

Linked Care Evaluation Hornsby Ku-ring-gai Coordinated Care Trial, Local Evaluation Client Experience Report

Author:

Strazzari, Stefani; Fisher, Karen; Fine, Michael; Doyle, Jenny; McNab, Justin; Harris, Mark; Powell Davies, G; O'Brien, Terry

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LINKED CARE EVALUATION HORNSBY KU-RING-GAI COORDINATED CARE TRIAL

LOCAL EVALUATION CLIENT EXPERIENCE REPORT

SPRC Report 4/00

University of New South Wales Consortium
Social Policy Research Centre
Centre for General Practice Integration Studies
March 2000

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Contact: Publications, SPRC, University of New South Wales, Sydney, NSW, 2052, Australia.
Telephone: +61 (2) 9385 7800 Fax: +61 (2) 9385 7838 Email: sprc@unsw.edu.au

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UNSW Evaluation Consortium

Social Policy Research Centre

Stefani Strazzari, Karen Fisher, Michael Fine, Jenny Doyle, Justin McNab

Centre for General Practice Integration Studies

Mark Harris, Gawaine Powell Davies

Cost Analyst

Terry O'Brien

With assistance from Peter Saunders, Gil Srzednicki, Lynda Pawley, George Matheson, Brian O'Toole, Michael Bittman, Diana Encel, Bruce Bradbury, Jenny Chalmers, Louise Byrne, Mary-Rose Birch and Sharon Burke.

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Contacts for Follow up to this Report

Karen Fisher ph 02 9385 7800, fax 02 9385 7838, email karen.fisher@unsw.edu.au

Michael Fine ph 02 9850 8037, fax 02 9850 9355, email michael.fine@mq.edu.au

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Abbreviations and Glossary

ACAT	Aged Care Assessment Team, part of RACS
ADD	Ageing & Disability Department, NSW
AN-DRG	Australian National Diagnosis Related Group
ATC	Anatomical Therapeutic Chemical Classification
CACP	Community Aged Care Package
CEO	Chief Executive Officer
CC	Care coordinator
CCDM	Coordinated Care Data Management group
CCT	Coordinated Care Trial
CDHAC	Commonwealth Department of Health and Aged Care
CDHSH	Commonwealth Department of Human Services and Health (now Health and Aged Care)
CIARR	Client Information Assessment and Referral Record
Clients and participants	Linked Care referred to clients and consumers as ‘participants’ in order to differentiate between their role in Linked Care and their role as clients or users of community services. Generally this report retains that convention unless it is referring to the general client population, clients outside the trial or in tables. All names used in the report are pseudonyms.
CM	Case Manager
COAG	Council of Australian Governments
COPS	Community Options Program
DOCS	Department of Community Services, NSW
DRG	Diagnosis Related Group
DVA	Department of Veterans’ Affairs
Effective sample	Participants who responded to both the baseline and end trial participant questionnaires
GP	General Practitioner
HACC	Home and Community Care program
HCF	Hospital Contributions Fund
HCS	Home Care Service
HIC	Health Insurance Commission
HKCC	Hornsby Ku-ring-gai Coordinated Care
HKHCHS	Hornsby Ku-ring-gai Hospital and Community Health Services
IHD	Ischaemic Heart Disease
ILU	Independent Living Unit
IT	Information Technology
MBF	Medical Benefits Fund
MBS	Medical Benefits Scheme
MFC	Mercy Family Centre
MOW	Meals on Wheels, Hornsby Ku-ring-gai Hospital
NESB	Non-English-Speaking Background
NIDDM	Non-Insulin Dependent Diabetes Myelitis
NOS	Not Otherwise Specified
NSAHS	Northern Sydney Area Health Service

NSHNS	Northern Sydney Home Nursing Service
NUM	Nursing Unit Manager
PBS	Pharmaceutical Benefits Scheme
PHI	Private Health Insurance
PMMS	Patient Medical Management System
PSG	Peer Support Group (care coordinator meetings)
QCWP	Quality and Complaints Working Party
RACS	Rehabilitation and Aged Care Service, Hornsby Ku-ring-gai Hospital
SAH	Sydney Adventist Hospital
SF-36	Health and Well-being Survey (Short Form 36)
SNAP	Sub-Acute and Non-Acute Patient Classification
TCM	The Care Manager
TUS	Trial Utilisation System
UNSW	University of New South Wales

Part A Introduction

1. Introduction and Background

1.1 *Background to the CCTs and the Evaluation*

The Linked Care Trial was an innovative approach to linking health and community care services for people in need of ongoing care, established in 1996-97 in the municipalities of Hornsby and Ku-ring-gai in Sydney's northern suburbs. The trial formed part of a national program of Coordinated Care Trials (CCTs) established in 1996 to test whether it was possible to coordinate the care currently provided by a variety of different health and community care services and practitioners using funds pooled from a number of different Commonwealth and State programs. This flexible use of funding was to be managed by care coordinators (CCs) assigned to each participant,¹ using an individual care plan to help organise the medical care and social assistance that each would receive. The local evaluation of the Linked Care Trial was to test whether this approach could be practically implemented in the local community and, if so, to determine whether this led to a more effective use of existing resources with improved outcomes for participants and caregivers.

This client experience report reviews progress with Linked Care and the evaluation, from commencement of the live phase of the trial in 1997 to its formal conclusion in December 1999. Drawing on quantitative and qualitative data collected as part of the local evaluation, the report presents an analysis of a number of components of Linked Care from the perspective of participants.

The remainder of this introduction provides a brief overview of the background to the Coordinated Care Trials and specifically this trial, Linked Care. It also introduces the concepts relevant to evaluating client experience. This introduction also serves as a guide to the remainder of the report.

Incorporating the consumer perspective is a guiding principle for improving service provision. Underlying this emphasis on the consumer is the involvement of the person in their own care as essential to improving health outcomes (Barnes and Walker, 1996: 378; Wallerstein, 1993: 223-5). Client involvement in their health care and their maintained independence is fundamental to current government health policy at both Commonwealth and State levels, such as the Federal Healthy Ageing Campaign.² Australian policy has followed the international trend of gaining insight into the perspective of health care clients (Draper and Hill, 1995: 4; Opie, 1998; Pond, 1996).

The Australian Coordinated Care Trials (ACCT) were developed from a report in 1994 by the Council of Australian Governments which found the health and community service

¹ Linked Care referred to clients and consumers as 'participants' in order to differentiate between their role in Linked Care and their role as clients or users of community services. Generally this report retains that convention unless it is referring to the general client population, clients outside the trial or in tables. All names used in the report are pseudonyms.

² For instance, government funding can include patient satisfaction surveys as part of the requirements of evaluations (Ware et al., 1996: 319).

system needed to be reformed to more appropriately respond to people's care needs and also more efficiently manage the health care dollar. The trials were funded nationally by the Commonwealth Department of Health and Aged Care (CDHAC) and began 1 September 1997 and finished on 31 December 1999. Nine trials were set up nationally with another four trials established for Aboriginal communities. Funding from the May 1999 Federal Budget was allocated for a second phase of coordinated care trials.

The consumers in the Trials had complex care needs and were users of multiple health and community services. Coordination for these consumers was to be achieved within existing levels of resources in two ways. First, employment of a CC was to foster multi-disciplinary care planning and service provision more responsive to individual client needs. Second, fund-pooling of Commonwealth and State programs were to allow funding flexibility to support this coordinated, cooperative and integrated approach to service delivery. Therefore the Coordinated Care Trials were perceived to be potentially significant in the reorganisation of services and funding arrangements for health and community care for individuals.

Fundamental to the philosophy of the Coordinated Care Trials was placing the consumer of health and community services at the focal point of the model (Leigh et al., 1999: 1). This meant health interventions were to be targeted at individuals rather than populations. 'Consumer' was used in the trials to mean those with complex care needs and users of multiple health and community services.³

The importance of client involvement in the Coordinated Care Trials was underscored at various levels of implementation (the national guidelines and objectives; the requirements for the local trials; and the national and local evaluations). It was specifically included in one of the national hypotheses:

The extent to which *health consumers* are *partners* in the planning of the Coordinated Care Trial, the development of care plans and *empowered* through the coordination process.⁴ (Centre for Health Advancement and KPMG Management Consulting, 1997:6)

The primary means of involving Linked Care participants in decisions about their care arrangements was through the appointment of a CC. CCs were responsible for empowering service users by regularly contacting them and encouraging them to participate in the decision-making process. Linked Care implemented a number of quality control methods to ensure the involvement of participants in the coordination process and also receive participant feedback. The details and effectiveness of these mechanisms are discussed in Chapters 4 and 5 of this report.

Exploring the area of client empowerment is a large undertaking. Christina Victor raises questions which point to the complexity of researching client interests:

³ In this report the term 'consumer' has been used interchangeably with client because all people in the Intervention and Control groups were enlisted as current users of services. During the trial, Linked Care referred to clients and consumers as 'participants' in order to differentiate between their role in Linked Care and their role as clients or users of community services.

⁴ Local Evaluation emphasis.

Advocacy and empowerment are obviously key themes underpinning especially the community care developments; but how willing will agencies be to give real power to older people...? What inducements will organisations have to include the views of clients? Do clients have the skills to participate and what incentives will there be for older people to participate? ... There is also potentially an important conflict between the assessment, advocacy and financial activities of the case manager. If the case manager is a budget holder then there is a tension between his or her role in assessing the needs for care and responsibility as holders of a finite and cash-limited budget. How will case managers reconcile their conflicting tensions? What mechanisms will be established to ensure that assessments are based upon client needs and not the state of the case manager's budget? Will the client assessed at the end of the financial year get the same treatment as one seen at the start of the year? Clearly such issues must be addressed if older people ... are to be able to look forward to an equitable and effective system of social care. (Victor, 1991: 163, 167)

The local evaluation sought the experiences of participants in two ways: through data reported from service providers (e.g. exits, measures of disease control, participant profiles); participant reported data (e.g. SF-36, participants' perceptions and explanations of their experiences); and through participant questionnaires and qualitative interviews. The methodology employed for collecting participant reported data is described in Appendix 4.

Using these data sources, this report examines client experiences of Linked Care, and the impact of the Linked Care model on their experiences as users of health and community services.

1.2 Background to Linked Care

The Linked Care Trial was proposed in 1995 by the Northern Sydney Area Health Service (NSAHS) in response to a national call for expressions of interest in September of that year. NSAHS committed associated facilities and services through a joint expression of interest with the Hornsby Ku-ring-gai branch of the Northern Sydney Division of General Practice and a number of independent non-profit health and community services, most of which are funded through the Home and Community Care Program (HACC). Preparations continued throughout 1996 and 1997, and Linked Care formally commenced operation on October 1 of that year. It operated until December 1999, with a final evaluation report due by the end of March 2000.

Briefly, the model of care coordination proposed for Linked Care was that a care coordinator (CC) was to be appointed for each participant, either their GP or an employee from an agency that provides or could provide them with other health and community care. The CC, in consultation with the participant and relevant service providers, was to prepare or review a care plan for the participant at least every three months, covering both medical and other health and community care services. Care provided to the participant, and care coordination costs, were to be paid from a fund pool of health and community care funds. This was intended to provide a budget that was capped but flexible, within which the CC could seek the most cost-effective solutions to the participant's care needs. Services used

were to be reconciled against the care plan as feedback to the CC. CCs were to be accountable to each other for significant financial decisions through a Peer Support Group (PSG) structure.

Responsibility for the local evaluation of the Linked Care Trial was awarded to the University of New South Wales Evaluation Consortium (UNSW Evaluation Consortium) in December 1996, following a competitive tendering process. In 1997 responsibility for the national evaluation was contracted to a consortium between the Centre for Health Advancement at Flinders University of South Australia⁵ and KPMG Management Consulting. The design, development and management of quantitative data systems for the national evaluation was assigned to La Trobe University's Coordinated Care Data Management (CCDM) group.

1.3 Overview of the Report

Part A of this report (this section) provides an introduction to the report including the background to the trials and consumer perspective, presented in Chapter 1, and an explanation of the evaluation methodology, which is presented in Chapter 2.

Part B presents the findings of the evaluation. A description of the participants is provided in Chapter 3. This is followed, in Chapter 4, by findings about various organisational aspects of Linked Care from the participant perspective. These aspects include: financial management, care coordination, and the quality of Linked Care contact with participants. Chapter 5 explores client outcomes and the impact on carers. Chapter 6 examines client experiences of changes in service usage. The findings are drawn together in Part C by analysing how the Linked Care model performed from the participant perspective.

The report should be read in conjunction with the *Local Evaluation Final Report* and the other two thematic reports:

? *Service Provider Experience Report*

? *Whole of System Report.*

A separate volume of evaluation instruments accompanies the *Local Evaluation Final Report*.

These reports should also be referred to for information relating to care coordinators, service provider or General Practitioner (GP) experiences, trial management and administration issues, or financial arrangements.

During the course of data collection, much information was gained which fell beyond the scope and purpose of the evaluation. It is anticipated that this material will be further analysed to improve understanding of the Linked Care Trial, and to guide future policy directions.

⁵ This responsibility passed to Monash University in early 1999, due to the transfer of the Centre's director.

2. Methodology and Approach to the Local Evaluation

2.1 Background to the Evaluation

The local evaluation of the Linked Care Trial was undertaken by the UNSW Evaluation Consortium as part of the larger national evaluation of the Coordinated Care Trials (Coopers and Lybrand, 1997; CDHSH, 1996). It was also conducted as a consultancy in accordance with the specifications laid out in the tender brief from the NSAHS (NSAHS, 1997). The commissioning process thus set out the basic parameters of the research and determined the resources available for the evaluation.

National and Local Hypotheses

The *National Evaluation* and the *Local Evaluation Tender Requirements*, stated that the evaluation to test the primary hypothesis:

1. that coordination of care for people with multiple service needs, where care is accessed through individual care plans and funds are pooled from within existing programs, will result in improved individual client health and well-being within existing resources (HKCC Project, 1997a; CDHFS, 1996a).

It was also to test the hypotheses that the success of coordinated care would be affected by:

2. the extent of substitution between services;
3. the range of services and the size of the trial pool;
4. the characteristics of the clients;
5. the quality of the clinical and service delivery protocols;
6. the characteristics of the care coordination function;
7. the particular types of administrative arrangements;
8. the extent to which clients were partners in the planning and coordination process; and
9. that the primary results can be achieved without detriment to other key areas of government policy, particularly equity of access and privacy.

The evaluation also had to address *the extent of collaboration in care between those involved*, and *the quality of care* and number of related secondary hypotheses as set out in the national project documentation.

The local evaluation was also to determine the extent to which the trial was able to meet six primary objectives concerned with establishing the trial and five secondary objectives concerned with changing existing patterns of service usage. Two of the objectives emphasised issues which were not identified in the national evaluation, namely the *impact of coordinated care on informal caregivers*, and the introduction of *integrated, multidisciplinary assessment services* for frail aged people, people with severe disabilities and people with chronic medical problems in the trial area.

The national and local hypotheses are listed in full in Appendix 1. The evaluation conceptual framework is described in Appendix 2.

The remainder of this chapter refers only to the research designed to collect information from the participants. Methods used for other aspects of the Linked Care evaluation are listed in Appendix 3.

Recruitment

Participants for the Intervention group were recruited from the Hornsby Ku-ring-gai area with the Control group drawn from neighbouring Ryde Hunters Hill. At the close of recruitment in April 1998, 722 Intervention participants and 423 Control participants were involved. Both groups were recruited through their existing service providers, mainly HACC agencies, but also including GPs, based on their residence in the local community, complex care need, and use of two or more health and community services (Table 2.1). Mostly older people were recruited through this process but there were also a number of younger people with physical disabilities, including children.

Table 2.1: Linked Care Recruitment Process for Intervention and Control Groups

Criteria	Inclusion Requirements
Residence	? Be a resident of Hornsby or Ku-ring-gai Municipalities for inclusion in Intervention group
	? Be a resident of Ryde or Hunters Hill Municipalities for inclusion in Control group.
Living Arrangements	? Living in the community (i.e. not in a nursing home or hostel, but may be a patient in an acute hospital)
Support Needs	? Likely to require on going and high-level support
Primary Condition	? Physical ailment so that they are unable to live independently without community care or support by family
	? No primary need for mental health services
Service Use	? Currently used 2 or more health or community services (not including GP or pharmacy)
Consent	? The participant, or in the case of a person suffering from confusion or dementia, a responsible person, must be able to provide their informed consent
	? Their GP must not have excluded the person on clinical grounds

2.2 Methodology for Clients' Experience Evaluation

Data from all Linked Care participants were gathered to provide information on client outcomes. Data on outcomes for participants were collected wherever possible by service providers and Linked Care. These data included:

- ? the number of participants continuing to live at home, admitted to a nursing home or hostel, the number who died, and the number who withdrew from the trial for other reasons or were discharged from services because they no longer required assistance;
- ? improvements in the access of participants and carers to services and changes in participant and staff satisfaction with the type and quality of care provided. These were monitored using questionnaires distributed to a sample of participants; and

- ? the health outcomes for participants, assessed using the SF-36 and other measures agreed with the local trial participants and consistent with those identified by the national evaluators. These included clinical indicators and data on health service outcomes, including changing patterns of service utilisation.

Triangulation was employed to explore participant experiences from a number of angles to overcome the limitations of using only one method (Dockrell, 1995: 50; Sarantakos, 1993: 169)

The participant perspective was sought in two main ways. First, a questionnaire was mailed to a sample of Intervention and Control participants in November/December 1998 and re-administered in October/November 1999. Additional written comments were sought from questionnaire respondents in order to provide greater insight into some aspects of participant experience. The mailed questionnaire had a high response rate with 86 per cent responding in 1998 and 96 per cent in 1999, although numbers were reduced by 1999 because of the exit rate of the trial.

Second, telephone interviews were conducted with a small number of participants from each group in September 1998, April 1999 and October 1999. While the questionnaire provided a broad overview of the participant experience, the interviews provided an in-depth perspective of participants' everyday experiences of their care. Interviews have been shown to be particularly useful when conducting explorative research (Minichiello et. al., 1995: 75; Vaus, 1990: 53). A supplementary method for exploring client experiences employed by the local evaluators was to utilise the extensive field experience and contacts made at Linked Care including: attending Linked Care staff meetings, Peer Support Group meetings for CCs, interviews and discussions with various Linked Care staff, service providers and consumer representatives.

The first two methods are discussed in greater detail below.

a) Participant Questionnaire

A longitudinal questionnaire collected information directly from people participating in the trial to observe how the trial influenced their experiences as compared to the Control group who received no trial interventions. The participant questionnaire was the main method of data collection from participants since it collected quantitative data from over 400 participants in the trial, and had longitudinal information from over 250 Intervention and Control participants.

The participant questionnaire was developed in three stages. Initially, published material on the development of other similar questionnaires were drawn upon. Then, discussions were held with people conducting other trials on their experiences of participant data collection. Lastly, the questionnaire was modified and adjusted through two pilots. Discussion with Linked Care staff and management and participating service providers, including care coordinators, continued throughout this process. The questionnaire was designed, as far as possible, to be simple and unrepentive for participants since there was already some comment from them about the burden of paperwork. Identification numbers, which ensured confidentiality, linked questionnaire responses to data already collected from all Linked Care participants at the trial administration level, including demographic information, SF-36 responses and reasons for exit (n=1145, I=722; C=423).

Five areas were explored in the questionnaire:

- ? service usage and types of support received;
- ? personal costs;
- ? participant experiences of health and community care;
- ? health and well-being; and
- ? informal and unpaid help.

This allowed the evaluators to collect data not gathered in other parts of the trial, particularly effects on participants and their carers, and to cross-reference with other gathered material.

A sample of 500, with equal numbers from Intervention and Control groups, was computer generated. The first administration had an 84 per cent response rate (after excluding participants who had exited from the trial). The questionnaire was re-administered to participants who had completed the first questionnaire and had not exited by November 1999. This produced a 90 per cent response rate, after exits were excluded. Descriptions of these sample groups are summarised in Table 2.2.

Table 2.2: Participant Descriptions for Total Population and Participant Questionnaire Sample

Participant group name	Description	Participant group		
		Intervention	Control	Total
All participants in Linked Care	All those participants in Intervention and Control groups.	722	423	1145
Participants not exited	Excludes all participants from Linked Care who exited before the end of the trial.	396	210	606
Participant questionnaire sample baseline	All participants who responded to the baseline November 1998 participant questionnaire (84 per cent)	213/250	208/250	421/500
Effective participant questionnaire sample	Participants who responded to both the participant questionnaires at the baseline November 1998 and end of trial November 1999 (90 per cent)	143/161	122/133	265/294
Participant interview sample	Sample of Intervention participants selected by CC type. Control matched by living arrangements (up to 3 interviews each).	11	12	23

Although Linked Care had been in its live phase for some time when the baseline participant questionnaire was administered, it approximates the trial baseline due to the staggered recruitment and delayed provision of some initial care plans. The questionnaire asked about service use in the six months prior to receiving the questionnaire. The two administrations of the questionnaire enabled the local evaluation to explore change in the care and satisfaction of participants over time and to observe any differences in that period between Control and Intervention participants.

b) In-depth Qualitative Interviews

A small sample of participants for qualitative interviews was drawn in equal numbers from Intervention and Control groups (Table 2.3). The participants were selected via systematic sampling. Selection of the Intervention participants was based on the three types of CC allocated:

- ? GP CCs;
- ? agency CCs; and
- ? full-time CCs.

The Control participants were matched based on the living arrangements of the Intervention sample (whether the participant was living alone or with others). When a participant exited the trial or did not wish to continue being interviewed from the first set of interviews, a replacement participant was selected for the second round (three participants were replaced in this way). Participants who exited in the second round were not replaced.⁶

The small numbers involved in the interviews means their experiences cannot be generalised to all Intervention and Control participants. However, these qualitative interviews provide a greater insight into personal experiences of care and supplement the questionnaire data. The in-depth material collected added detailed information about participant experiences and views. It would also appear to be an appropriate method to explore a trial offering individually tailored care plans and for gaining greater insight into the consumer perspective (Wilson, 1995: 249).

⁶ Two people from the Control group could not be interviewed in the third round. One person had relocated to a nursing home and another person had recently had an operation.

Table 2.3: Self-reported Characteristics of Participants in the Qualitative Interviews

	Intervention			Control		
	1 st Interview ^(a))	2nd Interview ^(b)	3rd Interview	1 st Interview ^(a)	2nd Interview ^(b)	3rd Interview ^(c)
Carer Status						
Mutual care situation	1	2	2	1	1	1
Carer for another	1	0	0	1	0	0
Cared for by another	5	4	5	5	5	4
No carer/ no live-in carer	3	3	3	3	4	2
Interviewee						
Participant	6	6	6	8	9	7
Carer	4	4	4	2	2	0
Care Coordinator	0	2	0	0	0	0

Notes: (a) One participant did not wish to be interviewed in the first round of interviews.

(b) One participant was interviewed while in hospital.

(c) One participant died before the third interview and two participants were unable to be contacted during this round of interviews.

The interviews were usually conducted by telephone and recorded with the consent of the participant. The length of the Interviews varied from 15 minutes to two hours. The interviews were semi-structured and incorporated issues addressed in the questionnaire, but were also responsive to issues the participants themselves raised. For the Intervention group, the care plan arrangements were checked against the care plan in the first and second interview. Exploring how care was organised and maintained, and how participants and carers perceived care, was another major focus of the interviews.

During the second round of interviews greater emphasis was placed on exploring the perceived benefits (or disadvantages) of Linked Care, having a CC for participants in the Intervention area, and whether Linked Care met participant expectations. Control and Intervention participants were asked about the nature of their GPs' involvement in their care and what they considered the role of their GP to be. The third interview focused on any changes that occurred and, in particular, asked participants to comment on their experiences of Linked Care.

Part B Findings

3. Description of the Participants

This chapter describes the participants recruited to Linked Care. Participants recruited to Linked Care were people with complex care needs living in the community, predominantly older people and people with disabilities. Target recruitment numbers were almost but not fully achieved. Further participant tables are presented in Appendix 4. Participant experience tables form Appendix 5.

3.1 *Demographics of the Linked Care Participants*

3.1a Baseline Characteristics

Final consents were obtained from 722 Intervention and 423 Control participants.⁷ When participants were recruited to Linked Care, their recruiter or CC was expected to complete a participant profile with them. This profile was included in data for the national data set and local evaluation. The participant profile data set was not completed until the last year of the trial, after Linked Care administration identified and corrected data entry errors and gaps in the data.⁸

Table 3.1 presents these demographic, household and income-related data for Intervention and Control participants. The number of missing cases for each item and group is noted at the end of the table.

The sample mainly consisted of older people, with over 80 per cent from the Intervention and Control groups aged 70 years or more, and well over 50 per cent from each group aged at least 80. Women, single participants, Australian-born participants, and participants from families where English was spoken at home were the predominant demographic features in both groups. There were no indigenous participants in either group.

Over 90 per cent of all participants lived in a house or flat, with many more owning their residence rather than renting. Given the age distribution of the sample it is not surprising that over 90 per cent from both groups described themselves as 'retired'. Roughly one-third from each group paid for private domestic help and both groups had similar proportions of Department of Veteran's Affairs (DVA) clients. Data on household income were dropped

⁷ Linked Care recruited 725 Intervention participants. No accurate demographic and service usage data about three participants who exited early in the trial was available to the evaluators.

⁸ The participant profile form was redrafted in the second year of the trial for ease of administration and data entry to correct a number of errors. Some of the errors had implications for the national data set. The first form asked for household rather than personal income. Some instructions were incorrect so that respondents missed questions e.g. marital status. The form asked for occupation, including prior to retirement rather than current occupation.

from the analysis due to missing data (many participants did not respond to the income related questions).

Table 3.1: Selected Baseline Characteristics of Linked Care Participants by Participant Group

	Participant Group			
	Intervention		Control	
	% ^(a)	n	% ^(a)	n
Participant Characteristics				
Age ^(b)				
<50	5.5	40	2.1	9
50-59	3.7	27	2.6	11
60-69	7.9	57	9.2	39
70-79	28.0	202	30.5	129
80-89	44.6	322	46.1	195
90 and over	10.2	74	9.2	39
	100.0	722	100.0	422
Gender				
Male	34.8	251	26.2	111
Female	65.2	471	73.8	312
	100.0	722	100.0	423
Marital status ^(c)				
Single	56.1	395	69.3	293
Couple	43.9	309	30.7	130
	100.0	704	100.0	423
Country of birth ^(d)				
Australia	77.7	557	76.4	323
Other	22.3	160	23.6	100
	100.0	717	100.0	423
Language spoken at home ^(e)				
English	97.8	697	89.6	379
Other	2.2	16	10.4	44
	100.0	713	100.0	423
Participant's accommodation ^(f)				
House, unit, apartment, flat	90.7	645	94.5	399
Independent living unit, hostel, other	9.3	66	5.5	23
	100.0	711	100.0	422
Tenancy ^(g)				
Owner	83.0	577	72.2	304
Renter	17.0	118	27.8	117
	100.0	695	100.0	421
Shares home				
Does not share	39.2	283	54.1	229
Shares with spouse	41.4	299	28.8	122
Shares with other	19.4	140	17.0	72
	100.0	722	100.0	423
Carer status ^(h)				
Carer not needed	14.0	100	24.2	102
Has a carer	63.8	455	40.1	169
Needs a carer	22.2	158	35.6	150
	100.0	713	100.0	421
Private Assistance				
Has private paid domestic help	32.8	237	28.1	119
No help	67.2	485	71.9	304
	100.0	722	100.0	423
Employment status ⁽ⁱ⁾				
Retired	90.4	644	93.6	395
Not retired	9.6	68	6.4	27
	100.0	712	100.0	422

Table 3.1 (continued): Selected Baseline Characteristics of Participants by Participant Group

	Participant Group			
	Intervention		Control	
	% ^(a)	n	% ^(a)	n
Participant Characteristics				
Health insurance^(j)				
Some private insurance	51.8	373	32.6	138
No insurance	48.2	347	67.4	285
	100.0	720	100.0	423
DVA status				
DVA card	17.5	126	18.9	80
No DVA card	82.5	596	81.1	343
	100.0	722	100.0	423
Cards status^(k)				
Has card	85.9	619	95.3	403
No card	14.1	102	4.7	20
	100.0	721	100.0	423
Education level^(l)				
Primary	13.2	94	20.8	88
Secondary	54.8	391	71.2	301
Tertiary	32.0	228	8.0	34
	100.0	713	100.0	423
Occupation^(m)				
Professional	32.3	230	21.5	91
Trade	44.4	316	59.3	251
Home duties	23.3	166	19.1	81
	100.0	712	100.0	423

Source: Participant profile collected by CCs and Linked Care staff, 1997 to 1999.

Notes: a) Percentages may not add to 100 due to rounding. b) 1 missing case (0 Intervention; 1 Control).
c) 'Single' includes widowed, divorced, separated and never married. 'Couple' includes de facto. 18 missing cases (18 Intervention; 0 Control). d) 5 missing cases (5 Intervention; 0 Control).
e) 9 missing cases (9 Intervention; 0 Control). f) 12 missing cases (11 Intervention; 1 Control).
g) 'Renter' includes 'Other' (2 cases). 29 missing cases (27 Intervention; 2 Control).
h) 11 missing cases (9 Intervention; 2 Control).
i) 'Not retired' includes children, students, employed, unemployed, home duties and other. 11 missing cases (10 Intervention; 1 Control). j) 2 missing cases (2 Intervention; 0 Control).
k) 1 missing case (1 Intervention; 0 Control). l) 9 missing cases (9 Intervention; 0 Control).
m) 10 missing cases (10 Intervention; 0 Control).

3.1b Comparison of Intervention and Control Groups

Although the participants in both the Intervention and Control groups were fairly similar overall, some differences between the two groups were also evident. A greater proportion of Intervention participants had a carer; well over 50 per cent had some private insurance compared to just over 32 per cent of Control participants; more of the Intervention group had tertiary level education; and Intervention participants who had had a 'professional' occupation greatly outnumbered Control participants who had had similar occupations.

The Intervention group also had greater proportions of males, married participants and participants from families where English was spoken at home. Compared to the Control group, more Intervention participants owned their home, many more shared their home with

another person, while less held a pensioner concession card or a health care card. This last characteristic also implies that fewer were in receipt of a government pension or benefit.

When assessing the impact of the intervention on the well-being of participants and on changes in service usage, differences between Intervention and Control participants which might influence the impact must be taken into account. Logistic regression analysis was carried out to estimate to what extent personal and other characteristics changed the odds of being in the Intervention group. The analysis also controlled for the influence of all other characteristics. The results are presented in Appendix 4, Table A4.1. The reference category is described at the end of the table. Only those results indicating a significant difference between the two groups (marked with at least one asterisk) are discussed.

The first panel shows two seemingly contradictory factors associated with Intervention group membership. Participants born overseas were 56 per cent more likely to be in the Intervention group compared to Australian-born participants, while participants who did not speak English at home were significantly less likely to be in the Intervention group. These results indicate that a large proportion of those born overseas were from an English-speaking country.

The second set of variables show that Intervention participants were over 3.6 times more likely to live in an independent living unit (ILU) rather than a home or flat. They were also significantly more likely to have a carer. Renters rather than owners were less likely to be Intervention participants.

Intervention group membership showed a negative relationship with both professional and trade occupations compared to the occupation of home duties. Tertiary level education significantly increased the odds of Intervention group membership by a factor of 5.1.

The results presented in Table A4.1 confirm some of the differences between the Intervention and Control groups evident in Table 4.2: language, tenancy, carer status, private health insurance, concession and health care cards, educational background and occupational background. In addition, two less obvious differences between the groups were found: country of birth and current living arrangements. These differences are taken into consideration in the analysis of participant outcomes and service usage.

3.1c Comparison of Participant Samples to all Linked Care Participants

Two primary methods of evaluation of participant experience were repeated participant questionnaires and participant interviews. The methodology was described in Section 2.2. This section compares the characteristics of the participant samples used for these instruments to all Linked Care participants.

Participant Questionnaire Sample

The participant questionnaire sample had similar characteristics to the total Linked Care participant groups in both the Intervention and Control group sub-samples as described above. The comparison is presented in Table A5.1, Appendix 5.

There were some differences within the effective participant questionnaire sample (participants who responded to the baseline and end of trial questionnaires) between the

Intervention and Control groups (marital status, language spoken, health insurance, tenancy, employment status, care status, education level and occupation). These differences were all similar to the differences between the Intervention and Control groups for the total Linked Care participants who had not exited at the end of the trial (Section 4.2b; Table A5.1 and A5.5). It could therefore be assumed that the participant questionnaire sample was representative of the total Linked Care participant group.

Accurate analysis on sub-populations was not possible because of the low numbers involved in the longitudinal analysis.

Participant Interview Sample

The interviewed participants were not representative of the total Linked Care participant group because of the method of selection (Section 2.2). Participants who participated in the telephone interviews had a variety of health conditions. Two of the Intervention participants were younger people with disabilities. Other participants from the two groups reported declining health associated with ageing, stroke and Parkinson's disease or had conditions such as leukemia, angina problems, continuing eye problems and paralysis. Most interview participants had a carer (usually daughter or spouse) and one participant from each group, while in poor condition themselves, were also the main carer for another person (Table A5.3, Appendix 5).

Carers completed the interview when the participant or carer felt that the participant was unable to answer directly due to illness, disability or confusion. Two carers from the Control group and four from the Intervention group were interviewed instead of the participant, which may indicate differences in the participants' level of need for assistance.

The qualitative interviews collected extensive material from most respondents and their experiences are reported throughout this report. All names used in the report are pseudonyms.

3.2 Diseases at the Baseline

Information on participants' diseases was provided by GPs as part of the medical care plan. Table 3.2 summarises this information by grouping it into disease categories and presenting mean nominations for each group.⁹ The first two columns show the mean for those participants who had at least one disease nominated within the particular disease category and indicates how many times on average a participant had a disease nominated from that category. Columns three and four show the means for all participants within the sample and provide a more general overview of differences between the Intervention and Control groups. Significance is indicated by at least one asterisk.

⁹ Data have been classified according to ICD-9.

Table 3.2: Baseline Comparison - Mean Nominations of Disease Category by Participant Group

		Participants within category ^(a)		All participants ^(b)		
		Intervention	Control	Intervention	Control	
Disease Category						
1.	Infectious and parasitic	1.22	1.20	.02	.02	
2.	Neoplasms	1.10	1.18	.11	.07	
3.	Endocrine, nutritional	1.14	1.19	.32	.32	
4.	Blood diseases	1.04	1.00	.06	.05	
5.	Mental disorders	1.17	1.21	.26	.21	
6.	Nervous system diseases	1.26	1.29	.54	.39	***
7.	Circulatory diseases	1.57	1.61	1.00	1.19	***
8.	Respiratory diseases	1.07	1.09	.22	.27	
9.	Digestive diseases	1.28	1.15	**	.28	.31
10.	Genitourinary diseases	1.08	1.08	.13	.15	
12.	Skin diseases	1.04	1.08	.09	.05	**
13.	Musculoskeletal diseases	1.47	1.33	**	.65	.69
14.	Congenital anomalies	1.18	2.00	*	.02	.01
15.	Perinatal	1.00	-	.002	-	
16.	Ill-defined conditions	1.20	1.13	.18	.12	**
17.	Injury and poisoning	1.05	1.18	.04	.05	
18.	Accidents	1.00	1.11	.03	.04	
19.	Communicable diseases	1.00	1.00	.01	.004	
20.	Family or personal history	1.14	1.11	.21	.26	
23.	Other	1.17	1.20	.20	.21	
24.	Specific procedures/aftercare	1.00	1.00	.002	.01	
Total ^(c)		n/a	n/a	4.38	4.40	

* p<0.1 ** p<0.05 *** p<0.01

Notes: (a) Total number of nominations for category /number of participants in category e.g. neoplasms among Intervention group = 57/52.

(b) Total number of nominations for category/total number of participants in participant group e.g. neoplasms among Intervention group = 57/527.

(c) Total number of nominations/total number of participants in group (Intervention = 2 310/527; Control = 1 217/276; Total = 3 527/803).

Leaving aside category 14, which described a very small number of participants (11 Intervention participants, one Control participant), the first two columns show that the participant groups had similar patterns of means, with circulatory and musculoskeletal averaging the highest. Only digestive diseases and musculoskeletal diseases were found to be statistically significant.¹⁰

Columns three and four show that circulatory diseases were most common in both groups, followed by musculoskeletal and nervous system diseases. Overall, significantly more

¹⁰ Digestive diseases (t=2.0, p<0.05); musculoskeletal diseases (t=2.1, p<0.04).

circulatory disease was evident among the Control group, while for the Intervention group, nervous system diseases, skin and ill-defined diseases were more common.¹¹

Diagnosis data were available for only 803 of the 1145 participants. Given the potential importance that type of medical condition may have on outcomes, future research might focus on this sub-sample of 803 participants so that disease data can be incorporated into the analysis.

No data on severity of disease were collected for the trial or evaluation. Comparison between the Intervention and Control groups about disease severity could therefore not be made either at the baseline or to measure changes during the trial. This should be kept in mind when comparisons such as changes in client outcomes and service usage are made in the report.

¹¹ Circulatory diseases ($t=-2.6$, $p<0.01$); nervous system diseases ($t=3.0$, $p<0.01$); skin diseases ($t=2.09$, $p<0.04$); ill-defined diseases ($t=2.0$, $p<.05$).

4. Organisation and Operation of Linked Care

This chapter describes participants' experiences of the organisational aspects of Linked Care. The chapter describes first, participant involvement in the organisation of Linked Care, including the management of the trial, consumer representatives, the Quality and Complaints Working Party and financial management. Section 4.2 describes participant experience of the care coordination processes, including empowerment, knowledge about the trial, their relationship with CCs, care planning and assessment. A summary is provided at the end of the chapter.

4.1 Participant Involvement in the Organisation of Linked Care

4.1a Trial Management

The focus on consumers, specified in the national aims of the Coordinated Care Trials, was incorporated in the implementation policies of Linked Care. As discussed in the introduction, participants gained access to Linked Care through their contact with their CCs. Participants were otherwise not directly involved in the management of Linked Care, except through the mechanisms described in the rest of this chapter (e.g. consumer representatives, Quality and Complaints Working Party, and financial management).

Linked Care and the local evaluation had a number of contacts with participants in the trial (Table 4.1). The participant questionnaire and telephone interviews were administered to equal samples from both Intervention and Control groups.

Table 4.1: Trial and Evaluation Contacts with Participants in the Linked Care Trial

Intervention participants	Control participants
Trial interventions	
Consenting process	Consenting process
Care plans	Medical care plan listed
CC assigned	
Consumer representatives	
Newsletter updates (occasional ^(a))	Newsletter updates
Trial initiatives e.g. medication review; hip protectors	
Re-consenting process	Re-consenting process
Evaluation process	
3 x SF-36 health and well-being questionnaires (total participant group)	
2 x Service usage and satisfaction questionnaires (sample)	
3 x telephone interviews (sample)	

Note: (a) Linked Care was aware of consumer complaints about receiving mail overload from the trial. On this basis Linked Care attempted to balance information provision against participant exhaustion.

Feedback to the Linked Care model from participants was to be facilitated through participants exercising their choice to remain in Linked Care; in the care planning process via CCs; through complaints mechanisms; and through the right to change CCs. Some implementation practices by CCs, service providers and Linked Care staff meant that participant involvement was not necessarily maximised during the operation of the model, as summarised below. Details about these processes are discussed in the remainder of the chapter.

- ? Care planning: the participant signature was required on the first care plan to indicate involvement and agreement. Signatures on subsequent care plans were unnecessary and participants did not always receive a copy. Some participants used the care plan as an administrative list of existing care arrangements.
- ? Complaints: participants could phone Linked Care administration to directly voice criticism or praise. Few complaints were made (15) and a number of formal positive letters and calls were received (11).
- ? Withdraw consent: while a minority of Intervention participants chose to withdraw from the trial (nine per cent), most Intervention participants remained with Linked Care.
- ? Right to change CC: it is unclear whether this option was taken up, and if participants felt able to make such a decision. Telephone interviews with participants suggested this procedure may have been incompletely implemented.

4.1b Consumer Representatives

During the establishment phase Linked Care management recruited 16 consumer representatives through advertisement in the local newspaper. Consumer representatives were reimbursed for their expenses at a rate of \$25 per hour. Their primary role during establishment was to sit on the six working parties. Five consumer representatives continued on the remaining working parties throughout the live phase. Through the working parties, the consumer representatives had a potentially significant role in the decision-making structures of Linked Care. They offered a more objective view on the Management Committee, for instance, when the provider interests were sometimes at odds with trial management interests.

All the consumer representatives thought that participants were not sufficiently involved in the design of Linked Care during the establishment phase. They recommended that both participants and consumer representatives be specifically consulted on their experiences of Linked Care if the model was to progress to a further stage.

When Linked Care entered its live phase, the consumer representatives sought to improve their means of representing the interests of Linked Care participants. Committee work and attendance at workshops and briefings did not bring them into direct contact with participants. The Management Committee agreed to publicise the role of consumer representatives. A Linked Care newsletter included a description of the consumer representatives and encouraged participants to contact them or Linked Care if they had any

questions or complaints. This description stimulated inquiries from participants both in the Intervention and Control area.

Approximately 30 inquiries were received from the Intervention group, including requests for changes in care. While many participant comments were full of praise for CCs, Linked Care and existing service providers, the consumer representatives noted that participants seemed reluctant to ask for help directly from service providers or CCs. Participant criticism focused on the lack of change in care received when the participant's CC was their existing service provider or GP.

Inquiries from Control group participants related to the quality of care they received and seemed to suggest a need for accessible complaints mechanisms. Where appropriate, these inquiries were referred to the service provider concerned.

The Management Committee was reluctant to allow consumer representatives to take a more direct role with participants. The Management Committee was of the view that risks of inappropriate contact included breaching participant privacy and contaminating evaluation data. Both management and consumer representatives waited throughout the trial for a response to the request from the Consumer Health Forum Coordinated Care Workshop to the National Evaluation Reference Group (NERG) to develop guidelines for direct contact with participants by consumer representatives before other decisions were made about contact.

4.1c Quality and Complaints Working Party

It was expected that quality assurance activities at Linked Care would be coordinated by the Quality and Complaints Working Party (QCWP) that met monthly. It had representatives from each of the major service providers, and three consumer representatives. Some members were CCs. The QCWP initially had a proactive role, overseeing the drafting of procedures and guidelines, and a reactive role, managing complaints. Both aimed to improve quality in Linked Care systems.

Few formal complaints were received by Linked Care (15 complaints; 11 compliments), and mainly in the early implementation stages. The QCWP appeared to work diligently to resolve the issues and improve the care coordination procedures as a result.

The working party seemed aware of the need to find more direction in the second half of the trial when it redrafted its terms of reference and asked for advice from the Hornsby Hospital Quality and Complaints representative. It was agreed that monitoring quality of care was the responsibility of medical and community service staff, while Linked Care management and QCWP would focus on the quality of care coordination. Initially these efforts resulted in the preparation of a checklist to measure the quality of care plans when they were received by Linked Care administration (e.g. legibility and participant signature).

Linked Care administration claimed that it had limited ability to enforce quality in the care plans because it did not directly employ the CCs. It could be argued to the contrary that Linked Care could have enforced quality through the contractual relationship where service providers were expected to provide care coordination services. The Linked Care

administration identified its role as that of providing suggestions and guidelines to the sub-contractors.

A strength of the QCWP meetings appeared to be discussion about daily issues of concern about Linked Care by those who had a working knowledge of how care coordination functioned in practice. However, although discussion was stimulated, there appeared to be a limit to substantive outcomes from the meetings. Many members of the QCWP, including Linked Care administration, expressed frustration about the meeting discussions that seemingly resulted in few resolutions. The meetings appeared to be a low priority for both Linked Care administration and the service providers. This was illustrated by the Linked Care director and agency senior managers' attendance at the other committees but not the QCWP. There appeared to be high turnover and irregular attendance among other representatives.

Linked Care acknowledged the restricted opportunities within this initial model to enforce quality measures on subcontracted care coordination. Accordingly, it encouraged the QCWP to direct its attention to future quality changes to inform development of care coordination in the next round of the trial.

4.1d Finance and the Fund Pool

Direct out-of-pocket costs of services to participants were not collected by Linked Care except as they related to the fund pool contributors.

While participants were not involved in decisions about allocation of resources from the fund pool or financial arrangements of the trial, participants continued to contribute to service costs.

A number of issues were raised by participants in relation to the cost of care:

- ? resistance to transfer to services that charge a participant contribution, e.g. from home nursing to home care;
- ? difficulties paying for services, e.g. the prohibitive cost of taxis for some participants meant they felt they had few transport options available; the cost of private podiatry; difficulty contributing to community services even with their pensioner status; caring obligations preventing carers from earning income; the high costs associated with nursing home entry, extra respite care and private services;
- ? independence facilitated through mechanisms such as DVA providing support in paying the costs of their participants' care; the disability card providing substantial discounts on taxis; and some participants referred to the CC as an effective advocate for receiving more services; and
- ? other resource restrictions such as budget caps in the health and HACC system.

Purchasing private services provided some users with autonomy. Participants who were able to afford private house cleaning felt they had some control over the quality of work done. If they had financial independence they could pay for extra support to remain at home or pay for taxis to overcome the difficulties of isolation or attempting to use inaccessible

public transport. Some interviewees reported being able to afford private hospital and respite care.

In May 1999, a training bulletin was distributed to CCs concerning financial management of agreements on participant co-payments. This bulletin was issued to clarify the arrangements and procedures where a participant or their carer was willing to, or offered to, make a co-payment. For example, Linked Care had, on different occasions, agreed to meet part of the costs of equipment or respite care where the family had agreed to pay the balance. A potential for conflict and confusion had arisen where an arrangement was made by a CC and family without a written agreement because invoices were not supported by any co-payment arrangement. In order to pay the invoice, and in turn seek the balance from the participant, a record of the agreement needed to be established.

One CC negotiated with a participant that since he had fixed her television antenna, obviating the need to pay for a repairer, she could pay for the two physiotherapist visits that she had previously refused to pay for. The story was an illustration of a strategy that avoids payment from the fund pool by encouraging the use of free or client-paid services. Another example was the effect of substitution on participant costs. A participant complained to the CC that substituting personal home care for home nursing cost Linked Care less but the participant more.¹²

Participants reported that the likelihood that they would contribute to community services decreased over the course of the trial for the Intervention participants only (Section 4.2c).¹³ This was supported by the Home Care Service report which stated they received fewer participant contributions than expected from the Intervention participants. If this was an accurate result, it could have important implications for the impact of the model of means-tested contributions by participants. It might reflect, for example, that CCs and service staff may have been less inclined to pursue a participant contribution from Linked Care participants, perhaps because they were aware the cost would be covered by the fund pool. However, for larger requests for additional services, there was evidence that CCs negotiated for co-payments from participants.¹⁴

Participants were not involved in decisions about the allocation of resources from the fund pool, except through their own care planning process. This could be seen to have limited their involvement in decisions about care. Financial decisions were discussed at Peer Support Group (PSG) meetings of CCs. At one PSG meeting CCs discussed the needs of a participant with motor neurone disease who wished to remain at home. They discussed the relative costs of caring for the person at home, in a nursing home or in a hospital. In this

¹² CC interviews and observation of PSG meetings.

¹³ Participant questionnaires, November 1998 and 1999. Changes in frequency of contributing to the cost of care was analysed and were significantly different over time for the Intervention participants. Over a third of Intervention participants (36.6 per cent) were less likely to contribute to their cost of care at the end of the trial, than when they began in the trial (15.2 per cent were more likely to pay). This was in contrast to the Control participants, where at the baseline fewer of them paid for care, but a quarter of them were more likely to pay for care than they had been by the end of the trial. The profile of payment was similar between the Intervention and Control areas at the end of the trial with about one-third of participants always or mostly paying for their costs of care (34.1 per cent Intervention and 29.7 per cent Control participants).

¹⁴ (Section 3.4d, *Local Evaluation Final Report*)

case, despite the costs being lowest in a nursing home, the CCs agreed to continue home-based care. Other payments from the fund pool were brought by CCs to Linked Care administration and the PSG. For example, issues discussed included whether to pay for a possum to be removed from a house; and how to pay for installing a hot water system. These examples indicate a step in the care coordination process where participants were absent from the decision-making about their access to care.¹⁵

4.1e Summary of Participant Involvement in Organising the Trial

Table 4.2 summarises the strategies undertaken at a management level to ensure participant involvement and voice in care planing. The Linked Care model supported participant involvement in the trial. However, practical ways of ensuring this in Linked Care were limited. Empowerment through the care coordination process is discussed further in Section 4.2.

Table 4.2: Participant Experiences and Perceptions of Trial Strategies to Ensure Participant Involvement

Trial Strategies	Participant Experience
Trial management procedures	Mechanisms to ensure participant involvement without over-burdening them with direct contact were implemented. The extent of participant familiarity and comfort with using those processes was probably rudimentary.
Consumer representatives (CRs)	Most CRs were not personally involved in Linked Care but represented consumer concerns at all trial working parties. Participants were encouraged to contact CRs. Some CRs were frustrated with the lack of influence they had in trial decisions. They were not present at PSG or service provider meetings where financial decisions for participants were made.
Quality and Complaints Working Party	The complaints handling process appeared effective in improving practice. The interpretation of the subcontracting relationship prevented enforcement of, and professional support for, care coordination tasks. The Quality and Complaints Working Party members were frustrated at times with its limited opportunities for implementing improvements.
Finance and the fund pool	Data on participant costs were inconsistently collected. Participants reported not contributing to the cost of care to the same extent as before the trial, or compared to the Control participants. Some participants felt being able to afford private services improved their access to appropriate care. Concerns raised by participants

¹⁵ Previous findings from care management models show that when control is gained over fund pool budgets client choice can become minimised, and in some extreme circumstances, side-lined (Richards, 1998: 85-86).

included expense of equipment, access to affordable respite and other associated costs.

4.2 Care Coordination

4.2a Introduction

In recent years case management, and one of its derivatives, care coordination, has become popular with Australian health funders as a means of improving the efficiency of resource allocation to participants with complex care needs. This section explores the ability of the Linked Care model of care coordination to meet that goal for participants with complex care needs who lived at home, predominantly older participants and some younger people with disabilities.

The model of care coordination in Linked Care was that each of the participants were appointed a CC who was either their GP or an employee from an agency that provided them with other health and community care. The CCs' formal roles were to assess, plan, arrange, monitor and review care needs and services. The CC in consultation with the participant and relevant service providers, prepared a care plan for the participant at least every three months, including both medical and other health and community services. Services provided to the participant, and care coordination costs, were paid for from a fund pool of health and community care funds. Services used were reconciled against the care plan as feedback to the CC. CCs were accountable to each other for significant financial decisions through a Peer Support Group (PSG) structure.

CCs were subcontracted from existing service providers. For most CCs therefore, care coordination was only one of their duties. However, during the trial full-time CCs evolved although they were still subcontracted. As a result of subcontracting arrangements with various service providers, CCs had variable knowledge and skills and came from a range of disciplines.

This section examines in more detail the various aspects of the care coordination model from the perspective of the participants, including empowerment, knowledge about the trial, their relationship with CCs, care planning and assessment.

4.2b Participant Experiences of Empowerment

Central to the care coordination model was participant involvement and empowerment and the extent to which they could negotiate in the care coordination process. Prerequisites for empowerment include knowledge and ability to influence changes (Opie, 1998: 189-192; Hunt et.al., 1997; Zambada et.al, 1998).

It was intended that the care coordination process would focus on addressing participant needs, with the active involvement of the participant to enhance their participation in choosing care. However, there seemed to be several constraints on this process. First, the CCs' concept of participant empowerment varied, and second and perhaps as a result of the first, participants' knowledge of their potential role in the process was also patchy.

The evidence from the evaluation was that participants were not always central to the care planning process. Participants reported they were confused about the role of the care

plan.¹⁶ Only half the CCs (56.5 per cent) reported they used strategies to involve participants in care plans (Table 4.5).

Participant involvement was discussed during PSG meetings and also in discussions amongst CCs. One CC, Abby, a full-time CC, discussed empowerment within a range of innovative strategies to encourage participation and participant control over their lives.

Care planning is most valuable because every case is different and every solution different ... Encouraging old hobbies and interests and seeing that make a difference ... Encouraging people to make their own decisions about their health, supporting ideas of prevention, self-empowerment ... (Abby, full-time CC)

This statement suggests Abby perceived her role as encouraging participant empowerment, through involving them in decision-making, as well as improving their lifestyle. This view presents health professionals as supportive of, and as a facilitator for, individuals' decisions.

Other CCs articulated the constraints they felt should be placed on client empowerment. Kerry, who was also a case manager for a number of years before her involvement with Linked Care, indicated that service users views could not always be implemented. Kerry emphasised the importance of listening to the client perspective, as she stated this was part of the necessary process of 'establishing trust, professionalism and hearing client aspirations', but she also said realism had to be brought into making decisions about care. Kerry felt that on the one hand clients – but more often their carers – had unrealistic expectations of the level of help required. Kerry said that in these situations she guided clients with her experience as a health professional. On the other hand, Kerry noted that service providers were also working within restricted budgets and unless clients could afford to pay extra, more help would not be available. It would seem involving participants was not merely a matter of granting their requests for care. Their needs appeared to be balanced against the needs of other participants, as interpreted by CCs based on their professional experience and knowledge. They decided, often in professional teams, how to manage limited budgets. This was despite the context of finance through the fund pool in the Linked Care Trial.

These two examples show how understandings of empowerment and participants' involvement were contested in the trial by CCs. They also raise the practical contradictions of implementing participant wishes within limited financial means (Kapp, 1989: 6; Kendig, 1986: 178-9).

The actions and strategies of individual CCs appeared to define the level of participant involvement. The following example shows how precarious participant involvement in care decisions can become. Mr Taylor, an older widower, was openly critical of his CC, Peter, and the care he received. He felt that his concerns were not listened to or addressed. By comparison, Peter reported Mr Taylor was 'manipulative' in his attempts to get more services. He stated Mr Taylor was not prepared to contribute to the costs of his care, was difficult with workers, already had many services in place and used services 'inappropriately' (for example Peter reported Mr Taylor tried to use Department of

¹⁶ Participant interviews.

Veterans' Affairs funding to increase the amount of house cleaning he received rather than use the extra care for social contacts as it had been allotted).

Peter approached his supervisor to ask if another CC should take over his role with Mr Taylor, but was advised that he could not expect to get on with all participants. While Peter was in the position to ask if he could no longer be Mr Taylor's CC, Mr Taylor was not supported in this right to decide who was involved in his care arrangements, although he was clearly dissatisfied.¹⁷

Mr Taylor was all too aware that his insistence on independence and control adversely affected service providers' attitudes toward him. As an experienced health professional he expected his knowledge to be given consideration, but realised this annoyed many providers. He had considered moving to a nearby nursing home, but changed his mind after making inquiries, commenting that he thought they would throw him out because they would not put up with him telling them what to do all the time. Empowering clients would appear to be dependent on effective social interactions which can be difficult to sustain with clients who may be insistent, unthankful and frustrating. This particular example seems to indicate the limitations to the ability of Linked Care's protocols to resolve such tensions equitably or with due consideration.

Implementing participant empowerment therefore appeared to be influenced by the discretion of the CC. This may have been a practical response by CCs for the efficient functioning of a cumbersome care coordination model.

However there were very few complaints lodged with Linked Care. Many participants interviewed reported friendly and supportive contacts with the care coordinator. For example Mrs Neave Burke had received much support for her son and daughter during extensive periods in hospital. She said:

[CC name] has been absolutely wonderful. And they can see things very quickly and put things into action, and not just talk about it. But that has been happening for quite some time... She has put a lot of these things into motion. (Mrs Neave Burke, Intervention)

Having a CC did not replace other people informally and formally involved in organising care for the participant (Table 4.3). As discussed in more detail in relation to the impact on carers (Section 5.2), most care was both arranged and provided by the participants and carers themselves, not by formal service providers or professionals.

¹⁷ Mr Taylor had requested particular staff but had been refused.

Table 4.3: Other People Involved in Organising Care with the Participant

	Participant group					
	All baseline responses		Effective Sample ^(a)			
			Intervention		Control	
	Intervention	Control	baseline	end trial	baseline	end trial
	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)
No one else provides CC	5.5	5.6	5.1	6.4	10.5	10.2
Participant themselves	36.2	31.0	40.1	36.2	49.1	48.3
GP	47.7	25.8	46.0	48.2	35.1	42.4
Other Service Provider	11.1	8.0	10.2	17.0	9.6	8.5
Family member/friend/ Neighbour	54.3	25.4	51.8	51.1	25.9	34.7
Other	5.0	6.5	6.6	4.3	4.1	10.2
Total	(318)	(287)	(219)	(230)	(170)	(182)

Source: Participant questionnaires, November 1998 and 1999

Notes: (a) Effective sample: participants who responded to both the baseline and end trial questionnaires.

Percentages do not add to 100 because these questions allowed for multiple responses.

In many cases participants reported that CCs did not have to extensively re-organise or introduce complex care arrangements for them. CCs often provided support rather than becoming actively involved in the coordination of care. Some CCs and Linked Care staff have surmised that perhaps the reason for this outcome is the relatively stable and good health of some of the participants.¹⁸ However, even for participants with complex care needs, a CC was not always needed if care arrangements were established.

4.2c Participant Knowledge and Relationship with Care Coordinators

Participants reported that having a CC was a positive experience during the trial and added to the ease of accessing appropriate care. The influence of CCs appeared to be delayed, according to the participants, perhaps due to the difficulty in implementing Linked Care processes, including allocating CCs to participants. One year into the trial, 36.8 per cent of Intervention participants were unaware of having a CC or did not know how to contact them (Table 4.4). By the second questionnaire this had reduced to 26.1 per cent.

Most Intervention participants were satisfied with their CC (over 70 per cent, increasing to 77 per cent by the end of the trial). Interestingly around 30 per cent of Control participants reported they had an assigned CC or case manager, and they were more satisfied with the arrangements than the Intervention participants.¹⁹

¹⁸ Questionnaire respondents' self-reported health showed only 35.1 per cent of Intervention participants considered themselves 'worse' than compared to others their age. The trial has suggested that for a future trial only those people requiring complex care needs should be recruited.

¹⁹ These participants were possibly accessing more intensive community care packages (COPs or CACPs). The participant results were not validated with service providers.

Table 4.4: Participant Knowledge of Care Coordinators and Case Managers

	Participant group					
	All baseline responses		Effective Sample ^(a)			
			Intervention		Control	
	Intervention	Control	baseline	end trial	baseline	end trial
	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)
Have an appointed CC or CM^(b)	***	***	***	***	***	***
Yes	68.5	30.1	66.9	80.7	30.6	28.1
No	21.0	57.4	21.3	14.3	55.9	66.1
Don't Know	10.5	12.6	11.8	5.0	13.5	5.9
	100.0	100.0	100.0	100.0	100.0	100.0
	(199)	(183)	(136)	(140)	(111)	(118)
Know how to contact CC or CM^(b)	**	**	**		**	
Yes	92.0	95.2	94.6	91.7	92.1	91.4
No	6.5	0.0	3.3	5.9	0.0	5.7
Don't know	1.4	4.8	2.2	2.5	7.9	2.9
	100.0	100.0	100.0	100.0	100.0	100.0
	(135)	(61)	(90)	(118)	(37)	(36)
Satisfaction with these arrangements						
Very happy/happy	75.6	88.5	70.0	77.1	86.5	88.9
Neither	20.7	8.2	27.8	22.9	10.8	11.1
Unhappy/very unhappy	3.7	3.3	2.2	0.0	2.7	0.0
	100.0	100.0	100.0	100.0	100.0	100.0
	(135)	(63)	(92)	(121)	(38)	(35)
Total	(213)	(208)	(143)	(143)	(122)	(122)

*p<0.1, **p<0.05, ***p<0.01

Source: Participant questionnaires, November 1998 and 1999; Appendix 4.

Notes: (a) Effective sample: participants who responded to both the baseline and end trial questionnaires.

(b) CC = Care Coordinator; CM = Case Manager.

Percentages may not add to 100 due to rounding.

The CC appeared to be pivotal to the experiences of participants in Linked Care. Few participants seemed to be aware of the operation of the trial, beyond the contact they had with their CC.

This could probably be explained by their prior relationship with the CC. For most participants their CC was an existing provider with whom they were familiar. Second, for many participants, the implementation of Linked Care was a slow process, due to the protracted establishment period. One participant expressed this in October 1998.

People seem to think I am independent and so [they] rarely offer [me] assistance. I am still waiting for [Linked] Care to provide the plan they offered me some months ago. I do not think I am independent – I just do not like using people if I can manage myself. (female, Intervention)

Participants indicated greater knowledge of Linked Care by the end of the trial.

Whenever help has been needed [name CC] could not be more patient and helpful. (male, Intervention)

My care organiser is a 'personality plus' person and I got most help by just speaking with her. (female, Intervention)

Linked Care service has been fantastic, I would hate to think we would do without this service. (female, Intervention)

I have asked for extra Home Care (housework) time for next year and was told to have this authorised by my GP and to contact Home Care and my GP at the end of October. This would be possible only because I belong to Linked Care. (female, Intervention)

Effective communication between the participants, and sometimes carers, with the CC was discussed by participants. In one case the carer had the main responsibility for caring for her husband. Her GP CC had encouraged her to become involved in the trial yet even by the third interview she was unaware that any benefits were supposed to emerge from her participation. Mrs Newman believed that the trial was primarily a research tool to understand how to improve services. To her knowledge her GP, of whom she spoke highly, remained important for her husband's medical needs. However Mrs Newman pointed out that although she was unaware of benefits, other participants had suggested being in the trial may be beneficial.

I don't know what goes on behind the scenes because I understand from some of the nurses with Home Care that their funds are so tight at present that it's the Linked Care participants who get extra help currently, whereas everyone else is a bit starved of funds. You know that's only hearsay so I don't know how much our involvement with Linked Care is being of help unbeknown to us.

[Are you getting extra services that you've been informed about?]

No, no. We are subsidised though and we were subsidised before we were in the Linked Care project. I'm just passing onto you something I have heard whereas I may say we don't have a lot of contact. Behind the scenes there could be more than I'm aware of. (Mrs Margaret Newman, Intervention carer)

A second carer, who initially had a GP appointed as her husband's CC, by the third interview was designated a service CC. By the third interview the latest CC had moved to a new job and they were unaware of another CC being assigned as a replacement. They said they were unaware of whom they should contact if they needed help.

For some participants changed care arrangements had become apparent even at that early stage of Linked Care. Participants referred to the favourable way Linked Care introduced and coordinated service provision.

The care and follow-up from Hornsby Hospital was excellent. The Linked Care Coordinator is very helpful and has worked out a care plan for me which I can join in more, when walking is not so tiring and awkward. (female, Intervention)

Another respondent was grateful for the extra support Linked Care could provide.

We find Linked Care very helpful if we need specified help and are very grateful for its assistance. At the moment I (wife) am able to care for my husband's needs. He is a wonderful patient, but should I need help I feel very reassured with the back-up of Linked Care. Thank you. (male, Intervention)

The interviews with participants indicated CCs could bridge the gap in participants' understanding between service receipt and the organisation of care. Most intervention

interviewees knew what services they could expect from Linked Care and how to access them. Most interviewees referred to a folder with contact information and other information provided by the CC. Others had their CC's contact number on a fridge magnet.

Participants reported particular benefits they perceived from having a CC. The Intervention group participants identified at least four benefits they perceived from having a CC:

- ? a sense of security if circumstances changed;
- ? a facilitator or advocate to access services and to avoid the burdensome and time-consuming processes involved in negotiating their case;
- ? a sympathetic health professional; and
- ? a centralised point of advice and information.

Sense of Security

Participants who relied on complex family care arrangements to remain at home felt a CC provided a sense of security, so that if the arrangements were disrupted alternatives could be made to keep them at home. Tony Gleeson's mother Angela felt relief from the full-time CC's reassurance of assistance.

My biggest fear was if I was ever sick what would I do about Tony being looked after at home ... If I had to have surgery or something happened to me she could arrange care for Tony... She could send someone to take over my role in the house for a few days... all she would have to do is have a meeting with her team and discuss it. But she did say it would be arranged within 24 hours... It really took a load off my mind. (primary carer, Angela Gleeson)

Similarly Mr Fred Neall realised that the stability of his care arrangements was dependent on the continued health of his wife.

One thing that we are quite conscious of is that if my wife's ability to do what she does suddenly decreased, we'd be in a pickle. We'd need help. But we feel we know where to go for it now. We'd give [name of full-time CC] a ring and say we need Meals on Wheels, we need somebody to clean, we need somebody to scrub me down occasionally because I can't stand up in the shower... An example was last week when I was sick and told to stay in bed for two or three days. My wife who is 87 next birthday, running round like a hairy goat, bringing me stuff to bed and looking after me. But that's what I mean. If she was to find that she wasn't able to do that, then we would need help. (participant, Mr Fred Neall)

Mrs Alice Norton, the main carer of her husband, felt confident help would be provided in an emergency after talking with her community CC.

Your doctor isn't always going to be available so that if you need help in a hurry particularly if I was going to be rushed into hospital²⁰ or something like that, somebody's got to look after my husband and Linked Care is the first one I'd ring

²⁰ This is in contrast to Linked Care's policy of not being an emergency service. This policy includes not giving participants out-of-business contact numbers, and subcontracting CCs to agencies that do not always replace CCs when they are on leave.

and say help... I know there are others who might have had more use out of it, I mean I don't call on them for little things because I feel there are other people who need their expertise more than I do, but I knew they're there as a back-up if I need them.

For participants in such situations it was anticipated that the CC would help carers, particularly in times of crisis or if the situation changed suddenly. Having a CC provided a sense of security for participants so they knew where to turn without having to shoulder the entire responsibility of making the arrangements themselves. However, participants' expectation that CCs could respond to crises is in contrast to the Linked Care model. Therefore, Intervention participants were unlikely to receive the expected immediate attention after business hours, on weekends or when part-time CCs were attending to other duties. Delays may also have been experienced in the implementation of care changes.²¹

Facilitator and Advocate

CCs were also seen to facilitate access to services. In the past accessing care had been seen by some participants as difficult. Mrs Alice Norton felt that having a CC meant that she had someone to:

... help you go through the maze of things that you're facing... This is, you know, peace of mind, know where to turn and get the information you need. (Mrs Alice Norton)

One participant, whose eyesight had been steadily deteriorating, found it extremely useful for the CC to make an appointment with a specialist in visual equipment. The participant's wife, who was also involved in the trial, was able to make use of a home delivery library service with the help of their CC. Mrs Betty Tiller was happy to learn about the existence of the Turramurra garden centre through a service CC visit. The CC also arranged for her to be put on the garden centre's client list. In these cases the CC facilitated access to services.

Other participants appreciated the more active role of CCs organising service provision, such as negotiating with services on behalf of the participant to increase care or make more flexible arrangements. Mrs Betty Tiller was happy when the CC organised to change her house cleaning to fortnightly assistance for shopping. Mrs Tiller preferred to be taken shopping because she had found it difficult to travel alone and she appreciated the 'change of scene'. This assistance also meant she could buy competitively priced products since the local grocery store 'charge like wounded bulls'. This idea of flexibility appears to be endorsed by some CCs.²²

Others had experienced an increase in care received. Mr Neall had home physiotherapy extended. When he no longer needed it, with the help of the CC, it was then transferred to

²¹ A CC indicated participants could not expect immediate community service provision since most participants would have needed to wait for assessments and for timetabling of staff; CC interview, September 1999.

²² One full-time CC also identified flexibility in financing service provision. She provided the example of applying for funding from Weight Watchers to help a participant lose weight.

his wife. Mrs Urma Oakes said she was grateful to her CC for securing an extra half-hour of Home Care.

Home Care... is the usual story – lots of demands and not enough money for the service. As it was [Home Care coordinator] was more inclined to cut me back rather than give me more... [Name CC] must have whispered in her pink ear because I was getting older and less mobile. (Mrs Urma Oakes)

Mrs Oakes found this extra half-hour increased the quality of cleaning, although she continued to juggle what jobs could be done in the limited time available every fortnight.

If I want to have some jobs done, I have to trade off other jobs she does. In other words I get them done once a month instead of once a fortnight. But because I'm an asthmatic... the bedroom has to be cleaned thoroughly because you've got the dust mites. (Mrs Urma Oakes)

Sympathetic Health Professional

CCs could be understanding and sympathetic health professionals. Participants considered it important that their concerns and priorities were listened to and valuable.²³ Mrs Nancy Burke appreciated the phone calls she received from her CC while she was in hospital as the CC provided cheerful company.²⁴ Mrs Alice Norton noticed the family GP CC became more concerned about how she, as a carer, was managing emotionally and how the GP had consequently had longer appointments with her and her husband.

[So is this different from before you were involved in the Linked Care project?]

Well, we've always been lucky with our GP, but maybe more with the emotional side for me and how I'm feeling and coping with things, which mightn't have been there before. It means that I can unburden myself with anything that's frustrating me. (primary carer, Mrs Alice Norton)

Centralised Advice and Information

The participants who had not extensively used their CCs' services still considered that being included in the trial was important. The CC was seen as a way to have easy and instant access to a community health system that they had found confusing and difficult to negotiate in the past.²⁵ Two participants pointed out that access to this type of support could be arranged differently. Mr Fred Neall, for example, said that the central contact was very important.

If we really need any help the answer is still the same, go to your coordinator. She's there now and we want to keep her there. Whether it be the same person

²³ Participants also appreciated discussing their experiences with the evaluators and were surprised at being asked. They often stated they preferred discussing these issues rather than filling out forms.

²⁴ The CC reported a more active role in this participant's care arrangements, particularly liaising with other family members and organising for Mrs Burke's return home.

²⁵ Whether the Linked Care arrangements could fulfil these expectations or whether it was economically feasible is considered in other areas of the evaluation (Final Report, Section 3.4b).

or how it's run is immaterial really as long as you've got somewhere to go, a central person that's got some information. (Mr Fred Neall)

One of the main advantages ... is that we now have the information of knowing where to go if we want something. Before, you got fragmented information here and there... but if you want to do it in a hurry as individuals we wouldn't have known where to go and ask for help. Since we've been in Linked Care we got the feeling... we know where to go... That is the big advantage because all the services in many cases exist [but] you don't know how to contact [them]. (Mr Fred Neall)

By the second round of interviews participants had received changes in their services, however, the administration of Linked Care remained puzzling. Mrs Betty Tiller for example found the difference between Linked Care and the services providers ambiguous.

Well I know they've got Linked Care because the girl that comes to take me shopping she does both of them, does their house. But other than that I wouldn't know because I don't ask them questions about what they're doing. (Mrs Betty Tiller)

4.2d Care Plans

The care plan had two parts: the medical care plan including diagnosis, medical attendances and medication information completed by the participant's GP; the remainder of the care plan including all other health and community service care. The care plan was to include all care planned for the participant, including formal and informal care. After preparing a handwritten plan, the CC submitted it to Linked Care administration to generate a computer version of the care plan with expected costs of services.

CCs were required to meet with participants to discuss care needs and prepare a handwritten plan for changes to care arrangements in the next quarter. Both the CC and the participant were required to sign the plan to indicate their participation in the process.

Only 7.5 per cent of care plans were signed by participants. This low figure should be treated with caution however, as CCs were told the signature was only required on the first care plan and data entry staff made some assumptions about participant signatures. However, principles of participant involvement should probably have encouraged a higher proportion than this.

Overall, 2881 care plans were prepared, an average of 6.3 plans per participant. This confirms that the model eventually supported both the preparation and regular review of a care plan for most participants. It falls short of the expected number of plans (3974 or 8.7 plans per participant)²⁶ by 38 per cent. Explanations could include administrative delays by Linked Care such as allocating or reallocating a CC; or CCs not fulfilling the requirement to prepare consecutive quarterly care plans.

²⁶ Calculated on the basis of quarterly care plans for 11923 active participant months in a 26-month trial, with an average of 459 active participants per month.

The process of preparing a care plan was intended to enhance participant involvement in choosing their care. The evidence from the evaluation was that participants remained peripheral to the care planning process. CCs were asked if they used strategies to involve participants in care plans (Table 4.5). Only half reported that they did (56.5 per cent) at the end of the trial, a significant decrease from the mid-trial, when 65.1 per cent said yes. Not surprisingly, less than 40 per cent thought care coordination had enhanced participant control in choosing care (37.8 per cent).

Table 4.5: Care Coordinator Strategies to Involve Participants

	1998		1999	
	n	%	n	%
Used strategies to involve participants in care plans				***
Yes	28	65.1	26	56.5
No	12	27.9	19	41.3
Don't know	3	7.0	1	2.2
Care coordination has enhanced participant control in choosing care				
Yes	18	41.9	17	37.8
No	18	41.9	22	48.9
Don't know	7	16.3	6	13.3

*** p<0.01

Source: CCs mid-trial and end of trial questionnaires, November 1998 and November 1999. Full-time CCs did not respond to the 1999 questionnaire.

Participants reported they were confused about the role of the care plan.²⁷ However they reported that having a care plan was useful as a reference for:

- ? telephone numbers for all services used;
- ? contact names of all involved in care arrangements;
- ? a list of all drugs used by participant; and
- ? a reference for participant, family and health and community service professionals.

Perhaps this function could have been achieved more simply by reporting on services used rather than attempting to prepare a planning document. This reported benefit to participants is encouraging for the promotion of the CIARR 'Yellow Book' system for leaving service information in the homes of participants.

Some participants, however, complained about the amount of paperwork associated with the care plan. One participant expressed suspicion about the care plan and expressed concern about becoming too reliant on organised care arrangements.

Telephone respondent participants all reported participating in the preparation of at least one care plan by the end of the trial. At the time of the first interview however two participants were without care plans and all care plans underestimated the actual services received (Table 4.6). Analysis following the second and third round of participant interviews revealed

²⁷ Participant interviews, participant questionnaire, November 1998 and 1999.

care plans were reliable and up-to-date even sometimes including services participants themselves may have forgotten (such as annual check-ups) and informal assistance.

Table 4.6: Level of Planned and Reported Service Use by Participants, October 1998

	Intervention^(a)	Control
Average number of services used per participant		
Self-reported	11.5	6.7
Care plan	7.1	-

Source: Participant baseline telephone interviews (20 participants), October 1998.

Notes: Excluding two Intervention participants without care plans

Although instructed to do so, CCs did not appear to regularly leave a copy of the care plan with participants. Some full-time CCs were of the opinion that a copy was only useful for participants if they were alert and interested (but this ignores the benefit of leaving the plan for carers and next of kin). A CC who had distributed the care plans reported that their participants telephoned back with corrections, which acted as a quality check. Despite patchy distribution of the care plan to participants, full-time CCs reported that many participants contacted them if they had new needs or to provide feedback.²⁸ This perhaps reinforces the view that the care plan itself was not central to the understanding of the care coordination role.

4.2e Assessment

A goal of Linked Care was to minimise duplication of participant assessments between referring agencies. No additional assessment procedures were designed specifically for CCs as it was assumed that the information would be available from existing service provider records. Linked Care attempted to avoid additional assessment and recording burden on participants, given the evaluation burdens already anticipated.

Interestingly, both Intervention and Control group participants were overwhelmingly satisfied with the level of tests and assessments they received both at the baseline and end of trial (Section 5.1).²⁹

It appears, therefore, that from the participant perspective the need to reduce assessment duplication was exaggerated. However, they did complain about the amount of paperwork in Linked Care.³⁰ In addition, although the care coordination process did not add to the assessment burden for participants and service providers, CCs could not necessarily utilise existing assessment and client information recording mechanisms.

²⁸ Full-time CCs interview 6 May 1999.

²⁹ From 80 to 90 per cent of Intervention and Control participants were satisfied with the level of tests and assessments they received both at the baseline and end of trial. Assessment was not raised as a concern in the interviews. Participant questionnaires, November 1998 and 1999; Participant interviews.

³⁰ Participant interviews.

4.2f Summary of Participant Experiences of the Care Coordination Process

Table 4.7 summarises the participant experiences of the care coordination process as discussed in this section.

Table 4.7: Summary of Participant Experience of Care Coordination Process

Objective	Result
Participant involvement	CCs determined the extent of participant involvement in the process. CCs and their employing agency decided how tensions were to be resolved. Linked Care protocols to involve participants and handle disputes did not appear to be effectively used. Complaints about CCs were rare and few exited the trial due to dissatisfaction with the trial.
Participant knowledge	Knowledge of the concept of 'care coordination' and the administrative distinction between Linked Care and service provision was generally unclear for participants. An effective CC appeared important for participants to understand how Linked Care may benefit their situation. Understanding of Linked Care was made more difficult because of the slow trial start-up.
Care coordination	Participants identified gaps in service that Linked Care addressed for them (e.g. back-up to existing care arrangements, single point of entry to service provision, sympathetic health professional, advocate). Solutions to these did not necessarily require the intensity associated with the Linked Care model. CCs also facilitated access to additional care. Participants identified the benefit of a CC as advocate. This could be at odds with financial efficiency hoped for from care coordination.
Care plans	Participants and carers found care plans provided a useful location for all relevant information (e.g. list all prescriptions and other drugs, relevant contact names and numbers). Care plans often recorded existing care rather than adding planning. Participants were not always provided with a care plan and in those cases were at a distance from the decision process.
Assessment	Few participants were concerned about level of assessments either conducted by medical or community services. Concerns related to travel and ease of access if they were required to leave their home for assessments.

5 Impact on Clients and Caregivers

Three groups of clients can be identified in relation to the impact of Linked Care. They are the participants enrolled in Linked Care, their carers and other clients outside Linked Care. Each of these groups is discussed in this chapter.

Participants recruited to Linked Care were people with complex care needs, living in the community, predominantly older people and people with disabilities. Target recruitment numbers were almost but not fully achieved. Final recruitment was 722 Intervention participants and 423 Control participants. The annualised exit rate was 27 per cent. A description of the participants is included in Appendix 4.

Linked Care did not produce a negative effect on outcomes for participants or their carers. Positive benefits were reported by participants and some CCs. However, the rates of death, hospitalisation or admission to a nursing home did not improve or worsen. This is consistent with the absence of a large shift in service usage patterns (Chapter 6).

Participants and carers in Linked Care, corroborated by reports from CCs, spoke of the benefits from having an appointed CC. They received better monitoring through the greater attention that, when combined with the financial flexibility of the fund pool, potentially increased access to services. It appears clients not involved as participants in Linked Care may have been disadvantaged but the evidence is ambiguous.

The chapter begins with a discussion about client outcomes from the perspective of the participants, service providers and Linked Care administration (Section 5.1). The impact on carers and clients not in Linked Care are discussed separately in Sections 5.2 and 5.3.

5.1 *Client Outcomes*

The results about outcomes for Linked Care participants were ambiguous. Linked Care did not have a negative effect on the outcomes of participants enrolled in Linked Care or their carers. Positive benefits were reported by participants and some CCs. However, the rates of death, hospitalisation or admission to a nursing home remained stable or worsened. Measurable differences with the health and well-being instrument, the SF-36, were not observed. Similarly, the health and well-being questions in the participant questionnaire did not reveal change.

5.1a Exits

Final consents were obtained from 722 Intervention and 423 Control participants. The number of Intervention participants fell to 396 by the end of the trial. The annualised withdrawal rate averaged 27 per cent (one to four per cent per month). When Linked Care was designed the management expected that the exit rate would be between 20 and 25 per cent. The exit rate also did not decline as expected over the life of Linked Care.

The most common reason for exiting was admission to a nursing home or hostel (18.2 per cent of Intervention exits); followed by death as the next most common reason (12.0 per cent). The rate of exit due to these two reasons was one of the outcomes that Linked Care

was hoping to improve through the intervention. Other reasons given by participants related to the burden of Linked Care or change of residence outside the catchment area. In the Control group, participants who decided to leave formed the largest group (18.4 per cent), with related deaths again being the second largest reason for exit (12.5 per cent). Both reason for exit and demographics of exited participants were similar for the participant questionnaire sample (Table A5.5, Appendix 5).

Of particular interest is whether, after taking socio-demographic characteristics into account, there was a difference in exiting between Intervention and Control participants. When disaggregated by type of exit, it was found that Intervention participants were much less likely to exit due to dissatisfaction, not-reconsenting and so on, than Control participants. They were also less likely to exit due to a related death. However, the analysis showed that their odds of exiting to residential care were significantly higher (a factor of 1.42) than for Control participants.³¹

Therefore this model of care coordination could be seen as possibly lowering participants rate of death but perhaps accelerating admission to residential care. Further analysis of the baseline severity of conditions would be needed to confirm this result.

5.1b Health and Well-being

SF-36 Results

The SF-36 Health and Well-being Questionnaire was used to measure change in participants health and well-being. In summary, as expected, there was very little change in participants' health and well-being as measured throughout the trial, comparing baseline, mid-trial and end of trial scores. Preliminary analysis identified the following differences.

- ? At the baseline, the Intervention participants scored significantly better than the Control participants on emotional role. At the mid-trial this changed to better scores for Control participants for physical function and social function. By the end of trial, bodily pain was significantly higher among Intervention participants.
- ? When scores for each item were examined, it was found that large proportions of Intervention participants had a worse score at the end of the trial for all measures except physical and emotional roles. A similar pattern was also evident among Control participants. When exited participants were included, the proportions of participants whose score worsened increased considerably.
- ? When controlling for differences in the baseline characteristics of the Intervention and Control participants, participants in the Intervention group were more likely to have a better or worse emotional role score (rather than an unchanged score). This pattern was repeated when exited participants were included. In addition, participants in the Intervention group were more likely to be the same rather than worse on the bodily pain score, compared to the Control participants.

³¹ Analysis was conducted using Cox proportional hazard analysis (*Local Evaluation Final Report*, Section 4.3a).

It appears that this model of care coordination was insufficient to significantly change the health and well-being of predominantly older participants.

Health and Well-being from the Participant Questionnaire

Participants were also asked to rate their health and well-being in the repeated participant questionnaire (Appendix 5). Most participants rated themselves as in the same or better health as others their own age, were satisfied with life in general and had a good or fair enjoyment of normal day to day activities (Table 5.1). Little change in self-reported health was reported over time and between Intervention and Control participants. Intervention participants were more likely to move to the extremes of the scale with their satisfaction and enjoyment with life and Control participants were more likely to move to the centre (Table 5.1).

Table 5.1: Self-assessed Health and Well-being by Participant Type

	Participant group					
	All baseline responses		Effective Sample ^(a)			
	Intervention	Control	Intervention		Control	
	% (n=)	%(n=)	baseline % (n=)	end trial % (n=)	baseline % (n=)	end trial % (n=)
Health compared to others same age						
Better	23.8	29.3	25.6	22.1	29.2	23.3
Same	40.9	44.9	45.9	42.9	43.3	46.7
Worse	35.2	25.8	28.6	35.0	27.5	30.0
	100.0	100.0	100.0	100.0	100.0	100.0
	(193)	(198)	(133)	(140)	(120)	(120)
Satisfaction with life in general						
	**	**	***		***	
Good	30.0	43.4	28.1	35.9	46.6	40.8
Fair	54.2	42.4	61.2	49.3	40.8	50.8
Poor	15.8	14.1	10.8	14.8	12.5	8.3
	100.0	100.0	100.0	100.0	100.0	100.0
	(203)	(198)	(139)	(140)	(120)	(120)
Enjoyment of normal day to day activities						
	***	***	**		**	
Good	27.9	42.0	28.1	35.2	46.7	37.0
Fair	53.4	40.0	61.2	49.3	40.8	49.6
Poor	18.6	18.0	10.8	15.5	12.5	13.4
	100.0	100.0	100.0	100.0	100.0	100.0
	(204)	(200)	(140)	(142)	(121)	(119)

* p<0.1, ** p<0.05, *** p<0.01

Notes: (a) Effective sample: participants who responded to both the baseline and end trial questionnaires. Percentages may not add to 100 due to rounding.

5.1c Satisfaction

The participant questionnaire asked eight questions about various aspects of care coordination to gauge participant satisfaction levels and to observe change over time.

However, there are a number of problems associated with investigating client satisfaction. Studies have revealed that in response to satisfaction surveys, older clients in particular are unlikely to criticise or rate poorly services they receive (Draper and Hill, 1995: 67). Other studies have found satisfaction surveys can be usefully employed to improve specific aspects of service provision, such as waiting time, and length of consultations (Client-Focused Evaluations Program, 1998:9).

These previous studies were taken into consideration when developing the participant questionnaire. Rather than asking for a general rating of satisfaction, respondents were asked to judge how often a particular event occurred on a five point Likert scale. This allowed participants to rate more concretely particular aspects of care coordination. These items included questions on how often they felt the following eight situations occurred: received the type of services needed; were the subject of repeated tests; care received was well planned and organised; wanted to complain about any care; difficult to get the services needed; participant or family members paid the cost of services; had a say in the services received; and service providers responded to changed needs.

The results showed that there was little difference between Intervention and Control participants in their satisfaction levels. Significant tests revealed there were differences between the two groups on only three items: had a say in the type of services received; services responded to changed needs; and self or family pay for the costs of care (Table 5.2).

Analysis of changes in satisfaction over time was also conducted (Table 5.3). When comparing the scores for change, only costs of care was shown to be significantly different. Intervention participants rated an improvement in receiving the type of services needed and difficulties getting services they needed. However, Intervention participants did less well on repeated tests, have a say and services responding to changing needs. Further analysis of changes in participant satisfaction with aspects of care coordination are presented in Table A5.6, Appendix 5. Future research could explore the significance of change within administrations at the baseline and mid-trial.

When analysed by CC type, some additional areas of significant improvements in satisfaction were identified. Participants with a full-time CC were more likely to have rated an improvement in receiving services they needed compared to participants with other types of CCs (Table A5.8). Similarly, participants with a GP were more likely to have rated services responsive to changes in care needs as worsening over the life of the trial (Table A5.8). These results should be read with caution, given the small number of respondents, the subjective nature of the answers and questions about the links between the ability of the CC to influence these outcomes in service satisfaction.

Table 5.2: Participant Satisfaction with Organisation of Care by Participant Group

	Participant group					
	All baseline responses		Effective Sample ^(a)			
			Intervention		Control	
	Intervention	Control	Intervention	Control	Intervention	Control
	% (n=)	% (n=)	baseline % (n=)	end trial % (n=)	baseline % (n=)	end trial % (n=)
Unnecessarily repeated tests/assessments						
Always/Mostly	4.2	5.4	2.6	2.5	5.5	4.2
Sometimes	8.3	9.5	7.3	7.4	10.0	7.3
Rarely/Never	87.5	85.1	89.9	90.1	84.4	88.6
	100.0	100.0	100.0	100.0	100.0	100.0
	(167)	(148)	(109)	(121)	(90)	(96)
Received type of services needed						
Always/Mostly	84.3	89.1	87.9	89.4	89.9	87.5
Sometimes	8.7	6.7	6.5	5.3	8.1	7.7
Rarely/Never	7.0	4.2	5.6	5.3	2.0	4.8
	100.0	100.0	100.0	100.0	100.0	100.0
	(183)	(164)	(124)	(132)	(99)	(140)
Have a say in type of services received						
Always/Mostly	72.6	65.6	77.9	72.8	68.5	56.4
Sometimes	10.5	8.8	6.2	8.0	8.4	16.8
Rarely/Never	16.9	25.7	15.9	19.2	23.2	26.7
	100.0	100.0	100.0	100.0	100.0	100.0
	(171)	(159)	(113)	(125)	(95)	(101)
Care received well planned and organised						
Always/Mostly	87.5	92.3	87.9	85.9	94.1	92.4
Sometimes	5.7	3.0	5.2	8.6	3.0	1.9
Rarely/Never	6.8	4.8	9.6	5.4	3.0	5.6
	100.0	100.0	100.0	100.0	100.0	100.0
	(174)	(169)	(116)	(128)	(101)	(106)
Service providers respond to changing needs^(g)						
	***	***	***		***	
Always/Mostly	40.0	23.4	38.4	30.0	21.5	25.9
Sometimes	5.4	5.1	4.8	3.1	6.5	4.6
Rarely/Never	7.6	4.6	6.4	8.5	0.9	10.2
Needs had not changed	47.0	66.9	50.4	58.5	70.1	59.3
	100.0	100.0	100.0	100.0	100.0	100.0
	(184)	(175)	(125)	(130)	(107)	(108)
Difficult to get services needed						
Always/Mostly	7.4	6.1	4.3	5.4	6.1	5.9
Sometimes	18.4	11.7	18.1	10.9	12.2	10.9
Rarely/Never	74.2	82.2	77.5	83.6	81.6	83.2
	100.0	100.0	100.0	100.0	100.0	100.0
	(173)	(163)	(116)	(128)	(98)	(101)
Wanted to complain about care						
Always/Mostly	0.6	1.8	0.0	1.6	2.0	2.9
Sometimes	11.0	10.8	10.6	11.5	8.9	11.5
Rarely/Never	88.4	87.4	89.4	87.0	89.1	85.6
	100.0	100.0	100.0	100.0	100.0	100.0
	(172)	(166)	(113)	(131)	(101)	(104)
Self or family pay costs of care						
	***	***	***		***	
Always/Mostly	48.6	31.3	53.4	34.1	33.4	29.7
Sometimes	18.6	12.5	16.1	22.5	13.5	20.8
Rarely/Never	32.7	56.3	30.5	43.4	53.1	49.5
	100.0	100.0	100.0	100.0	100.0	100.0
	(176)	(160)	(118)	(129)	(96)	(101)

Source: Participant questionnaires, November 1998 and 1999

Note: (a) Effective sample: participants who responded to both the baseline and end trial questionnaires.

Table 5.3: Changes in Participant Satisfaction with Organisation of Care by Participant Group

	Participant Group			
	Intervention		Control	
Unnecessarily Repeated Tests/ Assessments	%		%	
Better	8.0		12.5	
Same	87.0		80.0	
Worse	5.0		7.5	
	100.0	(100)	100.0	(80)
Received Type of Services Needed				
Better	12.8		7.6	
Same	76.1		80.4	
Worse	11.1		12.0	
	100.0	(117)	100.0	(92)
Have a Say in Type of Services Received	**		**	
Better	10.5		15.1	
Same	71.4		58.1	
Worse	18.1		26.7	
	100.0	(105)	100.0	(86)
Care Well Planned and Organised				
Better	9.3		3.1	
Same	79.6		90.6	
Worse	11.1		6.3	
	100.0	(108)	100.0	(96)
Service Providers Respond to Changing Needs^(a)				
Better	17.8		16.0	
Same	55.9		66.0	
Worse	26.3		18.0	
	100.0	(118)	100.0	(100)
Difficult to get Services Needed				
Better	16.5		12.5	
Same	71.6		72.7	
Worse	11.9		14.8	
	100.0	(109)	100.0	(88)
Wanted to Complain about Care^(b)				
Less likely	7.3		7.4	
Same	82.7		80.9	
More likely	10.0		11.7	
	100.0	(110)	100.0	(94)
Self or Family Pay Costs of Care^(b)				
Less likely	36.6		21.4	
Same	48.2		53.6	
More likely	15.2		25.0	
	100.0	(112)	100.0	(84)

** p<0.05

Notes: Percentages may not add to 100 due to rounding.

(a) Those who responded their needs had not changed were rated as 'sometimes' to calculate level of change.

(b) These responses do not clearly rate levels of satisfaction, or improvements in care.

The qualitative interviews explored participant satisfaction in further detail, revealing a complex picture. It suggested that it may be difficult for participants to untangle the differences between care coordination and the services they receive. This was discussed in greater detail in Section 4.2.³² Despite the differences in the levels of services received by interviewed participants, satisfaction was similar between Intervention and Control groups (Table A5.7, Appendix 5). Most participants were satisfied with their care and the amount of care they received. It appeared participants assessed this not in terms of a trial conceptualisation of ‘care coordination’, but in terms of whether they had particular concerns about the care they received.

5.2 Impact on Carers

Linked Care appeared to enhance the support to participants provided by carers. Although the number of participants relying on informal care did not change significantly, the combination of care provided by non-resident family decreased in comparison to the Control group. A possible explanation for this might have been that Linked Care might have supplemented residential family care, thereby assisting in the sustainability of the informal care.

Carers reported that their GP CCs had begun considering their holistic needs as carers when they attended medical appointments with their family member.³³ Both non-GP CCs with less than ten participants and full-time CCs were likely to plan more actions to meet the needs of carer support and disability than other categories of CC where these needs were identified.³⁴

Information was not directly collected on the impact of carers due to time and financial constraints. Data were collected indirectly in the participant questionnaire in a number of questions asking about help received from informal supports. Information was directly gained in a number of interviews where carers related experiences of care for themselves and people they cared for. Participants also discussed family, friends and neighbours involved in their care arrangements.

Use of Informal Care

By far the majority of Intervention and Control participants received some form of informal support.³⁵ Participants reported a high rate of reliance on informal support for everyday activities, including: shopping, transport, home maintenance, meal preparation, ongoing supervision and nursing. Both Table 5.4 and Table 5.5 show mainly family members, particularly spouses and children, were most likely to be relied upon. Table 5.4 also shows a high incidence of reliance on a combination of informal support. Table 5.5 indicates that

³² Satisfaction levels were discussed in the first telephone interviews to gain a baseline understanding of this aspect, but the interviews were primarily used for more in-depth qualitative analysis (Table A7.7, Appendix 7).

³³ Carer interviews.

³⁴ Linked Care and CDHAC analysis of care plan content, March 2000; Section 3.4d.

³⁵ Participant questionnaire.

informal supports were often relied upon to provide assistance and provided major support for shopping, transport, home maintenance, meal preparation, ongoing supervision and nursing.

Table 5.4: People the Participant Received Informal Help from in the past 4 weeks by Participant Group

	Participant group					
	All baseline responses		Effective Sample ^(a)			
			Intervention		Control	
	Intervention	Control	baseline	end trial	baseline	end trial
	%	%	%	%	%	%
No informal help	6.1	14.4	** 6.4	** 6.6	** 13.6	** 10.4
Family live with	37.6	32.2	36.7	34.3	35.2	17.4
Family live separately	21.2	22.6	22.9	19.7	17.0	17.4
Mix of family who live with/separately	9.7	6.8	8.3	21.9	6.8	32.2
Friends/Neighbours	7.9	11.0	5.5	2.9	15.9	8.7
Mix of family as well as friends/neighbours	17.6	13.0	20.2	14.6	11.4	13.9
Total (n)	(164)	(146)	(109)	(137)	(88)	(115)

** p<0.05

Source: Participant questionnaire, November 1998 and 1999; Appendix 4.

Notes: Percentages may not add to 100 due to rounding.

(a) Effective sample: participants who responded to both the baseline and end trial questionnaires.

Table 5.5: The Main Person Providing Unpaid Help to the Participant

	Participant group					
	All baseline responses		Effective Sample ^(a)			
			Intervention		Control	
	Intervention	Control	baseline	end trial	baseline	end trial
	%	%	%	%	%	%
No unpaid help	8.2	13.1	7.5	8.8	13.0	21.0
Spouse/partner	41.5	26.8	44.4	37.2	28.7	26.1
Parent(s)	8.7	2.1	11.3	9.5	0.9	0.8
Daughter	37.9	43.2	34.6	35.0	40.7	37.0
Son	29.2	33.9	30.1	32.8	34.3	28.6
Other relatives	12.3	15.3	12.8	13.1	11.1	17.6
Friends	18.5	15.8	16.5	13.9	19.4	17.6
Neighbours	17.4	16.9	16.5	13.9	17.6	19.3
Other	4.6	6.0	4.5	3.6	7.4	5.9
Total (n)	(348)	(317)	(237)	(230)	(187)	(207)

Source: Participant questionnaire, November 1998 and 1999; Appendix 6.

Notes: Percentages do not add to 100 because these questions allowed for multiple responses.

(a) Effective sample: participants who responded to both the baseline and end trial questionnaires.

Future analysis could investigate the extent of reliance on a network of informal supports which Day describes as 'modified extended family' (Day, 1985: 60).

Mrs Oakes described how she managed with the help of her extended family.

Well I have to depend on my husband and if he can't manage to take me I'll get my daughter to help. But what happened, with my doctors' appointments, I used to have them any time during the day, but since I've had to be transported I try very hard to get the appointments in the afternoon. My husband, I can have him transport me more easily in the afternoons. I know even with my daughter, the one that lives close, but she's got four children... If I need help with curtains she says, 'yes, I'll do that', but I can't push her too far... They care for me and things like that... When the chips are down... they wouldn't hesitate, even the one in the country would do the best she could do. (Mrs Urma Oakes, Intervention participant)

These findings about the high levels of support provided by family members reflects much other research showing the vital role of informal assistance, particularly family assistance (Fine and Thomson, 1995: 57; Graham et al., 1992: 261). Family can provide an essential balance between 'affective support' (such as attention, love, appreciation), and 'instrumental assistance' (such as housework, transport, financial assistance) (Day, 1985: 74). Participants also indicated family very often provided more than just time and help with specific tasks.³⁶ Very often when a partner, spouse or child had chronic or complex care needs family members arranged care at a very involved level. In some situations where the care recipient was incapacitated, primary carers had developed an expertise in understanding the appropriate care needed for the person.

Some carers appeared to consider it in the best interest of the family member not to want to forfeit their level of involvement in the organisation of care either to other carers or to professional support such as a CC, despite the difficulties it created for them. Support provided by families was not always unproblematic. Obviously as previous research has shown, the interests of carers and those who receive care do not necessarily coincide (Graham, 1999: 5). This became apparent in the interviews. Following are examples of this.

? Children could be bossy and treat their parent like children.

Mrs Chamberlain was grateful for her daughter driving fortnightly from Bowral to help out. However she also found her daughter could take over.

[Do you talk with your oncology specialist much about what help you need at all?]

[laugh] Listen here my dear, when we go to the doctor, our daughter does all the talking. She knows all the doctors. She does all the talking. We don't get a word in edge-ways! [laugh]... It does annoy me sometimes, but she knows more about medical business than we'll ever know... It's very frustrating. We just sit there and listen, or try to.

[You'd like to ask some questions.]

Of course I do. I do try sometimes, but I don't know, they sort of get passed off. Don't ask me why. Anyway, I'm not worrying, I'm feeling alright. As my daughter said, 'You're in remission, mum', so that's it.

³⁶ Participant interviews.

[So does your daughter talk about it with you afterwards?]

No! Don't be silly! You don't know Sister Brown! (Mrs Edna Chamberlain, Control participant)

- ? Carers could feel caring for a loved one was a responsibility they could not forgo and the responsibility of care created emotional tensions and contradictions.

Mrs Turner discussed the emotional conflicts of caring for her ageing mother.

It's hurtful for her to see people's attitude toward her changing, and she doesn't really know why. Some days she will say to me, 'Gee, what's wrong with me?' [words catching on tears] and I'll say 'Oh, mum, nothing's wrong. You're fine', because if she *knew* then she would just go down faster... She's still interested in what goes on around her and some days I could *kill* her, [laugh]. But she's fine really, that's me and my impatience really, because it takes extra patience to deal with someone who's in that way, you know, and not get frazzled.

[You might need a bit of care yourself sometimes?]

Well, I might! So far so good, you know... I got to the stage I was sort of crying a bit... I would just burst into tears, I was becoming oversensitive. (Mrs Irene Turner, Intervention carer)

- ? Carers could make decisions against the wishes of the person they cared for.

For example, Mrs Burke described how she realised with her failing health that she could no longer care for her husband and although he wanted to come home, it was organised he was to go to a nursing home: 'I couldn't take care for him unless there was a nurse there all the time'.

Mrs Shields, in the Control group, discussed how her children decided that she should go to a nursing home.

[Do you want to go there?]

No I do not. She took me out there and they showed me one of the rooms they had... but it was so small. I thought I couldn't live in this. You know to me it was a prison cell. It had a window, a door, a bed, and it had the ensuite, but apart from that there was nothing. I mean you had to walk to the dining room and that was a heck of a long walk ... if you didn't stay there you'd lose your money. You see that's another thinking that worried me.

\$85 000 for a little room like that, where I wouldn't be happy... and on top of that ... they take 85 per cent of your pension. And I said 'but how much is that going to leave me to live on?', and my son said to me, 'what do you want to live on? You get your meals.' I said to Jim, 'You'd like to have a little bit of money if somebody has a birthday, you like to send them a card or something.' ... I could just have respite for a fortnight. I'll look into that. I mean if you have respite care, it's like having a fortnight there like a holiday. See what it's like. When I came home I said, 'I felt like I was going into a geriatric place' and my son looked at me and said, 'what do you think you are mum?'... he thinks mum's ready for it. I wish to goodness, well I did say to him at one stage, 'Couldn't I', you see he's got a granny flat at his place, empty, but as he said, 'I'd have to put a shower and

toilet into it' and he said 'that wouldn't worry me...' but it would put so much extra value onto his house that he doesn't want to carry out it. So I don't want to press it.

The carers involved in daily support of a family member reported that managing alone could be difficult. They thought they needed skills such as negotiation, lateral thinking and empathy for the care recipient to manage the complex organisation of care.

For example, carers of three Intervention participants with disabilities reported these participants had unstable health and therefore required flexible care arrangements. In two of these situations the primary carer remained responsible for care arrangements throughout the trial.³⁷ Mrs Gleeson and Mrs Newman dealt with life-threatening situations for the persons they cared for. These carers were concerned to balance the arrangements in relation to quality of care, quality of life for the participant and adequate respite to do other tasks or recoup.

While neither carer claimed an expertise beyond the person they cared for they realised their role was vital. Mrs Newman did not realise her GP was to undertake extended responsibility as a CC. She continued to organise her husband's care. She stated that although an appointed CC may be useful, she was more likely to be in a position to respond to his changing needs.

Because I'm the one who sees him day to day and that doesn't always mean you recognise changes though. Very often someone who only sees him every three weeks will say 'gosh, that is different from when I was here' ... [But] if Greg needs something I do something about it. I don't wait for someone to step forward and say to me, 'look, he's got a rash all over his body we must do something about it', I try to do something or seek advice. (Mrs Margaret Newman, Intervention carer)

There were many occasions when Mrs Newman was responsible for organising arrangements to increase her husband's comfort, care and safety. She had to respond flexibly to a variety of situations. She related how she had to play the role of advocate when her paralysed husband sat hunched, slumped and aching in a chair after an operation lasting four hours. For Mr and Mrs Newman to go out, she organised times when there were not appointments or home visits, when a taxi for people with disabilities was available and for the journey to be wheel chair accessible. She said most areas of her life involved making arrangements for care of her husband, as well as maintaining her own and her husband's good humour and energy.

Mrs Gleeson was the primary carer for her son, Tony. His full-time CC was gradually involved more often in care arrangements, particularly as an advocate and facilitator, but Mrs Gleeson felt there was only so much the CC could do. The full-time CC was helpful in organising extra assistance.

It was quite difficult at the time but [name CC] was an advocate for me, talking to a particularly difficult lady I couldn't deal with any more at [name organisation] and she sorted all that out in the end ... There wasn't anyone else to turn to at this time

³⁷ In the third case, Mrs Mears, while primarily involved in her husband's care found the Aged Care Unit at Hornsby Hospital very helpful in organising care.

... I'm sure I wouldn't have got the ... respite hours without [name CC] who knows the situation. [name CC] has done the best she can in the situation. It is difficult to do anything else. (Mrs Mary Gleeson, Intervention, carer)

Over the years, Mrs Gleeson developed a complex range of support people and learnt to use each for their expertise. The CC appeared to be incorporated into this network. The network also included: sympathetic community service sector staff; institutional care and trusted volunteers for respite; trusted and respected specialist doctors for advice; church members; health professionals; and her husband for emotional support and advice.

Some participants stated they did not require intensive help from a carer and wished to remain independent as long as possible. They expressed a desire to accept only a certain level of assistance with organising their care without feeling controlled.

Beryl treats me as though I'm made of glass. [laugh] which I don't really want. 'Do you want to sit down, dear? Let me carry that, dear', 'I can manage, Beryl', oh no, [she] grabs my arm and steers me around. Makes her happy doing her job... All I need is somebody to say 'well what do you want round at so and so and I'll go and get it', so I give her the money and I sit there. Sometimes I feel as though my legs won't go any further... If I can do it, I putter along and do it... I try to do as much as I can. It's a case of if you don't use it you lose it. (Mrs Betty Tiller, Intervention, participant)

Even for these participants, they and their carers realised that circumstances could change (e.g. if the carer became sick or unavailable or the care needs became too great), having an impact on their reliance on a carer or a more formal mechanism such as the CC.

5.3 Impact on Clients not in Linked Care

One of the objectives of the trials was to implement the intervention without disadvantaging non-participants. There were four ways that clients outside Linked Care were potentially disadvantaged:

- ? if the infrastructure of a service provider was insufficiently flexible to be able to use the reimbursement from the Linked Care fund pool to increase the total hours of care provided by that agency, e.g. to employ additional staff;
- ? if payments to the service provider from the fund pool were not transferred to the branch so the cost of the additional care to participants was at least partly funded from a branch budget;
- ? if the payment for CCs was insufficient to cover the cost of employing them; or
- ? if the cost of service used to calculate capitation rates and service payments was inaccurate and did not cover the cost of care.

It was unclear to the evaluators the extent to which these four risks were avoided. Certainly a concern about inequity between clients in and outside Linked Care was expressed throughout the second half of the trial in 1999, particularly in relation to accessing assistance

from Home Care Services (HCS), the largest HACC service provider.³⁸ It was reported that if a participant had a change of circumstance requiring access to HCS care they were able to access that care, compared to other potential clients who could not access care because HCS personal care was reportedly capped since August 1998, and that this situation was reducing the care available to non-participants.³⁹

At the baseline, service providers feared Linked Care could be detrimental to clients outside Linked Care, if resources and care provided were capped and the effect was to allocate a significant proportion of care to participants.⁴⁰

CCs were also negative in their views. Over half thought there had been a negative impact on clients outside Linked Care (51.1 per cent; Table A6.1). Comments supporting this result described the negative impact on access to services for non-participants because of capped resources.⁴¹

Repercussions from perceptions by service staff of an inequity between clients in and out of the trial could be a continuing issue for a model such as this, if the perception resulted in a detrimental attitude to participants. Additionally, the perceived inequity could have created resentment towards Linked Care and its participants. A result might have been that providers were less willing to incorporate ideas from Linked Care in their service delivery processes (e.g. using the CIARR to enhance referrals) or to comply with expectations from Linked Care (e.g. covering for CCs on leave, or attending PSG meetings).

It would seem that the expansion of the model would continue to pose these risks to clients outside coordinated care. Even if financial reimbursement was accurately calculated and transferred, with smaller agencies, rigidities such as the availability of suitable staff or volunteers could be present. Similarly, for larger organisations, industrial relations issues concerning temporary staff could restrict their ability to continue to provide the same level of care to other clients.⁴²

The evidence about the impact on non-participants was sketchy. The implications from this limited analysis are that the Linked Care model could have been sustainable at a cost to clients outside the model. Second, greater provision of community and hospital-based services to a larger number of clients in this model may only have been possible if the flexibility of the structure of existing and possibly new service providers changed.

³⁸ From managers of service providers contributing to the trial, other service providers, CCs and reportedly from field staff at HCS.

³⁹ This is consistent with the increase in waiting list numbers for HCS and other service providers; Table A6.8a and A6.8b.

⁴⁰ Service provider baseline interviews, December 1997.

⁴¹ Service provider managers and CC mid-trial questionnaires.

⁴² Service provider manager baseline interviews.

6. Service Delivery

6.1 Service Usage Patterns

6.1a Results from the Linked Care Data

A vast data set of service utilisation was generated by Linked Care. Analysis for this report has only begun to explore the implications of the data. Analysis was conducted of both service usage and cost according to the basic service groups defined by the national evaluators. These groups were: hospital inpatient services; hospital non-admitted patient services; Home and Community Care Services (HACC); diagnostic and investigational services; pharmaceutical services, medical and specialist services; and other goods and services (catch all other category, mainly private providers).⁴³

Mean use and mean cost per month per participant in Linked Care were calculated for the period May 1998 to September 1999.⁴⁴ In addition to the broad service groups listed above, charts are included for sub-groups of participants, services and funders: HACC providers, and DVA, MBF and HCF clients. Outliers have not been removed (further analysis should include this alternative description of the data).

As discussed in Chapter 5, Linked Care did not appear to change the measured health outcomes of participants enrolled in Linked Care. Similarly, analysis of the service usage data found an apparent absence of major shifts in use and cost of service types. The exceptions were possible increases in use and cost of medical practitioner and specialist services and changes in care provided by specific HACC agencies. Detailed discussion of the results are included in the *Local Evaluation Final Report*, Section 5.4.

Participants and CCs reported that the model provided better monitoring, and that when combined with the financial flexibility of the fund pool, the model potentially increased access to, and use of, services. It is therefore not surprising that in the absence in a shift in service use, a possible increase in use was observed for some service types (e.g. community care).

Logistic regression was used to analyse changes in both service usage and cost according to the basic service groups.⁴⁵ Tables 6.1 and 6.2 show that increased use of medical

⁴³ Other service groups included in the national data set, but not in this analysis were nursing home or hostel services, non-MBS general or specialist medical services including coordinated care services, and services arising from the CCT context. Hospital non-admitted patient services data were charted, but not included in further analysis.

⁴⁴ Three month moving averages were calculated to minimise irregular monthly variations. Data were successively averaged by adding values for the month in question, and the month preceding and following. This was then divided by a moving or rolling average of the number of participants for the corresponding period.

⁴⁵ Two sets of variables were created. The first represented baseline usage for the month of June 1998 calculated as a three-month average (May, June, July). A second set was created to capture change over time, that is, end of trial (August 1999 – average of July, August, September) minus baseline (June 1998). The comparison of different months risks seasonal effects, minimised through the use of a three-month average. This was repeated for cost of service use. The approach controlled for baseline (largely demographic, Section 4.2b) differences that had the potential to influence outcomes. This allowed for changes in the amount and cost of service use to be analysed in terms of the Intervention alone. The regression predicts that with a given outcome (e.g. cost of service), and controlling for background differences, the participant is or is not from the Intervention group.

practitioner and specialist services was more likely to be found (by a factor of 1.2) among Intervention participants than a decrease in use. This was also found for cost, although to a lesser degree. No significant differences between Intervention and Control groups were found regarding total cost of services.

Although the fund pool analysis showed some changes in total service use, this is not immediately evident in the current analysis, apart from medical practitioner and specialist services. The results presented here, however, should be interpreted with some caution. First, the analysis only examines changes in cost and usage at two points in time (three-month averages for June 1998 and August 1999). Strictly speaking, the results only refer to changes between the means calculated for these two months. It should also be noted that the direction and strength of results is sensitive to and partly determined by which particular time periods are analysed, for example they may include winter seasonal effects in the end of trial month. Future research into the data, therefore, would utilise more sophisticated longitudinal techniques.

Further analysis on the relative change in service use of subgroups of service providers, service type, client type, CC type and service usage prior to exit is recommended. This would assist in identifying what client factors would predict changed use of services.

Table 6.1: Logistic Regression of Intervention Group Membership and Change in Use of Each Service, June 1998 and August 1999

	Coefficient	SE	Sig	Effect on Odds
Background variables				
Born overseas	0.5685	0.2709	**	1.7657
English not spoken at home	-2.0615	0.4924	****	0.1273
Lives in independent living unit	1.3234	0.3877	****	3.7563
Has a carer	0.8904	0.2689	****	2.4361
Renter	-0.6379	0.2640	**	0.5284
Tertiary level education	1.5623	0.2901	****	4.7699
Service groups				
Hospital inpatient (non-DVA)	0.2662	0.3590		0.8001
DVA hospital inpatients	0.0167	0.0964		0.9835
HACC-based services	-0.0051	0.0074		1.0510
Diagnostic and investigational	-0.0196	0.0378		1.0198
Pharmaceutical	-0.0404	0.0279		1.0413
Medical practitioner and specialist services	-0.1885	0.0638	***	1.2075
Intercept	0.7527			
n = 669; -2 log likelihood 700				

** p<0.05 *** p<0.01 **** p<0.001

Reference category: Australian-born; English spoken at home; lives at home (unit, flat etc); does not need or have a carer; owns home; secondary education level.

Table 6.2: Logistic Regression of Intervention Group Membership and Change in Cost of Each Service, June 1998 and August 1999

	Coefficient	SE	Sig	Effect on Odds
Background variables				
Born overseas	0.5573	0.2693	**	1.7459
English not spoken at home	-2.0907	0.4880	****	0.1236
Lives in independent living unit	1.3516	0.3858	****	3.8635
Has a carer	0.8129	0.2667	***	2.2545
Renter	-0.6329	0.2610	**	0.5310
Tertiary level education	1.5832	0.2889	****	4.8704
Service groups				
Hospital inpatient (non-DVA)	-5.2E-05	6.9E-05		1.0001
DVA hospital inpatients	-0.0002	0.0003		1.0002
HACC-based services	-0.0001	0.0002		1.0001
Diagnostic and investigational	-1.5E-05	0.0012		1.0000
Pharmaceutical	-0.0011	0.0010		1.0011
Medical practitioner and specialist services	-0.0022	0.0009	**	1.0022
Intercept	0.9966			
n = 669; -2 log likelihood 707				

** p<0.05 *** p<0.01 **** p<0.001

Reference category: Australian-born; English spoken at home; lives at home (unit, flat etc); does not need or have a carer; owns home; secondary education level.

6.1b Participant Reported Data on Service Use

The participant questionnaire provided a cross-reference with other information collected by Linked Care about service use. This section presents parallel results in relation to service groups described above including assistance with daily activities, medical service use and GP consultations.

Assistance with Daily Activities

The participant questionnaire provided a checklist for participants to identify if assistance was required for a particular activity and who provided the assistance (community service, privately paid, or family, friends or neighbours). Information was not collected on the frequency of assistance.⁴⁶

At the baseline, Intervention participants generally had higher service use than Control participants and this did not change over the life of the trial (Table 6.3). For some service types Intervention participants received even more help but mainly from informal caregivers. The source of the help varied for each activity.

- ? Community services provided major support for: housework, podiatry (Control participants), personal care, physiotherapy, day care and occupational therapy.
- ? Informal caregivers provided major support for shopping, transport, home maintenance, meal preparation, ongoing supervision and nursing.
- ? Private services provided major support for podiatry to the Intervention participants. There did not appear to be changes in use of private services as a result of Linked Care.

These results are consistent with the 1993-1994 HACC User Characteristics Survey. From the total NSW HACC clients 65 and over, just under half were provided with personal care (40.1 per cent); Linked Care participants (38.2 per cent). Similarly, most Linked Care and NSW HACC clients received assistance with housework (Fine and Thomson, 1995: 68-9).

⁴⁶ After consultation and piloting it was considered too complex for participants to complete frequency data. The *Service Provider Experience Report*, Section 3.1 details service level across the HACC area.

Table 6.3: Type of Assistance Received by Participant Group

	Participant group					
	All baseline responses		Effective Sample ^(a)			
			Intervention		Control	
	Intervention	Control	baseline	end trial	baseline	end trial
	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)
Housework				**		**
Assistance Not Received	21.7	20.9	20.0	12.0	22.7	22.9
Community Service	36.2	44.9	37.1	38.7	46.2	44.1
Privately Paid	13.5	7.7	15.0	15.5	6.7	7.6
Family/Friends/Neighbours	19.3	18.9	17.9	21.1	16.0	16.1
Community & Family	3.9	2.6	3.6	7.7	2.5	1.7
Private & Other Assistance	5.3	5.1	6.5	4.9	5.9	7.5
	100.0	100.0	100.0	100.0	100.0	100.0
	(206)	(196)	(140)	(142)	(119)	(118)
Shopping						
Assistance Not Received	33.8	41.8	35.7	30.3	41.2	38.1
Community Service	6.3	8.2	5.7	6.3	9.2	8.5
Privately Paid	2.9	3.6	3.6	4.2	5.0	4.2
Family/Friends/Neighbours	54.1	44.4	51.4	54.9	42.9	44.9
Community & Family	1.9	1.0	2.1	2.1	0.0	0.0
Private & Other Assistance	1.0	1.0	1.4	2.1	1.7	4.1
	100.0	100.0	100.0	100.0	100.0	100.0
	(206)	(196)	(140)	(142)	(119)	(118)
Transport				**		**
Assistance Not Received	38.6	46.9	39.3	31.7	47.9	48.3
Community Service	11.1	13.3	12.9	14.1	15.1	15.3
Privately Paid	2.4	3.1	1.4	4.2	3.4	4.2
Family/Friends/Neighbours	41.1	30.6	39.3	35.9	27.7	28.8
Community & Family	3.9	3.6	4.3	9.2	4.2	1.7
Private & Other Assistance	2.9	2.6	2.8	1.4	1.7	1.6
	100.0	100.0	100.0	100.0	100.0	100.0
	(206)	(196)	(140)	(142)	(119)	(118)
Home Maintenance			*		*	
Assistance Not Received	42.5	50	42.1	33.1	54.6	42.4
Community Service	6.8	8.7	5.7	7.0	9.2	9.3
Privately Paid	16.9	12.8	19.3	19.7	9.2	17.8
Family/Friends/Neighbours	29.0	24.0	28.6	30.3	21.8	22.0
Community & Family	0.0	0.5	0.0	2.8	0.8	0.0
Private & Other Assistance	4.8	4.1	4.3	7.0	4.2	8.4
	100.0	100.0	100.0	100.0	100.0	100.0
	(206)	(196)	(140)	(142)	(119)	(118)
Podiatry	***	***	**	***	**	***
Assistance Not Received	51.7	45.9	48.6	39.4	47.9	40.7
Community Service	13.0	28.1	14.3	18.3	28.6	35.6
Privately Paid	30.4	23.0	31.4	35.2	21.8	19.5
Family/Friends/Neighbours	3.9	2.6	5.0	7.0	1.7	2.5
Community & Family	0.5	0.5	0.0	0.0	0.0	0.0
Private & Other Assistance	0.5	0.0	0.7	0.0	0.0	1.6
	100.0	100.0	100.0	100.0	100.0	100.0
	(206)	(196)	(140)	(142)	(119)	(118)
Meal Preparation	*	*				
Assistance Not Received	44.0	58.2	47.1	42.3	59.7	56.8
Community Service	16.4	13.3	15.7	13.4	11.8	11.0
Privately Paid	1.9	2.6	1.4	3.5	1.7	2.5
Family/Friends/Neighbours	34.3	24.5	31.4	34.5	25.2	27.1

Community & Family	1.9	0.5	2.1	4.2	0.8	0.8
Private & Other Assistance	1.4	1.0	2.1	2.1	0.8	1.6
	100.0	100.0	100.0	100.0	100.0	100.0
	(206)	(196)	(140)	(142)	(119)	(118)

Table 6.3 (continued): Type of Assistance Received by Participant Group

	Participant group					
	All baseline responses		Effective Sample ^(a)			
			Intervention		Control	
	Intervention	Control	baseline	end trial	baseline	end trial
	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)
Personal Care						
Assistance Not Received	58.5	65.3	65.7	63.4	70.6	72.9
Community Service	14.0	16.3	10.7	12.0	15.1	14.4
Privately Paid	3.9	1.0	3.6	3.5	0.0	0.8
Family/Friends/Neighbours	11.6	7.1	10.0	11.3	7.6	6.8
Community & Family	8.7	7.1	5.7	6.3	5.9	3.4
Private & Other Assistance	3.4	3.0	4.3	3.5	0.8	1.6
	100.0	100.0	100.0	100.0	100.0	100.0
	(206)	(196)	(140)	(142)	(119)	(118)
Ongoing Supervision						
	**	**				
Assistance Not Received	65.2	76.0	69.3	59.2	79.0	74.6
Community Service	4.8	1.0	2.9	4.9	1.7	3.4
Privately Paid	0.0	0	0.0	0.7	0.0	0.8
Family/Friends/Neighbours	24.6	21.9	25.0	31.0	19.3	19.5
Community & Family	4.3	0.5	1.4	1.4	0.0	0.8
Private & Other Assistance	1.0	0.0	1.4	2.8	0.0	0.8
	100.0	100.0	100.0	100.0	100.0	100.0
	(206)	(196)	(140)	(142)	(119)	(118)
Nursing						
	*	*	*	***	*	***
Assistance Not Received	68.6	78.6	74.3	66.2	84.0	80.5
Community Service	6.3	6.6	3.6	4.9	5.9	8.5
Privately Paid	1.4	1.5	0.0	2.1	0.0	0.0
Family/Friends/Neighbours	22.2	11.2	21.4	24.6	9.2	8.5
Community & Family	1.4	2.0	0.7	0.7	0.8	1.7
Private & Other Assistance	0.0	0.0	0.0	1.4	0.0	0.8
	100.0	100.0	100.0	100.0	100.0	100.0
	(206)	(196)	(140)	(142)	(119)	(118)
Physiotherapy						
			*	**	*	**
Assistance Not Received	78.7	86.7	78.6	70.4	88.2	84.7
Community Service	12.1	8.7	12.1	14.8	9.2	7.6
Privately Paid	5.8	4.1	5.7	9.9	2.5	5.1
Family/Friends/Neighbours	2.4	0.5	3.6	4.2	0.0	0.0
Community & Family	0.5	0.0	0.0	0.7	0.0	0.0
Private & Other Assistance	0.5	0.0	0.0	0.0	0.0	2.5
	100.0	100.0	100.0	100.0	100.0	100.0
	(206)	(196)	(140)	(142)	(119)	(118)
Day Care						
	*	*		**		**
Assistance Not Received	88.9	86.2	90.7	83.1	85.7	81.4
Community Service	4.3	9.7	5.0	5.6	9.2	14.4
Privately Paid	2.9	0	1.4	2.8	0.0	0.0
Family/Friends/Neighbours	2.9	2.0	1.4	6.3	1.7	1.7
Community & Family	0.0	0.5	0.0	0.0	0.8	0.8
Private & Other Assistance	1.0	1.5	1.4	2.1	2.5	1.6
	100.0	100.0	100.0	100.0	100.0	100.0
	(206)	(196)	(140)	(142)	(119)	(118)
Occupational Therapy						
Assistance Not Received	87.4	92.9	86.4	86.6	93.3	90.7
Community Service	9.7	5.6	10.7	7.0	5.0	5.1
Privately Paid	1.4	0	1.4	0.0	0.0	0.8

Family/Friends/Neighbours	1.4	.5	1.4	4.9	0.0	1.7
Community & Family	0.0	0.0	0.0	0.7	0.0	0.0
Private & Other Assistance	0.0	1.0	0.0	0.7	1.6	1.6
	100.0	100.0	100.0	100.0	100.0	100.0
	(206)	(196)	(140)	(142)	(119)	(118)

* p<0.1, ** p<0.05, *** p<0.01

Source: Participant questionnaires, November 1998 and 1999.

Notes: Percentages may not add to 100 due to rounding.

(a) Effective sample: participants who responded to both the baseline and end trial questionnaires.

Medical Service Use

The majority of Intervention and Control participants reported regularly visiting their doctor (Table 6.4). Around 60 per cent in both groups had seen their doctor once a month in the last six months. They reported seeing their doctors when they were sick and also for regular appointments for check-ups or to renew prescriptions.⁴⁷

Table 6.4: Medical Service Use by Participant Group

	Participant group					
	All baseline responses		Effective Sample ^(a)			
	Intervention	Control	Intervention		Control	
			baseline	end trial	baseline	end trial
	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)
GP visits				*		*
No visits	1.2	1.0	1.5	0.0	0.5	1.7
1 visit	10.9	9.7	11.0	4.3	4.5	2.5
Approximately monthly	62.7	62.8	69.1	61.0	59.0	50.0
Approximately fortnightly	15.9	16.3	12.5	28.4	11.1	32.2
Approximately once a week or more	8.5	10.2	5.9	6.4	7.5	13.6
	100.0	100.0	100.0	100.0	100.0	100.0
	(200)	(196)	(136)	(141)	(119)	(118)
Total hospital admissions						
No Admissions	69.8	67.2	70.4	60.6	63.9	64.9
1 Admission	20.1	24.1	21.5	20.5	26.9	16.2
2 Admissions	8.0	6.7	5.9	12.9	8.4	12.6
3 Admissions	1.5	0.5	1.5	3.8	0.8	3.6
Over 3 Admissions	0.5	1.5	0.7	2.3	0.0	2.7
	100.0	100.0	100.0	100.0	100.0	100.0
	(198)	(195)	(135)	(132)	(119)	(111)
Total hospital days				*		*
No days	70.9	67.9	71.4	58.8	65.1	64.3
1 day	2.0	3.1	2.3	0.7	14.5	5.4
2 days to a week	8.2	13.5	9.0	13.2	12.8	7.1
1 week to a month	13.8	10.9	14.3	19.1	5.1	19.6
Over 1 month	5.1	4.5	3.0	8.1	2.6	3.6
	100.0	100.0	100.0	100.0	100.0	100.0
	(195)	(193)	(133)	(136)	(117)	(112)
Other hospital service visits			**		**	
No visits	77.8	83.9	75.4	72.9	82.5	77.3
1 visit	2.1	2.7	1.5	6.0	2.6	7.3
2 to 6 visits	8.8	4.3	9.7	5.3	7.0	8.2
7 to 14 visits	4.1	5.4	3.1	12.0	4.4	5.5
Over 14 visits	7.2	3.8	10.4	0.8	3.5	1.8
	100.0	100.0	100.0	100.0	100.0	100.0
	(193)	(186)	(134)	(133)	(114)	(110)
Medical or diagnostic visits						
No visits	48.2	50.5	42.2	37.9	46.9	29.2
1 visit	17.8	16.5	20.7	6.8	20.4	11.5
2 to 6 visits	27.4	27.5	29.6	41.7	26.5	46.0
7 to 14 visits	5.1	3.8	6.7	12.1	4.4	10.6
Over 14 visits	1.5	1.6	0.7	1.5	1.8	2.7
	100.0	100.0	100.0	100.0	100.0	100.0

⁴⁷ Participant interviews.

	(196)	(182)	(135)	(132)	(113)	(113)
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*p<0.1, **p<0.05, ***p<0.01

Source: Participant questionnaires, November 1998 and 1999

Note: Percentages may not add to 100 due to rounding.

(a) Effective sample: participants who responded to both the baseline and end trial questionnaires.

While most participants did not report hospital attendance, about 20 per cent had one hospital admission. About half the participants from both groups reported attending other medical specialist visits or diagnostic appointments.

The baseline results were not comparable to the end of trial responses to the participant questionnaire due to survey design.⁴⁸ However results showed that patterns remained similar between the two groups implying Intervention participant use of medical services had not been changed significantly relative to the Control group.

GP involvement in Linked Care is discussed separately because of their significance as CCs and primary health care providers. The remainder of this section describes the participants' experience of GP services during the trial.

Participants reported regularly visiting or being visited by their GP. The importance of the GP relationship was indicated in some of the questionnaire comments.

I only receive GP and family help. (female, Intervention)

Life is difficult owing to health... but is very happy with home situation and very helpful GP Dr [name]. (female, Intervention)

I am in very good health thanks to the Department of Veterans' Affairs and my local GP Dr [name] (male, Intervention)

I am happy I have the services of an Armenian doctor ... as it makes communication easier. (female, Control)

Some participants spoke of how they trusted and even treated their GPs as friends, extending the relationship beyond medical assistance. For example Mrs Turner says her mother Mrs Jemma Cartwright enjoys her visit to the doctor.

He sits and listens to her and she likes him a lot. She has a lot of faith in Graham. And so have I, I mean he's just lovely. He takes time, and that's important to old people, because they don't like to be hustled. All the oldies go to Graham. (Mrs Turner, Intervention, carer)

Mrs Gleeson found her relationship with the GP very supportive in assisting her with her son's disability and illnesses, particularly by responding to her concerns. She was particularly happy that he gave Tony's daytime carers lessons about administering his medication, explained his health to other significant family members and referred her to appropriate medical help.

⁴⁸ The baseline questionnaire asked about services used in the previous six months while the end of trial questionnaire asked about the previous 12 months.

Mrs Nancy Hargreaves' doctor understood she did not wish to go to a nursing home and advised her not to have a shoulder replacement because he thought it would inevitably mean she would not be able to remain at home.

I have a chat every time he comes in... He's a friend as well as a doctor. He's only around the corner... He wants me to do what I like. He knows I've got a good brain and I don't want to be treated as a non-competent person. (Mrs Nancy Hargreaves)

Participants from the Control group described similar stories.

This is not to suggest relationships between GPs and their patients were always unproblematic. Although rare for this trial, negative comments about GPs were mentioned in the participant questionnaire and interviews. Not all interviewees had a particularly close relationship with their GP or discussed issues other than medical concerns.

Interestingly, however, for participants with a good relationship with their GP, it did not always translate into good CC practice. Mrs Margaret Newman is loyal to her GP and was extremely happy with her support. She had always been helpful and made suggestions such as 'prodding me to see about respite care' but as she was the primary carer she remained responsible for finding out about the availability of respite care. From her GP's description of Linked Care she believed it was primarily research to explore:

what people need to have to keep someone at home with least possible worry to the carer and the person and for the greater comfort of that person at home... We came to it prepared to help so we were guinea pigs to say this is the sort of life a [name disability] leads at home and these are the things he needs.

She had thought that having a CC may overcome the difficulty of organising care, but felt unable to ask her GP to undertake the task.

You need a CC for that because hopefully the CC will know where to turn for this, that and the other. Whereas I don't and I've got to ring around, may be ring the social worker, start there, and ask about something, or maybe now that the Linked Care project is underway I would ring Dr X. On the other hand she is always frantically busy and I don't like to ring her just for an incidental thing. So I would probably chose to ring the Hornsby people [hospital] in the first instance to ask about something.

6.2 Participant Views on Service Delivery

Participants identified a number of issues about service delivery:

- ? quality and flexibility of service provision;
- ? friendliness and companionship of service provision;
- ? independence and privacy; and

? gaps in service.

These are discussed in further detail below.

Quality and Flexibility of Service Provision

Participants indicated concern about the quality and lack of flexibility in service delivery. These issues probably fell outside the scope of Linked Care since its focus was the coordination of services rather than the quality of care. Some CCs however viewed care coordination in a wider sense. One of these CCs said that coordination was about ‘making the service fit the participant, not the other way around’.⁴⁹ Their view therefore was that coordination was about achieving flexibility in services so that services responded more appropriately to individual participants.

When Mrs Shields’ regular Home Care cleaner changed, she was annoyed when the replacement did not arrive.

The [cleaner] I’ve had up to last week has done very good job, but unfortunately she didn’t come last week because she’s gone for a holiday to England. They rang me up on the Wednesday night to say they would have a relief coming for me on Thursday morning, half past nine. So I get up, and I get ready for it, half past nine. Half past nine and she rings to tell me she’s not coming... When anybody’s coming to me like that I’ve got to get out of bed and have my shower and be down stairs, which means I’ve got to give myself an hour and a half to have a shower and get dressed, make my bed, because if I’m upstairs I can’t hear them ring the front doorbell. So I just got to make sure I’m up early and get down there and be sitting waiting for them... [Mrs Natalie Shields, Control participant]

Mrs Yan did not want to increase the level of care for her mother, who suffered dementia, when she realised this would involve further assessments and changed carers and timetables.

They [service providers] just ask you questions and tell you what to do and... they say we don’t have this kind of service, we don’t have the kind of service... They referred me to an organisation in [suburb name] that speaks [native language of mother]... the lady did ring me and said she should come and assess mum, and the lady... said if we would like them to help they [would] want to change the whole package... But I said to her at the moment mum just copes with the lady who showers her from [service name] very well. If you change her I don’t think she would like it. You know old people, they don’t always like change, a change of face, [and] she might feel afraid... I think if you want to change the whole package, I don’t think it is a good idea. (Mrs Mary Yan, Control carer)

Many interviewees were critical of the quality of cleaning while also realising they were dependent on retaining the service because of their inability to complete house cleaning or various everyday activities themselves.

The Home Care girls are not, well, I think what they have been taught to do, make things look as nice as possible but as quickly as possible, and I understand

⁴⁹ PSG meeting 5 August 1999.

they have a lot of people to go to but they don't do under beds and things like that and I do have a bit of allergy trouble and I thought if I could pay to have it done privately I could say what I would like to have done which would also be vacuum cleaning. (Mrs Yolanda Turner, Control participant)

It is a service [house cleaning] which I appreciate and I don't try to make it any more difficult for them to get people to come to you that are necessary you know. Let me put it this way. No one cleans the house like you do. You see it is a basic service and they can't do a lot of things that need doing. (Mrs Urma Oakes, Intervention participant)

While participants may be critical of services, they were also appreciative of access to them.

People are hard-pressed to provide services at a weekend, but Home Care do it rain, hail or shine, weekends, public holidays, excellent services [but] also need more money... They're not trained nurses, but they're very skilled at what they do. They're trained in nursing and usually very practical people who hop in and do something. They don't have to be asked to rub his heels carefully or anything like that, they just do it automatically... Home Care has some faults but on the whole it is reliable and the people are outstanding... People who do the actual work... I'd say that Home Care is not *as* good as it could be, but it is jolly nearly, it's a very good service, I give it a very big pat on the back...(Mrs Margaret Newman, Intervention carer)

My Home Care girl calls, comes weekly and does my shopping and cleaning – Hoovering, cleaning bathroom and kitchen. I am very grateful for this help.

Purchasing private services provided some services users with autonomy. Participants who were able to afford private house cleaning felt they had some control over the quality of the work done. If they had financial independence they could pay for extra support to remain at home. Hornsby and Ku-ring-gai are northern suburbs of Sydney and are relatively economically well-off. Some of the participants were able to afford private hospital and respite care.

Some participants were able to pay for taxis to overcome the difficulties of isolation or attempting to use inaccessible public transport. Those who gained a disability discount when using taxis found this a great benefit.

Friendliness and Companionship of Service Provision

The actual service provision was only one aspect to the care that participants and carers received. Because of the isolation associated with immobility and poor health, service workers were often a regular source of companionship. The friendliness of the staff and other visiting health and community care professionals became a very important aspect of quality service.

Christian Community Aid people visit me from time to time to see if there is anything I need – I go on their fortnightly bus outings. They are caring people. I'm sure they would help me any time there was need.

They were friends instead of just people that came. Especially the ladies that showered him... They treated us as friends. One even came to see us. She was

going to Ireland and she came to see us before she went. (Mrs Nola Jobson, Control carer)

See, unfortunately at my age you lose all your friends... I used to do perms for pensioners, set their hair every week, and all this thing, and go to each other's place and have dinner and all that. It's all *gone*, because they all *die*. Only one friend of mine, she is in a nursing home and she's a few years younger than me, but she is already been there a few years. You can't make new friends. I love young people, but I always understand what would fine young people have with an old woman. [When she completed the first interview she said: 'Thank you very much for speaking to me. I am hungry to speak with people.'] (Mrs Liis Pedanick, Control participant)

Personal care service provision also meant that participants were dependent on nurses or community workers for showering, toileting or simply helping them move around their home. Obviously more sensitive and respectful workers were appreciated.

I am very grateful for the help I receive and for the kindness of the people who perform the duties.

Care excellent. Lots of trauma at present but everyone involved has been compassionate and helpful.

Most nurses pleasant, but a little more compliance with client's and carer's requests and a little more patience with client would be appreciate. Must emphasise such attitudes are the exception.

I really appreciate the help I receive from Home Care. I have always found this a supportive, caring organisation.

An amicable relationship with service providers was obviously very important for how participants and carers felt about the care they received. In one of the interviews, a carer found communication had broken down with a service provider and her Linked Care CC was able to step in and negotiate what she needed. Mrs Gleeson had been trying, unsuccessfully, to get a wheelchair.

It was quite difficult at the time, but [CC name] was an advocate for me, talking to a particularly difficult lady I couldn't deal with any more at PADP and she sorted all that out in the end. (Mrs Mary Gleeson, Intervention carer)

Independence and Privacy

Many participants viewed the use of formal services as an eventuality they hoped to avoid. The ability to remain independent was determined by the level of sympathetic support from family, being able to buy services, and being relatively healthy. Many preferred to rely on sympathetic family members, where personal needs and concerns were more likely to be taken into account.

Arranging and managing their own care needs was central to this, as Mrs Ingham pointed out.

We manage... I mean they would give me more... They'd come in and do more for you... But we don't need more... They've always said if you need extra help

always say. But I'm rather an independent person, I'm sure you can gather that. And I like to be left alone. Because we can manage. (Mrs Teresa Ifield, intervention, participant)

I used to have [name community worker] come and do two hours [cleaning] in the house. But then I decided I could do the floor cleaning quite as well as Ellen, because they are not allowed to do windows or move things... And I'll do it as long as I possibly CAN! I don't want to give in. (Mrs Tiller, intervention, participant)

Gaps in Service

There appeared to be gaps in the system that were not necessarily addressed by Linked Care. There were recurring concerns, both among Intervention and Control participants.

? Transport

Many participants were critical of available transport. While some reported having easy access to community bus services, many found it difficult to plan doctors' appointments, let alone have social outings. For example Mrs Newman explains the ordeal of planning an outing, even with access to a car with a hoist.

? Social Isolation

A number of questionnaire respondents discussed social isolation and the need for greater contacts with others, and the importance of socialising in their life.

I am 93. I get about six outings a month on our community bus and by private car volunteers. My health far from perfect, but able to enjoy a social life still. Good meals on wheels seven days a week... In touch with many friendly people.

We've always been active. We'd go away for holidays. I miss that now. We rely on a private bus company for tours but can't afford it all the time and can't please yourself. The area we live in is isolated. Hornsby is the only place for shops but buses don't come regularly.

I would like some social activity. I was a bowler until my bad accident. Sometimes I get so bored as I was very active... I do handcraft, knotting, crochet, sewing, garden when well enough... To go out I would need a helper.

? Lack of Flexible Respite Care

Questionnaire respondents and interviewees were critical of types of respite care available. Many participants found that while short-term respite would be useful for holidays or during hospitalisation of carers, the options were limited. Mrs Newman was very critical of the quality of care available for her husband.

The staff looked after him well, in so far as they would turn on the television for him and that sort of thing and change the channel. That sort of thing and have a little chat to him every now and then. But there was no facility or likelihood of anyone taking him down stairs and pushing him out into the fresh air for those two whole weeks... The second time he went there for a week and came back with an enormous fungal infection all around the groin area which the sister in charge

hadn't even mentioned to me when I picked him up. (Mrs Margaret Newman, Intervention carer)

However Mrs Newman did not feel she could openly criticise what was available because she feared that they may not accept him if she needed to send him there at a later time. Respite care did appear to be an area Linked Care was able to address through access to the financially flexible fund pool.

? Lack of supports for young people

Mrs Gleeson spoke about the difficulties of gaining appropriate care for her daughter. Although there were few young participants in the trial, a number commented on problems with the services available.

Community Options help with special outings... I would be happier if there were more young people (under 35) available to help me enjoy special activities.

Services for children with [disability] are pathetic if you do not have private funding. To date all quality services received have been paid for by parents.

6.3 Summary of Participant Experiences of Service Provision

Table 6.5 summarises the participant experiences of service provision as discussed in this chapter.

Table 6.5: Participant Experiences of Service Provision

Service	Participant Experience
GP consultations	Participants from both groups reported GPs as important to their health needs. GPs were more relevant for health issues, rather than arranging everyday care needs.
Community service providers	Participants reported high satisfaction with services, however there were some concerns, including lack of privacy, lack of control over time-tables and quality of work. Some participants were able to pay for services to maintain control. Many participants were grateful for the comfort workers provided.
Inpatient care	There was a mixture of reports. While many were grateful for the kind staff and treatment by doctors while in hospital, others complained of nurse shortages, lack of wide ranging knowledge within specialist wards, lack of observation, and in one case even negligence.
Nursing home respite care	It was reported there are a lack of flexible options for short-term respite (e.g. for a week or more). There was also criticism of the quality of nursing homes for either long-term or respite accommodation. Other participants were also critical of the costs involved in nursing homes.
Non-inpatient care	Many praised the services of the Ryde and Hornsby Aged and Rehabilitation Unit. After hospitalisation many older people or people with disabilities were referred to these out-patient hospital units where they could easily access advice and support, as well as therapy sessions and involvement in education programs.

Part C Conclusions

7. Conclusions on Client Experience

7.1 Introduction

At the completion of the live phase of the trial, Linked Care had been fully operational for approximately 21 months. Progress over the time from the initial expression of interest, through the establishment of the trial, recruitment of participants and the live operation of the trial to the conclusion was impressive. Linked Care was able to demonstrate a practical operational model, based on the principles of coordinated care, which operated within budget. This model served substantial numbers of people with complex care needs from the trial's catchment area in the Hornsby Ku-ring-gai municipalities over a prolonged period of time.

The three key elements of the coordinated care model – a fund pool, case management arrangements through CCs, and the use of individual care plans for all participants - were each well established. Within the constraints of the trial design, operational issues that arose during implementation were also effectively addressed by Linked Care management and other health professionals and service providers who participated as partners in Linked Care.

In this conclusion we review the implications of a number of the main findings of the evaluation of the participant experience. We reflect on the findings of the evaluation and seek to identify a number of issues of significance for the future viability of this coordinated care model of service funding and delivery.

The *Local Evaluation Report* contains a more detailed conclusion including reference to the national and local evaluation hypotheses.

7.2 Summary of Client Experience

Participants reported high satisfaction and a sense of security from having a CC. This was also so for Control participants who had case managers. Service providers reported that Linked Care benefited their participants. No measured improvement in health and well-being, either absolute or relative to the Control group, was observed.

Complexity and severity of participant need were not measured in the trial. The evidence from CCs indicated that participants with the highest level of need generally had robust care arrangements in place before recruitment to the trial. The ability of care coordination to improve their outcomes was limited. Similarly, ongoing care coordination does not appear to have benefited those with lower level support needs. Consequently, there are questions about the cost-effectiveness of ongoing care coordination for this group.

Participants with mid-range needs for support appear to have benefited most from care coordination in terms of opportunities for changes to care arrangements. The care needs of this group were often unstable and knowing which services to access and how to go about it

was often confusing and stressful for participants without the assistance of CCs. Once their condition and pattern of service use had stabilised, continuation of the care coordination function for this group appeared to deliver fewer benefits.

Intervention participants were more likely to enter a nursing home, but there was no evidence to link inappropriate actions of CCs with decisions by participants to enter residential care.

Analysis of the extent to which the outcomes of the trial were related to other participant characteristics, such as medical condition, age or type of residence, was not possible for this report. Further analysis of the available data is warranted.

Consumer representatives were active in the management of Linked Care. They provided a useful consumer view but reported they were unable to represent the participants.

CCs were required to actively involve participants in the care planning and care coordination process. They did not always fulfil that principle. For example they often did not leave a copy of the care plan with the participant. 20 per cent of participants reported they were still unaware they had a CC at the end of the trial.

There was no evidence that participant privacy was invaded through the Linked Care processes. However, care plans did not appear to be distributed as widely as anticipated in the care coordination process.

Access to care services by Linked Care participants was enhanced by the care coordination and fund pool mechanisms. There were no reported cases in which access by other clients was detrimentally affected by the operation of Linked Care.

Participants appeared to access similar medical care irrespective of their CC type. Participants in the Intervention group were able to access higher levels of community-based care than participants in the Control group.

Participants reported high satisfaction with the quality of care in both the Intervention and Control groups. These satisfaction scores tended to converge during the course of the trial. Participants did not report duplication of tasks as a problem.

Care plans prepared by full-time CCs were more likely to acknowledge the care provided by informal carers. CCs provided considerable assistance to family carers. This was reported to be highly valued by the recipients. Caregivers indicated improved satisfaction with Linked Care by the end of the trial, rather than being fearful of forfeiting their significant role in the life of their family member.

The contrast between the easy access for Linked Care participants to some community services, most notably the Home Care Service of New South Wales, while other applicants were placed on a waiting list, was widely criticised and regarded by many service providers as inequitable. Structural barriers within agencies might have disadvantaged non-participant clients. First, they might have been unable to accurately claim full reimbursement from the fund pool for services accessed by participants. Second, ability to employ additional and replacement staff appeared to be constrained. Evidence on this was inconclusive.

7.3 Lessons from Linked Care

In this section we concentrate on the implications of the findings that are of relevance to readers seeking to improve client empowerment, involvement in organising their care and choice in services appropriate to their needs.

? Client empowerment was largely determined by the interpretation of the care coordinator

It was intended that the care coordination process would focus on addressing participant needs, with the active participation of the client to enhance their involvement in choosing their care. However, there seemed to be several constraints on this process. First, the CCs' concept of client empowerment varied, and second and perhaps as a result of the first, participants' knowledge of their potential role in the process was also patchy. CCs and their employing agency decided how tensions were to be resolved. Linked Care protocols to involve participants and handle disputes did not appear to be widely used although few complaints were received. An effective CC appeared important for participants to understand how Linked Care may benefit them and facilitate access to new care arrangements. Participants did not always meet with their CC in the care planning process, nor were they always provided with a care plan. In these cases participants were at a distance from the coordination process.

? Additional coordination processes, but little or no impact on structure or practice

The establishment of the Coordinated Care Trials placed considerable emphasis on mechanisms for the coordination of existing services and health professionals. At the local level, attention was also given to the development of substitution strategies. Importantly, however, Linked Care was limited to working within constraints of the existing system of services. No structural changes in service operations were achieved or, in retrospect, envisaged. The outcome was that additional transaction levels were introduced into the local service system. These carried additional direct and indirect administrative and organisational costs while having at best, only an indirect impact on care provided to participants at the actual point of service delivery.

Following the lead provided by successful overseas trials of case management (Davies, 1992, 1994; Fine and Thomson, 1995) future trials may wish to change this emphasis. This could, for example, involve improved targeting of case management or limiting its duration. Other strategies could concentrate on developing more comprehensive development processes for service delivery, involving, for example, the establishment of multi-disciplinary home care teams or the introduction of skilled, multi-task care workers (as compared with the existing specialised approach). Greater use could also be made of comprehensive staff education strategies.

? Ongoing care coordination and care planning appear expensive and only necessary for some participants

While there has been considerable enthusiasm for the processes of case management (and its variants such as care coordination) and care planning amongst service providers and policy makers, the evidence from Linked Care suggests that these interventions were not cost-effective for at least a proportion of the participants. Future trials could constrain or target these interventions, limiting their application to short-term case management for those

whose needs are associated with a particular crisis (such as admission or discharge from hospital following unexpected illness) and targeting ongoing case management more closely to those most likely to benefit over time. One possible target group might be clients with extensive disabilities and chronic illnesses, unable to access services without mediation and needing ongoing adjustments and additional support not provided by existing agencies.

? The original COAG 'diagnosis' of problems with the health and social care system was inaccurate and exaggerated

The focus of this evaluation has largely been on the performance of Linked Care and on the outcomes of the coordinated care model for participants. However, the robust performance of the pre-existing system of services in the Control area, should command equal attention. The absence of significant differences in the outcomes of participants in the Control group in the Ryde Hunters Hill area demonstrates that the original 'diagnosis' of the problems with the health and social care system advanced by the COAG (COAG, 1995) was inaccurate and exaggerated. By portraying the system as expensive, crisis ridden, fragmented, inaccessible for consumers and unresponsive to their needs, many of the strengths of the existing system were overlooked. Further examination of the strengths of the existing system, using, for example, more detailed analysis of Control group area data, is warranted.

7.4 Conclusion

The results of Linked Care provide valuable insights into the operation of the health and community services system available to most residents of New South Wales. In the Intervention area, innovative service provision arrangements were put in place within a short period and were found to function with reasonable effectiveness to the general satisfaction of their direct users.

Doubts remain, however, about a number of aspects of the program. These include doubts as to effectiveness of the model for facilitating client involvement, the full cost and affordability of the innovative approach and doubts as to the true value of some of the planning mechanisms, especially care plans and the extensive use of care coordination for all participants. The failure to markedly improve outcomes for participants, in comparison with those of members of the Control group, also raises important questions about the identification of problems in the existing system of care.

Encouragingly, the results suggest that the system operating in the Control area functioned reasonably effectively, and that major health gains or improvements in the outcomes for consumers would not be easily achieved simply by improving care coordination arrangements. This is not to suggest, however, that improvements are not possible. Indeed much could be learnt from Linked Care that would be of benefit to the existing system. By reviewing the substitution strategies proposed in the trial, for example, it may be possible to identify cost-effective opportunities for improvement that can readily be adopted by existing services.

To those who promoted the trial, the results should be reassuring. They provide a strong testimony to the value of establishing large scale demonstration projects in the field of health care and have ensured that a wealth of information and experience will be available to inform future developments. The results presented in this report provide the first opportunity to

examine these issues comprehensively. Further analysis of the data collected should sharpen the lessons learned from Linked Care and yield further valuable insights into the operation of health and care services in the Hornsby Ku-ring-gai area, and across New South Wales and Australia.

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Appendix 1: National and Local Hypotheses

National Hypotheses

1. That *coordination* of care for people with *multiple service needs*, where care is accessed through *individual care plans* and *funds are pooled* from existing programs, will result in improved individual client *health and wellbeing* within *existing resources*.

That the success of coordinated care, as testing in the primary hypothesis, will be affected by:

2. the *extent of substitution* between services within the trial pool;
3. the *range of services* included in the trial and the *size of the pool*;
4. the *characteristics of the clients* to whom services are provided;
5. the *quality* of the clinical and service delivery protocols;
6. the *characteristics of the care coordination* function;
7. the particular *types of administrative arrangements*;
8. the extent to which health and community service *clients are partners* in the planning of the coordinated care trial the development of care plans and empowerment through the coordination process; and
9. that the primary results can be achieved *without detriment to other key areas* of government policy particularly in regard to equity of access and privacy including any impact on clients outside the trial.

Other areas to be examined are:

10. the extent of *collaboration in care* between those involved (including clients and informal caregivers), as expressed in such matters as communication, sharing common guidelines, care pathways and protocols; and
11. the *quality of care* provided, in terms of such measures as timeliness and consistency of the care provided, the financial and geographic accessibility of care, the cultural appropriateness of care, the reduction of duplication of tasks, and the evidence of efficacy as demonstrated through adherence to evidence based guidelines and other relevant measures.

Local Hypotheses

12. To improve the *health outcomes* and *social well-being* of people with *multiple service needs* while maximising their *ability to exercise choice* and *live independently* in the community by *coordinating care* from community and health services, within *existing resources and pooled funds*.

A further six primary objectives are concerned largely with getting the trial and its evaluation established and with implementing the mechanisms for pooled funding and service planning. These objectives, elaborated by the local evaluation working party, are:

13. to develop and implement a pilot of coordinated care which ... will *identify the characteristics of coordinated care* which contribute to the improvement in clients health and social wellbeing ...;
14. to establish a system of care planning for clients receiving care from *a range of providers* including funded services and *informal caregivers*;
15. to assess whether coordinated care can be provided ... in a way which demonstrates *cost-effectiveness*;
16. to operate the trial in a manner which has *no detrimental effect on access to care or privacy*;
17. to evaluate this pilot in terms of *client satisfaction*, outcomes relating to *health status* and *social wellbeing*, *provider satisfaction*, the *management model* (structure and process), *cost-effectiveness* and *carer satisfaction*; and
18. to create a 'pool' of funds from which services will be funded with *greater flexibility* and with a *closer match to clients' needs*.

Five other secondary objectives are concerned with changing existing patterns of service usage to realise the project's aims.

19. to provide a *service mix* that better meets the *needs of frail aged* people, people with *severe disabilities* ... and people with *complex chronic medical* problems in the Hornsby Ku-ring-gai areas.
20. to *substitute high cost, high dependency* support services with lower cost lower dependency services where appropriate to maintain clients in the most *appropriate environment*.
21. to *substitute inappropriate service usage* by more appropriate service usage by the introduction of *new funding* arrangements.
22. to test different approaches to care management...; and
23. to introduce integrated, multidisciplinary assessment services for this group.

Four major aspects of the intervention were also specified in the funding agreement and consultancy brief. These are:

24. the introduction of *new assessment* arrangements;
25. care management arrangements that include a *care coordinator* and a *care planning team* for the set of related needs;
26. the establishment of a *pool of funds* for the trial groups from which access to included services is funded *in accordance with the care plan*; and

27. *funding participating agencies according to an agreed schedule of fees.*

Appendix 2: Evaluation Conceptual Framework

As the number and range of hypotheses suggest, the evaluation of such a large-scale trial is a major undertaking in its own right. To help manage the complexity of the research task, a sound conceptual framework is essential. Building on the basic framework set out by the national evaluation and the NSAHS specifications for the local evaluation, the research design and methodologies were conceived as largely following the broader field of research in social policy. In this approach, data of different kinds, often collected using a number of different methods, are drawn together in order to inform decision making about policy issues. The approach is demanding but also eclectic and pragmatic, using different approaches when and as necessary, to collect, assemble and analyse different types of evidence in the most rigorous manner possible.

Research Questions

To assess the relative success of the reforms introduced in the Hornsby Ku ring gai district in meeting the broad aims and objectives of the trial, the evaluation needed to be able to determine whether the intervention led to improved outcomes for clients by increasing the effectiveness and efficiency of service provision, and not by relying on increased expenditure. As a first step towards the development of a methodological framework, the evaluation was conceptualised as an attempt to answer two related sets of questions.

- i. What specific innovations were planned in the trial? How were these actually implemented, what factors assisted or impeded the process, and what were the financial and organisational costs involved?*

Experience in Australia and overseas shows that plans for the introduction of major reforms are usually significantly modified and developed in the process of being implemented. The first set of research questions therefore focuses attention on issues of implementation and cost, drawing attention to issues concerned with the organisation of services and the processes of change and development that occur in attempting to develop a more integrated and effective system of provisions within the given economic and systemic constraints. It is essentially concerned with the organisational processes by which the Trial developed, and operated over time.

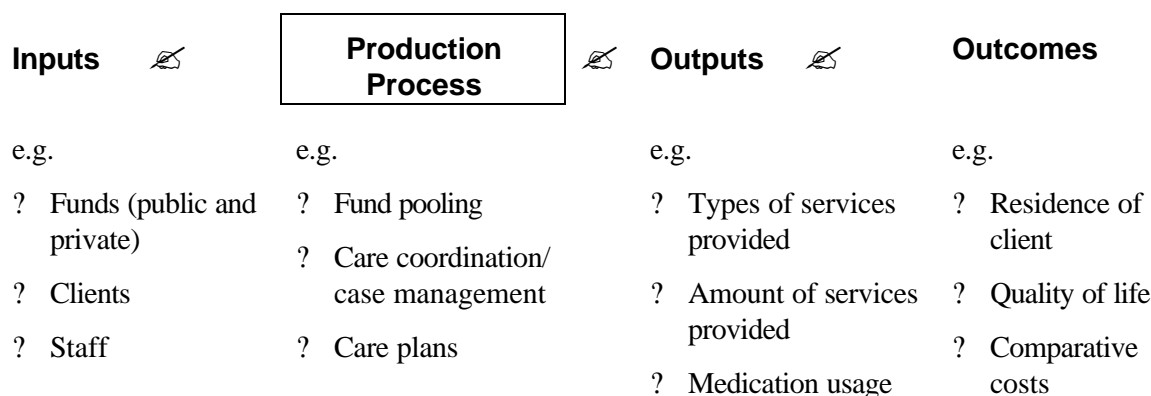
- ii. Have the innovations led to improvements in service provision which influence the outcomes for clients and their caregivers?*

This second set of questions concerned the outputs of services and the outcomes of service provision for actual and potential clients in the target group. Its focus is on the measurement of results for the participants.

To address the questions, three research paradigms were particularly important for this study. The first, the Production of Welfare approach (Davies et al. 1986, 1990), is essentially a conceptual scheme linking different components of the policy process. Derived originally from the economic analysis of production processes, the approach links together service inputs, outputs and outcomes. Drawing these together is the production process itself. For this study, the scheme provides a relatively simple and practical way of conceptualising the intervention, and of ordering the vast amounts of evaluative data material that the trial will generate.

Applying this schema to the Linked Care trial, the relationship between the different components of the project can be conceptualised as follows (Fig. 2.1):

Figure A2.1: The Production of Welfare Process and the Linked Care Trial



The second approach utilised in the development of the research design was based on the ethnographic tradition of social research, applied to the study of contemporary complex societies. Sometimes termed ‘Administrative Anthropology’, the approach uses methods such as participant observation, in-depth interviews and the analysis of documentary evidence, to obtain and analyse data on the evolution of administrative and organisational processes involved in the trial.

The third element of the research design developed for the evaluation is based on epidemiology, utilising a comparative approach in which the results for participants in the intervention group are compared with those for a matched control group of research subjects.

It is widely recognised that there are a clear advantages to be derived from using a randomised control group in medical trials. Randomisation of the trial subjects (participants) chosen from the same pool of subjects to the intervention and control groups allows for differences between individual subjects that might affect the outcomes of the study to be controlled for, providing a sufficiently large sample size is selected. Differences between the intervention and control groups can then be attributed only to the intervention and not to pre-existing differences between the two groups. However, there are often practical reasons and/or ethical for selecting a control group on another basis. Practical difficulties arose when seeking to use a matched control group from outside the trial area in the case of the Linked Care trial. Having considered the issue, the Evaluation Team endorsed the approach proposed by the trial management to select a matched control group from a comparable, neighbouring area, the Ryde Hunters Hill municipalities.

Appendix 3: Evaluation Data Sets

Data set	No. times administered	Data type	
		quantitative	qualitative
Participants			
1. Participant Profile (demographics)	2	x	
2. SF-36 Health and Wellbeing Questionnaire	3	x	
3. Participant Telephone Interview	3		x
4. Participant Questionnaire (service usage, support and wellbeing)	2	x	x
5. Service usage and care plan	continuous	x	
6. Medical care plan (diagnosis and measure of control)	2	x	
7. Participant exit data	1	x	
8. Allocation and reassignment to CCs	many	x	
Service Providers			
1. Service Providers Interview	1		x
2. Service Staff and Volunteer Questionnaire	2	x	
3. Service Provision Data Questionnaire	2	x	
4. Service Manager Questionnaire	2	x	x
5. General Practitioner Questionnaire	2	x	
6. General Practice Focus Group	1		x
Care Coordinators			
1. Care coordinator Interviews	1		x
2. Care coordinator Questionnaire	2	x	x
3. Care coordinator demographics and exits	1	x	
Organisation of Linked Care			
1. Consumer Representatives Focus Group	1		x
2. Consumer Representatives Survey	1		
3. Trial Staff Focus Group	2		x
4. Trial minutes, reports and policies			x

A separate volume of evaluation instruments accompanies this report.

Appendix 4: Participant Profile and Outcomes Tables

These tables supplement the participant profile and outcomes tables in Sections 3.1 and 5.1. Participant experience tables are listed in Appendix 5.

Table A4.1: Baseline Comparison: Demographic and Other Characteristics Associated With Intervention Group Membership

	Coefficient	SE	Sig	Effect on Odds
Demographic characteristics				
Male	.0717	.1783		1.0743
Age	-.0110	.0070		.9890
Single	-.0930	.2077		.9112
Born overseas	.4475	.1975	**	1.5644
English not spoken at home	-2.0798	.3832	****	.1250
Household characteristics				
Lives in independent living unit, hostel	1.2884	.3062	****	3.6268
Shares home with another person	.0986	.2102		1.1037
Has a carer	.8639	.2078	****	2.3723
Needs but does not have a carer	-.0424	.2006		.9585
Pays for private domestic help	-.0443	.1563		.9567
Renter	-.6433	.1986	***	.5255
Socio-economic characteristics				
Not retired	-.0674	.3239		.9348
Current/past occupation at trade level	-.5674	.2327	**	.5670
Current/past occupation at professional level	-.6296	.1912	***	.5328
Primary level education	.0554	.2014		1.0569
Tertiary level education	1.6389	.2223	****	5.1497
Financial characteristics				
Has pensioner concession or health care card	-5.987	.2931	**	.5495
Has DVA card	.0991	.1941		1.1042
No private health insurance	-.3440	.1559	**	.7089
Intercept	1.8879			

N = 1 099; log-likelihood 1214

p<.1 ** p<.05 *** p<.01 **** p<.001

Reference category: female; married; Australian-born; English spoken at home; lives at home (unit, flat etc.); does not share home; does not need or have a carer; does not have any paid domestic help; owns home; is retired; occupation is home duties, secondary education level; does not have a pensioner concession card or health care card; does not have a DVA card; has some private health insurance.

Table A4.2: Exits Per Month as a Proportion of Total Sample by Participant Group

	Intervention^(a)			Control		
	(No.)	(Cum No)	(Cum %)	(No.)	(Cum No)	(Cum %)
Month Exited						
1997						
October	1	1	.1	-	-	-
November	2	3	.4	-	-	-
December	4	7	1.0	1	1	.2
1998						
January	5	12	1.7	4	5	1.2
February	5	17	2.4	6	11	2.6
March	15	32	4.4	5	16	3.8
April	22	54	7.5	9	25	5.9
May	17	71	9.8	12	37	8.7
June	24	95	13.2	6	43	10.2
July	30	125	17.3	9	52	12.3
August	24	149	20.6	11	63	14.9
September	14	163	22.6	8	71	16.8
October	5	168	23.3	7	78	18.4
November	27	195	27.0	9	87	20.6
December	8	203	28.1	5	92	21.7
1999						
January	15	218	30.2	6	98	23.2
February	10	228	31.6	5	103	24.3
March	9	237	32.8	8	111	26.2
April	14	251	34.8	8	119	28.1
May	7	258	35.7	8	127	30.0
June	4	262	36.3	8	135	31.9
July	25	287	39.8	66	201	47.5
August	8	295	40.9	2	203	48.0
September	8	303	42.0	1	204	48.2
October	7	310	42.9	3	207	48.9
November	8	318	44.0	3	210	49.6
December	3	321	44.5	3	213	50.4
Total Exits		321	44.5		213	50.4
Participants who remained in trial		401	55.5		210	49.6
Total sample		722	100.0		423	100.0

Table A4.3a: Baseline Characteristics of Intervention Participants by Type of Exit

Participant characteristics	Intervention participants ^(a)				
	Participant decision	Entered residential care	Related death	Unrelated death	Administrative
	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)
Age					
<50	19.4	-	2.3	-	12.8
50-59	5.6	1.5	2.3	8.3	-
60-69	11.1	3.8	8.0	4.2	8.5
70-79	19.4	26.5	25.3	25.0	29.8
80-89	38.9	51.5	49.4	41.7	38.3
90 and over	5.6	16.7	12.6	20.8	10.6
	100.0	100.0	100.0	100.0	100.0
	(36)	(132)	(87)	(24)	(47)
Gender					
Male	33.3	28.8	46.0	58.3	31.9
Female	66.7	71.2	54.0	41.7	68.1
	100.0	100.0	100.0	100.0	100.0
	(36)	(132)	(87)	(24)	(47)
Marital status^(b)					
Single	68.8	59.7	56.5	47.8	51.3
Couple	31.3	40.3	43.5	52.2	48.7
	100.0	100.0	100.0	100.0	100.0
	(32)	(129)	(85.0)	(23)	(39)
Country of birth					
Australia	94.3	75.8	73.6	82.6	79.5
Other	5.7	24.2	26.4	17.4	20.5
	100.0	100.0	100.0	100.0	100.0
	(35)	(132)	(87)	(23)	(44)
Language spoken at home					
English	100.0	98.5	96.6	100.0	100.0
Other	-	1.5	3.4	-	-
	100.0	100.0	100.0	100.0	100.0
	(33)	(132)	(87)	(23)	(42)
Client's accommodation					
House, unit, apartment, flat	97.0	86.4	92.0	100.0	97.6
Independent living unit, hostel	3.0	13.6	8.0	-	2.4
	100.0	100.0	100.0	100.0	100.0
	(33)	(132)	(87)	(23)	(40)
Tenancy^(c)					
Owner	83.9	87.0	85.5	81.8	82.5
Renter	16.1	13.0	14.5	18.2	17.5
	100.0	100.0	100.0	100.0	100.0
	(31)	(123)	(83)	(22)	(40)
Shares home					
Does not share	44.4	49.2	29.9	20.8	51.1
Shares with spouse	30.6	37.1	43.7	50.0	36.2
Shares with other	25.0	13.6	26.4	29.2	12.8
	100.0	100.0	100.0	100.0	100.0
	(36)	(132)	(87)	(24)	(47)
Carer status					
Carer not needed	6.1	8.3	9.3	12.5	7.1
Has a carer	57.6	72.0	77.9	75.0	71.4
Needs a carer	36.4	19.7	12.8	12.5	21.4
	100.0	100.0	100.0	100.0	100.0

(33)

(132)

(86)

(24)

(42)

Table A4.3a (continued): Selected Baseline Characteristics of Intervention Participants by Type of Exit

Participant characteristics	Intervention participants ^(a)				
	Participant decision	Entered residential care	Related death	Unrelated death	Administrative
	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)
Private assistance					
Has help	30.6	28.0	39.1	16.7	25.5
No help	69.4	72.0	60.9	83.3	74.5
	100.0	100.0	100.0	100.0	100.0
	(36)	(132)	(87)	(24)	(47)
Employment status^(d)					
Retired	81.3	96.2	93.1	95.8	88.1
Not retired	18.8	3.8	6.9	4.2	11.9
	100.0	100.0	100.0	100.0	100.0
	(32)	(132)	(87)	(24)	(41)
Health insurance					
Some private insurance	61.1	57.6	57.5	45.8	46.7
No insurance	38.9	42.4	42.5	54.2	5.3
	100.0	100.0	100.0	100.0	100.0
	(36)	(132)	(87)	(24)	(45)
DVA status					
DVA card	16.7	11.4	19.5	16.7	10.6
No DVA card	83.3	88.6	80.5	83.3	89.4
	100.0	100.0	100.0	100.0	100.0
	(36)	(132)	(87)	(24)	(47)
Cards status					
Has card	80.0	83.3	79.3	79.2	89.4
No card	20.0	16.7	20.7	20.8	10.6
	100.0	100.0	100.0	100.0	100.0
	(35)	(132)	(87)	(24)	(47)
Education level					
Primary	21.2	10.6	12.6	13.0	16.7
Secondary	45.5	62.9	54.0	47.8	57.1
Tertiary	33.3	26.5	33.3	39.1	26.2
	100.0	100.0	100.0	100.0	100.0
	(33)	(132)	(89)	(23)	(42)
Occupation					
Professional	30.3	31.1	37.9	34.8	22.0
Trade	33.3	40.2	40.2	34.8	41.5
Home duties	36.4	28.8	21.8	30.4	36.6
	100.0	100.0	100.0	100.0	100.0
	(33)	(132)	(87)	(23)	(41)

Notes: Exit categories used in this section were derived from the national data set 'Reason for exit' variable and aggregated: participant decision (values 0 to 2, declined to reconsent, dissatisfaction or other stated reasons); entered residential care (value 3, hostel or nursing home); related death (value 6, related to conditions at basis of trial eligibility); unrelated death (values 5 and 7, other reason or cause unknown); administrative (values 4, 8 and 9, change of residence out of trial area, participant lost to trial follow-up, other reason).

Percentages may not add to 100 due to rounding.

(a) Includes 3 participants who exited on 31 December 1999 and 2 participants who exited in January 2000.

(b) 'Single' includes widowed, divorced, separated and never married. 'Couple' includes de facto.

(c) 'Renter' includes 'Other'.

(d) 'Not retired' includes children, students, employed, unemployed, home duties and other.

Table A4.3b: Baseline Characteristics of Control Group: Participants by Type of Exit

Participant characteristics	Control participants				
	Participant decision	Entered residential care	Related death	Unrelated death	Administrative
	% ^(a) (n=)	% ^(a) (n=)	% ^(a) (n=)	% ^(a) (n=)	% ^(a) (n=)
Age					
<50	3.8	-	-	12.5	3.4
50-59	2.6	2.3	-	12.5	3.4
60-69	7.7	6.8	15.1	-	10.3
70-79	30.8	11.4	30.2	25.0	17.2
80-89	46.2	50.0	43.4	37.5	55.2
90 and over	9.0	29.5	11.3	12.5	10.3
	100.0	100.0	100.0	100.0	100.0
	(78)	(44)	(53)	(8)	(29)
Gender					
Male	21.8	25.0	47.2	12.5	30.0
Female	78.2	75.0	52.8	87.5	70.0
	100.0	100.0	100.0	100.0	100.0
	(78)	(44)	(53)	(8)	(30)
Marital status^(a)					
Single	71.8	65.9	58.5	62.5	66.7
Couple	28.2	34.1	41.5	37.5	33.3
	100.0	100.0	100.0	100.0	100.0
	(78)	(44)	(53)	(8)	(30)
Country of birth					
Australia	75.6	77.3	77.4	75.0	66.7
Other	24.4	22.7	22.6	25.0	33.3
	100.0	100.0	100.0	100.0	100.0
	(78)	(44)	(53)	(8)	(30)
Language spoken at home					
English	96.2	90.9	94.3	100.0	83.3
Other	3.8	9.1	5.7	-	16.7
	100.0	100.0	100.0	100.0	100.0
	(78)	(44)	(53)	(8)	(30)
Client's accommodation					
House, unit, apartment, flat	97.4	97.7	92.5	85.7	93.3
Independent living unit, hostel	2.6	2.3	7.5	14.3	6.7
	100.0	100.0	100.0	100.0	100.0
	(78)	(44)	(53)	(7)	(30)
Tenancy^(b)					
Owner	75.6	72.7	73.1	62.5	62.1
Renter	24.4	27.3	26.9	37.5	37.9
	100.0	100.0	100.0	100.0	100.0
	(78)	(44)	(52)	(8)	(29)
Shares home					
Does not share	64.1	43.2	35.8	12.5	63.3
Shares with spouse	23.1	31.8	41.5	37.5	33.3
Share with other	12.8	25.0	22.6	50.0	3.3
	100.0	100.0	100.0	100.0	100.0
	(78)	(44)	(53)	(8)	(30)
Carer status					
Carer not needed	24.4	18.2	11.3	-	21.4
Has a carer	30.8	61.4	62.3	62.5	28.6
Needs a carer	44.9	20.5	26.4	37.5	50.0

	100.0	100.0	100.0	100.0	100.0
	(78)	(44)	(53)	(8)	(28)

Table A4.3b (continued): Selected Baseline Characteristics of Control Participants by Type of Exit

Participant characteristics	Control Participants				
	Participant decision	Entered residential care	Related death	Unrelated death	Administrative
	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)
Private Assistance					
Has help	28.2	29.5	15.1	25.0	20.0
No help	71.8	70.5	84.9	75.0	80.0
	100.0	100.0	100.0	100.0	100.0
	(78)	(44)	(53)	(8)	(30)
Employment status^(g)					
Retired	88.5	95.5	98.1	62.5	96.6
Not retired	11.5	4.5	1.9	37.5	3.4
	100.0	100.0	100.0	100.0	100.0
	(78)	(44)	(53)	(8)	(29)
Health insurance					
Some private insurance	32.1	29.5	30.2	25.0	26.7
No insurance	67.9	70.5	69.8	75.0	73.3
	100.0	100.0	100.0	100.0	100.0
	(78)	(44)	(53)	(8)	(30)
DVA status					
DVA card	16.7	18.2	30.2	12.5	6.7
No DVA card	83.3	81.8	69.8	87.5	93.3
	100.0	100.0	100.0	100.0	100.0
	(78)	(44)	(53)	(8)	(30)
Cards status					
Has card	93.6	95.5	94.3	100.0	96.7
No card	6.4	4.5	5.7	-	3.3
	100.0	100.0	100.0	100.0	100.0
	(78)	(44)	(53)	(8)	(30)
Education level					
Primary	20.5	29.5	9.4	50.0	16.7
Secondary	71.8	63.6	83.0	37.5	66.7
Tertiary	7.7	6.8	7.5	12.5	16.7
	100.0	100.0	100.0	100.0	100.0
	(78)	(44)	(53)	(8)	(30)
Occupation					
Professional	20.5	22.7	30.2	-	10.0
Trade	61.5	59.1	52.8	50.0	73.3
Home duties	17.9	18.2	17.0	50.0	16.7
	100.0	100.0	100.0	100.0	100.0
	(78)	(44)	(53)	(8)	(30)

Notes: Percentages may not add to 100 due to rounding.

(a) 'Single' includes widowed, divorced, separated and never married. 'Couple' includes de facto.

(b) 'Renter' includes 'Other'.

(c) 'Not retired' includes children, students, employed, unemployed, home duties and other.

Table A4.4a: Cox Proportional Hazards Regression: All Exiting Participants

	Model 1		Model 2		Model 3		Model 4	
	Risk Ratio	Sig	Risk Ratio	Sig	Risk Ratio	Sig	Risk Ratio	Sig
Intervention Participant	.9354		.7442	***				
Demographic characteristics								
Male			1.3578	***	1.4919	***	1.2400	
Age			1.0132	***	1.0081		1.0211	**
Single			1.0498	***	1.1859		.8394	
Born overseas			1.0166		.8792		1.4094	*
English not spoken at home			.4800	***	.8239		.3386	***
Household characteristics								
Lives in independent living unit, hostel			.7665		.7703		.7725	
Shares home with another person			.7144	**	.6881	**	.7806	
Has a carer			2.6126	****	2.7942	****	2.2777	****
Needs but does not have a carer			1.4812	**	1.5444	*	1.3834	
Pays for private domestic help			.7003	****	.7495	**	.6055	***
Renter			.9711		.9514		.9699	
Socio-economic characteristics								
Not retired			1.0321		.7029		1.7769	*
Current/past occupation at trade level			.7128	**	.6140	***	.9319	
Current/past occupation at professional level			.7133	***	.5574	****	1.0746	
Primary level education			.9805		.9121		1.1211	
Tertiary level education			.9401		.8717		1.2132	
Financial characteristics								
Has pensioner concession or health care card			.7328	**	.7672		.6637	
Has DVA card			.8428		.7424		.9949	
No private health insurance			1.0441		.9364		1.2054	
-2 log likelihood	7282		6563	****	3549	****	2364	****
N =	1145		1099		683		416	

Reference category: female; married; Australian-born; English spoken at home; lives at home (unit, flat etc.); does not share their home with anyone; does not need or have a carer; does not have any paid domestic help; owns home; is retired; occupation is home duties, secondary education level; does not have a pensioner concession card or health care card; does not have a DVA card; has some private health insurance.

* p<.1 ** p<.05 *** p<.01 **** p<.001

Table A4.4b: Cox Proportional Hazards Regression: Participants Who Decided to Leave Trial

	Model 1		Model 2		Model 3		Model 4	
	Risk Ratio	Sig	Risk Ratio	Sig	Risk Ratio	Sig	Risk Ratio	Sig
Intervention Participant	.2803	****	.2067	****				
Demographic characteristics								
Male			1.0123		1.4704		.8925	
Age			.9898		.9755	*	1.0057	
Single			.8621		1.3202		.6212	
Born overseas			1.1083		.2579	*	1.7059	*
English not spoken at home			.2145	**	4.1E-06		.1539	***
Household characteristics								
Lives in independent living unit, hostel			.2638	*	1.2E-06		.4489	*
Shares home with another person			.5850	*	.8638		.4720	
Has a carer			1.4630		1.5173		1.5352	
Needs but does not have a carer			1.6255	*	3.3740		1.3799	
Pays for private domestic help			.7874		.9998		.6731	
Renter			.8029		.3890		.8135	
Socio-economic characteristics								
Not retired			1.6399		.8426		2.5043	**
Current/past occupation at trade level			.8078		.3780		1.1807	
Current/past occupation at professional level			.8308		.3174	**	1.3239	
Primary level education			1.5944	*	1.7940		1.4515	
Tertiary level education			.9977		1.3049		.9661	
Financial characteristics								
Has pensioner concession or health care card			.5560	*	.4624		.5268	
Has DVA card			1.0488		1.3203		.8847	
No private health insurance			1.0846		.8178		1.2925	
-2 log likelihood	1469	****	1330	****	325	**	853	
N =	1145		1099		683		405	

Reference category: female; married; Australian-born; English spoken at home; lives at home (unit, flat etc.); does not share their home with anyone; does not need or have a carer; does not have any paid domestic help; owns home; is retired; occupation is home duties, secondary education level; does not have a pensioner concession card or health care card; does not have a DVA card; has some private health insurance.

* p<.1 ** p<.05 *** p<.01 **** <.001

Table A4.4c: Cox Proportional Hazards Regression: Participants Who Entered Residential Care

	Model 1		Model 2		Model 3		Model 4	
	Risk Ratio	Sig	Risk Ratio	Sig	Risk Ratio	Sig	Risk Ratio	Sig
Intervention Participant	1.8497	****	.1.4243	*				
Demographic characteristics								
Male			1.0934		1.2239		.9019	
Age			1.0412	****	1.0271	**	1.0763	***
Single			1.0022		1.0325		.6649	
Born overseas			.9792		1.0640		.9029	
English not spoken at home			.5278		.4807		.3804	
Household characteristics								
Lives in independent living unit, hostel			1.1097		1.3089		.5722	
Shares home with another person			.5480	***	.4613	***	.7957	
Has a carer			3.8217	****	4.3283	****	2.4736	*
Needs but does not have a carer			1.3145		1.7331		.6746	
Pays for private domestic help			.6879	**	.6312	**	.8922	
Renter			.9907		.8651		1.5288	
Socio-economic characteristics								
Not retired			.7545		.5484		1.2775	
Current/past occupation at trade level			.8607		.7394		1.3157	
Current/past occupation at professional level			.8494		.6837		1.4380	
Primary level education			.9163		.6345		1.6654	
Tertiary level education			.7987		.7430		.8952	
Financial characteristics								
Has pensioner concession or health care card			.7380		.8307		.6215	
Has DVA card			.6057	**	.5011	**	.8279	
No private health insurance			.9882		.8916		1.2010	
Intercept								
-2 log likelihood	2372	****	2147	****	1456	****	482	**
N =	1145		1099		683		416	

Reference category: female; married; Australian-born; English spoken at home; lives at home (unit, flat etc.); does not share home with anyone; does not need or have a carer; does not have any paid domestic help; owns home; is retired; occupation is home duties, secondary education level; does not have a pensioner concession card or health care card; does not have a DVA card; has some private health insurance.

* p<.1 ** p<.05 *** p<.01 **** p<.001

Table A4.4d: Cox Proportional Hazards Regression: Participants Who Died (Related Death)

	Model 1		Model 2		Model 3		Model 4	
	Risk Ratio	Sig	Risk Ratio	Sig	Risk Ratio	Sig	Risk Ratio	Sig
Intervention Participant	1.0089		.7042	*				
Demographic characteristics								
Male			2.0823	****	1.8087	**	2.3915	**
Age			1.0160	*	1.0263	**	1.0020	
Single			1.7638	**	2.0412	**	1.2037	
Born overseas			.9877		.9022		1.1014	
English not spoken at home	+		.8905		2.4379		.4929	
Household characteristics								
Lives in independent living unit, hostel			1.0718		.8619		1.7174	
Shares home with another person			1.3888		1.4398		1.0747	
Has a carer			2.9918	****	2.2424	*	4.8950	
Needs but does not have a carer			1.3782		1.0756		1.7083	
Pays for private domestic help			.7296		1.0766		.3210	***
Renter			1.0474		.9957		1.2645	
Socio-economic characteristics								
Not retired			.7543		1.0726		.3033	
Current/past occupation at trade level			.9058		.9911		.7874	
Current/past occupation at professional level			.7005		.7679		.5076	
Primary level education			.6458		1.1172		.4139	
Tertiary level education			.8455		.9084		.7457	
Financial characteristics								
Has pensioner concession or health care card			.6388		.6213		.6095	
Has DVA card			1.2984		1.0432		1.9227	
No private health insurance			.8506		.7676		.9086	*
-2 log likelihood	1881		1707	****	960	**	549	****
N =	1145		1099		683		416	

Reference category: female; married; Australian-born; English spoken at home; lives at home (unit, flat etc.); does not share home with anyone; does not need or have a carer; does not have any paid domestic help; owns home; is retired; occupation is home duties, secondary education level; does not have a pensioner concession card or health care card; does not have a DVA card; has some private health insurance.

* p<.1 ** p<.05 *** p<.01 **** p<.001

Table A4.5: SF-36 Response Rates by Participant Group

	Intervention n	Control n	Total n
Sample Size			
Original sample	722	423	1145
Participants aged less than 16	10	-	
Initial Sample	712	423	1135
Number of useable questionnaires:			
Baseline	657	376	1033
Mid Trial	421	266	687
End of Trial	388	201	589
In all administrations	388	199	587
Response rates	%	%	%
Baseline			
% of initial sample	92.3	88.9	90
Mid Trial			
% of preceding administration	64.1	70.7	66.5
% of initial sample	59.1	62.9	60.5
End of Trial			
% of preceding administration	92.2	75.6	85.7
% of initial sample	54.5	47.5	51.9
Trial Total			
% of initial sample	54.5	47.0	51.7

Table A4.6a: Baseline Characteristics of Intervention Group at Administrations of the SF-36

Participant Characteristics	Intervention Participants					
	Baseline		Mid Trial		End of Trial	
	Resp % (n=)	Non-Resp % (n=)	Resp % (n=)	Non-Resp % (n=)	Resp % (n=)	Non-Resp % (n=)
Age						
<50	4.4	16.9	4.0	7.6	5.7	6.3
50-59	4.0	1.5	4.8	2.3	4.9	2.4
60-69	8.1	6.2	9.5	5.6	8.8	6.9
70-79	28.3	24.6	29.0	26.6	30.7	24.9
80-89	45.8	32.3	44.2	45.2	43.0	46.4
90 and over	9.4	18.5	8.6	12.6	7.7	13.2
	100.0	100.0	100.0	100.0	100.0	100.0
	(657)	(65)	(421)	(301)	(388)	(334)
Gender						
Male	33.6	46.2	33.0	37.2	32.7	37.1
Female	66.4	53.8	67.0	62.8	67.3	62.9
	100.0	100.0	100.0	100.0	100.0	100.0
	(657)	(65)	(421)	(301)	(388)	(334)
Marital status^(a)						
Single	56.3	54.4	53.2	60.4	54.4	58.2
Couple	43.7	45.6	46.8	39.6	45.6	41.8
	100.0	100.0	100.0	100.0	100.0	100.0
	(647)	(57)	(421)	(283)	(388)	(316)
Country of birth						
Australia	77.1	83.9	78.9	76.0	77.6	77.8
Other	22.9	16.1	21.1	24.0	22.4	22.2
	100.0	100.0	100.0	100.0	100.0	100.0
	(655)	(62)	(421)	(296)	(388)	(329)
Language spoken at home						
English	97.7	98.3	97.4	98.3	96.9	98.8
Other	2.3	1.7	2.6	1.7	3.1	1.2
	100.0	100.0	100.0	100.0	100.0	100.0
	(654)	(59)	(421)	(292)	(388)	(325)
Client's accommodation						
House, unit, apart, flat	90.2	96.6	89.7	92.1	89.9	91.7
Indep living unit, hostel	9.8	3.4	10.3	7.9	10.1	8.3
	100.0	100.0	100.0	100.0	100.0	100.0
	(652)	(59)	(419)	(292)	(387)	(324)
Tenancy^(b)						
Owner	83.5	77.2	83.4	82.5	82.0	84.4
Renter	16.5	22.8	16.6	17.5	18.0	15.6
	100.0	100.0	100.0	100.0	100.0	100.0
	(638)	(57)	(421)	(274)	(388)	(307)
Shares home						
Client does not share	39.7	33.8	38.5	40.2	37.4	41.3
Shares with spouse	42.0	35.4	44.9	36.5	44.1	38.3
Shares with other	18.3	30.8	16.6	23.3	18.6	20.4
	100.0	100.0	100.0	100.0	100.0	100.0
	(657)	(59)	(421)	(301)	(388)	(334)
Carer status						
Carer not needed	14.7	6.8	18.1	8.2	18.6	8.6
Has a carer	62.7	76.3	56.3	74.7	56.7	72.3

Needs a carer	22.6 (654)	16.9 (59)	25.7 (421)	17.1 (292)	24.7 (388)	19.1 (325)
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Table A4.6a (continued): Baseline Characteristics of Intervention Group at Administration of the SF-36

Participant Characteristics	Intervention Participants					
	Baseline Resp % (n=)	Non-Resp % (n=)	Mid Trial Resp % (n=)	Non-Resp % (n=)	End of Trial Resp % (n=)	Non-Resp % (n=)
Private assistance						
Has help	33.8	23.1	35.4	29.2	35.1	30.2
No help	66.2	76.9	64.6	70.8	64.9	69.8
	100.0 (657)	100.0 (65)	100.0 (421)	100.0 (301)	100.0 (388)	100.0 (334)
Employment status^(c)						
Retired	91.4	79.7	91.4	89.0	89.9	91.1
Not retired	8.6	20.3	8.6	11.0	10.1	8.9
	100.0 (653)	100.0 (59)	100.0 (420)	100.0 (292)	100.0 (387)	100.0 (325)
Health insurance						
Some private insurance	51.3	57.1	49.2	44.5	47.7	56.6
No insurance	48.7	42.9	50.8	55.5	52.3	43.4
	100.0 (657)	100.0 (63)	100.0 (421)	100.0 (299)	100.0 (388)	100.0 (332)
DVA status						
DVA card	18.0	12.3	20.4	13.3	20.4	14.1
No DVA card	82.0	87.7	79.6	86.7	79.6	85.9
	100.0 (657)	100.0 (65)	100.0 (421)	100.0 (301)	100.0 (388)	100.0 (334)
Cards status						
Has card	85.8	86.2	87.2	84.0	88.7	82.6
No card	14.2	13.8	12.8	16.0	11.3	17.4
	100.0 (656)	100.0 (65)	100.0 (421)	100.0 (300)	100.0 (388)	100.0 (333)
Education level						
Primary	12.2	23.7	10.0	17.8	11.6	15.1
Secondary	54.7	55.9	56.1	53.1	54.1	55.7
Tertiary	100.0	100.0	100.0	100.0	100.0	100.0
	(654)	(59)	(421)	(292)	(388)	(325)
Occupation						
Professional	33.3	20.7	31.8	33.0	33.0	31.5
Trade	45.3	34.5	50.6	35.4	49.2	38.6
Home duties	21.4	44.8	17.6	31.6	17.8	29.9
	100.0 (654)	100.0 (58)	100.0 (421)	100.0 (291)	100.0 (388)	100.0 (324)

Notes: Percentages may not add to 100 due to rounding.

- (a) 'Single' includes widowed, divorced, separated and never married. 'Couple' includes de facto.
- (b) 'Renter' includes 'Other' (2 cases).
- (c) 'Not retired' includes children, students, employed, unemployed, home duties and other.

Table A4.6b: Baseline Characteristics of Control Group at Administrations of the SF-36

Participant Characteristics	Control Participants					
	Baseline		Mid Trial		End of Trial	
	Resp % (n=)	Non-Resp % (n=)	Resp % (n=)	Non-Resp % (n=)	Resp % (n=)	Non-Resp % (n=)
Age						
<50	1.8	4.4	1.2	3.9	1.5	2.8
50-59	2.9	-	3.0	1.9	3.0	2.3
60-69	9.3	8.7	9.8	8.3	9.5	9.0
70-79	31.6	21.7	34.2	24.4	37.3	24.4
80-89	46.0	47.8	46.2	46.2	45.3	47.1
90 and over	8.2	17.4	5.6	15.4	3.5	14.5
	100.0	100.0	100.0	100.0	100.0	100.0
	(376)	(46)	(266)	(156)	(201)	(221)
Gender						
Male	26.1	27.7	22.6	32.5	21.4	30.6
Female	73.9	72.3	77.4	67.5	78.6	69.4
	100.0	100.0	100.0	100.0	100.0	100.0
	(376)	(47)	(266)	(157)	(201)	(222)
Marital status^(a)						
Single	68.9	72.3	71.1	66.2	73.1	65.8
Couple	31.1	27.7	28.9	33.8	26.9	34.2
	100.0	100.0	100.0	100.0	100.0	100.0
	(376)	(47)	(266)	(157)	(201)	(222)
Country of birth						
Australia	75.5	83.0	77.1	75.2	78.6	74.3
Other	24.5	17.0	22.9	24.8	21.4	25.7
	100.0	100.0	100.0	100.0	100.0	100.0
	(376)	(47)	(266)	(157)	(201)	(222)
Language spoken at home						
English	89.4	91.5	89.8	89.2	86.6	92.3
Other	10.6	8.5	10.2	10.8	13.4	7.7
	100.0	100.0	100.0	100.0	100.0	100.0
	(376)	(47)	(266)	(157)	(201)	(222)
Client's accommodation						
House, unit, apart, flat	94.9	91.3	94.7	94.2	94.2	93.5
Indep living unit, hostel	5.1	8.7	5.3	5.8	6.5	4.5
	100.0	100.0	100.0	100.0	100.0	100.0
	(376)	(46)	(266)	(156)	(201)	(221)
Tenancy^(b)						
Owner	72.5	69.6	75.2	67.1	73.1	71.4
Renter	27.5	30.4	24.8	32.9	26.9	28.6
	100.0	100.0	100.0	100.0	100.0	100.0
	(375)	(46)	(266)	(155)	(201)	(220)
Carer status						
Carer not needed	24.3	23.9	28.2	17.4	30.8	18.2
Has a carer	40.3	39.1	35.7	47.7	34.8	45.0
Needs a carer	35.5	37.0	36.1	34.8	34.3	36.8
	100.0	100.0	100.0	100.0	100.0	100.0
	(375)	(46)	(266)	(155)	(201)	(220)
Private Assistance						
Has help	29.0	21.3	32.3	21.0	30.8	25.7
No help	71.0	78.7	67.7	79.0	69.2	74.3

(376)	(47)	(266)	(157)	(201)	(222)
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Table A4.6b (continued): Baseline Characteristics of Control Group at Administrations of the SF-36

Participant Characteristics	Control Participants					
	Baseline		Mid Trial		End of Trial	
	Resp % (n=)	Non-Resp % (n=)	Resp % (n=)	Non-Resp % (n=)	Resp % (n=)	Non-Resp % (n=)
Employment status^(c)						
Retired	93.6	93.6	93.6	93.6	95.0	92.3
Not retired	6.4	6.4	6.4	6.4	5.0	7.7
	100.0	100.0	100.0	100.0	100.0	100.0
	(376)	(47)	(266)	(156)	(201)	(221)
Health insurance						
Some private insurance	32.7	31.9	35.0	28.7	35.8	29.7
No insurance	67.3	68.1	65.0	71.3	64.2	70.3
	100.0	100.0	100.0	100.0	100.0	100.0
	(376)	(47)	(266)	(157)	(201)	(222)
DVA status						
DVA card	18.6	21.3	18.0	20.4	18.9	18.9
No DVA card	81.4	78.7	82.0	79.6	81.1	81.1
	100.0	100.0	100.0	100.0	100.0	100.0
	(376)	(47)	(266)	(157)	(201)	(222)
Cards status						
Has card	95.5	93.6	94.7	96.2	95.5	95.0
No card	4.5	6.4	5.3	3.8	3.4	5.0
	100.0	100.0	100.0	100.0	100.0	100.0
	(376)	(47)	(266)	(157)	(201)	(222)
Education level						
Primary	20.2	25.5	18.4	24.8	20.4	21.2
Secondary	72.1	63.8	73.7	66.9	72.6	69.8
Tertiary	100.0	100.0	100.0	100.0	100.0	100.0
	(376)	(47)	(266)	(157)	(201)	(222)
Occupation						
Professional	22.1	17.0	22.9	19.1	21.9	21.2
Trade	58.0	70.2	56.0	65.0	58.7	59.9
Home duties	19.9	12.8	21.1	15.9	19.4	18.9
	100.0	100.0	100.0	100.0	100.0	100.0
	(376)	(47)	(266)	(157)	(201)	(222)

Notes: Percentages may not add to 100 due to rounding.

(a) 'Single' includes widowed, divorced, separated and never married. 'Couple' includes de facto.

(b) 'Renter' includes 'Other' (2 cases).

(c) 'Not retired' includes children, students, employed, unemployed, home duties and other.

Table A4.7: Proportional Change of Lowest and Highest Possible SF-36 Scores by Participant Group

<i>SF-36 Item</i>	Baseline		End of Trial	
	Intervention	Control	Intervention	Control
	% (n=)	% (n=)	% (n=)	% (n=)
Physical function				
Floor	18.3	11.1	19.6	13.6
Ceiling	0.5	0.5	0.3	1.0
	(383)	(198)	(383)	(198)
Physical role				
Floor	63.0	66.8	61.2	64.0
Ceiling	9.9	6.0	10.7	8.1
	(381)	(197)	(381)	(197)
Bodily pain				
Floor	5.2	4.0	4.1	7.7
Ceiling	17.9	9.0	14.0	8.7
	(384)	(196)	(384)	(196)
General health				
Floor	2.6	1.5	1.8	2.0
Ceiling	0.5	-	0.5	-
	(384)	(198)	(384)	(198)
Vitality				
Floor	5.5	4.5	4.4	2.0
Ceiling	0.8	0.5	0.5	1.0
	(384)	(198)	(384)	(198)
Social function				
Floor	9.3	6.0	12.4	8.1
Ceiling	15.3	15.1	18.3	16.7
	(386)	(198)	(386)	(198)
Emotional role				
Floor	34.6	46.7	38.1	44.2
Ceiling	42.7	35.0	38.9	34.0
	(379)	(195)	(379)	(195)
Mental health				
Floor	0.5	0.5	0.3	-
Ceiling	5.4	5.5	4.7	3.5
	(372)	(193)	(372)	(193)

Table A4.8: Change in SF-36 Scores from Baseline to End of Trial by Participant Group

<i>SF-36 Item</i>	Excluding Exits		Including Exits	
	Intervention	Control	Intervention	Control
	% (n=)	% (n=)	% (n=)	% (n=)
Physical function				
Better	30.5	37.9	20.2	26.4
Same	24.5	23.2	16.2	16.2
Worse	44.9	38.9	63.6	57.4
	(383)	(198)	(580)	(284)
Physical role				
Better	27.3	24.9	18.0	17.3
Same	47.8	56.3	31.5	39.2
Worse	24.9	18.8	50.5	43.5
	(381)	(197)	(578)	(283)
Bodily pain				
Better	36.2	36.7	23.9	25.5
Same	21.6	16.8	14.3	11.7
Worse	42.2	46.4	61.8	62.8
	(384)	(196)	(581)	(282)
General health				
Better	41.7	40.4	27.5	28.2
Same	8.3	13.1	5.5	9.2
Worse	50.0	46.5	67.0	62.7
	(384)	(198)	(581)	(284)
Vitality				
Better	39.6	44.9	26.2	31.3
Same	8.3	9.6	5.5	6.7
Worse	52.1	45.5	68.3	62.0
	(384)	(198)	(581)	(284)
Social function				
Better	33.7	36.4	22.3	25.4
Same	25.1	22.7	16.6	15.8
Worse	41.2	40.9	61.1	58.8
	(386)	(198)	(583)	(284)
Emotional role				
Better	24.8	23.1	16.3	16.0
Same	45.4	55.9	29.9	38.8
Worse	29.8	21.0	53.8	45.2
	(379)	(195)	(576)	(281)
Mental health				
Better	36.7	42.9	24.3	29.9
Same	13.8	9.6	9.1	6.7
Worse	49.5	47.5	66.6	63.4
	(384)	(198)	(581)	(284)
PCS				
Better	48.9	49.7	32.0	34.4
Same	-	-	-	-
Worse	51.1	50.3	68.0	65.6
	(372)	(193)	(569)	(279)
MCS				
Better	47.3	45.6	45.6	31.5
Same	-	-	-	-

Worse	52.7 (372)	54.4 (193)	54.5 (569)	68.5 (279)
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Table A4.9: Logistic Regression of Intervention Group Membership and Change in SF-36 Scores

	Coefficient	SE	Sig	Odds Ratio
Background variables				
Born overseas	1.0092	.3575	***	2.7435
English not spoken at home	-2.4299	.5623	****	.0880
Lives in independent living unit	1.4592	.4341	****	4.3026
Has a carer	.9799	.3189	***	2.6641
Renter	0.6271	.2951	**	.5341
Tertiary level education	2.0761	.3544	****	7.9376
SF-36 Item				
Physical function				
Better	.0816	.2948		1.0851
Worse	.3726	.2904		1.4515
Physical role				
Better	.4336	.2770		1.5427
Worse	.1895	.3000		1.2087
Bodily pain				
Better	.0051	.3205		1.0052
Worse	-.4363	.3066		.6464
General health				
Better	.2987	.3709		1.3482
Worse	.3519	.3595		1.4218
Vitality				
Better	-.0926	.4121		.9116
Worse	.2009	.4125		1.2225
Social function				
Better	-.2858	.3079		.7514
Worse	.2648	.3032		1.3032
Emotional role				
Better	.5467	.2961	*	1.7276
Worse	.9873	.3015	**	2.6841
Mental health				
Better	-.5805	.3834		.5596
Worse	-.2380	.3705		.7882
PCS				
Better	-.0290	.3013		.9714
MCS				
Better	.4809	.3407		1.6175
Intercept	.8639			
n = 564 -2log likelihood = 725				

** p<.05 *** p<.01 **** p<.001

Reference category: Australian-born; English spoken at home; lives at home (unit, flat etc); does not need or have a carer; owns home; secondary education level, no change for each of the SF-36 items.

Table A4.10: Changes in Mean Scores SF-36 for Intervention Participants by Care Coordinator Type

Care Coordinator Type		SF-36 administration		Significance
		Baseline	End of Trial	
GP				
	Physical function	28.5	23.6	0.014
	Bodily pain	52.1	46.7	0.052
	General health	47.2	42.1	0.009
	PCS	28.6	26.8	0.053
Non-GP				
	Physical function	23.6	20.1	0.061
Full time CC				
	Physical function	27.8	25.0	0.086
	Vitality	42.0	37.7	0.007
	Mental health	74.3	70.7	0.006
	MCS	48.5	46.4	0.023

Note: Using paired sample T-Tests. Analysis with Wilcoxon Signed Rank Test gave similar significance results, except for PCS for GP CCs.

Appendix 5: Participant Experience Tables

Table A5.1: Comparison of Selected Characteristics of All Linked Care Participants and the Participant Questionnaire Sample

Participant Characteristics	Participant Group							
	Intervention				Control			
	All Linked Care		Client survey		All Linked Care		Client survey	
	Baseline	End trial	Baseline	Effective	Baseline	End trial	Baseline	Effective
	(n=)	(n=)	(n=)	sample	(n=)	(n=)	(n=)	sample ^(a)
	%	%	%	% (n=) ^(a)	%	%	%	% (n=)
Gender		***	*			***	*	
Female	65.2	66.7	65.3	65.7	73.8	77.1	73.6	74.6
Male	34.8	33.3	34.7	34.3	26.2	22.9	26.4	25.4
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(722)	(396)	(213)	(143)	(423)	(210)	(208)	(122)
Marital status		***		***		***		***
Single	56.1	54.8	55.0	52.4	69.3	72.4	68.8	69.7
Couple	43.9	45.2	45.0	47.6	30.7	27.6	31.3	30.3
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(704)	(396)	(211)	(143)	(423)	(210)	(208)	(122)
Age								
< 50	5.6	6.4	6.1	6.3	2.1	2.0	2.4	1.6
50-59	3.7	4.8	3.8	4.2	2.6	2.9	2.9	3.4
60-69	7.9	9.1	8.5	7.7	9.2	9.0	9.6	12.3
70-79	28.0	29.8	24.4	26.6	30.6	36.7	28.8	31.1
80-89	44.6	42.7	46.0	45.5	46.2	45.2	47.6	48.4
90 and over	10.2	7.3	11.3	9.8	9.2	4.3	8.7	3.3
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(722)	(396)	(213)	(143)	(422)	(210)	(208)	(122)
Language spoken		***	***	*		***	***	*
English	97.8	97.2	96.2	94.4	89.6	86.2	87.5	86.9
Other	2.2	2.8	3.8	5.6	10.4	13.8	12.5	13.1
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(713)	(396)	(211)	(143)	(423)	(210)	(208)	(122)
Country of birth								
Australia	77.7	77.3	76.9	79.7	76.4	77.6	76.9	78.9
Other	22.3	22.7	23.1	20.3	23.6	22.4	23.1	21.1
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(717)	(396)	(212)	(143)	(423)	(210)	(208)	(122)
DVA status								
Not DVA cardholder	82.5	80.1	81.7	79.0	81.1	81.0	80.3	77.0
DVA cardholder	17.5	19.9	18.3	21.0	18.9	19.0	19.7	23.0
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(722)	(396)	(213)	(143)	(423)	(210)	(208)	(122)
Health insurance		***	***	***		***	***	***
No private health insurance	48.2	51.3	45.5	47.6	67.4	64.8	64.4	63.9
Private health insurance	51.8	48.7	54.5	52.4	32.6	35.2	35.6	36.1
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(720)	(396)	(213)	(143)	(423)	(210)	(208)	(122)
Client's accommodation			***				***	
House, unit, apartment, flat	90.7	90.1	90.0	89.5	94.5	93.8	94.7	94.3
Independent Living unit, hostel	9.3	9.9	10.0	10.5	5.5	6.2	5.3	5.7
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(711)	(395)	(210)	(143)	(422)	(210)	(208)	(122)

Table A5.1 (continued): Comparison of Selected Characteristics of All Linked Care Participants and Participant Questionnaire Sample

	Participant Group							
	Intervention				Control			
	All Linked Care		Client survey		All Linked Care		Client survey	
	Baseline % (n=)	End trial % (n=)	Baseline % (n=)	Effective sample ^a	Baseline % (n=)	End trial % (n=)	Baseline % (n=)	Effective sample
Tenancy		***	***	**		***	***	**
Owner	83.3	81.5	82.4	82.5	72.2	72.4	71.5	69.7
Renter	16.7	18.5	17.6	17.5	27.8	27.6	28.5	30.3
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(693)	(395)	(210)	(143)	(421)	(210)	(207)	(122)
Employment status		**		*		**		*
Retired	90.2	88.4	91.0	90.9	93.4	94.8	94.2	96.7
Not retired	9.8	11.6	9.0	9.1	6.6	5.2	5.8	3.3
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(714)	(396)	(211)	(143)	(423)	(210)	(208)	(122)
Cards status		***	***	**		***	***	**
Has Cards	82.5	85.4	82.5	85.3	94.6	95.7	94.7	95.1
No Cards	17.5	14.6	17.5	14.7	5.4	4.3	5.3	4.9
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(721)	(396)	(212)	(143)	(423)	(210)	(208)	(122)
Education level		***	***	***		***	***	***
Primary	13.2	13.1	12.3	14.7	20.8	21.4	19.7	20.5
Secondary	54.8	53.3	52.1	51.7	71.2	71.4	73.1	73.0
Tertiary	32.0	33.6	35.5	33.6	8.1	7.1	7.2	6.6
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(713)	(396)	(211)	(143)	(423)	(210)	(208)	(122)
Occupation		**		**		**		**
Professional	32.3	32.6	29.9	30.1	21.5	21.9	22.1	18.9
Trade	44.4	48.5	47.9	48.3	59.3	58.6	58.7	63.9
Home Duties	23.3	18.9	22.3	21.7	19.1	19.5	19.2	17.2
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(712)	(396)	(211)	(143)	(423)	(210)	(208)	(122)
SF36 means								
PCS (baseline) ^(b)	27.9		28.3	29.1	27.3		27.3	26.8
	(636)		(202)	(137)	(371)		(200)	(119)
MCS (baseline) ^(b)	45.9		46.4	47.5	45.2		45.0	45.2
	(636)		(202)	(137)	(371)		(200)	(119)
PCS change 1-3								
Better	32.0	48.6	37.6	48.5	34.4	49.7	41.1	53.6
Same	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Worse	68.0	51.4	62.4	51.5	65.6	50.3	58.9	46.4
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(569)	(364)	(194)	(130)	(279)	(193)	(151)	(112)
MCS change 1-3								
Better	30.9	48.1	33.5	46.2	31.5	45.6	39.1	49.1
Same	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Worse	69.1	51.9	66.5	53.8	68.5	54.4	60.9	50.9
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(569)	(364)	(194)	(130)	(279)	(193)	(151)	(112)

* p<.1, ** p<.05, *** p<.01⁵⁰

⁵⁰ All significance tests in this Appendix relate to a comparison between the Intervention and Control group participants.

- Notes: Percentages may not add to 100 due to rounding.
- a) Effective sample: participants who responded to both the baseline and end of trial questionnaires.
 - b) Physical and Mental Component Summary scale

Table A5.2: Selected Characteristics of Participant Questionnaire Sample by Participant Group

	Participant group					
	All baseline responses		Effective Sample ^(a)			
	Intervention (213)	Control (208)	Intervention (143)		Control (122)	
			baseline	end trial	baseline	end trial
Who completed questionnaire	%	%	%	%	%	%
Participant	53.8	62.1	61.9	61.4	67.1	71.6
Family/Friend	43.2	33.7	34.4	36.4	25.2	19.8
Service Staff	1.0	1.8	0.7	0.7	1.9	7.8
Other	2.0	3.5	3.1	1.4	5.8	0.9
	100.0	100.0	100.0	100.0	100.0	100.0
	(199)	(171)	(134)	(140)	(103)	(116)
Living arrangements						
Live Alone	37.1	54.0	35.8	35.9	55.5	55.1
Live with Spouse/Partner	43.6	28.2	46.7	44.4	29.4	29.7
Live with Children	7.4	10.8	5.8	9.2	8.4	9.3
Live with Other Relatives	8.4	4.6	10.2	7.7	4.2	4.2
Other	3.5	2.6	1.5	2.8	2.5	1.7
	100.0	100.0	100.0	100.0	100.0	100
	(202)	(195)	(137)	(142)	(119)	(118)

Note: Percentages may not add to 100 due to rounding.

(a)Effective sample: participants who responded to both the baseline and end trial questionnaires.

Table A5.3: Self-reported Baseline Characteristics of Interviewed Participants

	Intervention (n)	Control (n)
Carer status		
Mutual care situation	1	1
Carer for another	1	1
Cared for by another	5	5
No carer/ no live-in carer	3	3
Interviewee		
Participant	6	8
Carer	4	2

Note: From first round telephone interviewees only, September 1998.

Table A5.4: Reasons for Exit by Participant Type for Respondents to the Participant Questionnaire

	Participant Group	
	Intervention	Control
	% (212)	% (208)
Reasons for Exit		
Remained in Trial	70.3	63.5
Participant decision	2.8	17.8
Entered residential care	13.2	5.8
Death	12.3	9.6
Administrative	1.4	3.4
	100.0	100.0

Note: Percentages may not add to 100 due to rounding.

Table A5.5: Comparison of Exit Status and Selected Characteristics of All Linked Care Participants and the Participant Questionnaire Sample

Participant Characteristics	Participant Group							
	Intervention				Control			
	All Linked Care		Client survey		All Linked Care		Client survey	
	Not Exited	Exited	Not Exited	Exited	Not Exited	Exited	Not Exited	Exited
	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)
Gender	***				***			
Female	33.3	36.5	34.9	38.1	22.9	29.6	26.5	26.3
Male	66.7	63.5	65.1	61.9	77.1	70.4	73.5	73.7
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(396)	(308)	(149)	(63)	(210)	(213)	(132)	(76)
Marital status	***	*	***		***	*	***	
Single ^(a)	54.8	57.8	53.0	59.7	72.4	66.2	71.2	64.5
Couple ^(b)	45.2	42.2	47.0	40.3	27.6	33.8	28.8	35.5
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(396)	(326)	(149)	(62)	(210)	(213)	(132)	(76)
Age			*				*	
< 50	6.3	4.6	6.7	3.2	1.9	2.3	3.0	1.3
50-59	4.8	2.5	4.7	1.6	2.9	2.3	3.0	2.6
60-69	9.1	6.4	8.1	9.5	9.0	9.4	10.6	7.9
70-79	29.8	25.8	24.8	23.8	36.7	24.4	31.8	23.7
80-89	42.7	46.9	48.3	41.3	45.2	46.9	47.0	48.7
90 and over	7.3	13.8	7.4	20.6	4.3	14.1	4.5	15.8
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(396)	(326)	(149)	(63)	(210)	(212)	(132)	(76)
Language spoken	***	***	***	*	***	***	***	*
English	97.2	98.4	95.3	98.4	86.2	93.0	85.6	90.8
Other	2.8	1.6	4.7	1.6	13.8	7.0	14.4	9.2
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(396)	(317)	(149)	(62)	(210)	(213)	(132)	(76)
Country of birth								
Australia	77.3	78.2	77.2	76.2	77.6	75.1	78.8	73.7
Other	22.7	21.8	22.8	23.8	22.4	24.9	21.2	26.3
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(396)	(321)	(149)	(63)	(210)	(213)	(132)	(76)
DVA status								
Not DVA cardholder	19.9	14.4	20.2	14.3	19.0	18.8	22.0	15.8
DVA cardholder ^(c)	80.1	85.6	79.9	85.7	81.0	81.2	78.0	84.2
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(396)	(326)	(149)	(54)	(210)	(213)	(132)	(76)
Health insurance	***	***	***	***	***	***	***	***
No private health insurance	48.7	55.6	53.0	58.7	35.2	30.0	36.4	34.2
Private health insurance ^(d)	51.3	44.4	47.0	41.3	64.8	70.0	63.6	65.8
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(396)	(324)	(149)	(63)	(210)	(213)	(132)	(76)
Client's accommodation				*				*
House, unit, apartment, flat	90.1	91.5	90.6	88.5	93.8	95.3	93.9	96.1
Independent Living unit, hostel	9.9	8.5	9.4	11.5	6.2	4.7	6.1	3.9
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(395)	(316)	(149)	(61)	(210)	(212)	(132)	(76)
Tenancy	***	***	**		***	***	**	
Owner	81.3	85.3	81.2	68.2	72.4	72.0	68.2	77.3
Renter	18.7	14.7	18.8	31.8	27.6	28.0	31.8	22.7
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

(396)	(299)	(149)	(61)	(210)	(211)	(132)	(75)
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Table A5.5 (continued): Comparison of Exit Status and Selected Characteristics of All Linked Care Participants and the Participant Questionnaire Sample

	Participant Group							
	Intervention				Control			
	All Linked Care		Client survey		All Linked Care		Client survey	
	Not Exited % (n=)	Exited % (n=)	Not Exited % (n=)	Exited % (n=)	Not Exited % (n=)	Exited % (n=)	Not Exited % (n=)	Exited % (n=)
Employment status	**		*		**		*	
Retired	88.6	92.7	89.9	93.5	94.8	92.5	95.5	92.1
Not retired	11.4	7.3	10.0	6.4	5.2	7.5	4.7	7.9
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(395)	(326)	(149)	(62)	(210)	(212)	(132)	(76)
Health card status	***	***	***	***	***	***	***	***
Has Cards	88.6	82.5	83.9	79.4	95.7	94.8	94.7	94.7
No Cards	11.4	17.5	16.1	20.6	4.3	5.2	5.3	5.3
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(396)	(325)	(149)	(63)	(210)	(213)	(132)	(76)
Education level	***	***	***	***	***	***	***	***
Primary	13.1	13.2	14.8	6.5	21.4	20.2	22.0	15.8
Secondary	53.3	56.8	51.0	54.8	71.4	70.9	71.2	76.3
Tertiary	33.6	30.0	34.2	38.7	7.1	8.9	6.8	7.9
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(396)	(317)	(149)	(62)	(210)	(213)	(132)	(76)
Occupation	*	***	**		*	***	**	
Professional	32.6	32.0	29.5	30.6	21.9	21.1	18.2	28.9
Trade	48.5	39.2	49.0	45.2	58.6	60.1	63.6	50.0
Home Duties	18.9	28.8	21.5	24.2	19.5	18.8	18.2	21.1
	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
	(396)	(316)	(149)	(62)	(210)	(213)	(132)	(76)
SF-36 means								
PCS (Baseline)	28.33	27.18	29.0	26.4	27.55	26.97	27.5	27.9
	(374)	(262)	(143)	(59)	(204)	(167)	(129)	(71)
MCS (Baseline)	47.36	43.78	47.4	44.11	45.48	44.95	45.1	44.8
	(374)	(262)	(143)	(59)	(204)	(167)	(129)	(71)
PCS change 1-3								
Better	48.6	2.4	49.6	7.3	49.7	0.0	51.2	0.0
Same	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Worse	51.4	97.6	50.4	92.7	50.3	100.0	48.8	100.0
	(364)	(205)	(139)	(55)	(193)	(86)	(121)	(30)
MCS change 1-3								
Better	48.1	0.5	46.8	0.0	45.6	0.0	48.8	0.0
Same	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Worse	51.9	99.5	53.2	100.0	54.4	85.7	51.2	100.0
	(364)	(205)	(139)	(55)	(193)	(86)	(121)	(30)

* p<.1; ** p<.05; *** p<.01

Notes: Percentages may not add to 100 due to rounding.

TCP Baseline excludes two cases included in CSS baseline due to removal from trial.

a) Includes widowed, divorced, separated and never married.

b) Includes married and de facto.

c) Includes gold and white DVA cardholder

d) Includes hospital insurance only, hospital insurance plus supplementary and extras, supplementary and extras only (no hospital insurance).

Table A5.6: Changes in Satisfaction of Participants with Aspects of Care Coordination CSS Baseline/Mid Trial by Participant Type and Selected Characteristics

	Intervention				Control			
	Better %	Same %	Worse %	n	Better %	Same %	Worse %	n
Received type of services needed								
<i>Gender</i>								
Male	20.9	67.4	11.6	43	12.5	70.8	16.7	24
Female	8.1	81.1	10.8	74	5.9	83.8	10.3	68
<i>Age</i>								
<60	7.7	69.2	23.1	13	0.0	83.3	16.7	6
60-79	16.2	70.3	13.5	37	7.5	77.5	15.0	40
80-99	11.9	80.6	7.5	67	8.7	82.6	8.7	46
<i>Living arrangements</i>								
Live Alone	10.5	76.3	13.2	38	8.5	83.0	8.5	47
Live with Spouse	17.0	71.7	11.3	53	9.7	67.7	22.6	31
Other	8.0	84.0	8.0	25	0.0	100.0	0.0	14
<i>Housing arrangements</i>								
Home Owner	14.3	61.9	23.8	21	7.4	74.1	18.5	27
Not Home Owner	12.5	79.2	8.3	96	7.7	83.1	9.2	65
<i>Private insurance</i>								
Some private insurance	11.3	77.4	11.3	62	14.5	74.5	10.9	55
No private insurance	5.9	82.4	11.8	34	8.6	79.3	12.1	58
<i>DVA client</i>								
Yes	11.1	88.9	0.0	27	10.5	73.7	15.8	19
No	13.3	72.2	14.4	90	6.8	82.2	11.0	73
<i>Pension/benefit recipient</i>								
Yes	12.6	77.7	9.7	103	8.2	81.2	10.6	85
No	14.3	64.3	21.4	14	0.0	71.4	28.6	7
<i>Language</i>								
English	13.3	76.1	10.6	113	6.4	80.8	12.8	78
NESB	0.0	75.0	25.0	4	14.3	78.6	7.1	14
Care well planned and organised								
<i>Gender</i>								
Male	11.1	80.6	8.3	36	4.2	87.5	8.3	24
Female	8.3	79.2	12.5	72	2.8	91.7	5.6	72
<i>Age</i>								
<60	7.7	61.5	30.8	13	0.0	100.0	0.0	6
60-79	13.2	73.7	13.2	38	2.4	85.4	12.2	41
80-99	4.1	87.7	5.3	57	4.1	93.9	2.0	49
<i>Living arrangements</i>								
Live Alone	2.9	91.4	5.6	35	5.9	88.2	5.9	51
Live with Spouse	12.5	75.0	12.5	48	0.0	89.7	10.3	29
Other	12.0	72.0	16.0	25	0.0	100.0	0.0	15
<i>Housing arrangements</i>								
Home Owner	7.9	82.0	10.1	89	4.4	89.7	5.9	68
Not Home Owner	15.8	68.4	15.8	19	0.0	92.9	7.1	28
<i>Private insurance</i>								
Some private insurance	5.3	84.2	10.5	57	5.6	91.7	2.8	36
No private insurance	13.7	74.5	11.8	51	1.7	90.0	8.3	60
<i>DVA client</i>								
Yes	8.7	91.3	0.0	23	0.0	95.0	5.0	20
No	9.4	76.5	14.1	85	3.9	89.5	6.6	76
<i>Pension/benefit recipient</i>								
Yes	10.9	78.3	10.9	92	3.4	91.0	5.6	89

No	0.0	87.5	12.5	16	0.0	85.7	14.3	7
<i>Language</i>								
English	9.6	80.8	9.6	104	3.7	91.5	2.2	82
NESB	0.0	50.0	50.0	4	0.0	85.7	14.3	14

Table A5.6 (continued): Changes in Satisfaction of Participants with Aspects of Care Coordination by Participant Type and Selected Characteristics

	Intervention				Control			
	Better %	Same %	Worse %	n	Better %	Same %	Worse %	n
Difficult to get services needed								
<i>Gender</i>								
Male	20.0	75.0	5.0	40	13.6	68.2	18.2	22
Female	14.5	69.6	15.9	69	12.1	74.2	13.6	66
<i>Age</i>								
<60	38.5	30.8	30.8	13	16.7	66.7	16.7	6
60-79	11.1	77.8	11.1	36	13.2	65.8	21.1	38
80-99	15.0	76.7	8.3	60	11.4	79.5	9.1	44
<i>Living arrangements</i>								
Live Alone	17.1	74.3	8.6	35	10.9	73.9	15.2	46
Live with Spouse	14.3	75.5	10.2	49	11.5	65.4	23.1	26
Other	20.0	60.0	20.0	25	13.3	86.7	0.0	15
<i>Housing arrangements</i>								
Home Owner	13.5	75.3	11.2	89	4.8	79.0	16.1	62
Not Home Owner	30.0	55.0	15.0	20	30.8	57.7	11.5	26
<i>Private insurance</i>								
Some private insurance	19.3	63.2	17.5	57	3.2	77.4	19.4	31
No private insurance	13.5	80.8	5.8	52	17.5	70.2	12.3	57
<i>DVA client</i>								
Yes	12.5	83.3	4.2	24	5.6	72.2	22.2	18
No	17.6	68.2	14.1	85	14.3	72.9	12.9	70
<i>Pension/benefit recipient</i>								
Yes	17.0	71.3	11.7	90	12.3	75.3	12.3	81
No	13.3	73.3	13.3	15	14.3	42.9	42.9	7
<i>Language</i>								
English	17.1	71.4	11.4	105	10.8	74.3	14.9	74
NESB	0.0	75.0	25.0	4	21.4	64.3	14.3	14
Self or family pay costs of care								
<i>Gender</i>								
Male	70.6	57.1	14.3	42	25.0	55.0	20.0	20
Female	41.1	42.9	15.7	70	20.3	53.1	26.6	64
<i>Age</i>								
<60	53.8	38.5	7.7	13	0.0	40.0	60.0	5
60-79	41.7	44.4	13.9	36	23.7	60.5	15.8	38
80-99	30.2	52.4	17.5	63	22.0	48.8	29.3	41
<i>Living arrangements</i>								
Live Alone	40.0	48.6	11.4	35	26.2	52.4	21.4	42
Live with Spouse	36.5	46.2	17.3	52	23.1	50.0	26.9	26
Other	32.0	52.0	16.0	25	6.7	60.0	33.3	15
<i>Housing arrangements</i>								
Home Owner	33.3	53.3	13.3	90	21.3	57.4	21.3	61
Not Home Owner	50.0	27.3	22.7	22	21.7	43.5	34.8	23
<i>Private insurance</i>								
Some private insurance	36.7	48.3	15.0	60	11.1	55.6	33.6	27
No private insurance	36.5	48.1	15.4	52	26.3	52.6	21.1	57
<i>DVA client</i>								
Yes	25.0	62.5	12.5	24	15.8	73.7	10.5	19
No	39.8	44.3	15.9	88	23.1	47.7	29.2	65
<i>Pension/benefit recipient</i>								
Yes	36.5	49.0	14.6	96	23.1	55.1	21.8	78
No	37.5	43.8	18.8	16	36.5	49.0	14.6	96

<i>Language</i>								
English	37.4	46.7	15.9	107	20.0	55.7	24.3	70
NESB	20.0	80.0	0.0	5	28.6	42.9	28.6	14

Table A5.6 (continued): Changes in Satisfaction of Participants with Aspects of Care Coordination by Participant Type and Selected Characteristics

	Intervention				Control			
	Better %	Same %	Worse %	n	Better %	Same %	Worse %	n
Have a say in type of services received								
<i>Gender</i>								
Male	12.8	74.4	12.8	39	4.5	77.3	18.2	22
Female	9.1	69.7	21.2	66	18.8	51.6	29.7	64
<i>Age</i>								
<60	0.0	76.9	23.1	13	0.0	66.7	33.3	6
60-79	13.8	63.9	22.2	36	14.3	62.9	22.9	35
80-99	10.7	75.0	14.3	56	17.8	53.3	17.8	45
<i>Living arrangements</i>								
Live Alone	15.6	65.6	18.8	32	17.4	50.0	32.6	46
Live with Spouse	8.3	75.0	16.7	48	12.0	68.0	20.0	25
Other	8.0	72.0	20.0	25	14.3	71.4	14.3	14
<i>Housing arrangements</i>								
Home Owner	12.6	70.1	17.2	87	15.0	58.3	26.7	60
Not Home Owner	0.0	77.8	22.2	18	15.4	57.7	26.9	26
<i>Private insurance</i>								
Some private insurance	12.7	70.9	16.4	55	3.4	69.0	27.6	29
No private insurance	8.0	72.0	20.0	50	21.1	52.6	26.3	57
<i>DVA client</i>								
Yes	13.6	72.7	13.6	22	11.8	41.2	47.1	17
No	9.6	71.1	19.3	83	15.9	62.3	21.7	69
<i>Pension/benefit recipient</i>								
Yes	9.0	69.7	21.3	89	16.3	56.3	27.5	80
No	18.8	81.3	0.0	16	0.0	83.3	16.7	6
<i>Language</i>								
English	10.9	72.3	16.8	101	12.3	60.3	27.4	73
NESB	0.0	50.0	50.0	4	30.8	46.2	23.1	13

Source: Participant questionnaires, November 1998 and 1999.

Table A5.7: Baseline Satisfaction and Level of Service Use of Interviewed Participants

	Control (n)	Intervention (n)
Satisfaction levels		
Satisfied	6	6
Unsatisfied	4	4
Number of services used per client		
Average	Average	Average
Self-reported	6.7	11.5 ^(a)
Care plan	-	7.1 ^(a)

(a)excluding two Intervention participants without care plans, September 1998.

Table A5.8: Client Satisfaction by Care Coordinator Type

Satisfaction Change	GP CC	Non-GP CC	Full-time CC
Type of services needed*			
Better	4.0	3.2	21.3
Same	80.0	83.9	70.5
Worse	16.0	12.9	8.2
	100.0	100.0	100.0
	(25)	(31)	(61)
Respond to changing needs *			
Better	19.2	9.1	22.0
Same	38.5	60.6	61.0
Worse	42.3	30.3	16.9
	100.0	100.0	100.0

	(26)	(33)	(59)
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*p<0.10

Source: Participant questionnaires, November 1998 and 1999.