trials in general, and the SHCN CCT in particular, suggested that no one or two diseases would be sufficiently prevalent to justify strategies based on the use of clinical protocols for these diseases. Third, the use of clinical protocols is contentious, provoking debate about the overall role of care coordinators and whether its effects are empowering or disempowering for the client/patient. These factors limiting their application, though, do not necessarily need to operate for the second round of trials.

The second of the factors above (viz. diversity of illness experience) certainly should not. Even in the SHCN CCT with the extreme diversity of the illness experience of its client population, it became clear by the end of client recruitment that a small number of diseases were very prevalent in the client population. This can be seen from the following:

- **There were 283 clients in the Trial with a mental health diagnosis - 16% of all clients and 24% of the high-risk group.**
- There were 628 clients with cardiac diagnoses - 36% of all clients and 50% of the high-risk group.
- There were 274 clients with respiratory diagnoses (excluding upper respiratory tract infection) - 11% of all clients.
- There were 183 clients with diabetes (mainly Type 2 diabetes) - 16% of all clients and 24% of the high-risk group.

Given these figures, the argument for the initial non-use of clinical protocols in the Trial disappears.

The third of the factors listed (viz. disempowerment of clients) also should not limit their application if it is appreciated that clinical protocols per se do not disempower clients/patients. Other features of the care coordination process, in parallel with the use of clinical protocols (such as non-medical case managers and service coordinators and/or care plans which incorporate features that empower clients) should ensure that clients are not disempowered by the use of clinical protocols.

For these different reasons it is concluded that there is a strong, though not overwhelming, case for strengthening coordinated care through the greater incorporation of clinical protocols in the care planning process.

9.4 Care coordination and the place of self management

Self-management of chronic illnesses has been an important recent initiative of the Commonwealth Government. As a recent edition of the *British Medical Journal* indicates, disease management of chronic illnesses includes self-management. An editorial in this issue noted:

> 'Recently, three programmes have been developed that enhance the ability of patients with chronic disease to participate in their health care. Each places patients in a central role and has been tested experimentally.'

The first is self management education that addresses continuous use of medication, behaviour change, pain control, adjusting to social and workplace dislocations, coping with emotional reactions, learning to interpret changes in the disease and its consequences, and use of medical and community resources. Participants experience reduced symptoms, improved physical activity, and significantly less need for medical treatment. Some benefits have lasted years beyond the education. An important element for participants is learning from each other, and the principal reason for benefit is growth in confidence in their ability to cope with their disease (Lorig et al, 1993; Lorig et al, 1999).

The second approach is group visits. These are recurrent meetings of groups of patients with their principal doctor. The agendas are largely set by the patients and concern problems they encounter from their disease. Participants experience increased quality of life, much slower decline in activities of daily living, greater satisfaction, and reduced use of medical services (Beck et al, 1997).

The third approach is remote medical management via the telephone or electronic communication. Chronic disease is particularly suitable for remote management, especially when there is continuity between the patient and service provider. In randomised trials telephone management has been shown to reduce cost and to improve the health status of participants compared with patients receiving usual care. (Wasson et al, 1992, in Simon et al, 2000).

As these various self-management strategies make clear, there are a number of strategies for coordinating care that may exist either alone or may co-exist with care planning. They point the way to further developments in coordinated care and diversity in its application locally. There is a strong argument, as coordinated care is progressively introduced into the Australian health care system, for these diverse coordinated care programs to be trialed and evaluated so as to identify the single or suite of programs that best meets the needs of the Australian population.

9.5 Selecting the client population most able to benefit

Selection of the eligible client population for coordinated care remains a matter for debate. It may be that coordinated care has greater impact on patients before they reach the end stage of their disease(s) or on patients with different diseases or mix of diseases than others. The evidence to define which client group is most able to benefit from coordinated care however does not exist. It would be necessary to compare its relative efficacy – the relative potential magnitude of effects assuming complete adoption across different diseases and stages of diseases. It would then be necessary to compare its relative effectiveness in the context of Australian health care system assuming limited adoption against an unknown level of coordination services at baseline. These statements also apply to the introduction of clinical guidelines both in the presence or absence of strategies to overcome barriers to their introduction.

It is possible though to make some general observations about the need for, and the capacity to benefit from coordinated care, and also general observations about some common (albeit related) debating points such as:

- Should programs be population-wide?
- How tightly targeted should programs be?
- Should programs be aimed at clients with one single disease rather than a number of diseases?

9.5.1 Need and capacity to benefit

These concepts, though related, are not identical. Need may be defined in terms of the existence or severity of a disease state(s). As such, it implies a need for services. The provision of these services does not, just by the fact of their existence, mean that the patient will benefit. Or if they do benefit, this may not be in the way that is anticipated. For example, patients may be reassured by the existence of a service but it may not produce a health benefit or a health service benefit such as the prevention of a hospital readmission. Further it is necessary to distinguish between the relative economic costs of coordinated care interventions that produce benefits of the same magnitude. As noted above, much better information is necessary to define which interventions produce the greatest benefits and at the lowest cost.

It can be observed however that while it is intuitively true that patients with the greatest needs - the most severe illness(es) – are most suitable for coordinated care, it needs to be empirically demonstrated that they have the most capacity to benefit and at the lowest cost. Until this is so demonstrated, it would seem worthwhile to entertain a wider range of possible client groups as being suitable for coordinated care.

9.5.2 Should programs be population-wide?

In policy terms, the answer is straightforward – yes. The Commonwealth's intention in undertaking the Coordinated Care Trials is to test their value but with the expectation that this will be demonstrated and that coordinated care will be rolled-out nationally and become a major health service delivery reform. To assess its value on a population-wide basis would seem essential for this, not only on equity grounds but also to assess whether it can gain wide support from carers, not just the enthusiastic few, and form an important part of a reformed system of health care. The SHCN CCT clearly did implement a 'population-wide' program of this nature – it included those who had a one-off acute episode of care but who were subsequently in good health as well as those with chronic illnesses.

The only possible disadvantage to this approach is that it focuses on effectiveness rather than efficacy at a stage when it is not completely clear what it is about the package of reforms that constitute the Coordinated Care Trial, that produces benefits to patients or that it does so within existing budgets. This is the difficulty of 'getting inside the black box'. There is perhaps an argument here for simplifying the intervention to one component and perhaps restricting it to one disease state only in order to achieve conceptual and experimental clarity. Whether a single intervention such as this is likely to produce a program impact that is important to patients could be debated.

A better alternative is to proceed with a program that employs multiple strategies, that is population-wide, and that attracts the allegiance of the wider health care community to produce a program impact that is important to patients. At the same time, through a program logic approach, the conduct of 'little' experiments within the rubric of the wider Trial could be used to investigate a whole number of hypotheses about what (if anything) it is within the coordinated care package that produces benefits to patients. Such an approach is at the heart of the Realist Evaluation movement, popularised by Pawson and Tilley (1997) and identified by Kalucy et al (2000) in their reflections on the conduct of the evaluation of the HealthPlus Coordinated Care Trial.

9.5.3 How tightly targeted should programs be?

This is essentially a debate about obtaining the best outcome in minimising false negative and positive rates. False negatives occur when coordinated care programs have eligibility criteria that exclude individuals who could benefit from coordinated care. False positives occur when coordinated care programs have eligibility criteria that include individuals who are unlikely to benefit from coordinated care. Typically it is difficult to minimise both simultaneously. In other words, if the eligibility criteria are drawn to include all potential clients who could benefit from coordinated care (ie minimise false negatives), a number of clients unable to benefit from coordinated care are likely to be included. If the eligibility criteria are drawn to minimise the number of clients unable to benefit from coordinated care, a number of potential clients who could benefit from coordinated care are likely to be excluded.

The advantage of defining eligibility criteria that minimise false negatives rather than false positives as its first objective is that it is subsequently possible to identify clients who constitute these false positives and remove them from the trials. There is however a cost and an inconvenience and discomfort to the individuals who form this group.

Given that 70% of intervention clients in the SHCN CCT were classified as low risk, it might be considered, at least with hindsight, that the eligibility criteria, while minimising false negatives, did create a large number of false positives. If historic service use is to form the basis for establishing eligibility in future Trials, options such as exclusion of clients with only one episode of care or raising the cutoff for high expenditure service use above $4,000 over two years could be considered as ways of reducing the false positive rate.[22]

9.5.4 Should programs be aimed at clients with one single disease rather than a number of diseases?

This issue has been indirectly considered as part of the discussion regarding whether programs should be population-wide. Broadly the argument is the same. It is desirable to study more than one disease in order to increase the study's policy relevance. However, it should be possible to nest substudies within the main study and investigate the effects of coordinated care on particular diseases and so 'get inside the black box'.

This was done to some extent in the SHCN CCT to investigate the care panels introduced with late funding at Trial midpoint. Given these circumstances, it was only possible to engage in studies that did not involve randomisation and without prior sample size calculation to ensure that adequate statistical power existed.

In a future Trial, it should be possible to stratify the study population on the basis of nominated diseases such as cardiac, respiratory, diabetes or mental health prior to randomisation and to randomise within these strata. Given the large sample sizes necessary in the coordinated care trials for policy reasons, it should be possible to undertake these substudies with adequate sample size and statistical power.[23]

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22 Another issue with regard to historic high expenditure service use, as an eligibility criterion is whether it does truly minimise false negative rates. Other trials recruited clients using multiple entry points to advantage. Supplementing historic use with either self- or carer-referrals could further reduce false negatives.

23 Since these diseases often coexist in the one patient, it may be necessary to combine some of these disease classifications or create a new multiple diseases category.

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Annexure to Chapter 9

Secondary Initiatives: The Care Panels

9A.1 Introduction[24]

Within the SHCN CCT the primary intervention was care planning and implementation. A number of secondary intervention initiatives were developed after the Trial had started. Four of these secondary intervention initiatives involved targeting particular disease groups and making use of 'best practice' guidelines to address ways of improving clinical outcomes and service utilisation for the people in those groups. Table 9A.1 shows the number of intervention clients in each major disease group. The largest number clients in the group with a cardiac diagnosis and the smallest number in the group with a diabetes diagnosis.

Table 9A.1 Intervention clients in the major diagnostic groups

Diagnoses	Clients with a care plan (N=1,749)		Percentage of diagnostic group per risk level		
	Number	Percentage	Low-risk	Medium-risk	High-risk
Cardiac	628	36%	30%	53%	50%
Mental health	283	16%	6%	21%	24%
Respiratory	274	16%	Data not available		
Diabetes	183	10%	7%	6%	24%

In 1998 and 1999 a mail survey of GPs was undertaken and in the second wave of the survey a number of questions were included to assess the impact of the four initiatives.[25] They were asked specifically if the initiative involved any of their Trial patients with the targeted disease diagnosis and what effect the initiative had on the management of these patients with regard to:

- evaluation and investigation of the disease;
- identification of relevant risk factors;
- management of the disease; and
- patients' understanding of the disease.

The questions were repeated four times – once for each initiative.

24 This section of the report draws on information supplied by Louise Greene at the Trial and the 1999 GP survey.

25 An outline of the survey methodology is contained in Chapter 12.

9A.2 Cardiac care improvement initiative

Within the group of 628 intervention clients who had cardiac diagnoses, the most common ICD9 diagnostic categories were Essential Hypertension (224 clients) and Ischaemic Heart Disease (211 clients). Clients with these two disease states constituted the target population for the cardiac initiative. A multidisciplinary panel was formed, and included practitioners from both the acute and primary sectors who provided care to clients with cardiac disease as well as a consumer representative, to guide the initiative.

A clinical protocol was developed in the form of a desk top aid for GPs (*Desktop Guide to the Management of Secondary Prevention of Cardiac Disease*) and individual pre-labelled care pathways prepared for those clients who had the target disease mentioned in their care plan. These pathways were sent to the clients care coordinators by mail and to compensate them for the time it took to examine and apply the guidelines the GPs were reimbursed the cost of a short consultation ($21). Where a GP felt that the client was not appropriate for the care pathway they were asked to return the pathway indicating this. Three hundred and ninety-two of 492 care pathways (80%) were completed and returned.

In the 1999 survey, 139 respondents indicated that they had clients in the target group, and 43 (31%) indicated that the initiative involved their patients.

Table 9A.2 Impact of the cardiac initiative on clinical practice

	GPs	Helped greatly		Helped		Did not help	
	Number	Number	Percent	Number	Percent	Number	Percent
Evaluation & investigation	43	3	7%	15	35%	25	58%
Identification of risk factors	43	2	5%	16	37%	25	58%
Management of problem	43	4	9%	17	40%	22	51%
Patient's understanding	42	2	5%	12	29%	28*	66%

* Includes one GP who indicated that the initiative had hindered

9A.3 Mental health care improvement initiative

Among the 283 intervention clients with a mental health diagnosis, the most common ICD9 diagnostic categories were Depression (119 clients) and Unspecified Anxiety (50 clients). One hundred and fifty-eight GPs were involved in the care of the clients with a mental health diagnosis and 14 clients in this group were involved in 25 unplanned admissions. Following a GP Needs Evaluation survey, it was decided to mount an initiative aimed at GPs with clients in the Trial rather than an initiative aimed at these clients more directly.

To improve communication between GPs and the local area mental health service a Mental Health Liaison Service was developed by the Dandenong Area Mental Health Services. The liaison officer made 6 outreach visits to 30 GPs in their clinics, to improve the level of confidence and skills of GPs when dealing with a mental health disorder through the use of an existing program (SPHERE – a National Depression Project). Four CME-accredited educational sessions were conducted. The needs evaluation ascertained that 82% of GPs were interested in having a continuing medical education program on mental health.

In the 1999 survey, 127 respondents indicated that they had clients in the targeted group, and 27 (21%) indicated that the initiative involved their patients.

Table 9A.3 Impact of the mental health initiative on clinical practice

	GPs	Helped greatly		Helped		Did not help	
	Number	Number	Percent	Number	Percent	Number	Percent
Evaluation & investigation	26	4	15%	10	39%	12	46%
Identification of risk factors	26	4	15%	9	35%	13	50%
Management of problem	26	5	19%	9	35%	12	46%
Patient's understanding	26	5	19%	8	31%	13	50%

9A.4 Respiratory care improvement initiative

Similarly to the cardiac initiative this one also involved a multidisciplinary panel to guide the initiative and the development of a best practice guide (*Desktop Guide to the Management of Secondary Prevention of COPD*) and a care pathway based on those guidelines. A practice outreach visit to individual GPs was made to deliver the guide and care pathways and a financial incentive to encourage the application of the care pathway was made available. A respiratory physiotherapy service for use on a group or individual basis was made available. One hundred and fifty-one GPs were involved in the care of the clients in the target group identified by this initiative.

In the 1999 survey, 116 respondents indicated that they had clients in the this group, and 38 (33%) indicated that the initiative involved their patients.

Table 9A.4 Impact of the respiratory initiative on clinical practice

	GPs	Helped greatly		Helped		Did not help	
	Number	Number	Percent	Number	Percent	Number	Percent
Evaluation & investigation	38	3	8%	14	37%	21	55%
Identification of risk factors	38	1	3%	11	29%	26	68%
Management of problem	38	3	8%	8	21%	27*	61%
Patient's understanding	38	2	5%	14	37%	22	58%

* Includes two GPs who indicated that the initiative had hindered

9A.5 Diabetes care improvement initiative

There were 183 intervention clients in the Trial with diabetes (mainly Type 2 Diabetes) involving 120 care coordinators and there were 52 admissions between (July 1997 and June 1998) involving 11 patients.

Rather than establishing a care improvement panel the Trial decided to work with a program recently established by the Dandenong DDGP: Complete Diabetes Care. The program included care coordinators in their register of GPs with the support of the Trial resources.[26] The program involved putting diabetic clients onto a register system and having an in-built reminder system for key elements of care.

In the 1999 survey, 132 respondents indicated that they had clients in the this group, and 44 (33%) indicated that the initiative involved their patients.

Table 9A.5 Impact of the diabetes initiative on clinical practice

	GPs	Helped greatly		Helped		Did not help	
	Number	Number	Percent	Number	Percent	Number	Percent
Evaluation & investigation	44	5	11%	20	46%	19*	43%
Identification of risk factors	44	4	9%	21	48%	19	43%
Management of problem	44	7	16%	18	41%	19**	43%
Patient's understanding	44	5	11%	19	43%	20*	46%

* Includes one GP who indicated that the initiative had hindered
** Includes two GPs who indicated that the initiative had hindered

9A.6 Conclusions

In terms of GP involvement, only one-third or less of the GPs who had clients in the target groups for these initiatives indicated that they had Trial patients who were involved. The diabetes and respiratory initiative had the highest level of involvement (33%) and the mental health initiative the lowest, 21%. In terms of the impact, the GPs rated the diabetes and mental health initiative most helpful. Fifty percent or more of the GPs who had patients involved indicated that the initiatives had either 'helped' or 'helped greatly' in the evaluation and investigation of the disease, the identification of relevant risk factors, the management of the disease and the patients' understanding of the disease. There were very few comments on the questionnaires but the few that were there give some idea of why these initiatives were helpful.

> *I don't think any of my CCT patients were in, but we had these visit and they were of use, mainly in understanding local psychological services better. (*Mental Health Initiative, GP 1206)

> *Largely reinforced need for regular review in patients' thinking.* (Diabetes Initiative, GP 1240*)*

[26] See Chapter 1, section 1.4.1 for a discussion of the implications of this strategy

In these terms the respiratory and cardiovascular were the least successful initiatives. These were the two initiatives that developed desk top management guides and individual care paths for intervention clients. Once again the GPs comments give some idea of why these initiatives were less successful.

> *Both patients have received tertiary care for heart disease and so have already had a full work up.* (Cardiovascular Initiative, GP 1003)

> *Respiratory at Springvale Community Health Centre not available at the time of first request.* (Respiratory Initiative, GP 1156)

> Pat*ient already plugged in to relevant services.* (Respiratory Initiative, GP 1347)

However, one GP did say of the cardiovascular initiative:

> *The booklet was helpful to me re lipids and smoking guidelines.* (Cardiovascular Initiative, GPP 1271)

Planning for these initiatives did not begin until mid 1998 and they were not fully implemented until 1999. Therefore they had only been in place for a short while when the 1999 survey of GPs was undertaken. However, the results of the survey do suggest that the initiatives involving care panels, management guides and individual care paths were less successful in terms of their impact on GPs clinical practice than the other two.

Endnote

Other initiatives included the service utilisation report initiative and the pharmacy strategy group initiative. A formal evaluation of these initiatives was not undertaken.

1. Service utilisation report initiative

Bimonthly reports of service utilisation (MBS, PBS, SHCN, RDNS) by clients in the Trial were made available to 193 GPs (care coordinators) willing to participate and willing to accept the privacy provisions of the Trial. Care coordinators were surveyed with regard to the usefulness of the information contained in the reports.

2. Pharmacy strategy group initiative

A pharmaceuticals high-user group was identified – 326 (approx 20% of clients) were prescribed more than five scripts, this forming 87% of all scripts. 45 (approx 3% of clients) were prescribed more than 20 scripts, this forming 33% of all scripts. Four initiatives were mounted:

1 Drug information telephone service
2 Medication counselling for at-risk clients
3 Medication check up service for GPs (8 only performed)

Practice outreach – academic detailing in relation to Non-Steroidal Anti Inflammatory Drugs (NSAIDs) and Helicobacter Pylori eradication (40 individual or group visits). There was evidence of reduction in scripts prescribed for NSAIDs but not H2 antagonists, proton pump inhibitors or Bismuth.

Chapter 10

The SHCN CCT risk assessment tool – a review

10.1 Development of the risk assessment tool

The coordinated care model implemented by the Southern Health Care Network Coordinated Care trial (CCT) incorporated three levels of coordinated care:

- A basic level for clients whose health status was such they required minimal intervention and were, broadly, capable of managing their own care;
- An intermediate level for clients whose health was impaired and who were deemed to be at risk. These clients were assigned to an intermediate level of coordinated care drawing upon the expertise of a service coordinator who assisted them access the services they needed; and
- A high level of coordinated care for patients with poor health prognosis. These clients were assigned to intensive care coordination, with access to a case manager.

The purpose of these different levels was to offer greater assistance to clients with more complex health problems and greater risk of hospitalization. The assistance was to best maximize clients' health and well-being and, within the available resources, minimize hospital admissions. To achieve this, the CCT needed an instrument to allocate clients to the appropriate care coordination level. The CCT's criteria for such an instrument were that it had to be:

1. capable of matching clients with a clinically appropriate level of coordinated care;
2. short and easy to administer, so that participating GPs could administer it without any formal training;
3. sufficiently sensitive so it could be re-administered at different points throughout the CCT trial and at these points identify client movement between different care levels;
4. generic so that it was applicable across a wide variety of diseases and health states; and
5. valid and reliable, in the sense of being able to predict the needs of clients for care coordination, which it was postulated should reflect expected health service use, (of medical services, pharmaceuticals, hospital in-patient and out-patient services and community based services), as well as self care capacity.

Potential instruments analysed

The issues in measurement implied in these three levels and five criteria were discussed in a previous report to the CCT (Hawthorne 1997a). Reviewed in this same earlier report were several functional status instruments, including the:

- Barthel Index (modified)
- Case Manager's Decision Guide (CMDG); the *High Risk Screening Assessment Instrument*
- Dartmouth COOP Function Charts (COOP)
- Functional Independence Measure (FIM)
- Instrumental Activities of Daily Living Scale (IADL)
- Older American Resources and Services (OARS)

Several health status instruments were also reviewed, (Hawthorne 1997b), which could have been considered for use as a risk assessment tool, including: the Assessment of Quality of Life Index (AQoL); the Health Utilities Index (HUI-III), the 15D, the Quality of Well-being Scale (QWB) and the Sickness Impact Profile (SIP). None of these instruments met the criteria outlined above, and the SHCN CCT determined to develop its own special purpose instrument, which became the *Risk Assessment Tool* (RAT). The nature of the instrument is described in Section 10.2, below. For the purposes of allocation to care level, at baseline RAT scores were classified into three categories:

Risk level 1: score 9–13, scores presumed to indicate a low level of coordinated care needed,
Risk level 2: score 14–20, scores presumed to indicated need for a moderate level of care coordination,
Risk level 3: score 21–27, scores presumed to indicate need for a high level of care coordination.

As a newly developed instrument which had not been validated, the quality of the Risk Assessment Tool and its capacity to perform the function of allocating trial participants to distinct levels of care coordination need was not known. The purpose of this Chapter is to report on our assessment of the performance of the Risk Assessment Tool. Specifically in this Chapter we report on:

- The psychometric properties of RAT, given that no formal piloting or psychometric developmental work was undertaken prior to its implementation;
- whether the pre-determined cut-off points (as nominated above were appropriate); and
- whether the RAT instrument predicted future health care needs. This is relevant both as an indicator of the need for coordinated care, but also as a possible data source for determining the Funds Pool for an enrolled population.

Elsewhere in this Report, the views of GPs and others on the robustness of the RAT for the allocation of participants to three care coordination levels is reported. The analysis reported in this Chapter, uses the treatment cohort's data to examine the psychometric properties of the RAT instrument and to report on it's predictive power in relation to health service use.

Data sources

The data presented in this Chapter come from three sources:

a) Baseline RAT scores were entered directly from completed RAT forms where the forms had been filled in by clients' GPs. All these cases were CCT treatment clients. No control clients were administered RAT.
b) The Medical Benefits Schedule (MBS), Pharmaceutical Benefits Schedule (PBS) and hospitalization data were supplied by the SHCN CCT; and
c) The demographic, SF36 and AQoL data came from the baseline CCT evaluation data collected by the Centre for Health Program Evaluation (CHPE).

Data were collected from these three sources for all 1790 intervention cases to whom the RAT instrument was administered. Although the CCT enrolled 2074 cases in the treatment group, only 1789 cases were assigned RAT scores at baseline; non-RAT cases have been excluded from this analysis. The data were entered from the original RAT instrument questions and an audit undertaken to verify the data; RAT scores were then computed. This procedure provided for an investigation of actual RAT scores rather than the GP or SHCN scores, which were contaminated by the occasional coding error (see Section 10.3).

Regarding MBS, PBS and other service data, the data period covered from individual activation in the trial to either trial exit or June 30 1999. Generally these data are presented as service or cost per trial day to account for the different periods spent in the trial.

The characteristics of the SHCN CCT population have been described in Chapter 3 and are not repeated here. Clients of the SHCN CCT cover a wide age range from infants, to the very elderly, all disease groupings, from the very sick to those in excellent health. A large minority (41%) were born outside Australia but for 89% English was the preferred language. On average participants (control and intervention group) have a low income (mean personal income $11,323), likely to be on a pension or in receipt of a government benefit (62%), have low private health insurance cover (14% reporting private hospital cover), with 13% reporting that they needed a caregiver.

Participants were also on average in poorer heath than the general community. For instance, compared with the mean rate of hospital admissions for Victoria in 1995-6 of 194/1,000 (AIHW 1998), the mean admission rate among the intervention group was 0.69 per client year in the CCT, or 697/1,000 clients/per year[27]. This is 331% higher than the Victorian average. Mean use of MBS services for Victoria in 1996-7 of 8.8 for males and 12.9 for females per person per year (AIHW 1998), compares with a mean 15.1 per person per year for the SHCN CCT intervention clients. Health status is also identified as poorer based on the SF36 scores, of 42.5 and 45.7 respectively for the PCS and MCS, which compares with the Australian norms, (ABS 1995), of 49.7 for the PCS and 50.1 for the MCS scales.

10.2 The risk assessment tool

Given the limitations of the reviewed instruments, one of the recommendations from the Hawthorne (1997a) review was to develop a screening instrument based on the *High Risk Screening Assessment Instrument* (CHPDM 1996). This recommendation was accepted, and a 9-item instrument was developed by the CCT, the *Risk Assessment Tool* (RAT). A copy is presented in the Annex to this chapter.

Development of RAT

Based on the instruments reviewed by Hawthorne (1997a), and drawing on the expertise of the General Practitioners Reference Group (GPRG), the SHCN CCT developed the RAT instrument to meet with the criteria outlined above. The GPRG acted as a development committee and met weekly over a period of six weeks. After confirming that none of the available instruments were suitable, the GPRG set about defining the purpose and role of the RAT. A high priority was that GPs would be willing and able to complete it. The issue of GPs' assessment of patients was not discussed as it was assumed GPs would be familiar with their patients and with their social and medical needs.

[27] Missing data were of two types: (a) data which were omitted due to some unknown reason, but which were technically available, and so were not missing at random; and (b) genuine missing data, which was missing at random. Unfortunately, there was no method of identifying which kind of missing data was applicable to each case. The effect of this confounding on the analyses has not been determined, and the report, particularly Sections 4 & 5, should be read with this caveat in mind.

The method of instrument construction was somewhat haphazard and dictated in part by the urgency to have an instrument in the field at the commencement of the Trial. The process consisted of preparing drafts which were reviewed at subsequent meetings or between meetings. Drafts were considered by both members of the GRPG, the SHCN CCT team and the evaluators at the CHPE. In addition, in an attempt to ensure the validity of the instrument, efforts were made to match the instrument with selected CCT clients' tracking phase medical service usage. This was done by applying an abridged version of the proposed instrument to selected clients and then extracting their data. Based on these methods, putative levels of 'risk' were determined to allocate clients to particular levels of care coordination.

Although this enabled links between assigned care levels and service utilization to be demonstrated, the data were historical whilst the assigned levels were based on current health status; the validity of RAT scores predicting future needs and requirement for care coordination was not investigated. At the end of the six weeks, the final version of the *Risk Assessment Tool* was ready.

Description of RAT

The RAT was intended to be completed by a client's care coordinator (the client's GP), and consists of 9 items, each with three item response levels. The 9 items cover:

- A general assessment of the client's ability to self manage their health care needs
- An assessment of the client's social needs
- The degree to which the client requires assistance with activities of daily living
- An estimation of the number of specialist visits required by a client in the next 12 months
- An estimation of the number of other health care services likely to be used
- The complexity of the client's health status
- Client's use of medications
- The likelihood of the client staying in hospital and the length of that stay
- An estimate of the likely level of care coordination needed by the client.

Scoring of RAT was by simple summation: the response levels were summed to produce a score where the scale endpoints were 9 and 27; the higher the score the greater the level of need. These scores were then re-coded into three categories:

1. 9–13. These scores presumed a low level of coordinated care would be needed
2. 14–20. Presumed a moderate level of care coordination
3. 21–27. Presumed a high level of care coordination would be needed.

Results of application of the RAT

During data entry, 29 cases were identified where there were inconsistent responses or scores, (the handling of these items is noted in the Full report Volume IV).

The frequencies of item responses are given in Table 10.1. Although all figures suggest most clients were rated as needing the minimum level of care coordination, there were differences in the data distribution between the items. (See Figures 3.1 to 3.9 Volume IV).

Table 10.1 Distribution of responses to the nine questions on the RAT

Question	Score 1 Low risk	Score 2 Medium risk	Score 3 High risk
Q 1 General coping	71%	19.4%	9.5%
Q 2 Need for social support?	81.4%	15.8%	2.8%
Q 3 Capacity to self manage ADL	85.3%	7.8%	6.9%
Q 4 Expectation of GP and/or specialist visits	56.8%	33.2%	10.0%
Q 5 Expected use of other health services	74.4%	19.5%	6.1%
Q 6 Complexity of illness	32.5%	40.3%	27.2%
Q 7 Use of medications	75.5%	20.6%	3.9%
Q 8 Likelihood of in-patient stay	79.3%	14.9%	5.8%
Q 9 Overall need for care coordination support	74.2%	21.4%	4.5%

RAT questions with fewer than 5% of cases loading on any one response were questions 2, 7 and 9. This is indicative that these questions did not adequately discriminate between cases.
The opposite observation, but leading to the same conclusion, is made of question 6; here 27% of cases were assigned to level 3, suggesting this item also failed to adequately discriminate between cases, by it being too easy to be scored on level 3. Generally, these four items would be excluded from further analysis on the grounds of poor characteristics. They have, however, been retained given their inclusion by GPs and subsequently by the CCT in the computation of RAT scores.

RAT scores were summed and the distribution examined. These data are presented in Figure 10.1 and Table 10.2. These show that scores were distributed over 96% of the possible range, with a positive skew towards the higher end of the range; thus demonstrating an inverse relationship between the assessed need for a high level of coordinated care and the numbers of clients so assessed.

The distribution of cases into the predetermined risk levels is shown in Figure 10.3. This shows that while 70% of cases were assigned to the lowest risk (and hence lowest care coordination level) only 4% were assigned to the highest risk category (highest care coordination provision).

Figure 10.1 RAT score distribution

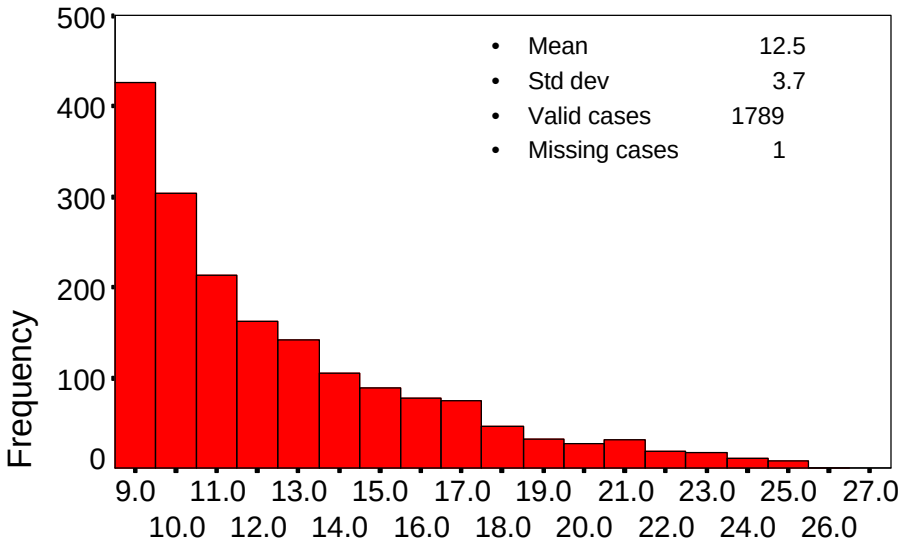
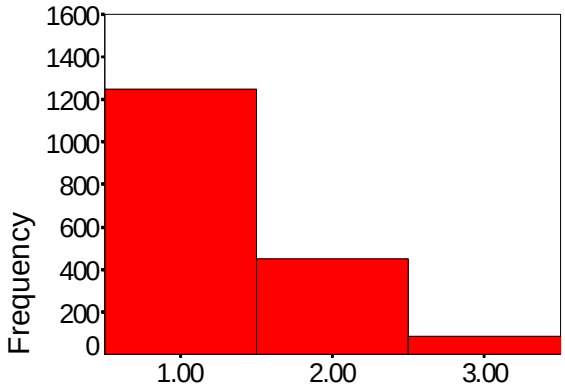


Table 10.2 RAT raw scores

Value	Frequency	Percent	Valid Percent	Cumulative Percent
9	427	23.9	23.9	23.9
10	304	17	17	40.9
11	214	12	12	52.8
12	163	9.1	9.1	61.9
13	142	7.9	7.9	69.9
14	105	5.9	5.9	75.7
15	89	5	5	80.7
16	77	4.3	4.3	85
17	75	4.2	4.2	89.2
18	46	2.6	2.6	91.8
19	32	1.8	1.8	93.6
20	28	1.6	1.6	95.1
21	31	1.7	1.7	96.9
22	19	1.1	1.1	97.9
23	17	0.9	1	98.9
24	11	0.6	0.6	99.5
25	8	0.4	0.4	99.9
26	1	0.1	0.1	100
Missing	1	0.1		
Total	1,790	100	100	

Figure 10.2 Risk assessment levels

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Low risk	1	1250	69.8	69.9	69.9
Moderate risk	2	452	25.3	25.3	95.1
High risk	3	87	4.9	4.9	100.0
	.	1	.1	Missing	
	Total	1790	100.0	100.0	



This data is based on the original RAT forms. The RAT risk assessment levels used by the CCT, however, were based on those computed by the GPs. Twelve of the 1789 cases were misassigned by the GPs, based on recorded responses to the RAT, including one case which should have been assigned to the 'high' risk cohort that was assigned to the 'low' risk cohort. Full results are reported in Figure 10.4. Overall, the data suggested there were few problems with using the RAT instrument to assign participants to a care coordination level.

10.3 Rat validation

Although the descriptive statistics presented in the previous section imply the RAT instrument performed as expected, they do not provide any evidence for the measurement validity or reliability.

Validity

Validity is concerned with the 'truthfulness' of an instrument or scale; i.e. it addresses the question of how well a test actually measures what it purports to measure. As such it is the keystone upon which a test rests as it enables a researcher to make inferences from test scores to reality; that is it provides the justification for using and interpreting a scale or instrument.

Issues in validity

There are three issues which underpin validation of an instrument.

1. There must be an actual relationship between the universe or concept being measured and the scale used to measure it. Both the scale and the universe must be stable, and must be able to be measured reliably.
2. The trial sample providing the validity data must be heterogeneous and preferably randomly selected; if the group is homogenous the validity estimate will be spuriously low. This is particularly an issue where the sample has been screened in some way during the selection process.
3. There is no commonly accepted method of determining validity, but the procedures widely recognized apply to all types of validity. Validity is assessed with a trial group, which should be a sample drawn from the same population as the research sample.

Types of validity

Generally it has been accepted there are three aspects of validity:

- *Content validity*. Refers to how well a test result samples (the measurement on the scale) from a universe so that the researcher can generalize from this sample of items to the total universe. The purpose of measurement is to make inferences from the measurement to the whole of reality, i.e. the generalizability of measurement to the universe, whether it be a universe concerned with knowledge, attitudes or behaviours. Thus Lennon (1956;294) described content validity as: ".. the extent to which a subject's responses to the items of a test may be considered to be a representative sample of his responses to a real or hypothetical universe of situations which together constitute that area of concern to the person interpreting the test." The term *face validity* is often used interchangeably with content validity, but it is not the same thing. Face validity refers to whether a scale 'looks right' upon inspection of the item content; as such it is useful from a public relations perspective, but it possesses no technical merit.

- *Construct validity*. This is where an instrument is to be interpreted as a measure of some attribute which has been inadequately defined, i.e. scale scores can be used to infer certain concepts. This implies the researcher accepts an underlying construct as an adequate definition of whatever it is that is being measured. This is usually defined by the researcher. If no adequate construct is defined, the content of the instrument defines the construct that is being measured (Cronbach & Meehl 1955). If a scale has construct validity, subjects' scores will vary in accordance with the theoretical underlying construct.

- *Criterion validity* (including both *concurrent* and *predictive* validity). This relates to the relationship between scale scores and either other independent measures (criteria) or other specific measure (predictors). *Concurrent validity* refers to the scale's validity regarding subjects' performance now; i.e. to what extent do obtained scores reflect the present situation. *Predictive validation* is where a scale score now can be used to predict some future performance; i.e. scale scores predict some future universe.

Regarding the RAT instrument, no specific tests were undertaken during instrument construction to provide any content validation: it was informed by the reviewed instruments, and reflects GPs' beliefs concerning the factors likely to influence the level of care coordination needed to maximize health and well-being and minimize the risk of hospital admission. As such it may be said to possess 'face validity'; i.e. it looks 'right', but the formal properties behind this have not been established. This study does not report further on the content validation of the RAT instrument.

For construct validity, again no definitions of 'health', 'well-being' or 'hospitalisation risk' have been made available. As such the primary focus of the test of validity was examination of the internal structure of the RAT and examining the relationship between RAT scores and various demographic variables, the hypothesis being that while RAT scores would vary on those variables presumed to be strongly associated with health status (e.g. the presence of a caregiver), but the scores would not vary on variables for which there was no logical link with health status (e.g. gender).

Finally, criterion validity. In this study this has been examined using other data from the CCT as the criteria against which the RAT instrument is assessed, viz. hospital admissions, MBS service use, PBS service use, the SF36 scores and the AQoL scores. The findings in this section provide some insight into cut-off scores used by the CCT for assignation to care level.

Construct validity, psychometric properties

Standard psychometric procedures were used to examine the internal structure of RAT, specifically item correlation, exploratory factor analysis and reliability (internal consistency). Moderate correlations calculated between the different RAT items suggest that the RAT items were measuring different, but related, concepts[28] (see also Volume IV).

The principal components factor analysis, found that all 9 items were related to a common concept or universe; 62% of the variance was explained by the 9 items. The internal consistency of the scale was $\alpha = 0.85$, which suggested excellent reliability. The principal components analysis also revealed the presence of two factors (eigenvalues: 4.2 and 1.4 respectively). This analysis demonstrates that although the RAT instrument was conceived of as measuring different aspects of need as defined by the level of coordination of care — the common underlying universe — it contains two quite distinct scales; one on service (five items) and one covering ability to cope (four questions). The correlation between these sub-scales was moderate ($r = 0.53$), suggesting they are measuring separate, but related concepts.

Although factor analysis examines the internal structure of an instrument, it does not attach any particular meaning to each of the identified factors or scales. This is conventionally achieved by examining the content of the pivotal items (i.e. those items loading the highest on each factor). The principal components analysis suggests that item 9 (the GP assessment of the likely level of care coordination needed by the client) is the pivotal item.

[28] This poor correlation is not surprising: a well person on no medications could be expected to be reported as having no informal care needs. Likewise, a person who is ill but who is on effective medication may also have no informal care needs.

Relationship with other indicators of health status[29]

The socio-demographic status variables collected from CCT clients were divided into two groups: those which, on logical grounds, should not vary by RAT status (i.e. for which there was no compelling reason that these would be associated with health status leading to particular levels of care coordination need). These were gender, age, place of birth, language spoken at home, marital status and education. A second group were hypothesized would vary by RAT status (i.e. which were assumed to be associated with particular care coordination needs): being accommodation, caregiver status, pension status, private health insurance.

The data for gender show little difference by risk level, (females slightly more likely to be assigned to level 1, males to level 2 , but no difference in gender for level 3 (5% for both). Age and RAT score data are presented in Figure 10.5. This shows that there was a low correlation
(r = 0.26) between age and RAT scores; suggesting that RAT was not particularly sensitive to clients' ages.

Figure 10.5 Rate vs age

In relation to place of birth, those born overseas were more likely to be classified at level 3 when compared with the Australian-born (6% versus 3% of the Australian-born). Consistent with this, there were significant differences in RAT scores by the language spoken at home, with English-speakers more likely to be classified as Level 1, (72% versus 62%). There was however no significant difference between the two groups in relation to service use, MBS, PBS or hospital admissions.

For relationship status, CCT clients were dichotomized into two groups: those living in a relationship (of any type) and those who reported they were single (regardless of the cause). Those in a relationship were significantly more likely to be classified at level 1 (75% versus 56% of the singles), and that those who were single were more likely to be classified at level 2 (38% versus 21% of those in a relationship) and level 3 (6% and 4% respectively).

[29] The interpretations in this section are based on examination of the residuals from the χ^2 analyses. In some cases this results in descriptions which are not immediately obvious from the raw data in the figures.

If it is assumed that the presence or absence of a caregiver provides a crude dichotomous estimate of health status and need for more intensive care coordination support, it could be expected that RAT-scores would be highly associated with caregiver status. This is apparent, in that 16% of RAT level 1 clients report a caregiver, compared with 50% of level 2 clients and 67% of level 3 clients.

Relationship between accommodation and living arrangements and RAT level are complex, except that clients living in either a retirement village or nursing home were more likely to be classified at level 2 or level 3 (37% and 12% respectively, compared with 28% and 6% for those living alone and 23% and 4% for those sharing accommodation.

Socio-economic variables

Formal education was defined at three levels: those who completed primary school, those who completed high school, a technical and further education (TAFE) certificate or reported 'other' educational qualifications, and those holding a university degree. Primary school-only clients were more likely to be assigned to levels 2 and 3 (34% and 10% respectively compared with 23% and 4% for those completing high school and 13% and 2% for university graduates. (See Table 10.6)

Table 10.3 Coordinated care level by educational status

Risk level	Formal Education		
	Completed primary school n=221	Completed high school/TAFE etc. n=1105	University degree n=134
level 1 low risk	56%	73%	84%
level 2 medium risk	34%	23%	13%
level 3 high risk	10%	4%	2%

Health Care Card holders were significantly less likely to be classified at RAT level 1 (59% compared with 88% of non health care cardholders), and more likely to be classified at level 2, and level 3 (34% and 7% compared with 11/1% respectively for non-cardholders). However there is no significant relationship between RAT scores and private health insurance status.

Criterion validity

In the letter forwarded to the GPs describing the function of the RAT instrument, the CCT explained that it was designed to identify clients in need of care coordination "... to maximize patient wellbeing and minimize unplanned hospital admissions". To assess criterion validity, it could be expected from this that there should be an association between measures of patient wellbeing, service use and hospitalisation.

For the purpose of this analysis, these concepts were operationalised using the following measures.

1. **Wellbeing**: Baseline data from both the SF36 and the AQoL were analysed. For the SF36 the two summary measure scales (physical component score and the mental component score) were used as health status indicators. For the AQoL, the global utility scores were used as measures of patient health-related quality of life (HRQoL).
2. **Service use**: Based on frequency counts for SHCN CCT participants of the number of medical services used (MBS) and the number of pharmaceutical scripts (PBS) captured by the HIC.
3. **Hospitalisation**: Two measures of hospitalization are reported here: a dichotomous variable of whether a patient was admitted to hospital, and the number of days a patient was in hospital.
4. **Combined service costs**: Costs of all services used were computed and calculated as combined service cost per client day in the CCT. This procedure adjusted costs for the length of time that individual clients were in the trial.

Wellbeing: patients' health status (the SF36)

It was expected there would be a moderate to high correlation between RAT and the SF36 summary scales. The correlation between the RAT and the SF36 summary scores are shown in Figures 10.5 and 10.6. There is a moderate correlation between RAT scores and the SF36 Physical Component Score (r = –0.50) indicating that these two scales are measuring different, but related, concepts. The correlation between the RAT and the SF36 Mental Component Score is much lower (r=-0.26), suggesting these two scales are measuring different concepts. These findings suggesting that RAT instrument is moderately associated with patients' health status, but has a stronger association with patients' physical health.

Figure 10.4 RAT & SF36 PCS scores

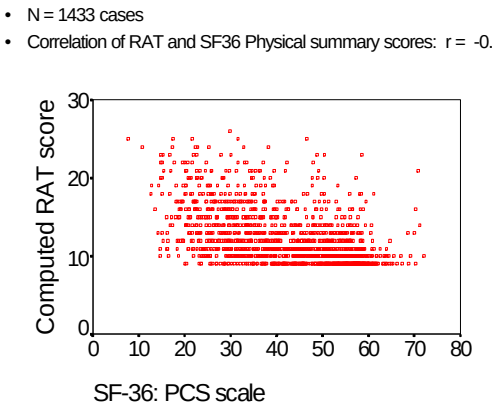
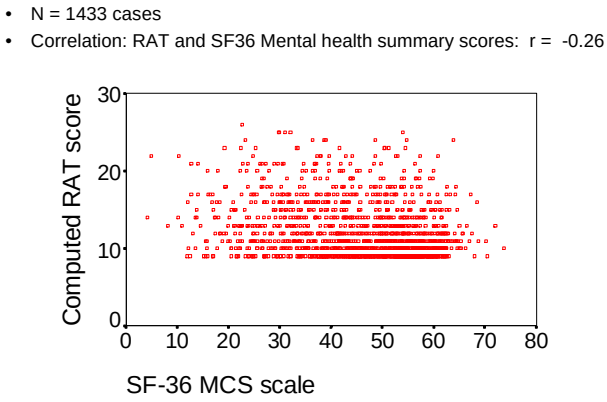


Figure 10.5 RAT & SF36 MCS scores

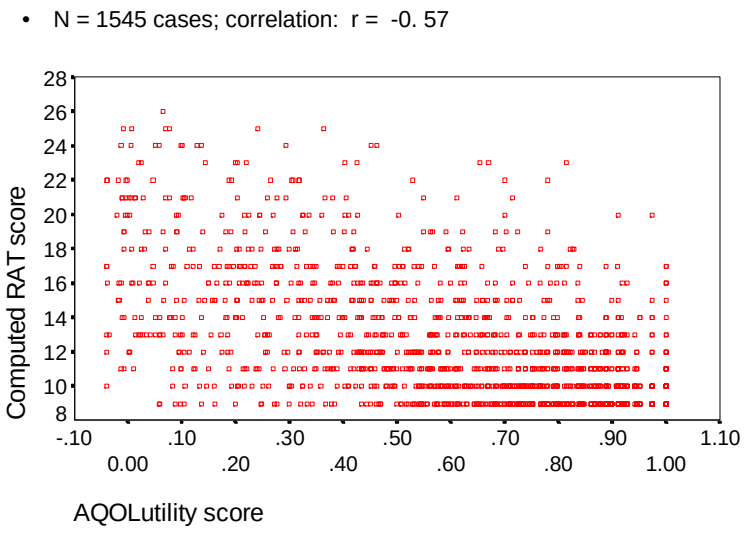


Wellbeing: quality of life (the AQoL)

The AQoL provides a utility index of health related quality of life based on five dimensions referring to dependence on medical care, capacity for independent living, quality of social relationships, physical senses and psychological well-being. Each dimension has three items, and each item has 4-levels ranging from normal health to worst health state (Hawthorne and Richardson 1995; Hawthorne, Osborne et al. 1996). Scores from four dimensions are combined together in a multiplicative model to derive the utility values.[30] The instrument was developed from a theoretical conceptualisation of health-related quality of life, based on the WHO's definitions of health, disease, disability and handicap. (WHO 1958; WHO 1980).

It was expected there would be a moderate to high correlation with the AQoL's scores, since both instruments are (theoretically at least) concerned with patients' health status. Both have items measuring patients' coping ability, use of medications and medical care and social relationships. The correlation between the RAT and the AQoL was –0.57 (see Figure 10.7). This may be slightly lower than expected but suggests the RAT and AQoL measure different, but related, concepts.

Figure 10.6 RAT & AQoL scores



Service use: MBS and PBS

The relationship between RAT scores and the MBS data is shown in Figure 10.8. It was expected there would be a high correlation, based on the assumption that MBS service usage and the RAT items covering service usage — the four items measuring likely GP/specialist use, other health service use, illness complexity and medication use — would be measuring the same thing. The obtained correlation of r = 0.36 is, at best, a moderate correlation. The relationship between RAT score and use of PBS items is given in Figure 10.9, where the correlation is shown to be r = 0.36, also a moderate correlation.

30 The Illness dimension is not used in utility computation (Hawthorne et al 2000).

Figure 10.7 RAT & MBS service usage

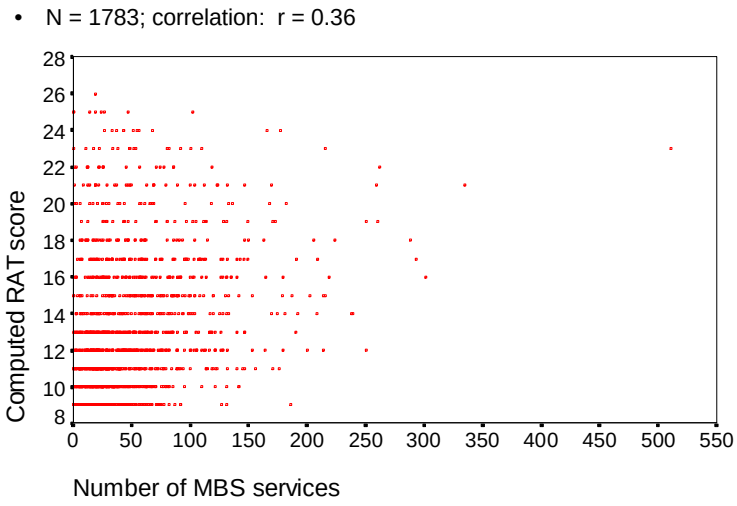
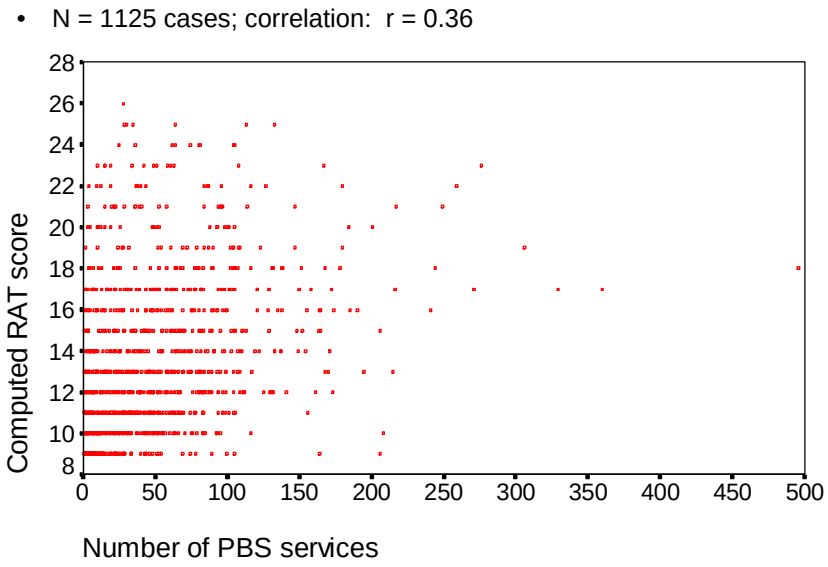


Figure 10.8 RAT & PBS scripts



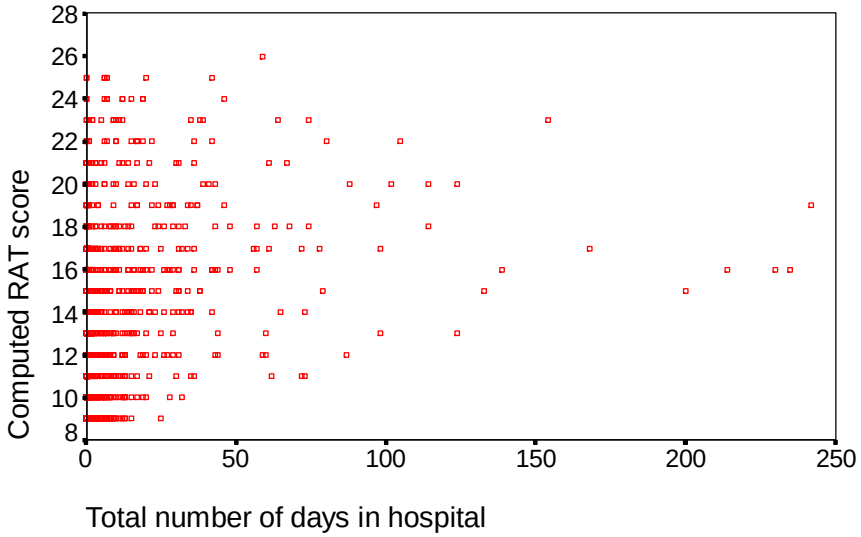
Hospitalisation: inpatients

CCT clients were dichotomously coded into those who had been admitted to hospital during the study period and those who were not admitted. RAT scores are associated with hospital admittance, with 35% of RAT level 1 patients admitted over the primary Trial period, (to June 30 1999), compared with 67% of level 2 patients and 77% of level 3 patients. This indicates that the RAT instrument discriminates between those likely to be admitted to hospital and those unlikely to be so.

In relation to total beddays, there is a modest correlation (r = 0.32) between RAT scores and total days in hospital, as demonstrated in Figure 10.10.

Figure 10.9 RAT and hospital bed days

- Correlation between RAT and days in hospital: r = 0.32



Outpatients

Cases were dichotomized into those who had been treated as an outpatient and those who had not. When this was examined by RAT level the data in Table 10.7 were obtained. Level 1 cases were somewhat less likely to be treated as outpatients, at 21% compared with as were 36% of level 2 and 31% of level 3 cases.

Table 10.4 RAT and outpatient status

	OUTPATIENT STATUS				TOTAL	
	NO		YES			
	Number	Percent	Number	Percent	Number	Percent
Low Risk (Level 1)	986	79%	259	21%	1,245	100%
Medium Risk (Level 2)	287	64%	164	36%	451	100%
High Risk (Level 3)	60	69%	27	31%	87	100%
TOTAL*	1,333	75%	450	25%	1,783	100%

Note:
* 7 missing observations

Royal district nursing service use

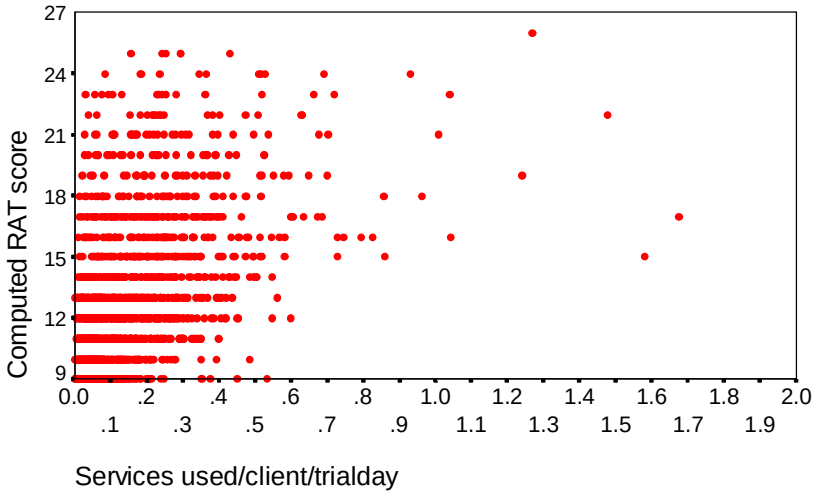
There were significant differences in the use of RDNS services by RAT levels. Of all RDNS service users, 38% were cases classified at level 1, 41% were from level 2 and 20% were level 3 cases. When examined by RAT level, reported RDNS use was 3% of those classified at level 1, 10% of those classified at level 3 and 24% of those classified at level 3.

Total health service use

A limitation of the above analyses is that a person may use one medical service in lieu of another or may use services in combinations. Therefore an index of combined service use per client day in the CCT was devised and the relationship with the RAT score calculated. As shown in Figure 10.12 the correlation is quite good (r=0.53) given it is based on individual patient level data.

Figure 10.10 RAT vs all service use per client day

- Correlation between RAT and all service use: r = 0.53



10.4 Predictive power of the RAT

The 'ultimate' validation of RAT scores is their predictive power: to what extent do RAT scores predict service utilisation and need for care coordination support? Two methods are presented here, each serving a different purpose:

- First a conventional (simple) regression analysis is presented based on the individual client's data. This estimates the predictive power of RAT for an individual's service use.

- Then a grouped regression analysis is presented based on the use per client within strata (determined by RAT scores). This estimates the predictive power of RAT for the group's service use. Because of the reduction in data points, this procedure resulted in very high r^2 values, but would be relevant for example, in the planning of the delivery of services or for determining contribution rates to a Funds Pool. Where few cases were available at the higher RAT scores data have been grouped: RAT 22 with 23 (36 cases) and RAT 24, 25 and 26 (20 cases); (allocated to a score of 22 and 24 respectively .[31]

[31] Although regression is a robust statistical procedure where the requirements are that data are interval or ratio (Zar, 1984), a potential threat to the analyses was the non-normal distribution of data with most cases piling up at low RAT scores, as shown in Figures 3.11 & 3.12. Regarding the individual level analyses, the effect of this was investigated through analysing the data as per the RAT scores and then comparing this with grouped data for those scores where there were fewer than 20 cases, as described. The only differences in the r^2-values were for outpatient status (Figure 5.6) where r^2 = 0.04 rather than 0.03, and for RDNS use (Figure 5.14) where r^2 = 0.05 instead of 0.04. Given these small differences, the ungrouped results are presented.

The computational method used was the same in both analyses: for each dependent variable a dummy variable was computed and a simple regression equation constructed in which RAT scores were the independent variable. The database used in these analyses is presented in Table 10.8.

Individual variables were mapped against RAT scores in Figures 10.(13, 15, 17, 19, 21 and 23) for individual data analyses with regression lines. Figures 10.(14, 16, 18, 20, 22 and 24) present the grouped data analyses. As illustrated by each of the figures, the ability of RAT to predict service usage at the individual level for each attribute taken separately is between 2% and 16%, which is modest relative to results commonly reported in the literature in relation to risk adjusted capitation models.

While for grouped data high predictive power is indicated, with on average 52% of variance in service usage explained by grouped RAT scores, the improvement largely due to the reduction in data points. It will be observed that outliers have been retained in the analyses. They were retained on the grounds that unusual events occur in the health field and it is precisely these events for which health services are required.

Figures 10.13 and 10.14 show the data for hospital admissions. At the individual level admission was dichotomized into those who were admitted and those who were not; 55% of cases did not attend hospital. The results showed that 2% ($r^2 = 0.02$) of admissions could be explained by RAT scores. Turning to the group analysis, as shown in Figure 10.14, the data revealed that 25% of admissions could be predicted from the RAT scores.

The grouped method generally takes account of this skew since it is based on service use per client/day within strata. It is, however, subject to the caveat that in those strata with few cases the variability will be high due to the lack of homoscedasticity. Hence the amalgamation of RAT scores in the grouped analysis where there were fewer than 20 cases.

Table 10.5 Service use database

RAT	ADMIT	ADMITY	LOS	LOSY	OUTP	OUTPY	MBS	MBSY	PBS	PBSY	PSY	PSYY	RDS	RDSY	COST_T	COSTY
9	116	.25	432	.61	66	.09	9837	14.47	2566	11.26	1	.00	11	.02	571080.0	833.85
10	87	.30	463	.92	58	.11	9278	19.03	4465	16.71	2	.01	9	.02	690224.9	1403.02
11	78	.58	607	1.73	51	.14	8244	23.46	5182	20.82	1	.00	7	.02	644841.0	1869.46
12	78	.82	763	3.21	41	.16	8452	31.63	6023	29.35	0	.00	8	.03	808472.7	3128.44
13	71	.82	688	4.42	43	.19	6309	27.08	4733	28.89	5	.02	5	.02	678487.9	3246.84
14	65	1.19	744	5.97	31	.23	6135	37.53	4470	34.71	5	.04	7	.04	757472.6	5745.27
15	60	2.46	959	7.75	25	.18	6153	49.75	4472	40.33	1	.01	4	.06	641319.9	5219.72
16	55	5.83	1588	16.61	36	.36	5089	48.71	4218	43.00	1	.01	7	.06	863947.7	8398.61
17	45	2.52	951	14.80	27	.24	5212	47.56	4667	44.93	3	.03	8	.07	731000.6	8473.69
18	30	1.47	753	11.38	18	.23	2956	39.34	3596	51.12	2	.03	2	.04	435833.2	6100.65
19	25	7.56	760	15.25	15	.28	2742	60.01	2054	57.42	1	.02	9	.17	399019.3	8675.61
20	21	5.34	664	28.56	12	.32	1594	36.79	1369	42.16	1	.02	6	.18	274665.9	9107.78
21	20	1.34	324	6.27	9	.17	2454	64.17	1589	43.04	2	.04	5	.18	276446.1	6238.81
22	31	3.26	870	17.83	15	.28	2563	50.42	2244	54.06	2	.03	8	.15	499747.2	9695.79
24	16	2.71	290	23.56	3	.20	1008	40.57	1063	56.75	1	.03	8	.43	190772.4	11550.95

Notes:

RAT = RAT score
ADMIT = Number of admissions at each RAT score level
ADMITY = ADMIT/ID/Year in CCT*
LOS = Number of days hospitalized at each RAT score level
LOSY = LOS/ID/Year in CCT*
OUTP = Number of outpatient attendances at each RAT score level
OUTPY = OUTP/ID/Year in CCT*
MBS = Number of MBS services at each RAT level
MBSY = MBS/ID/Year in CCT*
PBS = Number of PBS services at each RAT level
PBSY = PBS/ID/Year in CCT*
PSY = Number of PSY services at each RAT level
PSYY = PSY/ID/Year in CCT*
RDS = Number of RDNS services at each RAT level
RDSY = RDS/ID/Year in CCT*
COST_T = Total services costs for all services at each RAT level
COSTY = COST_T/ID/Year in CCT

* = Service or cost per client/day spent in the CCT, expressed as service/client/year

Figure 10.11 Predicting admissions admissions individual data

- Based on individual cases
- Adjusted r^2 = 0.02; I.e. 2% of variance in hospital admissions can be predicted from RAT scores

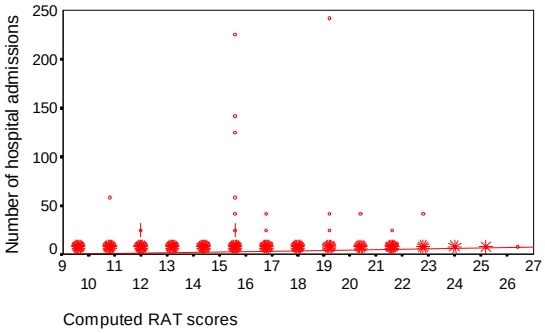
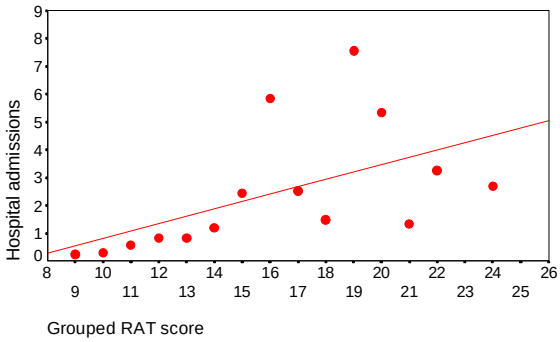


Figure 10.12 Predicting grouped data

- Based on grouped within strata data
- Adjusted r^2 = 0.25; I.e. 25% of variance in hospital admissions can be predicted from grouped RAT scores

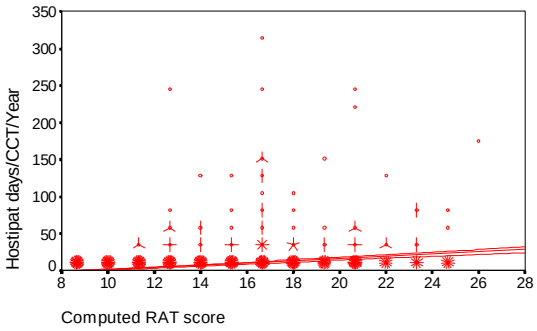


Regarding the days in hospital, the data at the individual level are shown in Figure 10.15. The corresponding predictive power of RAT scores was 8% (among those who were admitted, the predictive power of RAT was even lower at 6%). This finding suggests that at the individual level there was a weak association between RAT scores and length of stay. Figure 10.16 shows the aggregated group length of stay and RAT scores. This shows a high correlation between grouped RAT scores and time in hospital, with 64% of the variance in time in hospital explained by RAT score.

Figure 10.13

Predicting hospital bed days

- Based on individual cases
- Adjusted r^2 = 0.08; I.e. 8% of variance in hospital days can be predicted from RAT scores

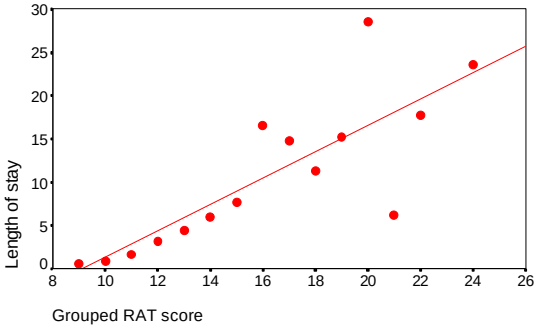


individual data

Figure 10.14

Predicting hospital bed days

- Based on grouped within strata data
- Adjusted r^2 = 0.64; I.e. 64% of variance in hospital length of stay can be predicted from RAT scores



days grouped data

Examination of the MBS data shows that there was a decline in MBS service use for those with RAT scores of 24+. The reason for this may relate to the high hospitalisation rate (of over 80%) so medical needs will be met as part of the hospital visit. The figures show a modest relationship between individual RAT scores and MBS use, at the patient level, 13% of MBS use was explained by RAT scores, while in the grouped analysis 53% of MBS service could be explained by RAT scores.

Figure 10.15

Predicting MBS use

- Based on individual cases
- Adjusted r^2 = 0.13; I.e. 13% of variance in MBS services can be predicted from RAT scores

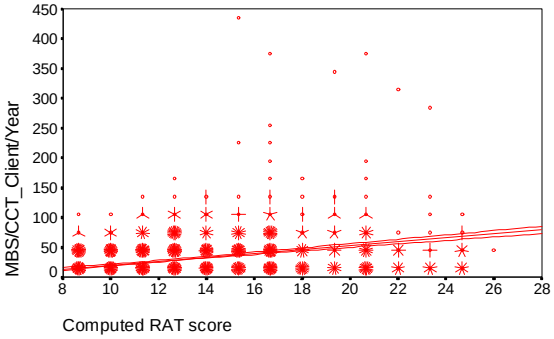
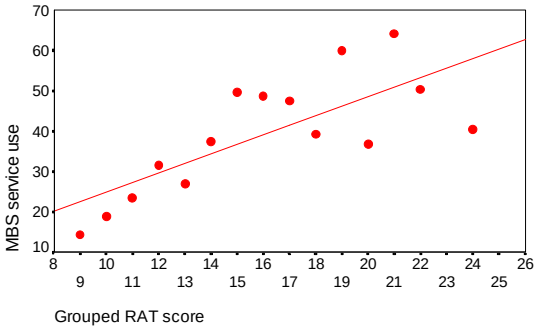


Figure 10.16

Predicting MBS use

individual data

- Based on grouped within strata data
- Adjusted r^2 = 0.53; I.e. 53% of variance in MBS service use can be predicted from RAT scores

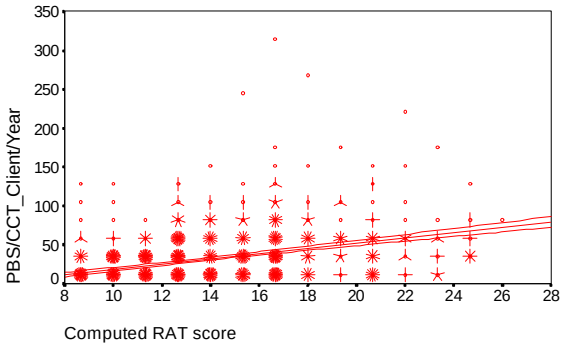


grouped data

The data for PBS usage are given in Figures 10.19 and 10.20. These show that at the individual level there was a reasonable predictive relationship between RAT scores and PBS usage, with 16% of PBS scripts explained by RAT scores. The group level analysis shows 82% of PBS usage is explained by RAT scores, a very strong relationship.

Figure 10.17

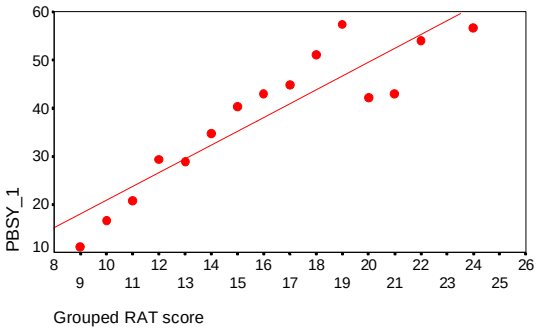
- Based on individual cases
- Adjusted $r^2 = 0.16$; I.e. 16% of variance in PBS scripts can be predicted from RAT scores



Predicting PBS use
Predicting PBS use

Figure 10.18

- Based on grouped within strata data
- Adjusted $r^2 = 0.82$; I.e. 82% of variance in PBS scripts can be predicted from RAT scores

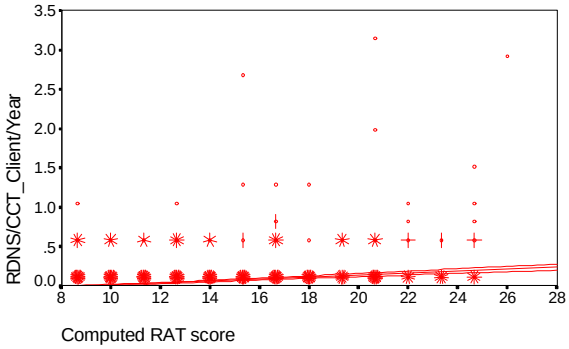


individual data
grouped data

Figures 10.21 and 10.22 show the predictive power of RAT regarding Royal District Nursing (RDN) use. At the individual level, RAT scores predicted 6% of use, while at the group analysis level the proportion of variance explained was 66%.

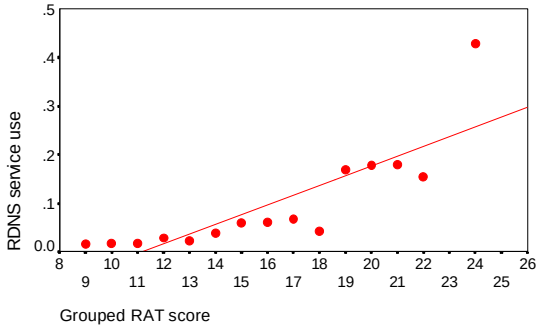
Figure 10.19

- Based on individual cases
- Adjusted $r^2 = 0.06$; I.e. 6% of variance in RDNS service use can be predicted from RAT scores



Predicting RDNS use **Figure 10.20**
Predicting RDNS use
individual data

- Based on grouped within strata data
- Adjusted $r^2 = 0.66$; I.e. 66% of variance in psychiatric service use can be predicted from RAT scores



grouped data

Finally, total health service costs were computed and RAT scores used to predict these. The results are presented in Figures 10.23 and 10.24. As shown in Figure 10.23, 13% of total health care costs for any

individual can be predicted from their RAT score. When grouped, RAT scores explained 83% of total health care costs.

Figure 10.21 Predicting total service costs individual data

- Based on individual cases
- Adjusted r^2 = 0.13; I.e. 13% of variance in total service costs use can be predicted from RAT scores

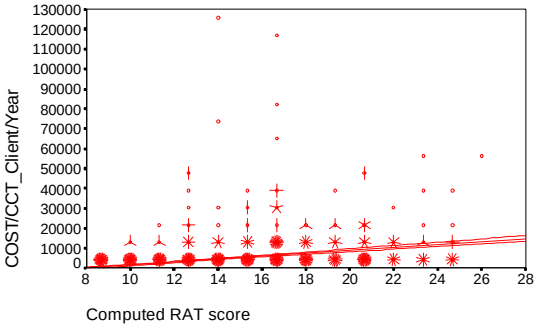
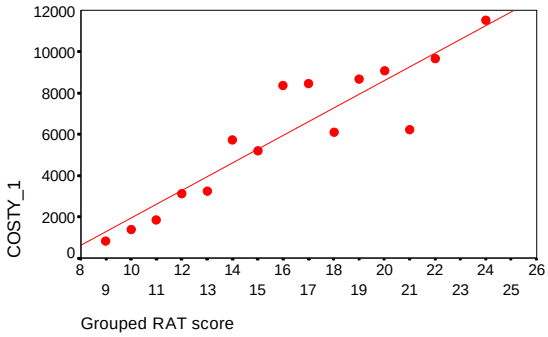


Figure 10.22 Predicting total service grouped data

- Based on grouped within strata data
- Adjusted r^2 = 0.83; I.e. 83% of variance in total service costs can be predicted from RAT scores



10.5 Discussion and conclusions

The key issues arising from the explication of the RAT instrument can be grouped into three areas:

1. issues covering the internal structure of the instrument;
2. those concerned with its validity and reliability; and
3. it's predictive power.

Generally, the evidence examined in this Chapter, and elsewhere in the Evaluation Report, suggests that overall the RAT instrument has served its purpose well: it easily and reasonably efficiently classified the CCT clients into three levels — low, moderate and high — for the purposes of care coordination. Examination of the residuals (see Volume IV), suggests it achieved this classification through identifying those not at risk rather than those at risk; i.e. it appears to work in the opposite manner to the original intention. As such its validity and reliability for identifying high-risk clients has yet to be fully established.

RAT's internal structure

The data in Section 10.3 showed that whilst all RAT items performed satisfactorily, 2 items did not adequately discriminate. These were questions 2 and 3. Question 2 probed social supports and Question 3 informal care needs. Whether this matters has not been fully explored, although deleting these items from the factor analysis improved the explanatory power of the model from 61% to 65% of the variance. Exclusion of these items (or revisions) may be considered in future development of the RAT instrument.

There is also some evidence that using the GPs to sum RAT scores and then assign a care coordination level led to misclassification (in <1% of cases) due to summing errors. This may be considered a trivial random error, or may have been a deliberate `reclassification' on the part of the GP, which may or may not be considered appropriate. The factor analysis revealed the presence of two sub-scales within the RAT instrument, measuring service use and coping ability. The internal consistency, a measure of reliability, was reported as $\alpha = 0.85$; indicating excellent properties.

Validity and reliability

The first step in establishing the validity of RAT was to investigate whether RAT scores systematically varied by various socio-demographic variables. The results showed that there was no systematic variation by clients' ages, the language spoken at home or by private health care insurance. Significant differences were reported for gender, birthplace, relationship status, educational status, accommodation, caregiver status and social security card status. Overall, these findings suggest that the RAT instrument may be sensitive to several non-health status indicators, indicators which are however related to a person's health status and ability to cope within the health system.

RAT scores were also examined against those obtained by the SF36 and the AQoL, health status and health-related quality of life measures respectively. These analyses showed a moderate correlation with the SF36 physical health status scores, a low correlation with the SF36 mental health status scores, and a good correlation with the AQoL utility scores. The lower correlation with the SF36 MCS scores ($r = –0.26$) suggests that the RAT may not be very sensitive to mental health status.

There is a modest relationships with MBS and PBS usage and cost and RAT scores. Hospital admission is also related to RAT level. Regarding overall service use as measured by combined health care costs, Figure 10.12 shows a moderately high correlation ($r = 0.53$).

Prediction with RAT

The key findings were that at the individual level the RAT instrument performed patchily, although well relative to reported risk adjusted capitation models, (based on multiple regression analyses), where anything above 10% is considered exceptional. The strongest relationship was between RAT scores and the number of PBS scripts (16% of variation being explained). Thirteen percent of total service use costs was explained by RAT scores, as was 13% of MBS services.

At the group level, the predictive power of the RAT instrument was considerably enhanced; primarily due to the reduction in data points. But the analyses are potentially useful from a health planning perspective. RAT scores explained 82% of the variation in the number of PBS scripts, 53% of MBS service usage and 64% in length of stay, 31% of outpatient status, 66% of RDNS service use. Overall, RAT scores predicted 83% of all health care costs combined (MBS, PBS, in-patient, out-patient, RDNS).

On average, RAT scores at the individual level explained 7% of the variation in service use compared with 52% of variation in service use at the group level. These findings imply that the RAT should not be relied upon to reliably predict individual service usage; but may be appropriate for group prediction.

The evidence regarding instrument validity may be more driven by the clients obtaining low or moderate RAT scores and using few MBS, PBS or other health care services. There appears less predictive power in discriminating between high risk clients. This may be partly due to the small number of high risk clients (87 cases), but perhaps just a simple lack of discrimination at scores over 19.

Improving the model

In the preliminary report on the RAT instrument it was noted that misclassification of clients scoring '14', '21' and perhaps '22' on RAT seemed to have occurred. However with the more extensive database available for this study, which involved all CCT treatment clients, over the full trial period and where the data were computed as client/day service use, no such misclassification has been identified.

The extensive patient level data provides the opportunity to reconsider the RAT scores and their allocation to care coordination level and the possible use for estimation of health service use and cost. A review of the cost information might suggest a reclassification of levels as defined in Table 10.8. This shows six levels, from no risk to very high risk, with the ratio of relative cost increasing with grouped risk level, to be over 12 times for those with a risk score of 22 and above compared with those with a risk score of 9. The relative risk for days in hospital shows an even steeper gradient. With a 32 fold use of bed days for those with a risk score of 22 (mean 20 bed days/person year) relative to those with a risk score of 9 (mean 0.6 bed days per person year).

Table 10.6 Possible reclassification of risk level

Risk score			Mean total health cost per equivalent patient year	Relative total cost
9	n = 427	no elevated risk	$ 833	1.0
10,11	n = 518	low risk	$ 1,596	1.9
12,13	n = 305	low moderate	$ 3,184	3.8
14,15	n = 194	high moderate	$ 5,503	6.6
16-21	n = 289	moderately high	$ 7,920	9.5
22+	n = 56	very high risk	$10,358	12.4

In terms of Funds pooling, the RAT score together with socio-economic and demographic data could be combined in a multiple regression model to establish the best predictor of health service use and cost. This has not been done.

Subject to the data caveats outlined in the report, the conclusions about the RAT instrument are that it appears valid and works, GPs found it easy to use, it has good psychometric properties, it is sensitive to clients in different health states, and that it could be usefully employed to allocate CCT clients to different levels of 'risk' for care coordination purposes. It may also be a good predictor of health service use and cost.

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Annexure to Chapter 10

Risk assessment tool

Date of risk assessment:...../.../.....
Client Name:..... Care coordinator: .....

Risk indicator (circle score which best fits client)	**If client best fits the statements in this column, score 1**	**If client best fits the statements in this column, score 2**	**If client best fits the statements in this column, score 3**
General description 1....2....3	Clients is able to self manage their health care needs	Client may need guidance at times but is generally able to initiate and comply with appropriate care recommendations	Client is dependent upon others to manage their care
Social factors 1....2....3	Client does not have significant social needs	Client has limited social supports	Client's social support system is inadequate for their needs
Informal care needs 1....2....3	Able to self-manage. Can generally arrange access to services and comply with own care requirements	Needs some assistance with two activities of daily living	Needs assistance with most activities of daily living
Likely GP & specialist visits 1....2....3	<10 visits likely in the next 12 months	Between 10–20 visits likely in the next 12 months	>20 visits likely in the next 12 months
Other health service utilisation 1....2....3	Occasional/Intermittent use of health and/or community services	<3 health and/or community services used in an ongoing way	Uses more than 3 health and/or community services continuously
Complexity of illness 1....2....3	No chronic illness. Current conditions likely to resolve	One chronic condition occasionally made unstable by acute condition	Major co-morbidity or multi-system abnormality
Regular medications 1....2....3	Uses <5 medications regularly	Uses 5–10 medications regularly	Uses >10 medications regularly
Likely hospital stay 1....2....3	Likely to spend <5 days in any hospital in next 12 months	Quite likely to spend 5–10 days in any hospital in next 12 months	Most likely to spend >10 days in any hospital in next 12 months
Likely level of care coordination needed 1....2....3	Self-managing client; able to seek appropriate help for themselves and comply with recommendations	Some complexity around medical and/or social factors; but mostly able to complex with care recommendations. May need help to organise and schedule services	Complex medical conditions, compounded by social factors. Limited ability to comply with health plans without close supervision and support

Sum of circled scores:
.....

≤ 13 = Level 1 (low risk)
14–20 = Level 2 (medium risk)
21+ = Level 3 (high risk)

Chapter 11

Administrative arrangements including the role of consumers

This Chapter outlines the management and administrative arrangements for the Southern Health Care Network Coordinate Care Trial (SHCN CCT), notably the role of the key participants. It draws pm the GP questionnaire, a review of various Trial materials and a broad understanding of the health system reform literature.

11.1 Trial management structure

The Guidelines developed by the Commonwealth for the national coordinated care trials, set the boundaries for establishing the model at each of the nine sites. Each Trial established its own administrative arrangements, with substantial flexibility in the final arrangements. The respective roles of the key participants was defined and redefined over the course of the Trial, in response to experience gained. This was inevitable given Coordinated Care represented an entirely new model of care.

The SHCN took the initiative in developing the initial concept for the Trial and invited the Dandenong and district and Pakenham Divisions of General Practice, as well as the five community health centres in the region to participate. Without the support of all of these key constituencies the Trial could not have proceeded.

A Memorandum of Understanding between the SHCN and the Divisions outlined the partnership arrangements including the Trial partners' roles, responsibilities, outcome expectations, performance indicators, funding and expenditure frameworks, and communication and reporting requirements relating specifically to care coordination. The Network as the Trial sponsor held the overall responsibility for the Trial as well as the funding, information technology and management-oriented monitoring functions.

> 'The Dandenong Division of General Practice, as a member of the Trial team, is responsible for the management of care coordination. This involves educating, recruiting and assisting GPs in their role.' (DDDGP, 2000)

Each partner brought to the arrangement particular areas of expertise and the administrative arrangements allowed them to concentrate on those areas. The Division thus had primary responsibility for the care coordination role, while the Trial management could focus on the mechanics of recruitment/withdrawal, financial management, data management etc. The case management and service coordination functions reported through the care coordination manager, who was a member of the Trial management team, but also worked closely with the Division of GP.

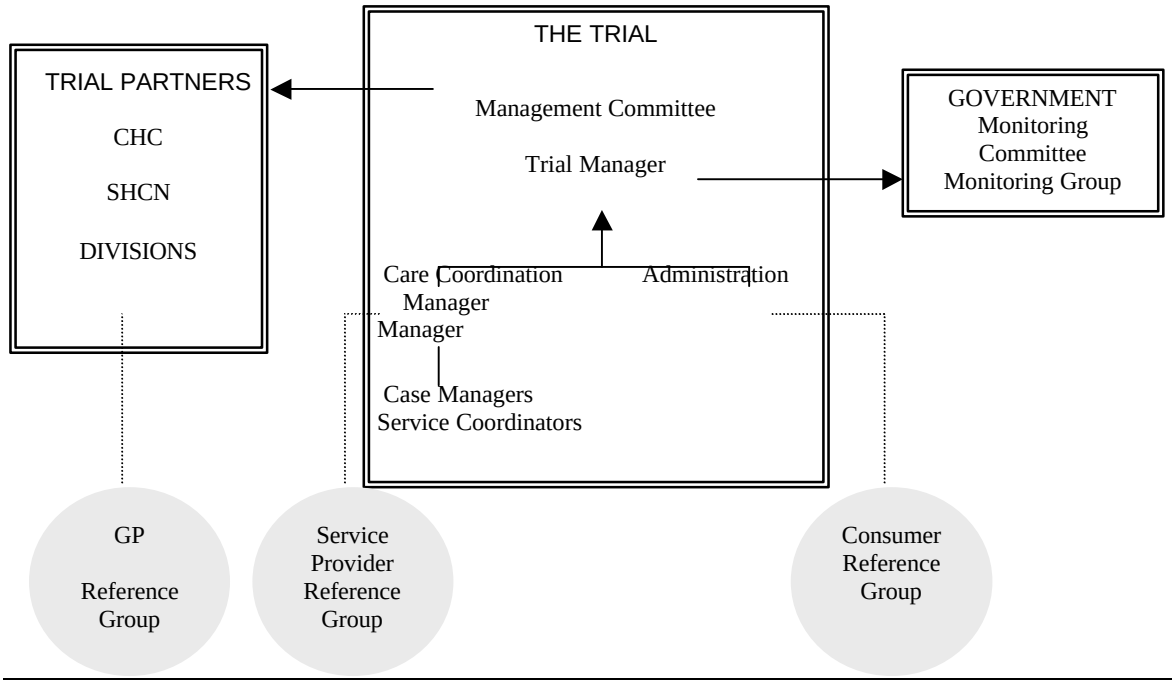
A consumer reference group, a GP reference group and service provider network were also established early in the Trial, to provide advice and feedback to the Trial and the Division on pertinent issues. (See below for description of the role of the consumer reference group).

In Figure 11.1 the management structure is outlined, in which is also identified the management committee, consisting of representatives of the Trial partners - the Divisions of GP, the SHCN and the community health centres, plus an external representative.

The Trial manager was also required to report to a Monitoring Committee, of State and Commonwealth Government representatives concerning financial monitoring of the Pool. Two regular news letters were distributed, `the Review' for the care coordinators (GPs) and other providers, and `Lets Talk' for persons enrolled in the Trial, control and intervention group participants, to keep all informed about Trial issues, and maintain contact.

SHCN Trial management team was located in a separate building at Dandenong and District Hospital. The Division ran their management functions from the Dandenong Division of GP, (which was close to the SHCN CCT offices) and the case managers and service coordinators, were located within community based agencies, (such as the Springvale Community Health Centre). Their location within the community agencies was to enhance access to local knowledge and to promote links and share expertise with community service agencies. It is not clear whether this proved effective. The GP Divisions would have preferred the service coordination/case management functions to have been located in the SHCN CCT offices.

Figure 11.1 Management and service delivery responsibilities



Although all parties acknowledged the importance of health system reform and the need for more effective integration of health care for the patient, each went into the process with different philosophies about how to achieve this. In particular there were differences around how to meet the requirement for budget neutrality, dictated by the Commonwealth. Some of the Trial partners thought additional services should be made available up front, consistent with the provision of best practice care, presuming that cost savings would accrue later. While the SHCN CCT management, given the responsibility for managing the Funds Pool and ensuring its financial viability, adopted the policy, enunciated from the beginning, that spending outside pre-existing eligibility criteria should only occur once a surplus had been generated through savings. That is, the Funds Pool, in the first instance was only to pay for traditional services, plus care planning, service coordination and case management. This was a source of some tension, between the parties. It also created a contradiction in terms of the principles underlying the care coordination and funds pooling model. The Divisions of GPs had hoped funds would be available to purchase services, nominated in care plans, to test the proposition that additional spending in the community sector would lead to savings in the acute sector.

There is, by its nature, a conflict between the funds holder role, which demands financial responsibility and the service provider role driven by a patient advocacy perspective. The former demands cost control the latter demands best practice care, which may be more expensive. This represents one of the challenges in translating the coordinated care model from theory to practice. It has yet to be established that sufficient cost savings can be generated that will fund the care coordination role, administration costs and additional services. But if alternative services are not purchased, how are the resource shifts to be achieved and cost savings generated. While if other services are purchased and savings do not ensue, budget neutrality would then require a cut in basic services, also not desirable.

11.2 Trial establishment

The Trial was a major experiment in health system reform and the way in which this experiment was to be operationalised was not clear at the outset. The inherent complexity of the issues to be resolved and the sheer number of decisions to be made were quite extraordinary. This was exacerbated by the tight time-lines imposed by the Commonwealth. The new arrangements were to be delivering services to an enrolled client group, by July 1 1997, allowing the SHCN Trial only nine months to get the Trial up and running. This was virtually impossible.[32] The establishment tasks, which were many and complex included:

i) **Establishment of a management structure** to oversee Trial set up and Trial implementation.

ii) **Selection of precise criteria for entry to the Trial** the approach to recruitment and likely rate of recruitment.

[32] The SHCN CCT was the only trial to formally go live on July 1. Other trials became fully operational towards the end of 1997. As a consequence the end date for the Trials was extended from June 30 to December 31 1999.

iii) **Development of a basis for determining the Funds Pool** to reflect expected service use and cost. This required identification of a sample of potential clients and their recent health service experience. A firm of actuaries was employed to calculate contributions to the Funds Pool from this data. Negotiations were then required with the Commonwealth Government, the SHCN and other key service providers, concerning their participation in the Trial and in the pooling of funds to reach agreement concerning the basis on which funds would be pooled.

iv) **Determination of criteria by which services would be accessed and paid for** from the pool, in negotiation with the key players.

v) **Establishment of a payment system** for the recording of services used by trial participants and for payments to service providers, timing for activation of payment into and through the Pool.

vi) **Development of a care coordination model** its broad structure and philosophy underpinning the model, whether alternative levels of care coordination should be provided, care coordination services to be offered, the role of the various players and the relationship between them.

vii) **Development of a risk tool** and basis of allocating clients to alternative care coordination levels.

viii) **A procedure for completion of care plans** development of a care plan proforma, the process for completion and peer review, fee to be paid, development and implementation of a training program.

ix) **Adoption of an evaluation model and the nature of the control group** a randomised control Trial design was adopted, with participants randomised once informed consent was obtained. A decision was made for unequal randomisation to increase the chance of participants getting into the intervention group, to encourage participation.

x) **Recruitment** of intervention and control clients and of GPs to act as care coordinators. A recruitment strategy had to be devised that would ensure large numbers were enrolled - a Commonwealth requirement of the Trials. Recruitment into the Trial, also meant a process for obtaining informed consent. Those who consented to participate in the Trial and were randomised into the intervention group, were then asked to nominate a GP, (expected to be their `usual GP') to act as care coordinator. The GP was then approached by the Trial to fulfil the role of care coordinator.

xi) **On-going recruitment of staff for Trial set up and implementation** - determine staffing requirement (job descriptions etc.), and staff training (eg of the service coordinators, case managers), establish team management arrangements.

xii) **Setting up of data collection systems** to monitor Trial for management information purposes and for evaluation purposes.

xiii) **Revisiting trial objectives** and review opportunities for service development.

The demands of the trial development phase and the challenge of completing it at all, let alone within a 9 month time frame cannot be overstated. Many of the tasks were reliant on input from other tasks for their completion, further compounding the difficulty of completion within the available time. That this Trial (and others) were able to move from the planning to the live trial stage (with only minor delays) is a credit to the tenacity and commitment of all those involved in the trial establishment process.

The pressure of the Trial establishment Phase was not without cost, in terms of a tenseness in the relationships between the various players (which changed over time) and in the adoption of an expensive computing/data management system. At the same time many of the decisions taken at pace, such as the development and application of the risk assessment tool, proved to be quite sound. It can also be observed that other coordinated care trials with longer establishment time frames, even where less ambitious in scope (such as the NSW diabetes integrated care trial[33]), have not necessarily managed the establishment phase any better. Difficulties in recruitment, problems with data collection and a strained relationship between participants, appear to be common. Part of the role of the coordinated care model is to force various provider groups to negotiate around issues which they view differently. The achievement of system change, which requires a change in the attitudes and behaviours of the key players, may not be achievable without some conflict.

11.3 Consultation processes

The organisational structure as outlined above incorporates various opportunities for consultation. Three reference groups were set up to inform the Trial management.

The General Practitioner Reference Group

The General Practitioner Reference Group was established to provide guidance on implementation of the care coordination model and to provide advice to the SHCN CCT management on all aspects of care planning. Members contributed to the development of the Risk Assessment Tool, and provided feedback on the GP survey. They were not uncritical of aspects of the Trial design and implementation.

The Consumer Reference Group

The Consumer Reference Group was 'established in order to advise trial management of issues and concerns to consumers as they relate to the development and implementation of the trial' (Southern Health 1996). From the perspective of the members of the consumer reference group the SHCN appears to have succeeded in this aim. Feedback to the evaluators from the groups indicated that they felt they had a voice on the trial. They were consulted about the way privacy issues would be dealt with. They saw drafts of all material and made comments which were fed back to the trial and the local evaluators.

[33] NSW Department Health, Diabetes Integrated Trial Workshop, Sydney December 1997. The groups were the GP Reference Group, the Consumer Reference Group, and the Service Provider Network (see Figure 11.1), designed to inform Trial management on pertinent aspects of implementation.

The group was made up of representatives of the 'Chronic Health Alliance, a community representative, Dialysis and Transplant Association, Migrant Resource Centre, a representative for those with psychiatric illness.' (SHC Network Quarterly Report 1996). The personal qualities of the representatives on the Consumer Reference Group were seen to contribute to its success who were regarded as articulate and willing to participate in the discussions.

The Trial embraced an 'empowerment' approach in its relationship with the members of this group which involved the education of group members and attendance at conferences. Although the Consumer Reference Group did seek membership on the Trial Management Committee, which did not occur. However, overall their role was seen to be effective and one members reported that attendance at a conference had made her realise how good the model adopted by the SHCN CCT was in comparison to other trials. Attendance at the Consumer Reference Group meetings was consistently good throughout the Trial, further supporting the conclusion that the participants found it to be worthwhile.

The Service Provider Network

The Service Providers Network was not in the original management structure but established on the initiative of the service coordinators, to facilitate communication and information sharing between the Trial and the community agencies. Meetings of this group provided a forum to discuss and develop strategies to address structural barriers that impede communication between GPs and other service providers and between service providers. Representation on this group was wide ranging. As well as the Trial and the DDGP it included:

- Department of Human Services,
- Dandenong Psychiatric Hospital,
- Dandenong and District Hospital,
- Monash Medical Centre,
- Post Acute Care Program,
- Adult Community Treatment Team, Dandenong District Hospital,
- Royal District Nursing Service Berwick,
- Kingston Centre,
- Berwickwide Community Health Centre,
- Windermere Child and Family Services,
- City of Casey Home Care Program,
- Southern Eastern Migrant Resource Centre.

Communication with professional staff in the acute sector were problematic in the early days of the trial but feedback to the local evaluators indicated that this had improved when the service provider meetings were set up. The service providers felt that they could ring Care Coordination Manager if they had difficulties relating to the Trial that they were not able to resolve.

11.4 Trial focus

While the overall objective of the Trial was to implement an alternative model of health service funding and delivery, over the course of Trial establishment and implementation, the immediate focus shifted, depending on the current imperative. For instance at the beginning of the Trial, securing funding into the Pool was an imperative. This meant an intense concentration on recruitment of clients, the trigger for contributions from the SHCN and the HIC into the Pool.

Recruitment

While the recruitment process was structured and efficient, the pace of recruitment demanded also placed substantial pressure on staff:

> 'The recruitment drive ran for 18 weeks. The client database was divided into 10 batches of approximately 1,000 clients with a new batch rolling out each week. Each batch took approximately 4 weeks to complete, from initial contact through to consent received.' (Ross, Stoelwinder, Allwell 1999: 162)

The pace of recruitment and the handling of the recruitment process almost entirely by post and through a third party agency appears to have created some confusion for clients. Informed consent processes are inherently problematic. Many find the very concept of a control and intervention group difficult to grasp. Some agreed to participate believing that they would get lots of help which did not eventuate. Comments on the GP survey also indicated that some clients were confused.

> *Most patients have no idea what it [the Trial] is about and half of the consultation for the care plan was used in trying to explain what it is about.* (1998 GP Survey ID 1150)

> *Informed consent was virtually non-existent. No patient I interviewed really understood what they agreed to enter into.* (1998 GP Survey ID 1131)

Another preoccupation of the establishment phase and early implementation was the information management task, which had to inform the evaluation, service provision and management. The IT system represented a large infrastructure cost. To try to maximise the benefit from this expenditure a key design feature of the system was short and long-term flexibility. The IT system was described in the following way.

> 'The system is a mini data warehouse and data capture, analysis and reporting are its main functions. It has been developed to capture extensive information about the enrolled population, and has interfaces to service providers (Health Insurance Commission, hospitals, Royal District Nursing Service, community health centres). It has the capacity to add other service providers in the future (eg Health Insurance Funds, Home and Community Care).' (Ross, Stoelwinder, Allwell 1999: 162)

There was on-going criticism of the data system, particularly in terms of its cost, the delay in getting it up and running and the capacity to interrogate it in relation to key information requirements.

Achievement of resource shifts

Once recruitment was complete, which ensured the status of the Trial and income to the Funds Pool, management focus shifted to achieving the objectives of the Trial itself, particularly resource shifts from acute and emergency care to programmed community based care. It was hoped that this would reduce costs.

A range of strategies was pursued to manage the risk related to funds pooling and to promote service substitution. The care panels were seen to be integral to this with their promotion of best practice care which, it was postulated, would reduce at least in the longer term, complication rates and some health service costs. There was also a specific focus on unplanned admissions. Care coordination team members, including the service coordinators and case managers, were asked to contribute to a reduction in unplanned admissions. The way this matter was handled created considerable stress in those involved in the delivery of the care coordination activities.

Concern that the intervention was not reducing unplanned admissions led to the establishment of an Unplanned Admissions Working Party. Membership consisted of two general practitioners, a specialist from the acute sector, a member from the Centre for Clinical Effectiveness and members of the care coordination team, including the care coordination manager and a case manager. The objectives were to identify individual unplanned admissions, determine which were preventable and recommend strategies to prevent further hospital episodes. The conclusions contained in the Report of the Preventable Admissions Working Party were as follows:

> 'Attention has been given to unplanned admissions in the trial on the assumption that they were in some way preventable and that this was an avenue to reduce expenditure on acute care. Examination of unplanned admissions indicated that most were appropriate and perhaps even planned.' *(Osborne 1999, Report of the Preventable Admissions Working Party)*

The difficulty in trying to reduce hospital admissions is not unique to the SHCN Trial. It may be that reducing unplanned admissions is an appropriate long-term performance indicator but the very nature of the intervention (a relatively short-term experiment in health system reform) made it less suitable.

However, the analysis of hospital admissions and costs suggests that coordinated care may in fact have achieved some service substitution, from the acute to the community sector. As discussed in Chapter 6, while the costs of medical services was higher in the intervention than the control group, the costs of acute services were slightly lower in the intervention group, and was falling over the course of the Trial. In-patient costs went from 15% higher in the intervention group during the first twelve months to 11% below control group costs. If admissions just to Monash Medical Centre and Dandenong and District Hospital are looked at, a 7.5% reduction in acute care costs across the Trial period, till end June 1999 is observed. This however was achieved at the expense of an increase in admissions to other Victorian hospitals. Thus the focus on reduction in unplanned admissions may well have resulted in some cost shifting, as well as a genuine shift in the pattern of care.

Trial wind-up phase

As an experiment and an organisation, the Trial was transient. The short term nature of the service being offered had to be taken into account from the beginning. Responsibility towards the clients meant the need for a process to ensure a successful transfer, particularly of those with case managers, post Trial. Management also had to focus on other strategies for closure, such as the transfer of assets and computer equipment and archiving of medical records. There was also a desire to consolidate what had been learnt from the Trial, to determine how this learning could be used for the development of future coordinated care trials and contribute to the wider debate on health system reform.

11.5 The role of the care coordinator

The Trial focused on developing the role of the GP as care coordinator with primary responsibility for the client. This was reinforced by giving to the role of care coordinator the tasks of: implementing the risk assessment tool, developing the care plan and conducting care plan reviews to monitor change in service needs or risk level. GP involvement initially occurred via their patients who (due to their high recent use of acute services) were approached to participate in the Trial and allocated to either the intervention or control group. Patients allocated to the intervention group were asked to nominate their usual GP as their care coordinator. These GPs were then approached by the Trial to take on the role of care coordinator. Only a small number of GPs declined to participate at this stage, approximately 30.[34] If a GP did decline and the patient wished to remain in the trial, another GP (or specialist if more appropriate), was approached to take on the role of care coordinator. However, it is probable that some patients invited to participate in the Trial declined on the advice of their GP.

The recruitment method via the client meant that there was some degree of coercion in getting GPs to participate. Whether this is undesirable or an effective strategy for achieving maximum penetration of the new model of care in a short time frame is a matter for debate, but it did create some ill feeling amongst care coordinators. Interestingly as reported elsewhere, the views of GPs about the value of coordinated care, seems to have become more favourable over the course of the Trial, certainly for level 2 and level 3 clients.

To assist these GPs to take on the role of care coordinator the General Practice Reference Group and the Division conducted training programs and developed a resource manual for participating care coordinators. There was some difficulty in getting GPs to attend the training sessions and some training sessions were conducted in the GPs' surgeries. Approximately 160 GPs attended training sessions or further education on site, representing just under 50% of GPs acting as care coordinators.

[34] Ross, Stoelwinder and Allwell 1999:p157.

To remunerate GPs for their work as care coordinators a scale of fees was introduced for developing and reviewing care plans, case conferencing and attendance at education sessions (see Table 11.1). Generally the GPs thought the reimbursement appropriate. Although given the time actually allocated to the care plan, which will reflect in part the complexity of the patient, it meant vastly different rates between GPs. (See Table 11.2.)

Those GPs who did attend the training sessions found them to be of moderate use. Thirty percent of GPs who responded to the 1998 GP survey indicated that they had not attended the training sessions, (a lower proportion than the total groups). Of those who did attend, one third rated it as 'very useful', 61% indicated the training was of 'some use' and 7% rated it as 'useless'. Nine percent of GPs responding to the 1998 survey said that they did not read the information kit. Of those who did read it, one quarter rated it as 'very useful', 62% rated it of 'some use' and 12% rated it as 'useless'.

The schedule of fees for GPs undertaking the role of care coordinator is shown in Table 11.1. It might have been fairer to have had a separate payment for implementing the risk assessment tool and then a separate care planning rate that depended on the risk level to which the patient was allocated. (Although this may have distorted the completion of the RAT).

Table 11.1 Schedule of fees for GPs undertaking care coordination

	FEE
Completion of a initial care plan with the client (including implementation of risk assessment tool)	$120
Care plan review	$30
Attendance at a training session after hours	$75
Case conferencing	Sliding scale fee

Source: Ross, Stoelwinder and Allwell, 1999:

The care coordination function involved the care coordinator implementing the RAT and then undertaking a care plan and working as a team with the case manager and service coordinator (where relevant) to implement the patient's care plan. The formal process of care planning was expected to require the GP to spend approximately one hour with the patient, to take a holistic perspective of the patient's health and develop a health strategy jointly with the patient. As shown in Table 11.2, 49% of GPs responding to the 1998 survey indicated that they spent less than 30 minutes developing the care plan with their high and medium-risk clients, and 87% indicated that they spent less than 30 minutes developing the plan for their low-risk clients.

Table 11.2 Time GPs spent developing the care plan

	High and medium-risk patients		**Low-risk patients**	
Less than 15 minutes	5	3%	109	46%
15 minutes and up to 30	82	46%	96	41%
30 minutes and up to one hour	83	47%	28	12%
One hour or more	7	4%	3	1%
Total	177	100%	236	100%

The model requires the care coordinator to undertake the care planning process jointly with the client and, in some instances, with the client's family. In the 1998 GP survey, 22% of responding GPs indicated that they had not involved their low-risk clients or the client's family in the development of the care plan and 7% of GPs developed the care plan without involving their high and medium-risk clients or the clients' families (see Table 11.3).

Table 11.3 Participants' involvement in developing the care plan

	High and medium-risk clients		Low-risk clients	
GP alone	12	7%	52	22%
GP and client	109	63%	157	67%
GP, client and family	43	25%	21	9%
GP and family	9	5%	3	1%
Total	173	100%	233	100%

The qualitative data indicated the concerns GPs had about the care planning process. These included:

(i) The negative impact it would have on their practice and remuneration if introduced more widely.

We simply don't have the time (both in regard to actual time and also from the financial aspects with GP fees so low) to spend hours on the phone and providing reports – this is unpaid labour. (1998 GP Survey Id 1027)

The ability to provide coordinated care positively would be a function of how busy the GP is and how much time he [or she] can assign to being a coordinator. (1998 GP Survey Id 1077)

(ii) The futility of care planning with low-risk patients and the need for targeting the intervention

[The Trial] has not had any impact on low risk patients. Waste of resources. (1998 GP Survey Id 1014)

Coordinated care should be offered to only complex patients. (1998 GP Survey Id 1048)

(iii) The need to develop the documentation to make it more user-friendly.

I think doing the paperwork is excessive and non-productive. (1999 GP Survey Id 1223)

There was an awful lot of paperwork. The patient resented being told she had to come to see me to complete the paperwork and she asked to be withdrawn from the Trial. (1999 GP Survey Id 1036)

These comments, together with the quantitative results of the GP questionnaire, highlight the need to continually revise and review care planning protocols and training methods.

11.6 The role of service coordinator and case manager

Two case managers and two service coordinators were recruited from community based agencies to support the care coordination function and the care planning process. They were accountable to the client's care coordinator for client related activity, reported back to the care coordinator on all matters relating to the client and provided a written report prior to patient review. The protocol required the service coordinators and case managers to get in touch with the care coordinators, but an acceptable process for doing this, that met the needs of all parties had to be worked – mostly by trial and error. At the same time, the case managers and to a lesser extent the service coordinators had greater responsibility around non-medical aspects of patient care, extending also to support for carers.

GPs responding to the 1998 survey indicated that most of the contact with the case managers and service coordinators was by telephone. Although only a small number of GPs had face-to-face contact with the case managers and service coordinators, this form or contact was rated more highly than the indirect methods: 75% to 86% of the GPs indicated that face-to-face contact was either 'very useful' or of 'some use' (see Table 11.4).

Table 11.4 GPs' rating of their contacts with service coordinators and case managers

	NUMBER OF GPs					
Case Managers	**Phone contacts**		**Fax contacts**		**Face-to-face contacts**	
Very useful	33	25%	15	24%	7	58%
Some use	46	35%	19	31%	2	17%
Useless/No opinion	53	40%	28	45%	3	25%
Total	132	100%	62	100%	12	100%
Service Coordinators						
Very useful	35	24%	15	19%	5	36%
Some use	58	40%	32	41%	7	50%
Useless/No opinion	53	36%	31	40%	2	14%
Total	146	100%	78	100%	14	100%

Over time, the initial difficulties involved in working as a team dissipated as service coordinators and case managers found ways to manage their relationship with the care coordinators.

Initially the two service coordinators were expected to manage about 500 clients between them. Client contact was expected to be of limited intensity as the scope of the job is regarded as clerical and coordinating requiring about 10 hours of service coordination per client over the two years of the Trial. It became apparent that the assumptions underlying the definition of the role of service coordinator were not appropriate to all level 2 clients. The role of the service coordinator changed over the course of the Trial to become more flexible. With some of the clients it was appropriate for the service coordinator to offer a more comprehensive service.

One of the benefits of involving a team approach to client care is that team members approach client care from a different perspective. GPs, by virtue of their training and role, base their approach on a clinical perspective which they may, or may not, broaden to include social issues.

As the team relationship has developed, GPs have been able to recognise benefits for their own practice and for the clients from having case managers and service coordinators involved in the care of their patients. In the survey of GPs they were asked for their views concerning the impact of the Trial on their Trial patients in regard to the patients' understanding their illness, the patients' ability to self-manage and their ability to be involved in the care decisions concerning their illness. It also asked about the impact of the Trial on family members' understanding of the patient's illness, ability to assist in the care of the patients and their ability to cope with the patient's illness. As shown in Table 11.5 GPs were more likely to indicate the Trial was helpful for high and medium-risk patients and their families than for low-risk patients and more likely to indicate that it was helpful for patients rather than family members.

Table 11.5 GPs indicating that the Trial had helped patients and family members

	GPs with low-risk clients			GPs with high and medium-risk clients		
	Total	N	%	Total	N	%
Helped patients	205	57	28%	176	100	57%
Helped families	204	36	18%	173	67	39%

In the Trial model of care coordination the care coordinator stipulates via the care plan the services patients need and the service coordinator or case manager follow-up in an attempt to ensure the clients get the services. This process has been inhibited by two factors: the management decision not to provide funds to purchase services until savings occurred and clients inability to access the services that are available.

11.7 The balance between providers and consumers

As discussed elsewhere, coordinated care to be most effective in addressing the problems of allocative efficiency (an inappropriate health service mix) and technical efficiency (poor quality or high cost care), needs to address both supply side and demand side issues. The interface between care coordinators and other parts of the service system is essentially about enhancing the quality of care and responsiveness of the service system on the supply side. However, coordinated care can also work to enhance the role of the patient and their family to more effectively participate in the decisions about their own care.

Some aspects about this Trial were empowering of consumers as individual patients and as a group, and other aspects tended to entrench provider dominance.

The way individuals were enrolled into the trial was essentially empowering of them as patients. They were directly approached, and could make the decision themselves about whether to participate, even though they may well have sought the advice of their doctor or other health professionals. Certainly the GPs recognised a shift in power and that they were effectively recruited into the trial by the patient, rather than the other way around.

Also in ensuring that patients with the most complex care needs had access to a case manager to work closely with them and act as their advocate can be empowering for the patient and their families. It is not however entirely clear whether the service coordinator and case manager roles were implemented according to empowerment principles. Case management can also be associated with dependence unless empowerment of the patient is an explicit objective and incorporated into the role.

The development of the Care Plan provides, in theory, an opportunity for patients and their families to work with the GP to revisit their care needs and to reconsider priorities and possible approaches management. The lack of training of GPs around the task of care planning and about the involvement of patients in this process has probably weakened this aspect of the Model. It is clear from both GP and patient responses that the quality of the care planning process was very mixed in terms of the level of involvement of patients, and scope of health issues covered. Clearly some patients were not at all involved, while others were very involved. As noted in Chapter 2, the more involved the patient felt in the care planning process and the more valuable the care plan, the more likely were they to report that coordinated care had enhanced their quality of life. That is a most interesting finding.

On balance the SHCN CCT had some features that were empowering of consumers, but in other ways, provider dominance was not tackled. If the program had continued there would have been opportunities to have enhanced the consumer role, for instance by a revision to the care planning form and by working with GPs to enhance the quality of the care planning activity. Service coordination and case management could also formally incorporate an empowerment philosophy, rather than leave the model of case management and service coordination up to the philosophy and approach of the individual worker. This is not to say that these roles were not conducted in a most professional manner, which they were, but that a formal statement about the philosophy under which they are to operate would presumably be valuable to the individual worker as much as to the client and care coordinator.

The lack of discretionary funds has to some extent limited the capacity of clients to gain access to needed services. Although as noted, elsewhere, intervention clients still did better in this regard than control clients. However, the provision of a small pool of funds to have been available on request, according to set (but flexible) guidelines could potentially have generated substantial additional responsiveness to clients at relatively little additional cost.

While in the second half of the Trial some patient self care initiatives were introduced, there was only very limited funding made available for improved patient self care. Given the evidence of the value of effective patient self care as an important means to enhance patient outcomes, and the recognised gap in current health funding and delivery arrangements for pertinent services, greater funding for nurse education and other patient self care support would have been expected.

Finally the role of the consumer reference group seems to have been relatively successful in providing a voice for the consumer with management, and this would seem to be a valuable component to incorporate in any future model of coordinated care.

Chapter 12

Impact of the Trial on the service system

12.1 Introduction

The Southern Health Care Network Coordinated Care Trial (SHCN CCT) was an experiment in system level change designed to improve health outcomes for people within existing resources. In early 1998 a decision was made to extend the quantitative data collection to an investigation of the impact of the SHCN Trial on the health care delivery system and surveying participating GPs to obtain their responses and reactions to coordinated care was seen as an appropriate means of achieving that aim. Data collection occurred in two waves of a mailed questionnaires, September-October 1998 and September-October 1999.[35]

The model of coordinated care implemented by the SHCN CCT included both primary and secondary systemic interventions. The primary interventions involved care planning and implementation for all intervention clients and the secondary interventions involved a series of initiatives aimed at helping GPs in their clinical practice with specific disease groups and high users of services and prescription medicines.[36] The impact of both interventions were explored in the GP survey but this chapter focuses on the data relating to the impact of the primary interventions. In particular it looks at the impact of the Trial on:

- GPs' clinical practice,
- communication within the service delivery system, and
- access to services.

It also presents an analysis of GPs' perceptions in relation to the possible impact of introducing coordinated care more widely in Australia.

12.2 Impact on GPs clinical practice

Prior to the first wave of the survey, feedback from the GPs indicated that they believed the Trial had not fundamentally altered the nature of their role. They indicated that they were coordinating care for their patients before the Trial started and that situation had not changed. The comments on some of the questionnaires supported this view.

> *GPs already act like care coordinators.* (GP 1137)
>
> *Good GPs currently coordinate patients' care but without all the paperwork.* (GP 1146)
>
> *I feel the Trial has proved what many of us already know – GPs are already the care coordinators for their patients.* (GP 1297)
>
> *GPs do this [care coordination] work already, largely at no or little cost.* (GP 1243)
>
> *Any competent GP is, or should be, acting as care coordinator in his/her practice at present.* (GP 1326)

35 A detailed analysis of the response rates is shown in the annex to this chapter.

36 See Annexure to Chapter 9.

However, other comments indicated that the GPs' effectiveness as care coordinators can be undermined if they are under severe time constraints.

> *The ability to provide coordinated care positively would be a function of how busy the GP is and how much time he [she] can assign to being a coordinator.* (GP 1077)

> *It is hard to concentrate on patient care in a busy practice if one has to stop and often talk at length to other health professionals. If I want help I will arrange it in my own time – frequently at home when I have the time!* (GP 1027)

In both waves of the survey GPs were asked about the impact of coordinated care on two dimensions of clinical practice: patient management and tracking care. They were asked to indicate whether the Trial had 'helped greatly', 'helped', 'hindered', 'hindered greatly' or had 'no or mixed effects' for:

- five elements of client management dimension, and
- four elements of tracking care. (see Figure 12.1)

The questions were asked twice: once for high and medium-risk patients and once for low-risk patients.

Figure 12.1 Elements of patient management and tracking care included in the GP survey

Dimension	Element	Dimension	Element
Patient Management	• identifying all of their clients' medical needs • identifying the full range of medical services to meet those needs • identifying all of their clients' other needs (eg social) including flow on to family • identifying the full range of allied health professionals (eg physios) to meet those other needs • identifying the full range of social and welfare workers to meet those other needs	Tracking Care	• organising medical and other services that their clients need • making sure clients actually get the medical and other services the GP intended for them • reducing unnecessary duplication in any of the medical and other service clients were receiving • ending inappropriate care in any of the medical and other services clients were receiving

In the analysis of the responses for each dimension, GPs were divided into two groups – those who indicated the Trial had helped on at least one element in the dimension, and those who did not.

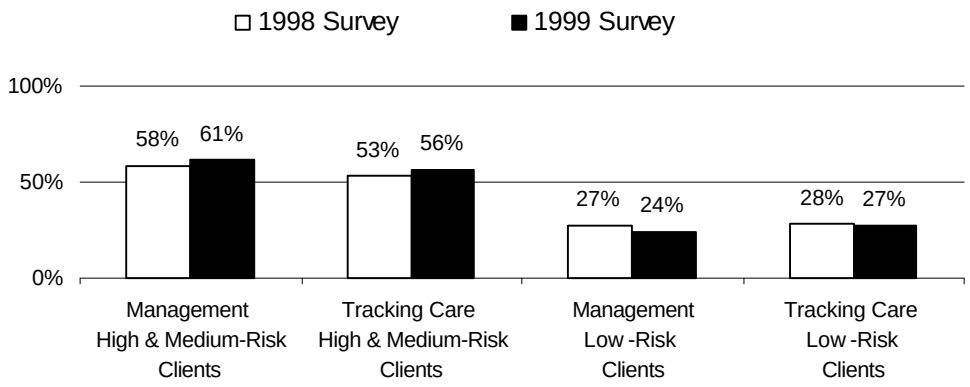
For GPs with high and medium-risk clients:

- between 53% and 61% of responding GPs indicated that the Trial helped on one or more of the elements over both waves of the survey, and,
- as the Trial progressed there was a slight increase in the proportion of GPs indicating that the Trial had helped on at least one element. (See Figure 12.2.)

In comparison, for GPs with low-risk clients:

- only 24% and 28% of responding GPs indicated that the Trial had helped on at least one element in each dimension, and
- as the Trial progressed there was a slight decrease in the proportion of GPs indicating the Trial had helped on at least one element. (See Figure 12.2.)

Figure 12.2 GPs indicating the Trial 'helped' on at least one element



In 1998 GPs were more inclined to indicate that the Trial helped in the identification of medical needs and services rather than allied health and social welfare needs and services. One year later, in 1999, they were more inclined to indicate that the Trial helped in the identification of allied health professionals. (See Table 12.1.)

Table 12.1 GPs indicating that the Trial 'helped' on the elements of client management

	High & medium-risk patients		Low-risk patients	
	1998	1999	1998	1999
Identifying medical needs	46%	46%	22%	16%
Identifying the full range of services to meet medical needs	46%	46%	17%	17%
Identifying other needs (eg social) including flow on to family	38%	40%	15%	16%
Identifying allied health professionals	43%	50%	15%	18%
Identifying social and welfare professionals	41%	46%	14%	17%

Over the years the context in which GPs work has changed with a wide range of community services becoming available. Some GPs indicated that they were aware of the range of services available and using them, but for others the Trial increased their awareness of the available services.

> *We are already aware of and using the services of allied health professionals and codifying this adds no further benefit.* (GP 1282)

> *I was made much more aware of the services available in the community.* (GP 1252)

The most pronounced differed difference between the two waves of the survey In relation to the tracking care dimension, was an increase of 6% in the proportion of GPs indicating that the Trial was helpful in reducing unnecessary duplication in medical and other services for medium and high-risk patients (see Table 12.2).

Table 12.2 GPs indicating that the Trial helped on the elements of tracking care

Elements of tracking care	High & medium-risk patients		Low-risk patients	
	1998	1999	1998	1999
Organising medical and other services	46%	47%	22%	24%
Making sure patients actually get the medical & other services	42%	44%	21%	21%
Reducing unnecessary duplication in medical & other services	30%	36%	19%	20%
Ending inappropriate care in medical and other services	22%	24%	16%	18%

The data in Tables 12.1 and 12.2 suggested that GPs views relating to the impact of the may have changed as the Trial progressed. To pursue this issue further the responses of GPs who responded to both waves of the survey were analysed (a panel study). This analysis revealed a complex picture.

In their role as care coordinators, GPs were exposed to different intensities of the intervention depending on the risk level and number of their Trial patients. Data were available on the 1998 risk-level of the patients of 206 GPs in the panel study. Thirty (15%) indicated that they had only high or medium-risk patients, 114 (55%) indicated they had high, medium and low-risk patients, and 62 (30%) had only low-risk patients at that time. When the 1998 risk-level of their clients is used as a proxy for GPs' level of exposure to the Trial then different patterns are evident in the changes in GPs' views over time. The most pronounced trends occurred in the responses of the 30 GPs with only high and medium-risk patients and the 62 with only low-risk patients.

As shown in Figures 12.3 and 12.4, the number of GPs with only high and medium-risk clients indicating that the Trial helped on the dimensions of patient management and tracking care increased for all but one element *(*identifying services to meet medical needs) between 1998 and 1999. By comparison, the number GPs with only low risk patients who indicated that the Trial helped on the two dimensions decreased across all the elements. (see Figures 12.5 and 12.6).

Responses for GPs with high, medium and low-risk clients were more mixed and fell between the upper and lower limits sets by the responses of GPs with only one type of client group.

Figure 12.3 Helped with high and medium-risk patient management: panel study GPs with only high and medium-risk patients (N = 30)

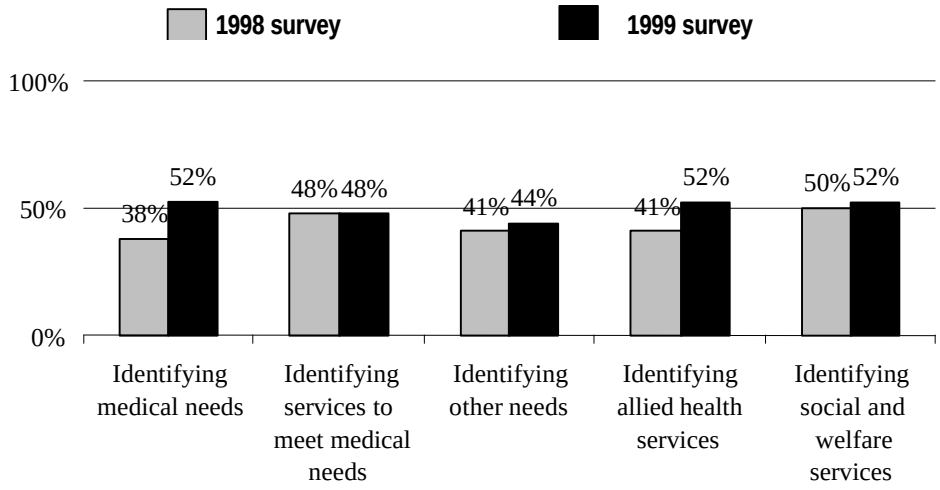


Figure 12.4 Helped in tracking care high and medium-risk patients: panel study GPs with only high and medium-risk patients (N = 30)

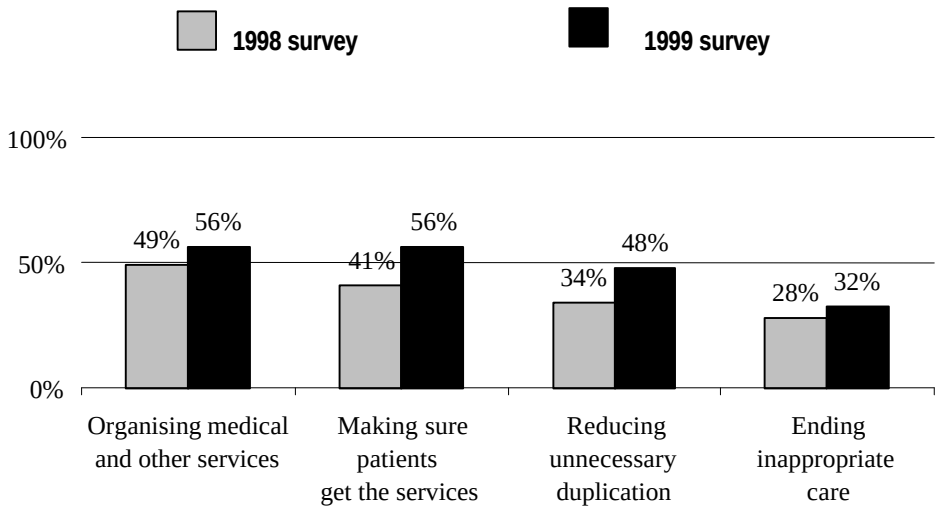


Figure 12.5 Helped with low-risk patient management: GPs with only low-risk patients (N = 62)

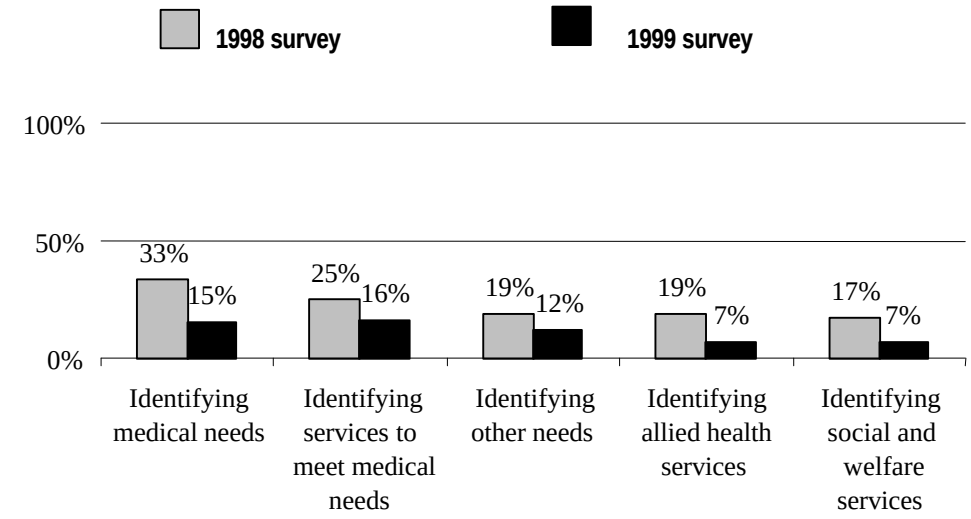
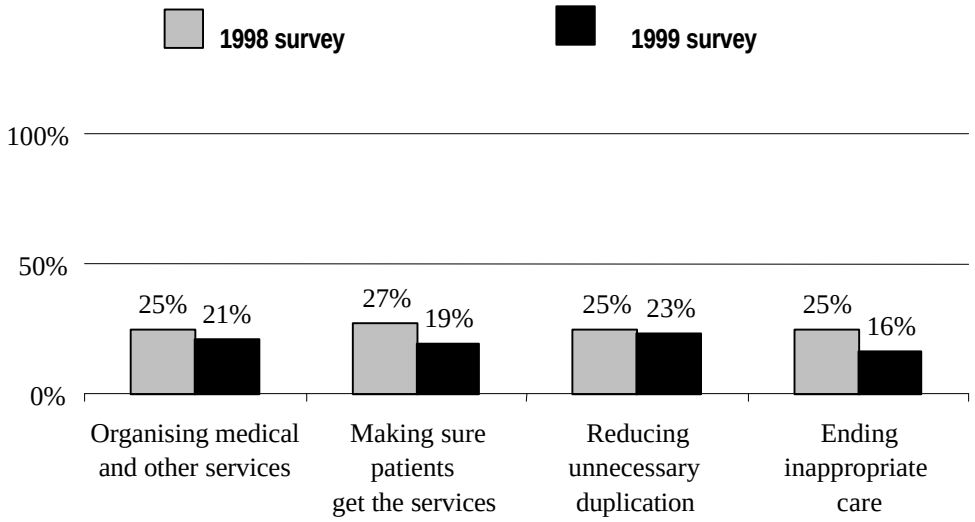


Figure 12.6 Helped with tracking care for low-risk patients: GPs with only low-risk patients (N = 62)



Analysis of the comments on the questionnaires indicated that the impact of the Trial on the two dimensions of clinical practice had been muted because of the nature of the patients involved in the Trial. Of the 301 questionnaires returned by GPs over the two waves of the survey 65 (22%) contained comments relating to this fact that the patients were 'inappropriate' There were several reasons for this.

- **Some patients were 'healthy':**

  Unfortunately I was only allocated healthy normal patients who required no services other than normal GP consultations. (GP 1015)

- **Some high and medium-risk patients (or their families) were self-managing:**

  Two of the high-risk clients are very self sufficient. (GP 1146)

  Patient [high and medium-risk group] was fully able to arrange appointments, etc. and informs me of such. (GP 1271)

- **Some were already being well managed:**

  Services were already in place (GP 1154)

  My high-risk level patient was already connected to Linkages who were providing services and coordination of care when required pre-Trial. (GP 1245)

For GPs the underlying reasons for 'inappropriate' patients being on the Trial were the eligibility criteria.

> *I believe the biggest mistake in this Trial was that patients were not selected because of the complexity of their condition - as their GPs were not asked – only about how much money Medicare spends on their case. The trial should have been done on really complex patients as most GPs need a team to manage the patients' case.* (GP 1104)

The problems of inappropriate patient selection were exacerbated by the small number of clients assigned to the GPs and compounded by clients withdrawing from the Trial.

> *Patient [high and medium-risk group] died earlier this year. She was very independent and did not see social welfare/support groups. She was under the care of three doctors all of whom communicated well. Close family members had free access to the doctors and gained much strength from each other.* (GP 1090)

> *I had only two patients involved in coordinated care. One expressed extreme disinterest and the other departed interstate ahead of the police.* (GP 1216)

At the time of the 1998 survey, 50% of GPs had no high-risk clients, less than 2 medium-risk and less than 3 low-risk clients (see Table 12.3).

Table 12.3 Number of Trial clients per GP reported in 1998 survey

	Mean	Percentile of GPs		
		25th	50th	75th
High-risk	<1	0	0	1
Medium-risk	1	0	1	2
Low-risk	3	1	2	5
ALL RISK LEVELS	5	1	3	8

12.3 Impact on communication

In 1999, Ross et al wrote:

> 'A major focus [of the Trial] is to establish and maintain improved communication … patterns for health service providers in the designated geographic area of the trial. This will encompass all health service providers; from general practitioners, medical specialists, hospitals, through organisations such as the Royal District Nursing Service and community health providers.'[37]

In both waves of the survey GPs were asked to rate the impact of the Trial on their communication with:

- local public hospitals (Monash Medical Centre, Dandenong Hospital),
- private medical specialists,
- community health centres, and
- other organisations (eg. Linkages, Mental Health Services).

In 1999 49% of responding GPs indicated that it had helped their communication with one or more of the service providers listed – up from 47% in 1998. Figures 12.7 to 12.9, show the response patterns for GPs who had high and medium-risk Trial clients only (Figure 12.7), those who had high, medium and low-risk clients (Figure 12.8) and those who had only low-risk clients (Figure 12.9).

Across all three groups of GPs, the area of least impact was communication with private medical specialists (27%, 13% and 18% of GPs respectively). For GPs with only high and medium-risk clients the area of greatest impact was in their communication with local public hospitals and community health centres (38% indicating the Trial had helped).

> *I received notification sooner when a patient was admitted to hospital.* (GP 1201)

For GPs with high, medium and low-risk clients, the area of most impact was in their communication with 'other' organisations (40% of those GPs indicating the Trial had helped), and for GPs with low-risk clients only the area of most impact was in their communication with local public hospital (40% indicating the Trial had helped). As with the other systemic impacts, The impact on communication was muted by the nature of the patients enrolled in the Trial.

> *Well patient who has not needed any attention and has not been seen by any other medical/welfare professionals. No communication needed.* (GP 1251)

[37] Ross, Pauline, Stoelwinder, Johannes and Allwell, Lisa (1999) 'The Southern Health Care Network Coordinated Care Trial', The Australian Coordinated Care Trials. Canberra, Commonwealth Department of Health and Aged Care. pp 149-164.

Figure 12.7 GPs with only high and medium-risk clients indicating the Trial 'helped' in their communication with other service providers in 1999

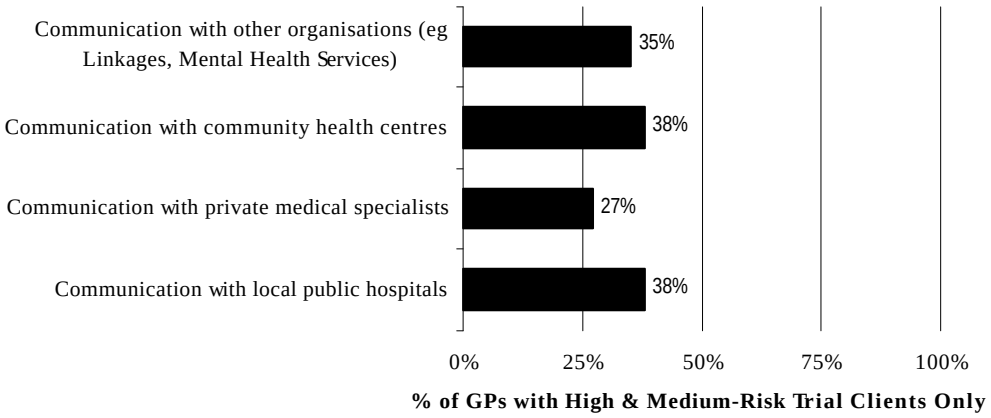


Figure 12.8 GPs with high, medium and low-risk clients indicating the Trial 'helped' in their communication with other service providers in 1999 survey

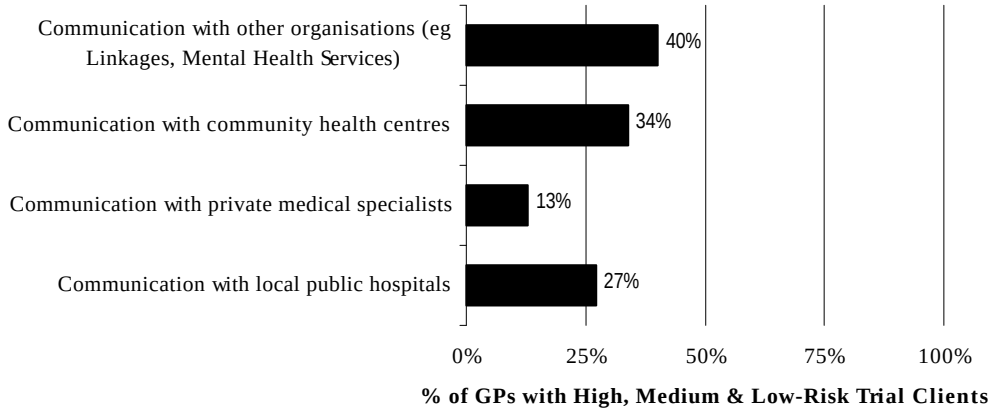
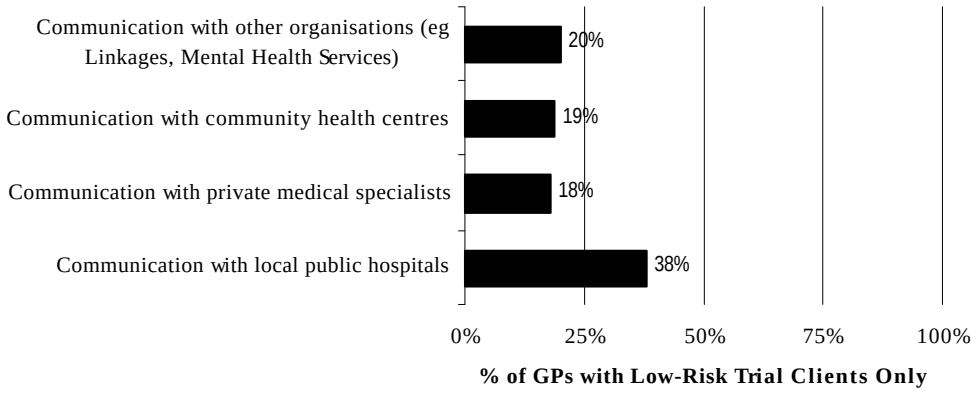


Figure 12.9 GPs with only low-risk clients indicating the Trial 'helped' in their communication with other service providers in 1999 survey



12.4 Impact on service provision

The current health system is characterised by a shortage of services and where services are provided there are often eligibility criteria which makes it impossible for those who do not fit the criteria to obtain them (see for example Chapters ? and ?). In this environment service coordinators and case managers had the job of implementing care plans for intervention clients without the benefit of brokerage funds to pay for extra services. Comments on the GP questionnaires indicated that they had been successful in doing this for some of the intervention group patients.

> *Coordinated care helped particularly with an elderly, depressed patient in arranging house visits and hospital treatment.* (GP 1171)

> *The case managers and service coordinators were invaluable in being able to slot these patients into the appropriate resources as required.* (GP 1260)

The efficacy of the case managers and service coordinators in being able to obtain services for the intervention clients was borne out by the data from wave 3 of the patient perception survey. In that survey, the ratio of intervention to control respondents was 2.6 : 1. Yet in the response to the question 'Over the last 2 years, which health-related items has the Trial been able to help you get?' intervention group respondents were over-represented in each category of health related item (see Table 12.4).

Table 12.4 Intervention clients indicating Trial helped them to obtain services

	Intervention Group Respondents (a)	Control Group Respondents (b)	Ratio Intervention to Control (a):(b)	Over-representation (a)
Allied health	43	6	7.2	2.8
Personal items	37	5	7.4	2.8
Personal help	28	4	7.0	2.7
Other	21	3	7.0	2.7
Home modifications	14	1	14.0	5.4
Financial help	10	0	>10	>3.8
Dental service	10	0	>10	>3.8

12.5 Important elements of coordinated care to retain

In 1999 GPs were asked how important they considered certain elements of the Trial were to the introduction of coordinated care on a wider scale. As shown in Table 12.5:

- over 85% of the GPs indicated that having the GP as the care coordinator and a fee for care planning were important;
- over 75% indicated that access to service coordination and case management were important;
- over 55% considered the risk assessment tool and patient utilization report were important; and
- less than 50% thought the care improvement panels and having the division review care plan would be important (over 10% thought these elements were unimportant).

Table 12.5 GPs' views about the importance of retaining key elements of the SHC Network Trial

	Important		Unimportant	
	Number of GPs	Percent	Number of GPs	Percent
GP as care coordinator	189	86%	11	5%
Fee for care planning	186	86%	6	3%
Service coordination	173	80%	8	4%
Case management	163	75%	7	3%
Risk assessment tool	126	58%	13	6%
Patient utilization report	119	55%	15	7%
Care improvement panels	88	41%	25	12%
Divisional review of care plans	85	39%	35	16%

12.6 Impact if introduced more widely in Australia

GPs were asked to try to put aside their direct experience of the Trial and rate the effect that coordinated care would have if it was introduced more widely into Australia on the following elements:

- care of chronic patients with complex care needs,
- care of other patients,
- the quality of Australian general practice,
- the quality of the Australian health care system,
- containing health care costs in Australia,
- general practitioner remuneration, and
- the status /prestige of Australian general practice.

A small number of GPs indicated that they were unable to answer this part of the questionnaire because their lack of participation in the Trial:

> *I am not a good candidate to answer this part as my exposure to [the Trial] is very minimal.* (Id 1217)

> *I did not have any experience of the process other than the initial orientation. Can't really comment.* (Id 1308)

But others did answer this part of the survey.

12.6.1 Impact on patient care

Analysis of the comments indicated that it would have a positive effect on the care of chronic patients with complex needs but not for other patients.

> *I have a few patients with chronic complex medical problem that would definitely have benefited from coordinated care had they been included in the Trial.* (GP 1076)

> *My patients in the trial were all low risk, self managing patients, and I found coordinated care contributed absolutely nothing. I wish I could have enrolled some of my elderly patients with multiple problems; I suspect coordinated care would have helped them.* (GP 1138)

> *For particularly complicated patients with social issues the program could enhance the standard of care.* (GP 1146)

> *Unnecessary visits for Level 1 would be negative.* (GP 1309)

Seventy-two percent of the responding GPs indicated that coordinated care would have a positive impact on the care of chronic patients with complex needs. Only 30% thought it would have a positive impact on the care of other patients (see Table 12.6).

Table 12.6 GPs views of the impact of coordinated care on patient care

	Care of chronic patients		Care of other patients	
	Number of GPs	Percent	Number of GPs	Percent
Positive effect	156	72%	65	30%
No/mixed effect	53	24%	131	60%
Negative effect	9	4%	21	10%
TOTAL	218	100%	217	100%

12.6.2 Impact on the quality of health care

Just under half the GPs responding to the 199 survey indicated that they thought coordinated care would have a positive effect on the quality of Australian general practice and the Australian health care system if it was introduced more widely in Australia. Less than 10% thought it would have a negative impact (see Table 12.7)

Table 12.7 GPs views of the impact of coordinated care on the quality of health care in Australia

	General practice		Health care system	
	Number of GPs	Percent	Number of GPs	Percent
Positive effect	100	46%	96	45%
No/mixed effect	98	45%	105	49%
Negative effect	19	9%	14	6%
TOTAL	217	100%	215	100%

12.6.3 Impact on costs, remuneration and prestige

One-third of responding GPs indicated that coordinated care would have a positive impact on containing health care costs and just under one-third indicated that it would have a positive effect on GP remuneration. One-quarter indicated in would have a negative effect on containing health care costs and 19% a negative effect on GP remuneration (see Table 12.8). Seventy-four GPs (35%) indicated that it would have a positive impact on the status/prestige of Australian general practice and 26 (12%) indicated it would have a negative impact.

Table 12.8 GPs views of the impact of coordinated care on containing health care costs and GP remuneration

	Containing health care costs		GP remuneration	
	Number of GPs	Percent	Number of GPs	Percent
Positive effect	71	33%	65	31%
No/mixed effect	89	42%	106	50%
Negative effect	54	25%	39	19%
TOTAL	214	100%	210	100%

Annexure to Chapter 12

GP survey methodology

In 1998, questionnaires were mailed to 369 GPs 4 of which were returned because the GP concerned was no longer working at the surgery where the questionnaire had been sent and were not longer actively involved in the Coordinated Care Trial - they were out-of-scope. This meant that questionnaires were mailed to 365 in-scope GPs. The adjusted response rate for 1998 is 76%. One GP indicated in the 1998 questionnaire that s/he did not wish to have any further involvement in the evaluation. In 1999 questionnaires were mailed to 364 GPs and of these, 14 were found to be out of scope. Two hundred and thirty-three completed questionnaires were received and 10 were received from GPs indicating why they felt they were unable to complete the questionnaire. The adjusted response rate for 1999 is 70% (see Table 12.1).

Table 12A.1 Response rates

	1998	1999
Completed questionnaires (a)	277	244**
Number mailed (b)	369	364*
Raw response rate (a) / (b)	**75%**	**67%**
Known out-of-scope (c)	4	14
Assumed In-scope (d)	365	350
Adjusted response rate (a) / (d)	**76%**	**70%**

Notes:

** Excluded one GP who wrote on the wave 1 questionnaire that s/he did not want any more involvement.

** Includes 10 returned questionnaires in which the GP did not complete all the questions but included comments as to why they did not wish to do so and these have been entered in the comments database and one that arrived too late to be included in the analysis.

Across both waves of the survey a total of a total of 301 care coordinators responded to the survey Two hundred and eighteen GPs responded to both waves of the survey, 58 responded in 1998 only and 24 responded in 1999 only (see Table 12.2).

Table 12A.2 Patterns of response to the survey

	1998	1999
Responded in 1998 only	58	
Responded in 1999 only		24
Responded in 1998 and 1999	218	218
Unknown*	1	1
TOTAL	277	243

Notes:

* Serial number removed on returned questionnaire.