UNSW SYDNEY

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

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

Publication details:
Report No. SPRC Report 5/00
0733418724 (ISBN)
1446-4179 (ISSN)

Publication Date:
2000

DOI:
https://doi.org/10.26190/unsworks/297

License:
https://creativecommons.org/licenses/by-nc-nd/3.0/au/
Link to license to see what you are allowed to do with this resource.

Downloaded from http://hdl.handle.net/1959.4/34418 in https://unsworks.unsw.edu.au on 2024-03-28

Social Policy Research Centre

Centre For GP
Integration Studies
University of New South Wales

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

LOCAL EVALUATION FINAL REPORT

SPRC Report 5/00

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

For a full list of SPRC Publications see, www.sprc.unsw.edu.au or
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

ISSN 1446-4179
ISBN 0 7334 1872 4

March 2000

The views expressed in this publication do not represent any official position on the part of the Social Policy Research Centre. This report was produced to make available the research findings of the individual authors, and to promote the development of ideas and discussions about major areas of concern in the field of social policy.

UNSW Evaluation Consortium

Social Policy Research Centre

Michael Fine, Karen Fisher, Jenny Doyle, Stefani Strazzari, 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.

Thank you to all the clients, carers, Linked Care staff, Management Committee and Working Party members and service provider staff who so willingly participated in the evaluation. All names used in the report are pseudonyms.

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

Contents

UNSW Evaluation Consortium i

Contacts for Follow up to this Report i

Contents ii

Tables vi

Abbreviations and Glossary ix

Part A Introduction 1

1. Introduction and Background 1
   - 1.1 Background to the CCTs and the Evaluation 1
   - 1.2 Background to Linked Care 3
   - 1.3 Overview of the Report 4

2. Methodology and Approach to the Local Evaluation 5
   - 2.1 Background to the Evaluation 5
   - 2.2 Conceptual Framework of the Evaluation 6
   - 2.3 Evaluation Methods and Other Issues 7

Part B Findings 13

3. Organisation and Operation of the Coordinated Care Trial 13
   - 3.1 Establishment and Operational Issues 13
     - 3.1a Establishment Timeframe 13
     - 3.1b Recruitment process 15
     - 3.1c Participant Involvement in the Organisation of Linked Care 17
     - 3.1d Information Technology 18
     - 3.1e Results from the Establishment and Operational Mechanisms 21
   - 3.2 Management and Governance Arrangements 22
     - 3.2a Management Structure 22
     - 3.2b Northern Sydney Area Health Service 23
     - 3.2c Service Providers 23
     - 3.2d Consumer Representatives 27
     - 3.2e Linked Care Administration 28
     - 3.2f Results from the Management and Governance Arrangements 29
   - 3.3 Finance and the Fund Pool 31
     - 3.3a Introduction 31
     - 3.3b Financial Structure 32
     - 3.3c Fund Pool Development 33
     - 3.3d Infrastructure Budget 38
     - 3.3e Financial Outcomes 39
     - 3.3f Client Costs 42
     - 3.3g Service Usage Data 43

3.3h Financial Management by Care Coordinators 46
3.3i Results from the Financial Management 50
3.4 Care Coordination 53
3.4a Introduction 53
3.4b Care Coordinators 54
3.4c Care Coordination Process 61
3.4d Care Plans 61
3.4e Peer Support Groups 68
3.4f Assessment 69
3.4g Participant Category Care Protocols 70
3.4h Quality Assurance Activities 72
3.4i Participant Experiences with Having a Care Coordinator 73
3.4j Service Managers Expectations of Care Coordination 75
3.4k Results from the Care Coordination Mechanisms 76
3.5 Service Substitution 81
3.6 Linked Care Initiatives 83
3.6a Clinical and Service Delivery Prompt Sheets 83
3.6b Clinical Advisory Group 84
3.6c Medication Review 85
3.6d Hospitals Notification System 89
3.6e Hospital Issues Working Party 90
3.6f Hip Protectors 92
3.6g Results from the Specific Linked Care Initiatives 92
4. Impact on Clients 94
4.1 Background to the Client Focus 94
4.2 Description of the Participants 96
4.2a Baseline Characteristics of the Linked Care Participants 96
4.2b Comparison of Intervention and Control Groups 96
4.2c Comparison of Participant Samples to all Linked Care Participants 102
4.3 Client Outcomes 105
4.3a Exits 105
4.3b Health and Well-being 110
4.3c Satisfaction 116
4.3d Measure of Disease Control 120
4.3e Service Provider and Care Coordinator Experiences of Client Outcomes124
4.3f Client Experiences of Benefits of Having a Care Coordinator 125
4.3g Further Analysis 128
4.4 Impact on Carers 129
4.5 Impact on Clients not in Linked Care 135
4.6 Conclusion about the Impact on Clients 137
5. Service Delivery 139
5.1 Service Provider Profile 139

5.1a Hospital-based Services 139
5.1b Community-based Services 141
5.1c General Practitioners 144
5.2 Service Delivery Processes 146
5.2a Entry to Services 147
5.2b Managing Demand 147
5.2c Duration of Service Delivery 148
5.2d Cost and Charges 148
5.3 Impact on Care Coordination and Service Integration 150
5.3a Care Coordination or Referrals? 150
5.3b Internal Organisational Coordination 152
5.3c Inter-Service Integration 153
5.3d Medical and Community Service Cooperation 155
5.4 Service Usage Patterns 157
5.4a Data Collection Limitations 157
5.4b Results from the Linked Care Data 159
5.4c Participant Reported Data 167
5.4d Service Provider Experiences of Service Usage Patterns 174
5.5 External Changes 176
5.6 Service Delivery Conclusions 177
Part C Conclusions 179
6. How the Linked Care Model Performed: a Synthesis of Results 179
6.1 Support for the Primary Research Hypothesis 179
6.2 Secondary Hypotheses 181
7. Conclusion 189
7.1 Introduction 189
7.2 Cautions Interpreting the Findings 190
7.2a Difficulties Arising from the Trial Approach 190
7.2b Difficulties Arising from the Implementation Process 192
7.2c Limitations of the Evaluation 192
7.3 Linked Care's Interventions in Review 193
7.4 Lessons from Linked Care 195
7.5 Concerns about Wider Introduction of the Model 197
7.6 Conclusion 199
References 200
Appendix 1: National and Local Hypotheses 207
Appendix 2: Evaluation Data Sets 210
Appendix 3: Local Evaluation Financial Analysis 212
Appendix 4: Participant Experience Methodology 214

Appendix 5: Service Usage Charts 217
Appendix 6: Participant Profile and Outcomes Tables 230
Appendix 7: Participant Experience Tables 253
Appendix 8: Service Provider Evaluation Tables 266

Tables

Table 1.1: Milestones in the National Timeline for the Coordinated Care Trials 3
Table 2.1: Summary of Evaluation Measures 8
Table 3.1: Milestones in Hornsby Ku-ring-gai Coordinated Care Trial 14
Table 3.2: Participants Recruited 16
Table 3.3: Trial and Evaluation Contacts with Participants in Linked Care 18
Table 3.4: Results from Operational Mechanisms 21
Table 3.5: Management Committee and Working Parties 22
Table 3.6: Service Providers and Funders in Linked Care 24
Table 3.7: Expectations and Impact of Linked Care on Service Organisation 26
Table 3.8: Results from the Management and Governance Arrangements 30
Table 3.9: Estimated Size of the Fund Pool to Operate from October 1997 to December 1999 33
Table 3.10: Fund Pool Contribution Rates by Contributor, November 1999 34
Table 3.11: Estimated and Actual Proportion of Fund Pool Contributions to October 1999 35
Table 3.12: Fund Pool Contributors' Billing and Contribution Status 37
Table 3.13: Balance of Fund Pool Contributions and Payments by Contributor, December 1999 37
Table 3.14: Financial Analysis, September 1997 to December 1999 39
Table 3.15: Service Usage Data Collection by Linked Care Administration 45
Table 3.16: Authorised Additional Services by Care Coordinator Type 47
Table 3.17: Expected Cost of Participants' Care by Care Protocol Category, 1997 48
Table 3.18: Results from the Financial Management 52
Table 3.19: Care Coordinator Type by GPs and Subcontracting Agencies, December 1999 56
Table 3.20: Care Coordinators and Participants by Care Coordinator Type 56
Table 3.21: Estimated Annual Care Coordination Hours and Payment by Participant Protocol Categories 61
Table 3.22: Care Coordinator Strategies to Involve Participants 64
Table 3.23: Level of Planned and Reported Service Use by Participants, October 1998 65
Table 3.24: Care Plan Content by Care Coordinator Type 66
Table 3.25: Participants by Care Protocol Category 70
Table 3.26: Participant Knowledge of Care Coordinators and Case Managers 74
Table 3.27: Other People Involved in Organising Care with the Participant 74
Table 3.28: Theoretical Benefits and Shortcomings of Some Case Management Models and the Linked Care Experience 78
Table 3.29: Results from the Care Coordination Mechanisms 79
Table 3.30: Service Substitution Strategies 81
Table 3.31: Medication Reviews Summary 86
Table 3.32: Results from Specific Linked Care Initiatives 93
Table 4.1: Descriptions for All Participants and Participant Samples 96
Table 4.2: Selected Baseline Characteristics of Linked Care Participants by Participant Group 98
Table 4.3: Baseline Comparison - Mean Nominations of Disease Category by Participant Group 103
Table 4.4: Selected Baseline Characteristics of Participant Groups by Exit Status 106
Table 4.5: Proportion of Exits by Participant Group 109
Table 4.6: SF-36 Mean Scores by Participant Group for Three Administrations during the Trial 113
Table 4.7: Self-assessed Health and Well-being by Participant Type 115
Table 4.8: Client Satisfaction with Organisation of Care by Participant Group 117
Table 4.9: Changes in Client Satisfaction with Organisation of Care by Participant Group 119
Table 4.10: Measure of Disease Control: Number of Diagnoses by Patient 121
Table 4.11: Measure of Disease Control: Most Common Diagnoses 121
Table 4.12: Measure of Disease Control: First Rating of Control for Each Diagnosis 121
Table 4.13: Measure of Disease Control: Change Between the Two Measurements 122
Table 4.14: Measure of Disease Control: Change Between the Two Measurements Intervention and Control Groups by Diagnosis Groups 122
Table 4.15: Care Coordinator Views: Linked Care has More Benefits than Disadvantages, November 1998 and November 1999 124
Table 4.16: People the Participant Received Informal Help from in the past 4 weeks by Participant Group 130

Table 4.17: The Main Person Providing Unpaid Help to the Participant 130
Table 4.18: Participant Experiences of Linked Care 137
Table 5.1: Service Personnel Views of Service Integration: Description of Care Provided to Clients, 1998 and 1999 153
Table 5.2: Expectations and Impact of Linked Care on Service Integration 154
Table 5.3: Logistic Regression of Intervention Group Membership and Change in Use of Each Service, June 1998 and August 1999 161
Table 5.4: Logistic Regression of Intervention Group Membership and Change in Cost of Each Service, June 1998 and August 1999 161
Table 5.5: Type of Assistance Received by Participant Group 169
Table 5.6: Medical Service Use by Participant Group 172
Table 5.7: Expectations and Impact of Linked Care on Service Usage 175
Table 7.1: Successful and Problematic Initiatives in Linked Care 194
Table A3.1: Local Evaluation Financial Analysis September 1997 to December 1999 212
Table A3.2: Local Evaluation Financial Analysis September 1997 to December 1999 - Excluding Trial Related Costs and Infrastructure Grant 213
Table A4.1: Descriptions for All Participants and Participant Samples 215
Table A6.1: Baseline Comparison: Demographic and Other Characteristics Associated With Intervention Group Membership 230
Table A6.2: Exits Per Month as a Proportion of Total Sample by Participant Group 231
Table A6.3a: Baseline Characteristics of Intervention Participants by Type of Exit 232
Table A6.3b: Baseline Characteristics of Control Participants by Type of Exit 235
Table A6.4a: Cox Proportional Hazards Regression: All Exiting Participants 238
Table A6.4b: Cox Proportional Hazards Regression: Participants Who Decided to Leave Trial 239
Table A6.4c: Cox Proportional Hazards Regression: Participants Who Entered Residential Care 240
Table A6.4d: Cox Proportional Hazards Regression: Participants Who Died (Related Death) 241
Table A6.5: SF-36 Response Rates by Participant Group 242
Table A6.6a: Baseline Characteristics of Intervention Participants at Administrations of the SF-36 243
Table A6.6b: Baseline Characteristics of Control Participants at Administrations of the SF-36 246
Table A6.7: Proportional Change of Lowest and Highest Possible SF-36 Scores by Participant Group 248
Table A6.8: Change in SF-36 Scores from Baseline to End of Trial by Participant Group 249
Table A6.9: Logistic Regression of Intervention Group Membership and Change in SF-36 Scores 251
Table A6.10: Changes in Mean Scores SF-36 for Intervention Participants by Care Coordinator Type 252
Table A7.1: Comparison of Selected Characteristics of All Linked Care Participants and the Participant Questionnaire Sample 253
Table A7.2: Selected Characteristics of Participant Questionnaire Sample by Participant Group 256
Table A7.3: Self-reported Participant Characteristics in Qualitative Interviews 256
Table A7.4: Reasons for Exit by Participant Type for Respondents to the Participant Questionnaire 256
Table A7.5: Comparison of Exit Status and Selected Characteristics of All Linked Care Participants and the Participant Questionnaire Sample 257
Table A7.6: Changes in Satisfaction of Participants with Aspects of Care Coordination by Participant Type and Selected Characteristics 260
Table A7.7: Baseline Satisfaction and Level of Service Use of Interviewed Participants 264
Table A7.8: Differences in Client Satisfaction by Care Coordinator Type 264
Table A8.1: Care Coordinators Views of Linked Care, 1998 and 1999 266
Table A8.2: Service Personnel Views of Service Integration, 1998 and 1999 269
Table A8.3: Service Personnel Views of Service Integration - Care Coordinators Compared to Non-Care Coordinators, 1998 and 1999 273
Table A8.4a: Hornsby Ku-ring-gai Community-based Agencies Client Profile (estimates) 1996-97 276
Table A8.4b: Hornsby Ku-ring-gai Community-based Agencies Client Profile (estimates) 1998-99 276
Table A8.5a: Hornsby Ku-ring-gai Community-based Agencies Financial Data (estimates) 1996-97 277
Table A8.5b: Hornsby Ku-ring-gai Community-based Agencies Financial Data (estimates) 1998-99 277
Table A8.6a: Hornsby Ku-ring-gai Community-based Agencies Staff Profile (estimates) 1996-97 278
Table A8.6b: Hornsby Ku-ring-gai Community-based Agencies Staff Profile (estimates) 1998-99 278
Table A8.7a: Estimated Duration of Service Provision for Current Clients, December 1997 279
Table A8.7b: Estimated Duration of Service Provision for Current Clients, November 1999 279
Table A8.8a: Size and Length of Waiting Lists (percentage, weeks), December 1997 279
Table A8.8b: Size and Length of Waiting Lists (percentage, weeks), November 1999 279

Table A8.9: Hornsby & Ku-ring-gai Hospital & Community Health Services Client Profile (estimates) 1996-97 280
Table A8.10: Hornsby & Ku-ring-gai Hospital & Community Health Services Staff Profile (estimates) 1996-97 280
Table A8.11a: Hospital Separations for Residents Aged 65 years and over, Hornsby Ku-ring-gai, 1997 and 1999 281
Table A8.11b: Hospital Separations for Residents Aged 65 years and over, Ryde Hunters Hill, 1997 and 1999 282
Table A8.12a: HACC Services in the Intervention and Control Areas, November 1997 283
Table A8.12b: HACC Services in the Intervention and Control Areas May 1999 283
Table A8.13: Summary of Demographic Information of GPs, 1997 and 1999 284
Table A8.14: Average Consultations per GP in the Quarter, Hornsby Ku-ring-gai and Ryde Hunters Hill, 1997 to 1999 284
Table A8.15: GPs with less than 1000 Patient Contacts per Quarter, Hornsby Ku-ring-gai and Ryde Hunters Hill, 1997 to 1999 285
Table A8.16: Rate of Imaging Ordered in Quarter per 100 Patient Contacts, Hornsby Ku-ring-gai and Ryde Hunters Hill, 1997 to 1999 285
Table A8.17: Rate of Pathology Ordered in Quarter per 100 Patient Contacts 286
Table A8.18: Ease of Referral to Selected Types of Service - Percentage of GPs Agreeing that Referral is Easy, 1997 and 1999 287
Table A8.19: Percentage of GPs Agreeing that Communication with Selected Types of Service is Satisfactory, 1997 and 1999 288
Table A8.20: Percentage of GPs Agreeing that Patients See them Coordinating their Clinical and Community Care, 1997 and 1999 288
Table A8.21: GP Satisfaction with Aspects of Providing Care for Patients with Complex Care Needs, 1997 and 1999 288
Table A8.22: Self Reported Levels of Involvement with Patients in the Linked Care Trial for GPs Aware of the Trial, 1997 and 1999 289
Table A8.23: GPs Aware of the Trial Reporting Problems for Patients Arising from the Trial, 1997 and 1999 289
Table A8.24: GPs Aware of the Trial who Agree that the Benefits of the Trial Outweigh the Disadvantages for Selected Groups, 1997 and 1999 289

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
Division of General Practice	Hornsby Ku-ring-gai Division of General Practice (incorporating Ryde)
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 Questionnaire (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

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 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 final evaluation 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 findings with respect to a number of separate components of Linked Care. It also identifies the conditions which underlie the achievements of Linked Care and considers obstacles that constrained the achievement of trial goals or which could have affected the evaluation.

The remainder of this introduction provides a brief overview of the background to the Coordinated Care Trials and specifically this trial, Linked Care. This introduction also serves as a guide to the remainder of the report.

1.1 Background to the CCTs and the Evaluation

The proposal for the establishment of what became known as 'coordinated care' can be traced to the reform proposals advanced by the Council of Australian Governments (COAG) in 1995. A report published by the Council in April of that year (COAG, 1995) identified 60 different programs for health and community services in Australia, some operated by State governments, others by the Commonwealth or by both levels of government. This complex system of organisation and funding, which also involved funding from private health insurance funds and individuals and their families, was seen as providing a number of perverse financial and organisational incentives that promoted the duplication of basic tasks such as assessment and referral, often skewing service use towards more intensive and expensive interventions than may be required.

[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.

The system of health and social care was seen to be in a state of near crisis and in need of drastic overhaul. It was argued that the complexity of provision and the problems and inefficiencies in the provision of health and community services arose from the rigidity of program boundaries, from the duplication and overlapping responsibilities of State and Commonwealth programs, and from the absence of competition between service providers. For example, it was simple for general practitioners (GPs) to prescribe medications for their chronically ill patients, but relatively difficult to obtain assistance with physiotherapy or housekeeping. It was possible to refer on to community services, but there was no guarantee that their referral would be accepted, as the fixed budgets under which most services operated meant they were unable too assist all applicants and may have had to set priorities amongst applicants. It was also difficult to introduce innovative approaches to service provision to fill gaps in the local system, as there was little flexibility allowed to those at the local level over the way in which existing funds could be deployed.

To overcome problems such as these a reform agenda was proposed which would draw the existing 60 programs together in to one of three streams of care:

? a *General Care* stream, for those who required occasional primary care;

? an *Acute Care* stream, providing specialised acute and follow-up care services for those with acute care needs; and

? a *Coordinated Care* stream, to meet the needs of those with disabilities or chronic illnesses with complex care needs, requiring continuing care (COAG, 1995a).

It was subsequently proposed that a series of large scale trials should be undertaken to test the efficacy of the proposed models, before any large scale system change was introduced. These trials were, initially, to be focused on the coordinated care stream.

Expressions of interest in conducting trials were called for in September 1995 by the (then) Commonwealth Department of Human Services and Health (CDHSH, 1995). Of the approximately 50 submissions received, twelve were selected and funded for the Tracking Phase, which provided the proposed trials with an opportunity to develop and refine their initial proposals and to firm up links between the participating services and agencies. From the twelve, nine trials were given Commonwealth approval and funding to proceed in 1996. Along with the Care Net Trial established in the Illawarra region, Linked Care, sponsored by the Northern Sydney Area Health Service (NSAHS) was one of two trials to proceed in New South Wales (CDHAC, 1999).

Commonwealth priorities determined many of the operational characteristics of the nine successful trials and their evaluation. All trials were required to be large scale, with an initial minimum size of at least one thousand clients receiving the intervention. Trials were also required to nominate a control group of at least five hundred clients receiving 'standard' or normal services. The Live Phase of the trials was to commence October 1997, the recruitment phase to finish in April 1998 and the Live Phase to be completed in December 31 1999. A summary of the timeline for the CCTs is presented in Table 1.1.

Many of the detailed requirements of the evaluation were determined in similar way. Specifications for the evaluations of the trials were first developed by the evaluation team from Coopers and Lybrand Consultants and the Centre for Health Program Evaluation, as

trials were developing and refining their designs. Detailed requirements for the evaluation, at both national and local levels, were agreed upon, and published, first in a series of draft documents, then in a final *Evaluation Framework* (Coopers and Lybrand, 1997). As well as outlining the structure of local evaluations alongside a national evaluation, the framework provided a comprehensive inventory of the data required from different sources, and set out the evaluation hypotheses, which are discussed in the following section of this report.

Table 1.1: Milestones in the National Timeline for the Coordinated Care Trials

Date	Milestone
? September 1995	Initial call for Expressions of Interest
? August 1996	First design contract signed
? June 1997	First Live Phase contract signed
? April 1998	Recruitment completed
? March 1999	Completion of Interim Evaluation Reports by Local Evaluators
? August 1999	Release of National Interim Evaluation Report by National Evaluators
? December 1999	Completion of Live Phase of Trials
? March 2000	Final Data from Trials and Completion of Local Evaluation Reports
? July 2000	Final Reports of National Evaluation due

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 Australia[2] 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.

1.2 Background to Linked Care

The Linked Care Trial was proposed in 1995 by the NSAHS in response to a national call for expressions of interest in September of that year. The NSAHS committed associated facilities and services through a joint expression of interest with the Hornsby Ku-ring-gai Division of General Practice (incorporating Ryde) and a number of independent non-profit health and community services, most of which were funded through the Home and Community Care Program (HACC). Preparations continued throughout 1996 and 1997,

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

and Linked Care formally commenced operation on October 1 of that year. It operated until December 1999, with a final evaluation reports due by the end of March 2000.

Briefly, the model of care coordination proposed for Linked Care was that a CC was to be appointed for each participant, either their GP or an employee from an agency that provided 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, wherein 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.

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, Chapter 1, and an explanation of the evaluation methodology, which is presented in Chapter 2.

Part B presents the findings of the evaluation. These include issues concerned with the organisation and management of Linked Care, including establishment issues, financial management, care coordination, service substitution and medical intervention, as discussed in Chapter 3. Chapter 4 details the impact of Linked Care on clients, including a description of the participants, client outcomes, impact on carers and participant experiences. Following this, Chapter 5 focuses on service delivery. This includes service provider experiences, service usage patterns and the response from the whole system. The findings are drawn together in Part C, in terms of the national and local hypotheses (Chapter 6) and analysing how the Linked Care model performed (Chapter 7).

A separate volume of evaluation instruments also accompanies the report.

The report should be read in conjunction with the three thematic reports:

? *Client Experience Report*

? *Service Provider Experience Report*

? *Whole of System Report.*

2. Methodology and Approach to the Local Evaluation

2.1 Background to the Evaluation

The local evaluation of the Linked Care Trial was undertaken 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.

Evaluating such a complex trial with limited resources required careful conceptualisation, planning and prioritisation of the research tasks. This chapter provides an overview of the main elements of the research design and the methodologies employed by the UNSW Evaluation Consortium.

National and Local Hypotheses

The *National Evaluation* and the *Local Evaluation Tender Requirements*, stated that the evaluation was 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 a 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.

2.2 Conceptual Framework of the Evaluation

The framework adopted in this evaluation built on the basic framework set out by the national evaluation and the NSAHS specifications. 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

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.

Three research paradigms were particularly important for this study. The first, the Production of Welfare approach (Davies and Challis, 1986; Davis et al., 1990), is 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 generated.

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

Figure 2.1: The Production of Welfare Process and the Linked Care Trial

Inputs	Production Process	Outputs	Outcomes
e.g. ? Funds (public and private) ? Clients ? Staff	e.g. ? Fund pooling ? Care coordination/ case management ? Care plans	e.g. ? Types of services provided ? Amount of services provided ? Medication usage	e.g. ? Residence of client ? Quality of life ? Comparative costs

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, comparing the results for participants in the Intervention group with those for a matched Control group.

Linked Care used a matched Control group from a comparable, neighbouring area, the Ryde Hunters Hill Municipalities. Although the advantages of a randomised control group were recognised, the Linked Care management considered that randomisation raised very practical difficulties. The geographical control was accepted by the evaluators in spite of the greater difficulties in comparing the Intervention and Control groups.

2.3 Evaluation Methods and Other Issues

Data collection methods

Data were collected on each of the key topic areas discussed above, using quantitative data where available, and qualitative data and observations where appropriate. A summary of these types of data is found in Table 2.1. The different types of data are discussed after the table.

Table 2.1: Summary of Evaluation Measures

Inputs	Characteristics of services and services networks:
	- during Tracking Phase
	- at selected points during the trial
	Financial inputs analysed by category (administration, overheads, direct service provision, care coordination):
	- during Tracking Phase
	- at selected points during the trial
	Number and type of clients accepted and included in Intervention/Control groups
Processes	Process of care coordination
	Process of fund pool management
	Process of managing Linked Care
	Patterns of service provision:
	- during Tracking Phase
	- at selected points during the trial
	Difficulties reported by those involved in Linked Care
	Perceptions of staff and participants of changes in service operation and client outcomes
Outputs	Patterns/volume of services provided to participants:
	- at the start of Linked Care
	- over the course of the trial
Outcomes	Outcomes for clients:
	- death and admission to residential care
	- health and health related quality of life
	- measures specified by national evaluators: residence etc.
	Outcomes for caregivers
	Perceptions of staff and participants of client outcomes

Service Inputs

A detailed financial analysis was required to identify and trace costs incurred in each aspect of service provision. These data were provided by trial management, participating services and funding bodies. They were used to provide a basic service profile which related the cost of service provision to the characteristics of the client population. Data collected on service inputs as part of the evaluation included:

? information on the finance, staffing and cost of services; and

? the number, type and needs of clients referred, assessed and accepted for service.

A detailed cost analysis of the operation of individual services and of the local service network at different points in time was employed to distinguish costs of administration from other significant costs, including those of assessment and referral, direct service provision, transport and accommodation costs. The cost analysis also provided a fine grained portrait of changes in the way health and community services operated. Together with other data, this was also used to examine the factors affecting the access of consumers with different needs for services.

Processes

The study of organisational procedures and processes was based on observation and interviews with key service personnel at different stages of the projects. The process of change was observed by attendance at selected meetings and by focus groups and interviews (including telephone interviews) with medical practitioners, other service providers, service recipients and their caregivers. This component of the study also paid attention to the factors that influenced the organisation of the trial and the legal and professional constraints on the reform process. This component was regarded as a critical aspect of the evaluation since the trial was essentially concerned with organisational and inter-organisational change. It provided a context for interpreting the more quantitative data on inputs, outputs and outcomes.

Service Outputs

Data on outputs of services collected and analysed as part of the evaluation included:

? information on the numbers of participants with different profiles of need, receiving assistance; and

? information on the type, amount and frequency of assistance they received.

A comparative analysis over time shows changes in the pattern of service delivery and identify possible changes in the efficiency of service provision.

Outcomes for Consumers

Although measures of service output may show the efficiency of services, they do not indicate their effectiveness. Indeed, it is possible for services to increase their efficiency, at the same time reduce their effectiveness. To monitor effectiveness, measures of outcome were required. To address issues of this kind, basic data on outcomes for consumers were 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 caregivers 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 Health and Well-being Questionnaire, Short Form 36 (SF-36) and other measures agreed with Linked Care and consistent with those identified by the national evaluators. These included clinical indicators and data on health service outcomes, including changed patterns of service utilisation.

Major Topic Areas for the Evaluation

In practical terms, it was also found useful to distinguish different components or data collection topics. Three major topics of interest were highlighted in the evaluation:

? the organisation and management of Linked Care;

? participants experiences (service recipients and their caregivers); and

? the impact of Linked Care on service providers.

Further details of the evaluation data sets and research methods used in the evaluation of Linked Care are listed in Appendix 2. A separate volume of evaluation instruments also accompanies the report.

Impact of Trial Delays and Extensions on the Evaluation Methodology

The recruitment period for most of the Coordinated Care Trials was extended by three months to March 1998 (Section 3.1). The planned conclusion of Linked Care was also extended to 31 December 1999 and the due date for the evaluation to 31 March 2000. These extensions were needed to compensate for what, in retrospect were unavoidable delays in the commencement of the Live Phase due to delays and difficulties in the recruitment of participants. The extension was an opportunity to revisit the evaluation plan in light of significant changes in the intervention and the organisation of Linked Care.

Additions to the methodology were agreed upon in conjunction with the 6-month extension to the evaluation. These are summarised below:

? the measure of disease control was added as an additional health outcome measure to supplement the SF-36;

? collection of medical plan data for the Control group was added to obtain comparative diagnoses and medication for all participants;

? the repeat collection of participant profile data changes for both the Intervention and Control groups was added to analyse significant changes to living and health circumstances;

? reports on Linked Care's process of care coordination and its interaction with existing mechanisms for the coordination of care by service providers and the process of designing and modifying the fund pool;

? the impact of the Patient Medication Management System; and

? case study reports on selected participants.

Up to the mid-trial, the evaluators could only follow the development of the Linked Care systems, rather than their effectiveness. The lengthy development period meant that much less time was available to evaluate the effectiveness of the mature system. Some of the significant delays were:

1. Delays to the revision of the fund pool, which extended until the end of 1999. Financial data needed to be adjusted before evaluation of changes to financial and service usage data due to the intervention could commence (Section 3.3).
2. Initial care plans were not completed until the end of the mid-trial point (December 1998). This delay affected the analysis of resource inputs, outputs and outcomes for the Intervention group and by implication, the comparative analysis of the Intervention and Control groups.
3. CCs drafted and reviewed care plans without access to financial information during the first half of Linked Care. Missing information included: the cost of services included in the plan; the care protocol category of their participants; and the relative cost of all services. These were necessary to be able to make financially-based substitution decisions. The relationship between care coordination and fund pool management was therefore not operational (Section 3.4) during this part of the trial.
4. Delays were also experienced with the service usage data collection (Section 5.4).

These delays meant that the data available for analysis of service usage by participants in the first year was compromised for estimates of some items (Part B).

The Relationship Between the Evaluation and the Linked Care Trial

There was potential for conflict between the local evaluation and trial management whose work was being evaluated. The UNSW Evaluation Consortium was, however, fortunate in the professional approach taken by the Linked Care staff. This allowed the evaluators to provide advice about ongoing operational concerns while still monitoring the trial in an objective way.

In October and November 1997, the evaluators presented the Establishment Phase achievements to the Linked Care Tender Committee and tendered for the Live Phase evaluation. The process was prolonged by detailed discussions on clinical outcomes. The medical members of the Tender Committee, particularly the Division of General Practice and the NSAHS (sponsor) wanted more clinically relevant outcomes than the SF-36, but the evaluators were concerned about how this could be done within the budget. Ultimately a measure of disease control was devised which met both sets of requirements (Section 4.3d).

At first instance, the evaluators reported through the Linked Care director to the Management Committee, Evaluation Working Party and other working parties, rather than

directly to the sponsor. This could have created difficulties, if the evaluators produced findings that were critical of Linked Care management, trial director or Linked Care staff.

The evaluators worked from the Linked Care office one day per week. This provided opportunities for observation, discussion and advice. Formal reports were provided to working parties about findings that concerned their work. In all other respects the evaluators took care to minimise the impact of the evaluation on the intervention. Thus additional data collection requirements were kept to a minimum and briefings were held with trial management before any evaluation activities commenced.

Part B Findings

3. Organisation and Operation of the Coordinated Care Trial

This chapter describes the organisational aspects of Linked Care. Although there were delays in implementing Linked Care, as the chapter reveals, establishing an intervention in the context of a rapidly changing health and community service sector was a delicate process. Not only did Linked Care design the care coordination and fund pool mechanisms, but it also managed to develop successful relationships with the many partners to the process.

The chapter describes first, general operational issues for Linked Care, including the time to establish the model, the recruitment process and information technology issues (Section 3.1). The management structure to operate Linked Care is then discussed, including a brief description of the major partners in the project (Section 3.2). The design of the financial management systems are then outlined, including discussion of the operation of the fund pool and implementation of links between fund pooling and care coordination (Section 3.3). The evolution of the care coordination processes, including the characteristics of the CCs, the care planning and the innovative Peer Support Group (PSG) structure is then explained (Section 3.4). A summary of the service substitution strategies is presented in Section 3.5. The controversies involved in introducing specific trial initiatives to Linked Care are explored in Section 3.6. Each section follows a formula of describing the structure, processes and trial experiences of implementing the organisational aspect of Linked Care under discussion. The sections each conclude with a summary of the results.

3.1 Establishment and Operational Issues

3.1a Establishment Timeframe

The Linked Care Trial could be said to have completed difficult but successful establishment and implementation stages following the commencement of the Live Phase of the project in October 1997. A summary of important milestones in Linked Care's operation is presented in Table 3.1.

In the short time to the commencement of the Live Phase, Linked Care had achieved a great deal as shown in Table 3.1. These achievements included the establishment of a successful working partnership between a range of previously independent and often fiercely autonomous service providers and organisations, the commitment of the main service providers to contribute to Linked Care's fund pool, a draft practice manual for CCs, the development of a working project office, the recruitment of dedicated, professional and highly competent staff, and the development of appropriate consultative and decision-making structures for Linked Care. In addition, staff succeeded in recruiting over 400 participants from the Hornsby Ku-ring-gai area for the Tracking Phase, most of whom, it was anticipated, would take part in Linked Care as members of the Intervention group.

Recruitment of members of the Control group, from the neighbouring area of Ryde Hunters Hill had also commenced.

Table 3.1: Milestones in Hornsby Ku-ring-gai Coordinated Care Trial

	Date	Milestone
1995	January to September 1997	Tracking Phase: established partnerships with service providers and organisations, commitment from service providers to contribute to a fund pool, draft CCs practice manual, project office and staff, consultative and decision-making structures, recruitment of over 400 participants for tracking
1997	March	Appointment of the Local Evaluator
	October	Live Phase commenced, fund pool and infrastructure budgets operational, CCs allocated, IT system operational
		CC training
		Trial Utilisation System (TUS) information system delivered
	December	Baseline administration of the SF-36 (completed August 1998)
1998	February	Hospital notification system commenced
	May	Recruitment completed
		Peer Support Groups commenced
		Patient Medication Management System commenced
		TUS upgrade
	September	Fund pool revision commenced
	October	Final CCs allocated
		Strategic Planning and CC Workshops
	November	Resource list (care options) distributed to CCs
	December	Second administration of the SF-36 (completed August 1999)
1999	February	Service usage reports distributed to CCs
		Hospital Issues Working Group commenced
		TUS upgrade
	March	All participants had an active care plan
		Clinical Working Group
	June	GP Peer medication reviews commenced
	August	Hip protectors commenced
	November	Fund pool revision completed
		Third administration of the SF-36
	December	End of trial
2000	March	Local evaluation reports

Progress after the commencement of the Live Phase continued to be impressive, although delays were experienced in establishing and implementing some aspects of Linked Care's

operation throughout the remainder of the trial. Although the Linked Care management sought to adhere as closely as possible to the program's national schedules, a theme emerged of the underestimation of the complexity of the multiple tasks involved. Given the pioneering nature of many of Linked Care's undertakings it seems obvious, in retrospect, that unexpected difficulties would be encountered. These difficulties affected many aspects of Linked Care's operation, from the recruitment of participants through to the establishment of the computerised information technology system required to link the different data sources on services utilised by trial participants from both the Intervention and Control groups. Yet while difficulties remained in some areas, the record of Linked Care management in dealing with the problems encountered was impressive.

Delays were encountered, for example, in the recruitment of participants, which in turn affected other aspects of Linked Care. Recruitment of members of the Intervention group was officially drawn to a close in March 1998, three months later than had originally been planned. The delay in recruitment had implications for implementing Linked Care's operational systems (e.g. allocating CCs and finalising the fund pool) and for the evaluation data collection and analysis (e.g. SF-36; participant questionnaire and telephone interviews).

Subsequent delays were encountered in the finalisation of care plans for each participant in the Intervention group. As discussed in Section 3.4, some of these delays seem to reflect the inherent complexity of preparing care plans that involve a number of service providers from different health professions. But by far the most disruptive cause of delay was the failure of a number of CCs, particularly GPs, to complete the required paperwork. Eventually, a decision was made that where care plans remained outstanding after several months and after repeated efforts by trial administration to have them completed, new CCs were assigned to the participants.

Another source of unexpected difficulty arose from problems of linking different data sources together as part of the project database. These problems, which were generally eventually resolved, were thought to be establishment difficulties (Sections 3.3g and 5.4a). However, Linked Care continued to have data collection and transfer difficulties throughout the trial. Information technology is discussed in greater detail later in this section (Section 3.1d).

It is less clear whether difficulties and delays encountered in a number of other matters can be so readily ascribed to set up processes. The fund pool, for example, was successfully established, but its operation required revision of fund pool contributions from the different contributors that were not finalised until the end of the trial. As a consequence, the operation of the fund pool, was retrospective, with expenses incurred by participants being met from the pool rather than care planning being driven by the financial determinants of the fund pool (Section 3.3).

3.1b Recruitment Process

Criteria for entering Linked Care were that a participant had to:

? be a resident of Hornsby or Ku-ring-gai Municipalities;

? be living in the community (not in a nursing home or hostel, but may be a patient in an acute hospital);

? likely to need ongoing care or a period of high level support; and

? not have a primary need for mental health services.

They had also to:

? use two or more either health or community services, not including their doctor or pharmacy; or

? be unable to live independently without community care or support by the family.

In addition:

? 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 to participate; and

? their GP must not have excluded the person from participation on clinical grounds.

Participants were recruited to Linked Care through a combination of contact by existing service providers (mainly HACC agencies) and GPs, employed recruiters and public advertisements. This was to protect the privacy and interests of the participants. It prolonged the process by relying on the agencies being able and willing to allocate staff time to recruitment.

Experience of Linked Care indicates that recruitment took an average of four hours per participant to ensure informed consent and collect baseline profile data. Over 2,000 participants were interviewed. In the view of Linked Care administration, recruiting to the Tracking Phase, then repeating the process to recruit the same participants to the Live Phase was a time-consuming, probably wasteful strategy. The two-phase process was problematic because of the high exit rates due to death, withdrawal or moving to a nursing home or hostel, and the duplication to recruit remaining participants twice.

The target numbers for recruitment were almost, but not fully achieved, as listed in Table 3.2.

Table 3.2: Participants Recruited

	Date	Intervention	Control
Target recruitment	September 1997	1000	500
Final recruitment	May 1998	722	423

Considerable effort and resources were put into bringing the numbers closer to the targets of 1000 Intervention and 500 Control participants. Because of the slow response to recruitment efforts in the Intervention area, the recruitment period was extended until March 1998, six months after the start of the Live Phase. From April 1998, Linked Care did not actively seek new names but continued to follow up names of participants still in the recruitment process. Follow up activities associated with recruitment continued until August

1998. Achievement of less than the target recruitment number continued to be problematic when combined with the higher than expected exit rate (Section 4.3a).

Linked Care was a little more successful recruiting Control than Intervention participants, probably because the recruitment process had been streamlined before recruitment began in the Control area. From October 1997 to April 1998, 423 recruits were successfully enrolled to the Control group. The agencies were very cooperative. The most successful strategy was to receive names from GPs or other service providers for a recruiter to follow up.

Once a consent was obtained (the activation date), the recruiter was asked to complete a participant profile and the participant was sent an SF-36 within three weeks. It was intended that CCs prepared a care plan immediately but in practice for some participants this was delayed up to 12 months after consent.

That the final numbers of participants came to close to the original targets of 1,000 Intervention and 500 Control group members was a tribute to the persistence and commitment of Linked Care staff and recruitment sources. The delay in recruitment reflected a number of issues, including the limited number of potential subjects who met the conditions for recruitment in Linked Care's catchment area, a reluctance of some service providers to make referrals, a degree of participant resistance to taking part in an unknown and innovative experiment, and perhaps other factors. Most if not all these factors were outside the control of trial management and service providers participating in Linked Care.

3.1c Participant Involvement in the Organisation of Linked Care

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 and Quality and Complaints Working Party quality control mechanisms).

Linked Care and the local evaluation had a number of contacts with participants in the trial (Table 3.3). The participant questionnaire and telephone interviews were administered to equal samples from both Intervention and Control groups.

Table 3.3: Trial and Evaluation Contacts with Participants in Linked Care

Intervention participants	Control participants
Trial interventions	
Consenting process	Consenting process
Care plans	Medical care plan listed
CC assigned	
Consumer representatives	
Newsletters (occasional)	Newsletters
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 (all participants)	
2 x Participant questionnaires (sample)	
3 x Telephone interviews (sample)	

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 this chapter and Section 4.3.

? 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 (Section 3.4d).

? Complaints: participants could telephone the 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) (Section 3.4h).

? Withdraw consent: while a minority of Intervention participants chose to withdraw (9 per cent), most Intervention participants remained with Linked Care (Section 4.3a).

? 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 (Section 3.4i).

3.1d Information Technology

The Linked Care information technology (IT) system was a modification of existing software, The Care Manager (TCM), supplemented with the development of additional software, known as the Trial Utilisation System (TUS). The information system was developed specifically to:

? enable the capture and transfer of data required by the national and local evaluators;

? enable the management of the fund pool;

? support the generation of the care plans for CCs;

? capture and store planned and actual service utilisation data; and

? generate reports for decision support in the care planning, care coordination and fund pool management processes.

The design of the information system was primarily determined by the data requirements of the national evaluators (Faculty of Health Sciences, 1998).

The information system succeeded in meeting a number of the above objectives.

? Handwritten care plans were successfully entered into TCM and a printed copy of the care plan returned to the CCs.

? Utilisation, demographic, outcome, and financial data were collected, stored and retrieved in accordance with the requirements of the national evaluators.

? The Linked Care administration was able to retrieve essential management information about financial performance, care plans submitted by CCs and utilisation, recruitment and retention data about participants.

? The information system could be interrogated for specific reports, 'one off' studies and for integrity checks.

However, the information system also faced significant challenges, which are explored more fully throughout this report. These included:

? the timely production of printed care plans;

? the ability to cost the services listed on each care plan;

? the ability to obtain actual service utilisation records; and

? the ability to match planned with actual care services.

The Care Manager (TCM)

Data from the care plans was managed in TCM. The information system was operated and administered centrally within the Linked Care head office. This involved the CCs sending hand written care plans into the central office, Linked Care staff data entering the details from the care plans into TCM and the delivery of the printed care plan back to the CCs. Linked Care staff found the care plan data entry into TCM slow and cumbersome (Section 3.4d).

TCM was an application developed in Microsoft Access 2. This application was designed to assist an individual case manager's workload, it was not designed to capture over 3000 care plans generated by the whole of the Linked Care trial. The large number of care plans stored within TCM application resulted in a considerable reduction in its performance.

TCM application was owned by an independent vendor. Linked Care purchased the rights to this application and paid to have it modified to meet Linked Care requirements. Because

the application in use by Linked Care was customised, Linked Care was unable to obtain the version upgrades of this application. Within this arrangement modifications to TCM application were difficult to organise and costly to implement.

In relation to care plans, it was also one of the trials objectives to inform the CCs of the cost associated with the planned health care services. This proved to be a very difficult administrative exercise due to:

- the design of TCM and TUS not enabling the easy update of service costs. The database tables that held the costing details within the applications were difficult to access and administer;
- not being able to easily obtain price changes to the MBS and PBS schedules electronically; and
- not being adequately informed of all price changes for service at community-based health care agencies.

Trial Utilisation System (TUS)

Data about actual services used was managed through the TUS. The collection of records of services provided to Linked Care participants proved to be equally challenging as data about services planned. Actual service records were either obtained in electronic or hard copy format (Section 5.4a). The ideal was to obtain service records electronically. The transfer of electronic records from the individual service providers electronically required an individual software program to be developed for each of these agencies.

Transferring data extracts from service providers proved to be a complex process, requiring far more time and expertise than was initially identified. It was found that expertise in information technology and data management was limited in some of the community-based agencies. They were therefore restricted in their ability to verify and check the accuracy and completeness of the data extracts, which resulted in significant data quality issues for Linked Care.

Linked Care had difficulty developing reports to support CCs with decision-making (Section 3.3f). Problems included:

- a lag in obtaining actual service utilisation records after the actual service occurred. The lag in obtaining actual service records prevented participant service usage reports being useful to CCs in the review of services provided to participants; and
- the design of the Participant Service Usage Report developed over the period of the trial. This report attempted to match planned records with actual service records. The mapping process was too strict and resulted in reports that were not meaningful, except for comparing groups of planned and actual health care service, determined by the type of service (e.g. hospital in-patient services).

The information system appeared to adequately support the operation of fund pool (Section 3.3). Restrictions on the quality of data management seemed to be due to limitations in the data collection, data transfer and data entry rather than the information management system itself.

Over the period of the trial, the information system evolved as the coordinated care business processes and information requirements were more accurately defined. The licensing arrangements associated with TCM and the high costs associated with IT consultants hindered this development. Because of the time restrictions imposed by the design of the trial and the deliverable dates determined by the Commonwealth, the method for identifying IT support needs in the business process was poor. As a result, business processes and the IT to support them were developed simultaneously. This resulted in an information system that achieved its primary objectives but had a number of limitations.

3.1e Results from the Establishment and Operational Mechanisms

The Linked Care experience of establishing these operational issues is presented in Table 3.4.

Table 3.4: Results from Operational Mechanisms

Intervention	Results
1. Establishment timeframe	Establishment of a complex coordinated care model with multiple stakeholders was protracted. Parts of the establishment were dependent on successful completion of prior steps. An externally imposed timeframe was impossible to adhere to. The evaluation had to be mindful of the short operational period of many aspects of the intervention.
2. Recruitment process	Recruitment through existing providers was prolonged. A simplified process of referral from providers was more successful. Continuous recruitment would have assisted with the high exit rate.
3. Participant involvement	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.
4. Information technology	The complex IT system to capture participant-level planned and actual service use struck many obstacles, not all of which were overcome. The obstinate difficulties related to the quality of the data (collection, entry and transfer) rather than the IT system itself.

3.2 Management and Governance Arrangements

3.2a Management Structure

Linked Care was sponsored by the Northern Sydney Area Health Service (NSAHS). Linked Care was managed by the Linked Care organisation, headed by its Director, who was responsible to a Management Committee. The Management Committee included representatives from the sponsor, the fund pool contributors, consumer representatives, the Division of General Practice and a HACC representative, with an independent chairperson. Under the legal structure of the NSAHS, the Management Committee was responsible for decisions about the policy and financial arrangements in Linked Care. It operated similarly to a board of a medium size organisation. The Advisory Consortium was formed to advise on the establishment of the trial, but did not sit after this initial Establishment Phase as it duplicated the functions of the Management Committee.

Working parties reported to the Management Committee on a monthly basis. The same organisations as sat on the Management Committee were represented in the working parties. The working parties were the main means for Linked Care management to consult with stakeholders. At the start of the Live Phase there were six working parties. Three continued to operate: the Evaluation Working Party, the Quality and Complaints Working Party and the Finance Sub-Committee. The other three working parties (Care Coordination, Information Technology, and Professional and Industrial Issues) did not sit during the Live Phase, because the decisions about the establishment tasks for which they were formed were complete.[3] Changes in the management structure are illustrated in Table 3.5.

Table 3.5: Management Committee and Working Parties

	Establishment Phase	Live Phase
Management Committee	yes	yes
Advisory Consortium	yes	no
Finance	yes	yes
Evaluation	yes	yes
Quality and Complaints	yes	yes
Care Coordination	yes	part
Information Technology	yes	part
Industrial Relations	no	no

During the Establishment Phase and early Live Phase, some tension was generated by the complexity of the decision-making processes. Consultation involved systematic arrangements covering the many groups and Linked Care management, as well as bilateral

[3] The Care Coordination Working Party was reconvened in the last quarter of the trial to consider the design of the care coordination process for the next phase of Linked Care.

arrangements between Linked Care management and service providers. As Linked Care moved further into its Live Phase this tension appeared to dissipate somewhat, although some conflict remained.

Linked Care had to conform to national requirements, whilst at the same time needing to make local decisions in a flexible and autonomous manner. These conflicting expectations were made all the more difficult by the changes in personnel at the Commonwealth level.

Although it was originally thought that the division of responsibility for health care between the Commonwealth and the State would have been resolved, this was not the experience of Linked Care management. Indeed, difficulties arose with the definition and sharing of responsibility for problem solving and policy decisions between the national evaluators and the Commonwealth and State governments (for more detailed discussion, see Baldwin, 2000).

3.2b Northern Sydney Area Health Service

The NSAHS, as sponsor of Linked Care, a large fund pool contributor and a care coordination subcontractor, had to manage tensions between its many roles and with the smaller service providers participating in Linked Care. In the Tracking Phase of Linked Care, a decision was made not to incorporate a separate body to run the trial, but this made the sponsor a target of mild hostility throughout the trial. An example was the HACC agencies' fear that Linked Care had an emphasis on medical health instead of a more inclusive quality of life model.[4] However, it can clearly be seen from the discussion below that the committees did work collaboratively to manage Linked Care despite this in-built tension in the management structure.

3.2c Service Providers

The major service providers involved in Linked Care were the fund pool contributors, the agencies from which care coordination was subcontracted and a number of other agencies that provided services to the participants. Most of these providers supplied service usage data and were represented on Linked Care's management working parties. These aspects of their involvement in Linked Care are discussed in more detail throughout the report. The service providers and funders are listed in Table 3.6.

[4] MFC and HCS managers, service provider baseline interviews, December 1997.

Table 3.6: Service Providers and Funders in Linked Care

	Fund pool contributor	Care coordination subcontractor	Supplied service usage data	Management/ working party representation
Health Insurance Commission: MBS, PBS	yes	no	yes	no
NSAHS: HKHCHS[(a)], Royal North Shore and Ryde Hospitals inpatient services	yes	no	yes	yes
HKHCHS: Outpatient	yes	yes	yes	yes
Northern Sydney Home Nursing Service	yes	yes	yes	yes
Home Care Service	yes	yes	yes	yes
Department of Veterans' Affairs	yes	no	yes	no
Mercy Family Centre	yes	yes	yes	yes
HCF and MBF	yes	no	yes	yes
Other HACC services (e.g. Wesley, Meals on Wheels, transport, home maintenance, gardening)	no	no	sample	yes
General Practitioners (representing the Division of General Practice)	(HIC)	yes	(HIC)	yes
Pharmacists	(HIC)	no	(HIC)	yes

Note: (a) Hornsby Ku-ring-gai Hospital and Community Health Services

To evaluate the service providers' involvement in organising and designing Linked Care both questionnaire and interview data were obtained from the major health and community service providers in the Hornsby Ku-ring-gai area, with some additional document collection. The evaluators also attended many of the working party and consultation meetings.

Striking a balance between appropriate consultation and meeting externally imposed timeframes and constraints on the design was one of the major challenges for Linked Care management. The Establishment Phase of Linked Care revealed the service providers' admiration for the achievements and, at the same time, their frustration at the compromises imposed by the pace of change expected to implement Linked Care. Details of the development of the relationship are included in the *Service Provider Experience Report*, Section 4.1.

The individual local service managers were critical to the success of Linked Care because of their critical role in the establishment and operation of care coordination, the fund pool and other management processes. For these reasons their personal knowledge of and commitment to Linked Care was important. Unfortunately many of the service providers

restructured or their director was replaced during the first year of Linked Care. This probably had an impact in delaying Linked Care processes and negotiations with providers. Significant changes to the key agencies included:

? the senior executive of the NSAHS changed during the trial;

? the two branches of the HCS (one in the Intervention area and one in the Control area) amalgamated and the manager with the most involvement in Linked Care left the HCS;

? the board and senior management of the MFC changed twice, resulting in Linked Care negotiating with three different CEOs;

? NSHNS was restructured with a complete change in senior management, again resulting in Linked Care negotiating with three directors; and

? the director of the ACAT changed.

Changes such as these appear common within this dynamic sector and therefore need to be accounted for in any ongoing care coordination model.

In the process of consultation and decision-making Linked Care staff were generally seen to be readily available and supportive. The managers suggested that the lessons learnt in the complex process of establishing Linked Care, included:

? initially, more time should be spent explicitly discussing issues, agendas, fears and attitudes of parties to a trial, including the sponsor and participating service providers, instead of talking around these issues;

? decisions should be put on paper early and moves should be made to pilot processes before a trial goes live to minimise modifications during the live phase; and

? agreed policy statements and updated changes should be documented in a succinct form so that people can focus on the issues, without getting lost in the volumes of information and changes in expectations.

By the mid-point of Linked Care relationships between service providers and Linked Care administration appeared reasonably comfortable. No major conflicts had arisen and all contributors remained in the fund pool and represented on the management working parties. However, the organisational achievement of implementing a complex trial in such a short timeframe predictably had some casualties. Although understanding the need for rapid implementation, some service providers' were frustrated early in Linked Care at the limited opportunities for their concerns to be adequately addressed.

Perhaps the least reassured was the Division of General Practice, which continued to approach the development of initiatives proposed for the second half of Linked Care period with caution. Linked Care participated in monthly meetings of representative GPs from the Division to address these concerns. GP representatives on committees also appeared to have difficulty reconciling their representative role with the looser Division structure. For example, feedback to the Division from monthly Linked Care committee meetings seemed to be ad hoc. The participating GPs expressed frustration, perhaps born of unfamiliarity, with reporting through a bureaucratic system of management and administration.

Private Health Insurers

Having responded somewhat later than other stakeholders, the private health insurer contributions were treated differently to other fund pool contributors. The HCF and MBF funds were not added to the Linked Care fund pool, but operated as separate pools held by the companies. It was intended that two transfers be made to the Linked Care fund pool: a contribution for care coordination and payments for any care substitution that prevented or shortened hospital stays. Pool balances were to be transferred to Linked Care at regular intervals.

MBF and HCF did not transfer accurate service usage data to Linked Care until the end of the trial, except total financial figures. Without unit-level data, Linked Care was unable to verify the PHI summary analysis or make transfers to the fund pool.

The private health insurers did not take a pro-active role in Linked Care, such as responding to the need for unit record data transfers, taking an active role in substitution decisions, or promoting Linked Care opportunities to their members or the members' CCs. Rather the trial afforded them an opportunity to observe issues that arose when organising care coordination. Those observations may be of relevance to them if they also were to experiment further with managed care, funds holding, care coordination, or other forms of case management.

Responsiveness of Service Organisational Structures

Service provider managers were asked throughout the trial about their expectations and experience of Linked Care.[5] In relation to their participation in the organisation of Linked Care, they made interesting observations about the ability of their internal management structures to respond to the demands of the model, summarised in Table 3.7. These issues related to their own infrastructure barriers rather than faults with the Linked Care management model.

Table 3.7: Expectations and Impact of Linked Care on Service Organisation

Expectation	Service providers' experience
Organisation costs increase or remain the same	Hospital and HACC service managers reported increased costs because of trial effects (time, workload, duplication and inertia), subsidising CC time and their own limited administrative systems to seek reimbursement.
Inertia in service organisation to make structural changes	Service managers and staff in community- and hospital-based organisations complained about having to stretch existing resources further to meet the additional service and administrative demands of Linked Care, despite reimbursement from the fund pool.
Improvement in data information systems	ACAT reported the more accurate assessment of their normal operating costs for Linked Care was useful for

[5] Appendix 2 Evaluation Data Sets.

analysing the appropriateness of the ACAT budget.

3.2d Consumer Representatives

During the Establishment Phase Linked Care management recruited sixteen consumer representatives through advertisements in the local newspaper. Consumer representatives were reimbursed for their expenses at a rate of $25 per hour. Their primary role during the Establishment Phase 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 some times at odds with trial management interests.

They thought that participants were not sufficiently involved in the design of Linked Care during the Establishment Phase. As a result, 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 directly for help from service providers or CCs. Participant criticism focused on the lack of change in care received when the participants' CCs were their existing service provider or GP.

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

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.

3.2e Linked Care Administration

Linked Care operated with up to twelve staff (seven full-time equivalents) supporting the financial, care coordination, data management and policy development functions. The size of the administration was also to some extent predetermined by the numerous tasks necessary to fulfil the trial requirements, such as data management, evaluation and process recording. Therefore few opportunities for administrative efficiencies were open to Linked Care during this short trial with decreasing participant numbers.

The administration could be typified as a structured centralised system, where decisions were formalised through working parties, approved by a management committee, and their implementation was overseen by the administration. Lessons and decisions were rigorously recorded as the model evolved through the implementation.[6]

The administration also played a direct role in the care coordination function, such as providing a back up for the care coordination function (e.g. when CCs were absent and not replaced by their agency or when requests for additional financial expenditure were made between PSG meetings). In addition it also acted as a central point for coordination (e.g. admission data were provided by hospitals to the Linked Care office to notify CCs). This centralised position probably facilitated efficient decision-making but was at times also controversial.

Service provider managers, consumer representatives and CCs reported they felt supported by Linked Care staff and by their availability to listen to concerns and to accommodate changes in response to the issues.[7]

They made suggestions about improving the quality of the communication with Linked Care staff through written records about advice, decisions and outcomes from meetings.

The managers applauded two strategies used by the trial administration to enhance consultation:

? using consultants because of their familiarity with the service providers and their objectivity arising from their distance from the trial management; and

? arranging meetings between trial management and service provider management to inform each other, work through issues and promptly follow up outstanding decisions. When such meetings had been held to resolve matters with the ACAT and MFC, managers saw them as very constructive.

The *Service Providers Experience Report*, Section 4.1 discusses issues of relations between service providers and the administration in more detail.

---

[6] Whereas the administration's role was to act on decisions from the committee structure, at times this required pre-empting committee decisions, e.g. replacing the last round of PSG meetings in 1998 with a compulsory workshop.

[7] Service managers and CC questionnaires, Appendix 8; consumer representatives focus group, November 1997 and questionnaire, November 1999. This feeling of support declined, although not significantly, for CCs (77.3 per cent to 58.5 per cent; Table A8.1).

3.2f Results from the Management and Governance Arrangements

Table 3.8 presents a summary of the findings on management and governance arrangements.

Table 3.8: Results from the Management and Governance Arrangements

Stakeholder	Results
1. Management committees	The inclusive model of management provided multiple opportunities for participation in decision-making. It may have aggravated the delays in establishing the model, but the benefits from inclusivity appear to have been a purposeful choice.
2. Sponsor	The sponsor had potentially conflicting roles through being the sponsor, fund pool contributor and CC subcontractor. This lack of funder-provider split created tension with other agencies.
3. Service providers	Not all stakeholders made use of the inclusive management model. Some stakeholders remained hostile to the decisions. Some stakeholders made use of more direct communication with Linked Care. Additional structures for consultation with the Division of General Practice did not produce observable progress although it may have reduced resistance to involvement in Linked Care.
4. Consumer representatives	The structure of consumer representation was for the representatives to participate in the management processes to represent a consumer perspective rather than the participants' views. This offered objectivity at times of conflicting provider interests. Some consumer representatives would have preferred greater direct contact with participants.
5. Project administration	Operations were centralised with implementation discretion placed in staff and some decisions later reviewed by PSGs. Staff provided direct support to CCs for particular functions (e.g. organising PSG meetings) and upon individual request. The administration was a clearing-house for ideas and innovation.

3.3 Finance and the Fund Pool

3.3a Introduction

The Coordinated Care Trials tested whether it was possible to establish and operate a fund pool of financial contributions from a range of Commonwealth and State health and community service providers. This section of the report explores the process undertaken by Linked Care to establish and manage the trial infrastructure and fund pool.

Although a fund pool was successfully created, a number of establishment and operational limitations emerged during the process. These shortcomings raise questions about the efficacy of attempting to apply a complex model of fund pool establishment with a large number of contributors. In summary, the difficulties experienced in Linked Care related to the method of calculating a fund pool and the process of managing the relationship between the fund pool and care coordination functions.

The first difficulty experienced was the slow and approximate process of establishing and revising capitation rates to calculate the fund pool contributions. This was probably due to the gap between the precision of the fund pool model and the existing financial structure of the participating agencies. The fund pool model was based on calculating capitation rates for contributions to the pool, yet most contributors operated in the context of fee-for-service or block funding. The contributors' management information systems could not produce tracking data accurate enough to predict future use. Most providers did not manage their finances on a unit cost basis, nor have alternative accurate service usage data on record. Second, contributing agencies were largely unfamiliar with assessing the options and risks of participating in Linked Care or the implications of their balance of contributions to and payments from the fund pool experienced in the first half of the trial.

Because the fund pool maintained a significant surplus throughout the trial, decisions about managing a limited financial budget did not arise. In this respect the fund pool appeared to operate as a financial accounting mechanism, rather than a budgeting device interacting with and directing care coordination decisions.

The fundamental questions about first, the effectiveness of the fund pool in improving participant outcomes and service efficiency, and second, the nature of the apparent fund pool surplus are addressed below.

Evaluation

Financial management in Linked Care was of vital concern to the evaluation of the trial. The purpose of evaluating the finances was to assess whether the operation of the fund pool improved resource allocation through responding to opportunities for savings and substitution, and whether it resulted in benefits or disadvantages to participants or non-participants, such as changed access to services (UNSW Evaluation Consortium, 1997).

This financial evaluation compares Linked Care's goals and objectives with its achievements and the features of the model that contributed to the success or limitations of the fund pool (UNSW Evaluation Consortium, 1999a). There are three steps to this comparison: mapping the evolution of the model; assessing the evaluability of the data; and identifying components critical to the success or failure of parts of the model. These steps are summarised in the questions below.

1. **How did the financial management model develop during the course of the trial?**

Research was focused on identifying processes of negotiation and development involved in establishing the fund pool and on determining the size of contributions. Developments will be described in terms of the context, reasons, process, stakeholders, and the final effect of changes to the model.

2. **With the data available from Linked Care, was it possible to observe features of the financial management?**

Features included: the extent of service substitution; management of capped resources; the ongoing cost of infrastructure; the ongoing cost of care coordination, with or without a fund pool; fund pool contribution rates based on best estimates of usual care; CC financial decision-making informed by data on cost of services used; and financial viability of the model.

3. **Which aspects of financial management were critical to the financial viability of Linked Care?**

Critical aspects included: the method of establishing and revising fund pool contributions; the proportion of the fund pool spent on care coordination and administration costs; data information and reporting; financial control of CC decisions (preferred providers, participant categories, peer review, resource information, training, etc.); and service substitution.

This section reviews the three parts of financial management: the steps in establishing a fund pool; managing the infrastructure required to maintain its functioning; and integrating the fund pool with the process of care coordination.

3.3b Financial Structure

The Linked Care financial structure was divided in two: a fund pool and an infrastructure budget. The Commonwealth paid the latter. Cost centre accounting applied to both accounts and interest was attracted to the accounts, calculated daily. The former, the fund pool, consisted of health and community care funds contributed by eight agencies based on estimates of the cost of care that would have been provided to Linked Care participants without the trial. Participants were assigned a CC who, 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 care services. Care provided to the participant by the contributing providers and additional private care was paid for out of the fund pool, as were care coordination costs. 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 structure.

3.3c Fund Pool Development

When Linked Care was conceived there was no clear template from which to establish financial arrangements between its multiple partners. It was an ambitious goal to manage contributions from eight funding partners. It required balancing the financial demands of Linked Care with possible financial risk to the contributing agencies. Consequently, although a financial management structure was developed over the first half of the trial, it was not still fully operational 18 months later in March 1999. Table 3.9 illustrates the changes to the estimated size of the fund pool over the life of the trial.

Table 3.9: Estimated Size of the Fund Pool to Operate from October 1997 to December 1999

	Date of estimate	Projected total fund pool to end of trial (27 months)	Intervention participants
Live Phase proposal	(September 1997)	$12 529 374	1000
Final recruitment	(May 1998)	na[(a)]	722
First year revision	(October 1998)	$10 683 000	590
Second year revision	(October 1999)	$11 564 458	409
Final fund pool size	(December 1999)	$11 004 989	396

Note: a) Linked Care did not reestimate the size of the fund pool at this stage.

There were three main groups of fund pool contributors: the Commonwealth; the sponsor, the NSAHS; and HACC service providers. In addition, two private health insurers, HCF and MBF also agreed to be contributors after the start of the Live Phase.[8] Table 3.10 lists the contribution rates for each of the fund pool contributors, as originally estimated in 1997 and progressively revised in 1998 and 1999.

[8] The service providers involved in the trial included the fund pool contributors. Some of these providers also subcontracted care coordination to Linked Care and delivered services to the participants. Other service providers supplied care to the trial participants but were not fund pool contributors. Usual funding and payment arrangements operated for these agencies, rather than payment out of the fund pool.

Table 3.10: Fund Pool Contribution Rates by Contributor, November 1999

Contributor	Contribution per Intervention participant per month ($)	
	Initial	Revised
Contribution per participant in Linked Care		
MBS	129	129
PBS	113	113
Inpatient care (NSAHS)[a]	117	263
Non-inpatient care (HKHCHS)[b]	15	15
Home Nursing	90	63
Home Care Service	102	128
Contribution per client of the contributor in Linked Care		
Mercy Family Centre	90	340
DVA	433	790
HCF	405	405
MBF	-	428

Notes: a) Northern Sydney Area Health Service public hospital inpatient care for three participating hospitals.
b) Hornsby Ku-ring-gai Hospital and Community Health Service non-inpatient care.

Each service provider paid into the fund pool a contribution based on a capitation rate derived from participants' projected service use and agreed service costs. The proposed method of calculating the fund pool was to collect from each contributor tracking data of past care used by participants recruited to Linked Care, extrapolate from that data expected service use for the length of the trial and negotiate a cost per unit of care (HKCC, 1997). Further revisions of the fund pool were to be based on usage and cost comparisons with the Control group.

The process of establishing contribution rates for the fund pool was slow and far more approximate than anticipated by the Commonwealth or Linked Care. It took three years for each contributor to complete the fund pool establishment tasks from the point of considering involvement through to revising the contribution rates. The delay was in part due to the quality of data available, both in terms of measuring the frequency of care use and the costs of service types. It was also in part due to the considerable time required for possible contributing agencies to digest options and agree to risk their financial viability by participating in Linked Care. The agreed contribution rates could probably best be described as resulting from negotiation rather than scientific exactitude.

In retrospect, it may have been more realistic to acknowledge that the services' management information systems could not expect to produce tracking data accurate enough to predict future use. Most services did not manage their finances on a unit cost basis, nor did they have alternative accurate service usage data on record. The second note of realism would

have been to acknowledge that contributing agencies were not familiar with the methods and risks associated with fund pooling.

Fund Pool Revision

Fund pool revisions were planned as part of the financial management to assess whether to amend fund pool capitation rates for each agency as listed in the Live Phase proposal or as subsequently agreed upon. The national plan for the trials was that revisions would begin when recruitment finished and be repeated at least six-monthly throughout the trial period. The first revision of all capitation rates was due in the second half of 1998. However, the first revision of capitation rates was not completed until November 1999. Subsequent revisions were therefore not made.

The lengthy process of revision was probably due to the same reasons that made the original contribution calculations difficult. Service usage and cost data were unavailable or delayed and agencies were confused about the implications of deficits and surpluses from contributions to and payments from the fund pool experienced in the first half of the trial. The complexity of completing fund pool revisions should probably be taken into account in the design of a future fund pool.

Table 3.10 above showed that the revision of inpatient costs and DVA costs resulted in significantly higher contributions from them. This had the impact of increasing the proportion of the fund pool contributed by these partners, compared to the HACC agencies' proportion of contributions which decreased, as described in Table 3.11. The financial significance of revising the fund pool contributions is illustrated in this table. It compares the difference in the proportion of fund pool contributions from each partner as estimated in the Live Phase proposal, based on the number of participants and capitation rates for each agency, with the actual contributions from each partner to October 1999.

Table 3.11: Estimated and Actual Proportion of Fund Pool Contributions to October 1999

Contributor	Initial estimates September 1997 %	Actual contributions to October 1999 %
MBS	18	13.9
PBS	14	12.1
Inpatient care	16	31.0
Non-inpatient care	2	1.5
Home Nursing	12	9.6
Home Care Service	21	10.8
Mercy Family Centre	1	3.1
Department of Veterans' Affairs	9	16.6
HCF and MBF	7	0.9
Other	-	0.2
Total	100	100.0
Fund pool size	$12.5 million	$10.7 million

Total fund pool income over the length of the trial (27 months) was $11 004 989. This was slightly lower than the estimated size of the fund pool of $12.5 million (Table 3.11). This reduction was due to the lower number of participants recruited to the trial and the high exit rate. Although it appears that final fund pool size was reasonably consistent with the estimate at the start of the Live Phase, it can be seen from the large variation in some of the capitation rates listed in Table 3.11 that this could be described as a matter of happy coincidence. Most capitation rates increased after the revision compensating for the lower number of participants than expected in Linked Care.

Costing Service Usage

The agreed cost of services to Linked Care was the outcome of a prolonged negotiation process between Linked Care management and the service providers, informed by debates within the Linked Care working party structure and discussions with the Commonwealth about using marginal or average costs.

The evaluators have not tested or reviewed the actual costing methodology used by the service providers to determine the price charged to Linked Care. The area of health and community services costing is complex and to validate the pricing levels agreed by the service providers is beyond the scope of data available to the evaluators. Linked Care and the service providers also have limited information to validate the prices and some service providers did not have records from which to precisely calculate prices.

Operation of the Fund Pool

The fund pool appeared to operate as a tracking system or financial accounting mechanism to manage payments in and out of the fund pool, rather than a budgeting mechanism interacting with and directing care coordination decisions (Section 3.3h).

It appears that once contribution rates were agreed, payments in and out of the fund pool were hampered by the continuing data collection and transfer problems. Linked Care and contributors appeared to act in good faith to provide contribution and invoicing data as promptly as it became available. Linked Care's information technology seemed to be able to respond flexibly to the variable quality in data to match invoices with services used by participants (Section 3.1d). Table 3.12 summarises the status of each of the contributors in relation to invoicing and revision of fund pool contributions.

Table 3.12: Fund Pool Contributors' Billing and Contribution Status

Contributor	Billing	Fund pool revision
HIC (MBS and PBS)	Automated system. Invoices from CDHAC were reconciled against the HIC data.	No change after the revision.
HKHCHS[(a)], Royal North Shore and Ryde Hospitals (NSAHS): Inpatient services	Automated billing process.	Revised to a higher contribution. 1999 revision did not occurred because of missing data. Exclusion of outliers resulted in a surplus to the fund pool.
HKHCHS[(a)] Outpatient	Manual processing.	The quality of the service usage data was too inaccurate to facilitate a revision.
Northern Sydney Home Nursing Service	Automated system. Difficulties with IT changes[(b)]	Revised to a lower contribution
Home Care Service	Automated system.	Revised to a higher contribution
Department of Veterans' Affairs	Automated system.	Revised to a higher contribution.
Mercy Family Centre	Manual processing.	Revised to a higher contribution.
HCF and MBF	Operational but service usage data were not transferred to Linked Care except in an aggregated form until after the trial.	Remained the same. Transfer of the balance from PHI pools into the main fund pool did not occur until after the trial.

Notes: (a) Hornsby Ku-ring-gai Hospital and Community Health Services.
(b) Section 5.4a.

For most agencies contributions were greater than payments, except for the three HACC providers (Home Care Service, Northern Sydney Home Nursing Service and Mercy Family Service), as listed in Table 3.13.

Table 3.13: Balance of Fund Pool Contributions and Payments by Contributor, December 1999

Contributor	Balance $
MBS	329 871
PBS	810 778
Inpatient care	420 997
Non-inpatient care	0[(a)]
Northern Sydney Home Nursing Service	-7 983
Home Care Service	-434 268
Mercy Family Centre	-5 634
Department of Veterans' Affairs	279 589
HCF	71 101
MBF	50 563
Other (private providers)	-78 719
Total	1 436 297

Note: (a) Accurate tracking of service use and calculation of a non-inpatient capitation rate became too difficult for the hospital and trial to manage. They agreed to a zero balance of funds in and out of the pool (Section 5.4a).

During the lead up to the end of the trial, payments out of the fund pool remained lower than contributions, so strategic decisions about managing a limited financial pool did not arise (Section 3.3h).

Monitoring Group Reports

Linked Care management successfully submitted Monitoring Group reports each month, despite significant changes in the requirements and formatting. In relation to the evaluation, due to changes to the fund pool contributions following the fund pool revision, the content of the Monitoring Group monthly reports appeared to hold little value for comparative analysis, except as a historical record of the unrevised figures.

A volatile aspect of the reports was the presentation of data divided by month. The monthly data were retrospectively adjusted in the trial, and payments out of the fund pool for one month did not necessarily reflect all services provided in the previous month. Analysis on a quarterly basis eventuated as a more meaningful unit of analysis (Section 5.4).

The evaluators checked the raw service usage data against the Monitoring Group Reports to verify the reported payments to contributors. The service usage data appeared to be close but did not exactly match the report, which was explicable given the delay between date of service and date of claim from the fund pool. This presumably resulted from repeated updating of service usage records for previous months.

3.3d Infrastructure Budget

The second part of the financial management system was the infrastructure account. Funds for this account were paid in advance by the Commonwealth Department of Health and Aged Care (CDHAC) to cover the cost of establishing and operating Linked Care. Linked Care operated within its planned infrastructure budget throughout the trial. Financial viability to the end of the trial was dependent on a three per cent levy from the fund pool for administrative functions to manage the fund pool and care coordination process.

The financial analysis has divided the infrastructure budget into start-up and wind-up costs, trial costs and ongoing costs. The results are presented in Appendix 3 and discussed below. Costs are also divided between fixed and variable costs to address the question of what size fund pool would be required to support the ongoing infrastructure needed to operate a care coordination model similar to that developed in Linked Care.

Even within that evaluation framework however, design aspects of Linked Care dictated by CDHAC make it difficult to generalise about the infrastructure budget results. For example, one of the consequences of the policy of not having continuous recruitment to replace participants who exited was that Linked Care infrastructure was not able to reach a size large enough to take advantage of economies of scale. It is difficult in these circumstances to conclude when economies of scale would arise. Similar comments probably also apply to any economies of scale associated with the fund pool. Second, the limited timeframe for

Linked Care meant there was probably insufficient time to reap benefit from high establishment infrastructure costs incurred early in Linked Care. Service provider managers and CCs also reached this conclusion (Chapter 5).

3.3e Financial Outcomes

Linked Care managed to operate both within the fund pool budget and the infrastructure budget. According to its calculations in the NSW Monitoring Group Reports, the fund pool ended with a surplus of $1 302 919.[9] This included $410 916 in prepaid revenue from the Commonwealth. This was an unreviewed prepayment by the Commonwealth to take account of the higher HIC costs before participant exit (the MBS and PBS capitation rate continued to be paid to Linked Care for 6 months after the exit of each participant).[10] Given that there was a significant surplus in relation to the HIC contributions ($1 140 649, the sum of MBS and PBS payments; Table A3.1, Appendix 3) it seems unlikely that an additional payment was, in retrospect, necessary. This still leaves an impressive fund pool surplus of $892 003 (Table A3.1).

The financial analysis by the evaluators in the remainder of this section examined the viability of Linked Care in relation to the fund pool and infrastructure grants. The results are summarised in Table 3.14 and are presented in full Appendix 3.

Table 3.14: Financial Analysis, September 1997 to December 1999

	Full accounts	**Ongoing** full accounts less grants and start-up, trial-related and wind-up costs
	$	
Fund pool income	11 004 989	11 004 989
Infrastructure grant	3 064 590	
Other income	145 385	145 385
Total income	14 214 964	11 150 374
Service utilisation	-9 590 291	-9 590 291
Infrastructure expenses	-3 910 390	-1 264 736
Total costs	-13 500 681	-10 855 027
Income less costs	714 283	294 599

Note: See Appendix 3 for the detailed financial analysis tables.

[9] Fund pool income and expenditure were reconciled with the end of trial accounts and the Monitoring Group Report. There was a $21 599 difference in contribution income between the two, probably because of accruals.

[10] This prepayment was not included in the financial analysis in Appendix 3 and Table 3.14.

Finances are divided into three components in the analysis in Appendix 3:

? the ongoing cost of operating care coordination and the fund pool (the last column in Table 3.14; second to last column in Table A3.2);

? start-up and wind-up costs of establishing and finishing the model; and

? costs of administering a trial, incurred only for evaluation purposes.

Costs are also divided between fixed and variable costs.

When the fund pool income and infrastructure grants are combined, the analysis confirms that Linked Care operated within budget, with a surplus of $714 283 (Tables 3.14 and A3.1). This includes all start-up, wind-up, trial and ongoing costs.

When start-up, wind-up, trial costs and the infrastructure grant are removed leaving only ongoing costs to be supported by the fund pool itself, Linked Care still managed to operate with a surplus of $294 599 (Table 3.14 and A3.2). That is, the fund pool was sufficiently broad to cover both service utilisation costs (88.3 per cent) and infrastructure costs (11.7 per cent).

These apparent surpluses do not take account, however, of the accuracy of the calculation of the contributions to the fund pool. Discussion in Section 3.4 and Chapter 5 in this report about the limited opportunities for service reduction and substitution suggest that some of the large surplus after service payments ($1 414 698) is probably attributable to overestimation of contribution capitation rates.

This is particularly likely since the service usage analysis in Section 5.4 does not reveal any significant decreases in service usage in the Intervention group compared to the Control group. The only significant change was an increase in medical and specialist service use and cost. Even this change should be accepted with caution given the limitations in the data transfer from HIC (Section 5.4a).

The accuracy of the service usage data would also affect the analysis of the financial outcomes. Linked Care did not capture all the data, despite its intensive efforts. The shortcomings with the data are described in Sections 5.4. and 3.3g. The data were probably an underestimation of the full service use delivered by these providers to the Linked Care participants.

Further analysis of the relationship between the apparent financial outcomes and the service usage data is recommended, so that some of these concerns about the inconsistency between the fund pool surplus and the stable or increased service usage can be addressed.

These limitations aside (particularly with the income data), one significant outcome for Linked Care was that it was able to maintain ongoing infrastructure costs at under 12 per cent of the fund pool even in the initial two-year period (when establishment costs were high), under trial circumstances, with a small and reducing participant population. Generalising the model to a wider application it could be assumed that with economies of scale and opportunities for developing the efficiency of the model, the infrastructure costs as a proportion of the fund pool could reduce further.

3.3f Client Costs

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 charged 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 clients' 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 participants 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 on different occasions agreed to meet part of the costs of equipment or respite care where the family had agreed to pay the balance (Section 3.3h). 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 avoided 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.[11]

Participants reported that likelihood of them contributing to community services decreased over the course of the trial for the Intervention participants only (Section 4.2c).[12] This was supported by the Home Care Service report that they received fewer participant contributions than expected from the Intervention participants. If this result was correct, 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 (Section 3.3h).

3.3g Service Usage Data

Central to the financial management system of Linked Care was the collection and analysis of financial data. This included data relating to services used by the participants in Linked Care. Service usage data were used by Linked Care administration for three main functions:

? financial management, such as estimating the size of the fund pool and confirming invoices from fund pool contributors;

? care planning, to inform CCs of gaps in the care plans and as a basis for making care substitution decisions; and

? to observe patterns of care used by the participants, to inform the design of intervention strategies and to assess the impact of the intervention.

Establishing the data management system to support Linked Care proved to be a difficult exercise. This was despite the considerable development effort by Linked Care management to address the limitations to the data system.

Data supplied by the fund pool contributors to establish an operational fund pool were a priority for Linked Care. Data concerning the services that drew most from the fund pool seemed to be adequately collected. This involved MBS, PBS, inpatient services from the three major public hospitals, home care and home nursing services. Probably for this reason, other service usage data not critical to the fund pool management were given a

[11] CC interviews and observation of PSG meetings.

[12] Participant questionnaires, November 1998 and 1999. Changes in frequency of contributing to the cost of care was analysed (Tables 4.8 and 4.9) 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).

lower priority or were not collected. Therefore, there could be significant gaps in the data collected, particularly that which relied on manual data collection.

Control participant data were not used to form or revise the fund pool and consequently, it was not a priority for Linked Care administration to collect. The use of a geographical control made data collection more difficult because organisations had to be approached that had no financial interest in Linked Care. As a consequence, the data were not adequate for revising some capitation rates (e.g. inpatient and non-inpatient costs).

Table 3.15 summarises Linked Care administration's methods of collecting service usage data in the Intervention and Control areas. It also identifies the limitations of the data collected. The collection methods were designed by Linked Care administration in conjunction with the service providers.

For further discussion of service usage data see also Sections 3.1d and 5.4a.

Table 3.15: Service Usage Data Collection by Linked Care Administration

	Data collection and transfer methods for the Intervention and Control areas	Comparison between Intervention and Control
MBS	Electronic transfer. Linked Care did not pay or collect gap fee data.	Same data set.
PBS	Medicare number was to be with the usual pharmacist (PBS from other pharmacists may have been lost). Other medication data (non-PBS and client-paid) were not collected.	Same data set, but data capture may have been better in the Intervention area.
Public inpatient services	HKHCHS[(a)], Royal North Shore and Ryde Hospitals only.	Comparable but Control participants were less likely to use these hospitals.
Out of area public inpatient	Not collected, except in participant questionnaire.	Not comparable.
Private hospital inpatient	Only through MBF/HCF (see below), and the largest private hospital (25 per cent of all hospital admissions in this area for this age group in 1996).	Same data set.
Non-inpatient services	? Intervention: HKHCHS manual only; not effective. ? Control: participant questionnaire only.	Not comparable.
Accident and emergency	Participant questionnaire only.	Not comparable.
Sydney Home Nursing	Electronic transfer.	Same data set.
Home Care Services	Electronic transfer.	Same data set.
DVA	Electronic transfer from HIC.	Same data set.
MBF/HCF	Hospital claimed by the participant; electronic transfer; effective only at end of trial.	Same data set.
Mercy Family Centre or Community Options	? Intervention: manual collection from MFC 8/98. ? Control: participant questionnaire only.	Not comparable.
Meals on Wheels	Sample manual comparison month 1998 and 1999.	Comparable for sample month.
Other HACC services (transport, home maintenance and gardening)	Not collected, except in sample period in participant questionnaire.	Sample only.
Volunteer and unpaid services	Not collected, except in sample period in participant questionnaire.	Sample only.
Client-paid services	Not collected, except in sample period in participant questionnaire.	Sample only.

Note: (a) Hornsby Ku-ring-gai Hospital and Community Health Services

3.3h Financial Management by Care Coordinators

The link between care coordination and fund pooling, the two key parts of the coordinated care intervention, operated through the care planning process and associated financial discretion provided to CCs. Following the rationale of devolving budgetary responsibility to case managers (Davies, 1992: 58), Linked Care attempted to vest financial discretion in CCs and their Peer Support Groups (PSGs).

During the trial, the implementation of financial accountability mechanisms for CCs remained in question in two respects:

? the implementation of the envisaged information system to support care plan financial decisions proved to be more difficult than had been envisaged; and

? the effectiveness of CC peer review as a control on CC discretion about significant financial decisions was limited.

In addition the question of the willingness of some CCs to make care plan changes that had financial implications remained unclear. Only a minority of CCs requested changes to care plans that incurred a large financial cost.

Financial Guidelines

Linked Care provided guidelines to vest financial decision-making in the CCs, to restrict unnecessary withdrawals from the fund pool and to enable consistent decision-making. The procedures formalised requests for substantial increases in care or to substitute care from preferred providers with private agency care.

Accompanying the financial guidelines was a comprehensive list of care available from preferred and other providers in the Intervention area, complete with comparative costs. It was expected that CCs would use this resource to make financially rational decisions in care planning when substituting care or accessing new care.

The model was originally designed with financial requests to be made through PSGs rather than Linked Care administration. Requests were to be made in writing and faxed to other PSG members who were to respond by fax. Extraordinary meetings could be called for complex matters. Urgent requests could be decided by Linked Care and reviewed at the next PSG meeting.

A small number of financial requests were rejected either formally or informally by following the guidelines. Most requests were initially agreed to by the Linked Care staff rather than waiting for the next PSG meetings. Requests for additional services received from CCs were then described and ratified in the next PSG meeting. This encouraged problem solving and training about the financial guidelines.

It appears from initial analysis that GP CCs were the least likely to request additional services (Table 3.16). Interestingly the non-GP CCs with the fewest participants made the most costly requests (an average of $179 per participant for ongoing additional services and $252 for one off costs) and were also most likely to negotiate a participant co-payment.

Table 3.16: Authorised Additional Services by Care Coordinator Type

	Care coordinator type				
	GP	**Mini**	**Maxi**	**Full-time**	**Total**
Care coordinators	36	21	4	3	54
Participants coordinated	129	62	80	294	565
Ongoing additional services					
Number of requests	9	12	15	43	79
Number per participant	0.07	0.19	0.19	0.15	0.14
Cost to the fund pool	$8 619	$11 152	$5 962	$27 448	$53 181
Cost per participant	$69	$179	$75	$93	$95
Client co-payments	0	0	$727	$6 213	$6 940
One off additional services					
Number of requests	6	15	19	41	81
Number per participant	0.05	0.24	0.24	0.14	0.14
Cost of requests	$9 110	$15 603	$14 035	$35 540	$74 288
Cost per participant	$71	$252	$175	$121	$131
Client co-payments	$470	$2 250	$920	$2 270	$5 910

Source: Linked Care, March 2000.

Note: For the purpose of this analysis, Linked Care referred to non-GP CCs with <10 participants as mini-CCs; non-GP CCs with 10-20 participants and specific time set aside for care coordination as maxi-CCs.

Requests for additional services ranged from ongoing additional physiotherapy and respite to one off purchases of equipment. The most expensive items were contributions to the cost of wheelchairs ($4500) and one off live-in care ($4950). GP requests tended to relate mainly to physical needs (e.g. medication, bed pads, physiotherapy). Respite care was the most frequently requested service both as one off and ongoing care (48 requests) followed by personal care (30 requests).

Substituting Care

As more questions of care substitution and declining health were addressed, the exclusion of nursing home funds from the fund pool appeared to become more problematic. At one PSG meeting those attending 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. Despite the costs being lowest in a nursing home, they agreed to continue home-based care. This scenario reflected the potential difficulty of excluding nursing home costs from the fund pool.

In addition to decision-making about costly services, interesting questions about accessing free or cheap services were brought by CCs to PSG meetings. 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. To this extent, Linked Care also acted as a brokerage of free or inexpensive community opportunities.

The financial management of DVA clients was also discussed at PSG meetings. The potential for CCs to monitor, reduce or stop services to DVA clients, but not to affect entitlements, was discussed. It appeared that CCs were unfamiliar with the implications on their care coordination of participants who were DVA clients or privately insured.

Managing Client Budgets

At the end of the first half of Linked Care, each participant was categorised into one of three care protocol categories, derived from clusters of service use and cost (Section 3.4g). Table 3.17 lists the expected cost per year and per care plan (three months) for each care protocol category.

Table 3.17: Expected Cost of Participants' Care by Care Protocol Category, 1997

		Without hospital admissions		With hospital admissions	
Category	**Proportion of Intervention group %**	**Average cost/year $**	**Average cost/care plan $**	**Average cost/year $**	**Average cost/care plan $**
A	8	5660	1416	13000	3250
B	20	4800	1200	9900	2475
C	72	3800	950	7170	1790

The design of Linked Care was that after each quarterly review of care plans, CCs were to be informed by Linked Care of the expected cost of the care plan and the actual services used by the participant in the previous quarter. They could compare these figures against the expected average cost for that category of participant. A risk attached to deriving a participant budget from the fund pool estimate was that the budget may act to 'construct' the resultant expenditure. Linked Care had several checks against this risk, including accountability of all CCs to the PSG system.

The categories were abandoned in the second half of the trial, when it became apparent that there was considerable movement between categories and that the categories were not an accurate predictor of either service cost or CC time.

Service Usage Reports to Care Coordinators

For a short time in the second half of the trial, the Linked Care information system generated quarterly service usage reports to compare the cost of care plans and actual services, by participant, CC, PSG and total trial. The usefulness of the service usage reports in financial planning by the CCs remained in question at the end of the trial. The process was hampered

by the continued lack of accuracy in the reports (Section 3.1d) and the capacity of the CCs to understand them. Shortcomings in the accuracy of the reports included:

? service data collection problems (e.g. no PBS data above the safety net level, delay between service date and data transfer);

? unrecorded service use (e.g. private health insurance, additional approved private services, and participant out of pocket expenses);

? inaccurate costs;

? retaining participants who exited during the period in the reports; and

? retaining participants without a current care plan in the reports.

Linked Care discontinued distributing the reports to CCs for the remainder of the trial so as to maintain credibility with the CCs. Despite the resource intensiveness of the task, Linked Care remained committed to continuing to try to improve the quality of the reports. A simpler sample report generated by Linked Care at the end of the trial was sympathetically received by CCs in PSG meetings.

The full-time CCs reported that, even in their rough form, the participant service usage reports made them more aware of what services were actually used and the cost of these services. Some data, such as hospital admission and diagnostic procedures, could also be an indication of changed needs that they had not necessarily been made aware of through other parts of the care coordination process.

One of the main criticisms levelled at the reports concerned the fact that the reports could only be generated after the expense was incurred. Further, it was felt CCs had so little time that they could barely glance at the reports, let alone fully utilise them or compare the plan with the usage. They did not think they were essential for the CC role.

A consequence for the CCs of not preparing a current care plan was that Linked Care did not generate a service usage report about that participant. This appeared to doubly detract from the care coordination service to the participant because the CC was not even informed of unplanned services used by the participant.

The complexity of designing and operating the Linked Care information system, which Davies describes as an essential system support for case management (1992: 29), appears to account for the differences from the proposed interrelations between the fund pool and care planning processes (Section 3.1d). It remained in question whether first, it was feasible to implement a complex data reporting process; and second, whether CCs were willing to actively become gatekeepers to their peers' requests for services.

3.3i Results from the Financial Management

The operation of the fund pool raised a number of issues for the continuation of a coordinated care model. It is clear that Linked Care demonstrated that it was possible to create a fund pool. The extent to which the fund pool was able to provide a viable source of funding for all care needs of participants in the future, was less clear.

A summary of the financial management results are presented in Table 3.18.

Funds were pooled from eight service providers. This was supplemented by an infrastructure grant from the CDHAC. Linked Care achieved its first goal, which was to establish an operational fund pool from multiple contributors.

The financial management of Linked Care generated an apparent surplus of $714 283 of all costs and funds or $294 599 of ongoing costs and funds. This could be due to service substitution and financial efficiency in Linked Care. However, although inconclusive, the apparent surplus could also be explained by questions about the accuracy of the capitation rates, the incomplete collection of service usage data, questions about the division of administrative costs between establishment and ongoing costs, and the impact of a small number of participants with a high exit rate and no continuous recruitment.

There was little evidence of service substitution or savings opportunities from the operation of Linked Care. In fact, when the service usage analysis took account of differences between the Intervention and Control participants in baseline service usage and participant characteristics, it showed no decrease in use or cost of any of the services groups and an increase in one (medical and specialist services, Section 5.4b). This inconsistency between the fund pool surplus and the stable or increased service use should be examined further.

The administrative costs of the model were relatively high (29.0 per cent of all costs for Linked Care, or 11.7 per cent of ongoing costs), but this was probably because it was a small, temporary trial. The service providers also reported they incurred additional costs supporting the management and operation of Linked Care. One of the reasons for the higher than expected care coordination costs (7.0 per cent of all costs or 6.4 per cent of ongoing) was that the participant category tool was not effective in predicting the degree of care coordination required, perhaps because the tool was based on service use rather than risk, need or participant preference (Section 3.4g).

It could therefore be reasonable to conclude that the Linked Care model would not be self-sustaining without a supplementary infrastructure grant. Otherwise, the cost of care coordination and its accompanying infrastructure would need to be covered by a reduction in funds for services used by clients.

Observation of the financial model in Linked Care was useful for identifying the barriers to a fully functional financial system based on CCs facilitating access to care paid from a fund pool of multiple health and community service providers, described below.

The distribution of payments from the fund pool used an arrangement designating contributors to the fund pool as 'preferred providers'. This was different to the competitive or contestable pricing arrangements envisaged in the original documentation of the coordinated care approach (Fine, 1997: 14-5). However, the arrangement appeared to have merit both as a short-term consensus measure to encourage fund pool contribution,

and as a mechanism to enable funds to be more flexibly distributed between partners in a larger scheme. An instance of this was the balance of payments out of the fund pool towards HACC services and away from medical services.[13]

A related issue arose from the fact that many service providers operated as part of a larger system of public provision that did not have extensive service charging procedures. Many such services had difficulty adapting their administrative records to the reimbursement model required to support the management of the fund pool. Similarly, it appeared that some CCs subcontracted from the service providers were unfamiliar with making decisions based on financial information about care options.

[13] The service usage analysis showed similarly that although as a service group relative to the Control participants, use and cost of HACC services did not change significantly, within the group, Home Care Service use and cost increased and Northern Sydney Home Nursing Service use and cost decreased (Section 5.4b).

Table 3.18: Results from the Financial Management

Intervention	Results
1. Fund pool development	The process of calculating and revising the fund pool was achieved, but in an inconsistent manner between contributors. The complexities of the capitation rate were difficult for several providers to fully understand, with implications such as first revisions not being completed until the last month of the trial. The fund pool was operationally functional.
2. Infrastructure budget	Infrastructure costs were contained within the additional grant and a 3 per cent levy on the fund pool. The fund pool would have been insufficient to cover all establishment costs. It may possibly have covered ongoing costs.
3. Financial outcomes	Linked Care operated within its fund pool and infrastructure grant budget. A more restricted analysis of ongoing costs (excluding trial, start-up and wind-up costs and the infrastructure grant) also revealed a surplus and an infrastructure cost of 11.7 per cent of expenditure from the fund pool. Conditions on these conclusions include a possible overestimation of contribution rates, incomplete capture of service usage data and discretionary allocations of costs to start-up and ongoing expenditure. The apparent surplus is inconsistent with the service usage analysis (Section 5.4b).
4. Client costs	Data 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.
5. Service usage data	Difficulties included collecting and importing manual data; incompatible IT systems; and delays in data transfer. Many providers were unfamiliar with managing client-based data.
6. Financial management by CCs	The inaccuracy of the service usage reports to CCs and delay in providing financial information prevented this part of the intervention from being fully tested. The goal of CCs managing a budget could not be tested. Non-GP CCs appeared more willing to experiment with a wider range of care options.

3.4 Care Coordination

3.4a 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 clients with complex care needs who lived at home, predominantly older clients and some younger people with disabilities.

Care coordination, like other services, comes at the cost of the transactions incurred in the process of organising the care that other agencies deliver. Until the CCTs, this cost has tended to be contained within existing case management mechanisms. In Australia cost efficiency was gained through: 1) restrictive eligibility criteria, as with Community Options (COPs)/Linkages services and Community Aged Care Packages; 2) rationing that results from block funding when time-restricted case management or coordination is provided by agencies such as Aged Care Assessment Teams; and case management combined with funding initiatives such as individual packages or fund pooling.

Linked Care was different from previous initiatives. In its model care coordination moved from being a targeted or time-limited intervention to the designated mode for organising all care for all participants in Linked Care. The evaluation of Linked Care, therefore provided a valuable opportunity in two ways. First, it tested the robustness of different models of case management. Second, it assessed the suitability of these models for linking clients with ongoing needs with the wide range of services and sources of support that were included in Linked Care.

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. Their 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, but still subcontracted CC positions were created. As a result of subcontracting arrangements with various service providers, CCs had variable knowledge and skills and came from a range of disciplines.

The Linked Care model of case management could be typified as low intensity. The full-time CCs had up to 100 participants each and CCs were paid to provide case management

(CM) services for an average of 19 hours per annum.[14] Using a model of low intensity CM created tension with existing case managers in the sector who delivered a more intensive form of CM (for example, the COPs case managers)[15] and with trial CCs who felt it was their professional duty to perform more intensive tasks. Irrespective of extra time-consuming duties, perhaps the most significant issue in the conduct of care coordination was the delay experienced in the preparation of care plans (which were a compulsory task for CCs). Some CCs were GPs or service employees who continued to have a major role in direct care provision. A source of difficulty for CCs in these positions was their inability to dedicate all their time to the work of care coordination and the preparation of care plans.

Another distinguishing feature of Linked Care was the financial flexibility offered by forming a fund pool. However, there appeared to be little evidence of service substitution or gatekeeping by the CCs (Section 3.3h). Perhaps this was because the care coordination mechanism served only as a means of enhancing access to care in a system in which direct access to primary care and other facilities continued to operate independently of Linked Care.

This section examines in more detail the various aspects of the care coordination model including a discussion of who the CCs were, the process of care coordination, the role of care planning, the function of the Peer Support Groups, participant category care protocols, quality assurance activities and participant and service provider experiences of care coordination. A concluding discussion on issues and results from the Linked Care model of care coordination ends the section.

3.4b Care Coordinators

Subcontracted Care Coordinators

Linked Care chose a model of subcontracted care coordination to minimise duplication of existing coordination and cost and to build on existing client relationships. Several issues arose in relation to the subcontracting model of care coordination: a preference for specialist full-time CCs; problems associated with continuity of care for participants; and lack of accountability to Linked Care. The anticipated model of care coordination changed during the Linked Care trial. This section describes the development of the CC model and some of the reasons for the changes.

The care coordination function was subcontracted to GPs and employees of service provider agencies. Initially there were three types of CCs:

? GPs;

? non-GP service provider staff who added Linked Care coordination to their existing responsibilities; and

[14] During the first half of the trial they were expected to spend 10 to 16 hours depending on the complexity of the participant's care coordination needs. This was revised after surveying CCs about how much time they actually spent on care coordination tasks.

[15] Some Linked Care participants had both a trial CC and another community case manager.

? three 'super CCs' employed by three service providers to exclusively fulfil the Linked Care role. They were from the Aged Care Assessment Team and the Home Care Service and were responsible for over 80 participants each.[16] They are referred to as full-time CCs throughout the remainder of this report.

GPs were recruited to Linked Care through the Division of General Practice and given first option to care coordinate their patients who had joined Linked Care. If the GP did not accept that option, a CC was appointed from another agency that provided care to the participant. Miscellaneous participants, for example, those who did not receive ongoing care, were generally allocated to an agency with full-time CCs.

All participants were allocated a CC during the first year of Linked Care. Approximately 60 were reallocated in October 1998 because their GP CC had failed to write an initial care plan in the previous 12 months. The second reason participants were reallocated a new CC was employment changes within the agencies. Two Home Care Service (HCS) branches amalgamated. During the restructuring, only two full-time CCs remained responsible for all the HCS participants. Staff changes in Northern Sydney Home Nursing Service also meant that new CCs needed to be trained. Training new CCs was an ongoing management issue for Linked Care and agencies as they reallocated participants to new CCs due to regular staff turnover.[17]

Linked Care attempted to allocate CCs from the two agencies that managed Community Aged Care Packages (CACP), Mercy Family Centre and Wesley Gardens, to Linked Care participants who were CACP clients. This was to avoid duplication of care coordination tasks between Linked Care and CACP.[18]

Table 3.19 lists the agencies to which the care coordination function was subcontracted and the number of CCs at the beginning and end of the trial.[19]

[16] Two Northern Sydney Home Nursing Service relief staff had 17 participants each. Linked Care referred to these CCs as 'maxi care coordinators'.

[17] A participant was unaware that they had been reallocated a third CC after changing from a GP CC to an agency CC who resigned (participant interviews, October 1999).

[18] This allocation strategy was negotiated after disagreements about care coordination by some GPs who initially acted as these participants' CCs. The funding for the Wesley CACPs was not included in the fund pool. Management of CACP clients continued to be problematic and the subject of negotiation with the agencies.

[19] Final allocations of CCs were made at the mid-trial point. The number of participants continued to reduce during the second half of the trial. This reduced the number of CCs.

Table 3.19: Care Coordinator Type by GPs and Subcontracting Agencies, December 1999

	CCs trained n	Full-time CCs n	CCs at end of trial n
GPs	82	-	30
Home Care Service	5	2	2
Mercy Family Centre	7	-	7
RACS (ACAT)	10	1	5
NSHNS (Hillview)	17	-	2
NSHNS (Hornsby)	14	-	3
Wesley Gardens	2	-	1
Total	137	3	50

The number of participants for whom a CC was responsible varied considerably from an average of 98 for full-time CCs to three for GPs and other CCs (Table 3.20).

Table 3.20: Care Coordinators and Participants by Care Coordinator Type

	Care coordinator type				
	GP	**Mini**	**Maxi**	**Full-time**	**Total**
Care coordinators	36	21	4	3	54
Participants	129	62	80	294	565
Average participants per CC	3.6	3.0	20.0	98.0	8.8

Source: Linked Care and CDHAC Sydney analysis, March 2000.

Note: For the purpose of this analysis, Linked Care referred to non-GP CCs with <10 participants as mini-CCs; non-GP CCs with 10-20 participants and specific time set aside for care coordination as maxi-CCs.

Subcontracting care coordination presented several problems to Linked Care. First, difficulties arose because some CCs did not experience a link between their responsibilities and the financial return for care coordination. As a result, they therefore expressed resentment at the time commitment required to fulfil the full range of responsibilities of being a CC. [20]

The second concession from subcontracting care coordination was that Linked Care relied on the agencies to support their employees to fulfil the care coordination responsibilities. Similarly GPs were self-employed without direct support. CCs reported that the lack of

[20] Similarly, some CCs reported conflict when their Linked Care participants were not their ongoing service clients. If the Linked Care participants had comparatively lower needs than their other clients, they reported being frustrated about the time required to fulfil their CC obligations to participants that would otherwise not have been prioritised (Linked Care staff interviews 19-20 May 1999).

support compromised the quality of care coordination. Linked Care staff were of the opinion that for a model of subcontracted care coordination to succeed, active support and involvement from service line managers, and perhaps the Division of General Practice, was needed.

The final difficulty in relation to subcontracted care coordination was the continuity of care by non-GP CCs, both in terms of turnover and relief when they were on leave. Transition arrangements when participants changed service providers were not formally resolved between Linked Care and the subcontracting agencies and GPs.

These developments were interesting from the point of view of the evaluation. It appeared that with subcontracting agencies Linked Care possibly lost some of the value of subcontracting coordination; that is, the benefits of supplementing existing coordination duties and prior knowledge of participants. Instead, because Linked Care was not directly involved in the selection, supervision or quality control of the duties of CCs, the subcontracting model appeared to incur disadvantages compared to the slightly different model of full-time CCs employed by other trial administrations.

GP Care Coordinators

Initially GPs were the largest group of CCs (approximately 56 per cent). From Table 3.20 it is clear that despite Linked Care promoting care coordination by GPs, the final proportion of participants coordinated by GPs was less than one-quarter of all participants because each GP coordinated only a small number of participants. Without continuous recruitment, as participants left Linked Care, GPs also exited as CCs because they had no patients left in Linked Care. Similarly, many of the GPs who completed the training did not act as CCs because they did not have any patients in Linked Care. Other reasons for the exit of GPs included the prolonged recruitment process and the complexity of the CC role.

Although it could be said that for some GPs the quality control disadvantages to Linked Care of subcontracting described above were also present, at least the continuity of care benefits were maintained with GPs. However, it also appeared that even if GPs were diligent in their CC role, some found that fulfilling the five steps of care coordination obligations[21] were tedious and time consuming, particularly arranging and monitoring care.

Most GPs in the mid-trial focus group expressed the view that the GP role in care coordination should be central and one in particular felt that GPs who were interested in taking on more care coordination throughout the trial should be able to do so at any time. Joint assessments by a GP and social worker were suggested, as were clearer guidelines and procedures. In both the baseline and end of trial GP questionnaires most GPs reported that patients saw them as coordinators of their clinical care, but were significantly less certain that this was so with community care.

[21] Assessment, planning, arranging, monitoring and reviewing; Linked Care staff interview.

Full-time Care Coordinators

Full-time CCs represented a change in the strategy of some service provider managers who had originally intended to provide care coordination through existing staff.[22] These service providers decided there was sufficient financial security from the care coordination cost reimbursement by Linked Care to employ additional staff to specifically undertake the role. They reported this new strategy had the advantage that existing staff were not burdened with additional work.

The Quality and Complaints Working Party noted that the disadvantage of care coordination by specialist CCs was that the CC was not the care staff member who was already familiar with the participant and their needs through other service delivery. However, some non-GP service CCs reported that they were also not care coordinating participants with whom they had prior contact.

Despite these criticisms, apart from GPs, the only remaining subcontracting agencies that did not adopt the full-time CC model were the agencies whose CCs were also specialist case managers for CACPs and COPs. The Linked Care administration also reported that management of CCs was most successful in relation to the full-time CCs because this type of CC had the time and motivation to understand and implement the new processes expected by Linked Care. Nearly half of other CCs reported a conflict between their care coordination role and their other work (42.2 per cent; Table A6.1).

The full-time CCs thought that it had not necessarily enhanced the CC role being employed by a community-based service provider.[23] There were several reasons for this: being attached to a community agency had little credibility with some GPs; and the CCs tended to personify Linked Care within the agency and its attached stigma as generated by the inequity compared to other clients.[24] On the other hand, being employed by the hospital as a CC was reported as possibly having been an advantage because it facilitated direct contact, access to services, and a forum for discussing ideas. They thought that it had probably advantaged the subcontracting agencies to have full-time CCs located in their services because other agency staff became more familiar with the project, softened their attitude to the project and sometimes improved their service delivery when full-time CCs coordinated their clients.

Multidisciplinary Model

The multidisciplinary model of care coordination operated reasonably well throughout the trial. The multidisciplinary context of Linked Care provided an opportunity for the often disparate parts of the medical and broader health and community care sectors to share their expertise, especially in the context of the PSGs. Non-medical CCs were able to learn about and possibly influence the role of the medical practitioners in providing care, just as much as GPs could learn about recognising non-medical needs and accessing appropriate care.

---

[22] Full-time CCs were referred to as 'super care coordinators' in the trial.

[23] Full-time CCs interview 6 May 1999.

[24] See Section 4.5 for more discussion about perceived inequity.

There was some tension between the three types of CCs. Agency CCs expressed their disgruntlement to the evaluators and Linked Care management at the differentials between the CC types. Staff from some agencies perceived that Linked Care structure gave favourable treatment to GP CCs through:

? higher financial reimbursement for GPs;

? one session of training for GPs once the training process had been refined, compared to two sessions for staff from agencies; and

? an expectation by some agency CCs of lower quality care coordination from some GP CCs because of GPs' relatively lower exposure to the full range of health and community services.

Some GPs reported they found it time consuming to access non-GP CCs and other services, but they stated Linked Care appeared to have improved their patients' access to services and their own awareness of other services. GPs reported it had also improved awareness of and referral to GPs.[25]

Level of Involvement for Care Coordination

Debate about the difference between CCs and case managers continued throughout the trial. Some participants had both a CC and a case manager from their funding package. CCs had different views about whether the CC role supplemented or superseded the case manager role. One full-time CC thought that when their participants also had a case manager, the CC role effectively superseded the other.[26]

This tension was evident in other discussions of care coordination. The issue of what care coordination entailed was not resolved to the satisfaction of some of the community-based services. For example some case management service providers did not understand why CCs referred Linked Care participants for COPs. Their perception of this was that the CCs were not fulfilling their role.[27]

The Linked Care administration appeared to support a less 'hands on' role for CCs than provided by case managers. The divergent views about the CC role became apparent after a PSG meeting. A non-GP CC during the meeting had discussed helping a participant to access community services and deal with financial difficulties.[28] Linked Care staff later explained to the evaluator that this level of involvement was because of her professional role as case manager, whereas a CC was expected only to arrange the total balance of care including community and clinical care, rather than provide daily assistance.[29] This perspective was probably also more realistic for the full-time CCs with 60-80 participants.

[25] GP mid-trial focus group, November 1998.

[26] Full-time CCs interview 6 May 1999; Service Managers meeting 18 March 1999.

[27] Quality and Complaints Working Party, May 1999.

[28] PSG meeting 19 May 1999.

[29] Linked Care staff interviews, 19-20 May 1999.

Training

All CCs received training from Linked Care including: background and organisation of Linked Care, the responsibilities of being a CC, and writing a care plan. Procedures and resources were listed in a Care Coordinator Manual and this was updated with occasional bulletins when new procedures were developed or refined. As well as training about the care coordination procedures, considerable time was spent on gaining the CCs' confidence in Linked Care.

Interestingly, in the Establishment Phase CCs, both medical and non-medical, strongly stated that they knew how to coordinate care, and in fact that was what they did in their profession. Training was therefore offered on the Linked Care process only. It was apparent from the mixed quality of care plans and from comments at the mid-trial CC workshop, that some CCs found the care coordination process difficult. Linked Care required them to step aside from the familiarity of their discipline and recognise and act on broader needs.

The mid-trial workshop provided an update to all CCs who attended on trial progress, new procedures and included working sessions to develop quality control measures in care coordination and suggestions for future directions for the remainder of Linked Care. Priorities identified by the CCs to maximise the benefits of the multidisciplinary model included:

? improving the quality of the care coordination process; and

? increased education and training and education for CCs. This recommendation was not taken up by Linked Care. The only ongoing training opportunity was in the PSG meetings.

Payment

Remuneration of CCs initially varied according to the participant care protocol categories of their participants. Linked Care paid a fixed sum based on an hourly rate for an estimated annual number of hours of care coordination for each care protocol category of participant (Section 3.4g). The hours were estimated by Linked Care administration after prolonged discussion in the Care Coordination Working Party.[30]

The payment system was revised in the last year of the trial so that rather than relying on the participant care protocol categories to determine the level of payment to CCs, a flat rate of 19 hours per annum would be paid for non-GP CCs. The only remaining variation between subcontracting agencies was the hourly rate. The second change was to pay GP CCs only eight hours per annum, in recognition of their lower average time spent care coordinating and their ability to charge for normal consultation activities through Medicare. Table 3.21 illustrates that payment schedule.

[30] Some HACC agency representatives on the working party disagreed with Linked Care administration about estimations of care coordination time and therefore about reasonable financial return.

Table 3.21: Estimated Annual Care Coordination Hours and Payment by Participant Protocol Categories

	All participants	Client category A	B	C	Hourly rate
Initial rate 1997					
GPs[(a)]		16	12	10	$100
Non-GPs[(b)]		16	12	10	$30 – 35
Revised rate 1999					
GPs[(a)]	8				$100
Non-GPs[(b)]	19				$32 – 40

Notes: (a) Part of the GP payment was received through a Medicare consultation.
(b) Negotiated with each employing agency.

3.4c Care Coordination Process

Linked Care's care coordination process was deliberately developed as a mechanism to complement existing coordination provided by the service providers who contracted to supply the care coordination services.[31] Care coordination was expected to include five tasks:

? prepare a care plan;

? reach agreement with the participant and service providers;

? arrange the services;

? monitor the plan and participant's needs; and

? review the plan at least quarterly.[32]

Various administrative mechanisms were planned to support that process. They included data entry to generate a computerised care plan, service usage reports, quarterly attendance at Peer Support Group meetings, and bulletins to update the Care Coordination Manual. Details for each stage of the process are discussed in the remainder of Section 3.4 and in Section 3.3h.

3.4d Care Plans

A copy of the care plan designed by Linked Care is included in the volume of evaluation instruments. The care plan was modified during the trial in response to feedback from the CCs.

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

[31] For discussion of existing care coordination, see Chapter 5 and Section 5.3.

[32] These tasks are similar to the usual tasks of intensive case management (Naleppa and Reid, 1998: 64; Quinn, 1995: 239, 244).

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 arrangement 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 of signed plans than this.

A quality checking process was implemented to manage the transfer of data from the written care plans to the electronic format by Linked Care staff. Handwritten care plans were checked for completeness and legibility. After data entry, the electronic version was checked against the written version for comprehensiveness. These processes were implemented to overcome initial problems such as inaccurate transfer of data from handwritten care plans; and difficulties transcribing medication names and information on the frequency of service delivery. The steps appeared to result in improved quality and efficiency.

Linked Care administration struggled to implement its administrative obligations in the care coordination process. It was intended that a computer-generated version of the care plan be returned within three days of Linked Care receiving the handwritten version from the CC. The backlog of both the initial care plans and care plan reviews waiting data entry meant this data entry goal was not achieved throughout the trial period. A three-day turnaround is probably not achievable with the quality assurance measures that were part of the data entry process, even after the employment of additional data entry staff. Meeting other obligations hinged on the data entry process, obligations such as preparing quarterly reviews of the care plans, reminders for reviews; payment to CCs, copies of the care plans to service providers, and financial reports to CCs for discussion at PSG meetings.

The following issues were found to limit the efficiency of the care plan data entry process.

? The CCs forwarded hand written care plans to the Linked Care head office by either fax, mail or in person.

? A quality review process was required by the administrative staff to validate the details upon each written care plan. This process usually included contacting the CCs to check specific details.

? The data entry process into TCM was frustratingly slow, due to a poorly designed data entry screen within TCM application and TCM application being very slow.

One of the functions of the information management system was to inform the care coordination process through feedback of both the cost of care plans and service usage data. Feedback to assist CCs make care plan review decisions based on financial information only became partially operational in the second half of the trial (Section 3.3h).

A resource list of available care in the local community and the associated costs was also distributed to CCs by Linked Care to assist in preparing care plans in the same period. This list was planned from the beginning of Linked Care but its preparation took considerably longer than expected.

This prolonged roll-out of parts of the care coordination process probably delayed additional goals for care coordination, such as incrementally improving the mix of services delivered under care plans through substitution and regular reviews of needs.

CCs reported that only in a minority of cases did Linked Care create problems for delivering care (4.3 per cent)[33] or coordinating and planning care (19.6 per cent; Table A8.1). Given that Linked Care was intended to enhance coordination this latter result is of concern and may reflect the comments that the model duplicated rather than complemented existing coordination (Sections 3.3b and 5.3). By the end of the trial only 17.8 per cent of CCs had problems persuading services to cooperate in the care coordination process (Table A8.1), indicating some success in the care coordination process.

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)[34] 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.

Some care plans were not submitted until at least 12 months after the participants were activated in the trial. Some CCs found the process of recording plans on paper and reading written feedback alien and burdensome.[35]

The time spent on quarterly care plan reviews was significantly less than on the initial plans, but it continued to be a demanding process for some CCs and Linked Care administration as reviews appeared to continue to be part of the initial process of more thoroughly documenting existing service usage. Without reminder notices some CCs appeared unable to self-manage a care plan review process.

Some CCs, particularly full-time CCs, concluded that that having a written care plan was an important mechanism to set goals and provide a big picture of needs and goals. But there was disagreement about how far copies of the care plan should be distributed. For example, they felt that a copy should be given to the GP but not services like ACAT and HCS because its content was too difficult to understand for many participants and other service providers, and was often out of date or incomplete.

---

[33] Reported problems delivering care were significantly worse at the mid-trial (20.9 per cent).

[34] Calculated on the basis of quarterly care plans for 11 923 active participant months in a 26-month trial, with an average of 459 active participants per month.

[35] GP mid-trial focus group; GP and CC questionnaires, 1998 and 1999. As an example of the evolution of the process of care plan administration, a CC recounted that the Linked Care administration adjusted the care plan she had prepared by including the wife as of assistance to the participant, contrary to the participant and wife's perception of the caring role.

Participant Involvement in Care Plan Development

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 3.22). 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 3.22: 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.[36] 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 perhaps 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 (Section 3.4f).

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

Telephone respondent participants all reported being involved 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

[36] Participant interviews and participant questionnaires, November 1998 and 1999.

received (Table 3.23). Analysis following the second and third round of participant interviews revealed 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 3.23: 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.
Note: 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.[37] This perhaps reinforces the view that the care plan itself was not central to the understanding of the care coordination role.

Medical and Other Needs

One of the difficulties in the care planning process continued to be generating a link between the medical and community aspects of the care plans. Some GPs who were not CCs were very slow to provide medical care plans. It appears that Linked Care staff visiting or personally telephoning them was an effective, if costly, way of obtaining the medical data. These strategies were not as successful for the CCs themselves and Linked Care did not always forward a copy of the medical care plan to non-GP CCs.

On the medical side, Linked Care staff observed that some GP CCs did not appear sure that they wanted to adopt the community aspect of their care coordination role. At a PSG meeting some GPs expressed a lack of interest in the planning except as it related to medical issues.[38]

Non-GP CCs reported that it had generally been difficult to contact GPs or receive feedback from them. Providing GPs with a copy of the care plan was at least one way of keeping them informed. However, GPs reported that in some cases they were not given a

[37] Full-time CCs interview, 6 May 1999.
[38] Staff interview, 8 April 1999.

copy of the care plan about their patients by non-GP CCs.[39] Where they had shared ideas it was reported as useful for improving the care for the participant.

How to implement processes to improve the quality of the medical aspects of the care plan proved to be a continuing issue for the Quality and Complaints Working Party. GPs themselves were reluctant to be reviewed, as evidenced by the reaction to the Patient Medication Management System (PMMS) initiative (Section 3.6c). Agency CCs also expressed a reluctance to broach the professional divide of raising questions about medical care and expressed resentment at spending time at PSG meetings 'educating GPs about how to use services and fill out care plans.'[40]

The division between GPs and community-based service providers appeared to remain. Although both groups expressed their support for an interdisciplinary coordinated care approach there were criticisms of the lack of communication between CCs, GPs and community agencies about care available to participants.

Care Plan Content by Care Coordinator Type

Linked Care contracted analysis of the content of most of the care plans (2530) from the CDHAC to examine if there was variation in content by CC type (Table 3.24). It analysed the number and type of care needs contained in each care plan.[41]

The analysis did not attempt to link the documentation of care needs in a care plan to outcomes for participants. Nor did it suggest that the identification of more care needs was a good outcome. Recording fewer care needs could mean that the full range of participants' needs was considered but not documented. However, an argument could be made that documented care needs were less likely to be overlooked.

In considering the findings of the analysis there was no way of assessing the complexity or severity of the participants allocated to each type of CC. The spread of morbidity suggested participants allocated to each group of CCs were comparable.

Table 3.24: Care Plan Content by Care Coordinator Type

	Care coordinator type				
	GP	**Mini**	**Maxi**	**Full-time**	**Total**
Care plans	492	250	377	1 411	2 530
Average care plans per CC	13.7	11.9	94.3	470	46.9
Care needs on care plans	5449	3408	4934	17 753	31 544
Average care plan per participant	3.8	4.0	4.7	4.8	4.5
Average care need per care plan	11.1	13.6	13.1	12.6	12.5
Average care need per participant	42.2	55.0	61.7	60.4	55.8

[39] QCWP, May 1999; GP mid-trial focus group, November 1998.

[40] Care coordinator interviews, May 1998.

[41] The analysis also attempted to examine cost of planned services by CC type. In view of the limitations on the quality of the cost data no conclusions were drawn (Section 5.4a).

Source: Linked Care and CDHAC Sydney analysis, March 2000.

Note: For the purpose of this analysis, Linked Care referred to non-GP CCs with <10 participants as mini-CCs; non-GP CCs with 10-20 participants and specific time set aside for care coordination as maxi-CCs.

Although the caseloads differed between the types of CC, the average number of care plans per participant did not vary that greatly. No doubt the range of experience by CC type gained from preparing care plans had an impact on the learning opportunities about possible content of care plans (an average of 11 to 470 care plans per CC type, Table 3.24).

The average number of care needs per care plan did not vary a great deal between the four groups (11.1 to 13.6 care needs). There was wider divergence between the average number of care needs per participant ranging from 42.2 (GPs) to 60.4 (full-time CCs).[42]

The analysis also suggested that there was a difference in the type care needs identified by type of CC. GPs wrote care plans that had the lowest percentage of care needs identified in the following areas of need – nutrition, housing, hygiene, safety and security, socialisation, carer support and disability.

Even when GPs included those needs (nutrition, housing, hygiene, safety, socialisation, carer support, and disability), they documented fewer actions to meet these needs compared with the other types of CCs.

Non-GP CCs with less than ten participants (mini-CCs) had the highest percentage of care plans that documented the need for hygiene, socialisation, carer support and disability. They planned more actions to meet the needs of nutrition than other types of CCs.

Both mini-CCs 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.

GPs submitted the highest percentage of care plans that included a diagnosis related to blood disorders, digestive disorders and urinary disorders. In all other areas of need related to a body system disorder, care plans prepared by other types of CCs had a higher percentage of needs documented.

The number of actions planned by GPs were significantly higher that other types of CCs only when a diagnosis of digestive disorder was included in the care plan. In all other areas of need the number of actions planned by GPs was not statistically higher or it was significantly lower than that documented by one or more other category of CC.

Service Goals

Care plans also included a further field that has yet to be analysed, that of the service goals. Against each care need listed on the care plan was a planned service and associated service goal: improvement, palliation or maintenance. There were many missing values. At a minimum the proportion of each of the goals for the all Intervention clients at the baseline and end trial could be compared. It would also be possible to compare changes in goals for individual participants over time. A difficulty with analysing the service goals would be interpreting the implications of any change. For example a decrease in improvement goals

[42] This figure reflects the total number of care needs documented by the CCs over the life of the trial.

and an increase in maintenance goals could indicate that the improvements had been achieved or that CC had abandoned trying to achieve them. Further analysis by participant type, CC type, care need and planned services could also be undertaken.

3.4e Peer Support Groups

PSGs were intended to be an integral part of the care coordination process. CCs were expected to attend quarterly two hour PSG meetings to review the care plans written and the services used in that quarter, make financial decisions about changes to care plans, discuss problems and exchange ideas.

At each meeting CCs were to be provided with summary reports about their care coordination activities, and financial information about the care plans and service usage for each CC and the group as a whole. Each PSG had a notional allocation of the fund pool derived from the proportion of participants in each protocol category. This part of the care coordination process was never fully implemented, because of the limitations to the information system (Section 3.3h).

Issues arising at PSG meetings were documented to disseminate to other groups for information and discussion. The notes were taken without recording the name of the speaker, to encourage full participation.

During the trial seven rounds of PSG meetings were held. Initially, to accommodate all the CCs, 14 groups were organised. PSG members were selected to have representatives from different disciplines in each group. Full-time CCs attended more than one PSG meeting each round to represent the proportion of participants they were allocated, in terms of budget accountability to the PSG, to share their experiences and so that there was time to address issues pertinent to each of their participants.[43] As the number of CCs reduced the groups were consolidated into seven groups of up to ten CCs.

Attendance was a problem. On average less than 60 per cent of CCs attended meetings. Only full-time CCs fulfilled their requirements. GPs and non-GP CCs with few participants were least likely to attend. CC reimbursement was to have been contingent on attending but this rule was not enforced. It was envisaged that the same group of CCs would regularly meet to develop support and accountability to each other for the content of their care plan, including costs. However, the complexity of compelling up to 10 groups of 12 coordinators to meet at mutually convenient times each quarter proved too great. It appears that as a training forum, PSGs were not effective for CCs contracted under this model of care coordination.[44] The additional question of how useful the PSG meetings were for those CCs that attended was not analysed.

PSG meetings discussed issues such as improving the quality of the care plans (e.g. illegibility of care plans, incomplete data, and the plans addressing only some of the health and well-being needs of participants). The second round concentrated on encouraging the completion of initial care plans. Linked Care staff were concerned not to estrange CCs in the early stages of Linked Care by demanding too much. By the second round, CCs were impatient

[43] They reported this process as being repetitious; CC interviews, May 1999.

[44] The pattern of attendance may be different for an alternative model of care coordination. For example if care coordination was a greater proportion of the CCs' work responsibility.

to receive the resource list of available services and their costs, and the financial reports from Linked Care to enable the PSG meetings to focus on financial planning.[45]

The remaining PSG meetings continued to attempt to improve the quality of care coordination within the multidisciplinary framework through:

? reviewing participant service usage reports (that compared care plan and service usage costs and patterns. The information system did not deliver sufficiently accurate reports for this to be achieved fully(Section 3.1d));

? reviewing requests for additional services;

? reviewing complaints;

? providing educational support through reviewing selected case histories or exceptions on subjects such as substitution, disease group management and high service users; and

? providing training about new procedures (e.g. private hospital admissions; informing Linked Care of exits; printing CIARR, the area-wide common assessment form; medication reviews; and care plan reviews).

The multidisciplinary aspect of the PSG seemed to be its greatest strength. Some GP CCs discussed how they had learned from non-GP CCs about community services and the non-medical needs of their participants at these meetings. One GP described how they now viewed the participants as a special group because as CCs they were expected to know more about their patients than they would have in their normal practice.[46] The deleterious side of these learning opportunities was they reinforced negative perceptions about GPs held by non-GP CCs.

3.4f 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 4.2c).[47]

When Linked Care instruments were designed, they took account of compatibility with the standard HACC instrument under development, the Client Information Assessment and Referral Record (CIARR). A NSW HACC discussion paper promoted the use of the CIARR as one means of developing seamless service provision and greater communication between services (ADD and HACC, 1998: 37-9). Linked Care was also interested in

[45] The resource list was distributed by Noavember 1998 and partial financial reports were available in 1999.

[46] PSG meeting, 19 May 1999.

[47] Participant questionnaires, November 1998 and 1999; Participant interviews.

locating its care plan and communication booklet at the participant's home with the CIARR 'Yellow Book' which documented all relevant care information.

Although Linked Care had the capacity to print off CIARR reports, this facility was not used well by CCs or service providers. It was reported that only the full-time CCs used the facility when making a referral, such as to respite care. Other GP and non-GP CCs did not request a CIARR print off. [48] This was probably a reflection of the early stages of use and acceptance in the local agencies using CIARR,[49] although some of the agencies were already using it before Linked Care began (MFC, HCS and Neighbour Aid; Section 5.2).

The goal of integrating with existing assessment appears to have been limited in two respects. Service provider baseline investigations by the evaluators revealed few standard procedures for assessing and recording client information (UNSW Evaluation Consortium, 1999c). Second, even when the existence of an assessment was suspected, it may have been treated as an internal record not necessarily available to CCs.[50]

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.[51] 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.

3.4g Participant Category Care Protocols

At the end of the first half of Linked Care, each participant was categorised into one of three care protocol categories (high, medium and low cost: A, B and C), derived from clusters of past service use and cost. The categories were to be used as the basis of reimbursement to CCs: payment for coordinating a Category A participant was higher than B on the expectation that it would take more time. The second function of the categories was as the basis of informing CCs of the notional budget attached to a particular participant or their group of participants for financial decisions in care planning; and similarly as part of the grouping mechanism for feedback to the PSGs (Sections 3.4b and 3.3h).

Linked Care contracted the Family Medicine Research Unit at the University of Sydney to derive a clinical profile from service usage data on the first 381 Intervention participants. The categories are described in Table 3.25. They were derived from ten clusters of service cost data on eight variables from HIC, the NSHNS and the HCS. Diagnosis was not included in the cluster analysis, although it appeared to be a reasonable predictor of groups of multiple diagnoses, especially for the higher cost clusters.

Table 3.25: Participants by Care Protocol Category

---

[48] Staff interview, February 2000.

[49] HCS representatives explained that the CIARR has met with resistance from service providers unwilling to undertake further paper work. Linked Care may similarly find resistance as it has with the current care plan.

[50] Linked Care staff, March 2000.

[51] Participant interviews, October 1998 and 1999.

	Percentage of Intervention group	Description	Cost
Category A	8	complex,chronic,unstable	Highest average cost
Category B	20	complex, unstable	Medium cost
Category C	72	chronic, stable	Lowest average cost

An algorithm for categorising the entire participant group and a mechanism for moving participants from one category to another were developed, to recognise that service usage profiles of participants would change during the trial.[52] Linked Care administration expected changes to be from Category C towards A (higher cost), so they structured the categorisation to financially accommodate movement in that direction.

There were limitations to the category system. First, the services used by a participant and the cost of those services when they entered Linked Care could be a function of the success of the person negotiating access to care and which service providers they received assistance from rather than a function of need or diagnosis. Participants with similar needs could receive different services and were possibly in different categories.

Second, CCs mentioned a potential tension between low-cost service use and high care coordination time in the application of the categories. An example cited by CCs was the care coordination support needs for a carer of a person with dementia. Blind testing of the categories against initial care coordination time used by full-time CCs reportedly indicated the categories were an accurate predictor of care coordination time for approximately 75 per cent of participants.[53]

The implementation of the categories was delayed to the end of the first half of the trial because of the time taken to derive the algorithm and to draft the procedures associated with the implementation. The delay was problematic for CCs wanting to plan how much time to spend with each participant and what financial framework in which to make decisions. At the end of 1998, CCs were informed which categories their participants were in. A bulletin was prepared by the Linked Care administration to explain the category system and inform CCs of their participants' categorisation.

It appears that some participants were inappropriately categorised. For example, in some PSGs, the average cost of Category A participants was in fact lower that the average cost of the supposedly low-cost participants in Category C. In attempting to re-categorise the participants according to their current service usage patterns, the algorithm appeared to not be operational. Either the pattern of service usage had changed significantly from the time it was designed or it is too sensitive to change to be able to divide participants into appropriately sized categories.

CCs were reportedly frustrated about the apparent lack of usefulness of the categories, which did not reliably predict costs. In the proposed change to CCs payments, the categories were also abandoned as a means of predicting care coordination time.

[52] Updated service usage or cost data were not added to the analysis, so the method of categorisation was based on only the initial 381 participants.

[53] Linked Care administration analysis, 1998.

The difficulty of categorising participants to predict the required level of care coordination remained unresolved at the end of the trial. Even if categorisation was possible, the remarks from a full-time CC highlight the need for flexibility and reassessment of the categories. She reported that over the two years of Linked Care most participants had become more frail, requiring increased service and coordination levels to maintain them at home. On the other hand, once care arrangements had initially be made for other participants, time to review their needs was minimal. [54]

3.4h Quality Assurance Activities

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 the 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 with the subcontracting service providers. The Linked Care administration identified that its role was to provide suggestions and guidelines to the subcontractors.

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 the Linked Care administration, expressed frustration about the seemingly 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.

[54] Full-time CC interview, 30 August 1999.

Linked Care acknowledged the restricted opportunities within this initial model to enforce quality measures as discussed above and in Section 3.4b on subcontracted care coordination. Accordingly, it encouraged the QCWP to direct its attention to future quality changes to inform development of care coordination in Phase II of the trial.

3.4i Participant Experiences with Having a Care Coordinator

Participants reported that having a CC was a positive experience 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 3.26). 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, nearly one-third of Control participants reported they had an assigned CC or case manager (30.6 per cent), and they were more satisfied with the arrangements than the Intervention participants.[55]

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

? gave them a sense of security if circumstances changed;

? was a facilitator or advocate to access services to avoid the burdensome and time-consuming processes and to negotiate their case;

? was a sympathetic health professional; and

? offered a centralised point of advice and information.

Their descriptions of these benefits are reviewed in Section 4.3f.

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

Table 3.26: 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 sample 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.

Having a CC did not replace other people informally and formally involved in organising care for the participant (Table 3.27). As discussed in more detail in relation to the impact on carers (Section 4.4), most care was both arranged and provided by the participants and carers themselves, not by formal service providers or professionals.

Table 3.27: 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 surmised that perhaps the reason for this outcome was the relatively stable and good health of some of the participants.[56] However, even for participants with complex care needs, a CC was not always needed once care arrangements were established.

3.4j Service Managers Expectations of Care Coordination

At the baseline most service provider managers saw the Linked Care model of care coordination as an opportunity to formalise and improve on existing types of care coordination in the health and community care sectors.[57] They hoped it would improve outcomes for participants and relieve providers of the unpaid, time-consuming task of coordination. They proposed incremental improvement of the existing system by Linked Care rather than imposing a new regime. This they argued could be achieved through:

? coordinating the delivery of care provided by other agencies;

? being a single point of contact; and

? preventing wasted service use.

They raised cautions about the need to minimise financial cost and bureaucracy, and the need for training and guidance to ensure informed performance from CCs cognisant of accessing care from the full breadth of the health and community services.

They also had reservations about how fully the model could be implemented. The first risk to the success of Linked Care they reported was that the overlay of a formal care coordination model on existing coordination mechanisms might incur higher costs than benefits. Paid care coordination might displace coordination previously undertaken by the participants themselves, their families and caregivers, and by their service providers.

The second risk identified by some community service managers and GPs was that the Linked Care model could be an overly complex method of linking multiple agencies and care. They were hopeful that Linked Care procedures would become more flexible as CCs become more familiar with them. They thought that Linked Care could refine the model to maintain flexibility, facilitate prompt responses to changed care needs, and minimise recording processes.

[56] Questionnaire respondents' self-reported health showed only 35.1 per cent of Intervention participants considered themselves 'worse' compared to others their age.

[57] Service managers baseline interviews, December 1997.

All managers who were interviewed emphasised that, in their opinion, the success of Linked Care was dependent on the quality of the CCs. Managers identified two possible limitations to the quality of the CCs: coordinators' knowledge of the range of care; and their commitment of time to the process of consultation.

The mid-trial GP focus group found that some GPs reported that Linked Care had increased the role of the GP as CC and advocate for the patient. Some found it difficult to get to talk to non-GP CCs and to other services, resulting in a lot of time spent on the telephone. Some non-CC GPs reported little impact other than being expected to complete forms. Most GPs reported some improved communication and referral with other services. However there was some duplication of communication required around referral (e.g. to the CC and to the service being referred to). Some non-CC GPs felt 'out of the loop', being asked to provide information but not being informed of the outcomes.

By the conclusion of the trial, service managers reported that their expectations about improvements to existing care coordination appeared unfulfilled. Linked Care at times duplicated existing coordination.[58] Feedback from CCs to providers was patchy and there was no evidence of reducing wasted service use. In some cases, managers and staff appeared angered what they perceived as apparent wastage and inequity created by Linked Care participant access to services, such as care from the Home Care Service.[59]

3.4k Results from the Care Coordination Mechanisms

Linked Care successfully implemented a model of care coordination. The process of designing and implementing the model took longer than anticipated because like other parts of Linked Care, it was important to manage the relationships with all partners involved in the care coordination process. The following list includes the essential elements of the model:

? care coordination was subcontracted from agencies and GPs;

? CCs were drawn from a range of disciplines. This applied within the same agency;

? care plans were data entered by Linked Care administration, including a quality check procedure;

? care plans were reviewed quarterly;

? medical and general health and community care needs were incorporated into a single care plan; and

? training, support and financial decision-making were provided through Peer Support Groups.

Variations to the model emerged over the trial. A specialist role of CC developed within three subcontracting agencies, with two agencies handing most care coordination over to

[58] Linked Care designed mechanisms to avoid this where a formal case manager already existed but the case management agencies appeared dissatisfied with their effectiveness; Service manager and CC mid-trial and end of trial interviews and questionnaires; Section 3.4b.

[59] See Section 4.5 for a more critical discussion of the impact on clients not in Linked Care.

one or two staff. The number of GP CCs reduced by 50 per cent as the CC role became more defined and as their patients left Linked Care.

The role of care coordination continued to develop throughout the trial. Initially, service providers considered it was a role that they already undertook in their service delivery and clinical practice. It became apparent to many of them that Linked Care differed from their previous work within a professionally prescribed model. They found writing care plans complex, challenging and time consuming. Some CCs concluded that all needs could not be identified and addressed in one care plan period. Rather care coordination was an incremental task that developed as care plans were reviewed over time. They were not all convinced that writing a care plan was a useful process.

The effectiveness of the Linked Care model of care coordination can be assessed by looking at it as an example of case management. Theoretical benefits and shortcomings of case management models are summarised in Table 3.28 and discussed in relation to the Linked Care experience.

It appears that the Linked Care model measured well against the limitations to case management when it came to the impact on costs of and access to care for participants, probably because of combination of the care coordination mechanism with the operation of the fund pool. However, the limits to participant focus, bureaucratic ease and low transaction costs were not so positive. It could be said that Linked Care focused on establishing an operational model in this short trial from which to take these experiential lessons about the limitations to a simple, if bureaucratic, model.

Table 3.28: Theoretical Benefits and Shortcomings of Some Case Management Models and the Linked Care Experience

Theoretical benefit	Possible shortcoming	Linked Care Experience
1. Client focus	Focus instead is on the coordination of services and constraining costs.	Client focus during the care plan writing process was significantly limited in some cases. This probably compromised the quality of the needs and care actions identified by some CCs. However, there was little evidence to show that decisions made by CCs or the Linked Care administration inappropriately focused on the interests of the services rather than the participant. The extent of participant involvement appeared to be dependent on their individual CC.
2. Recorded process for assessing, planning, arranging, monitoring and reviewing access to care	Bureaucratic burden and delays, arising from delays or bottlenecks in the assessment and approval processes.	All stakeholders complained of the paperwork burden and limitations of the information system. This was aggravated by most service providers being unfamiliar with written accountability for assessment and care arrangements, few written referrals and a multiplicity of providers with inconsistent information systems. Congruent reforms to those in Linked Care in the health and community service sector (e.g. CIARR) appear to be slowly but progressively changing service providers' recording practices. The failure of the Linked Care information system to produce quick computer generated care plans or accurate service usage reports, did not alleviate CCs' sense of bureaucratic burden. Some participants and CCs reported benefits from written care plans (a method of focusing whole of person needs, attributing cost to actions, information for all service providers caring for a participant).
3. Specialised staff focused on care planning	High transaction costs of CM services, arising from the fact that the approach requires payment of an additional level of service personnel who do not actually provide care or direct assistance.	CCs identified unnecessary costs associated with their role through reports such as some participants once stabilised did not need quarterly reviews; resistance to preparing care plans for participants they did not assess as having priority over higher need participants not in Linked Care; and some lack of understanding about how their CC role varied from their regular professional practice.
4. Access to services appropriate to client needs	Access to care may be affected, leading to unfair limits on access to certain services or to inappropriate use of services assigned by attentive and concerned CMs.	Access to care for Linked Care participants was enhanced by care coordination, particularly in conjunction with financing from the fund pool. For some but not all CCs, this was due to their advocacy role, additional assessment and a more holistic approach to needs and care options. It is possible that care coordination had a negative on clients not in Linked Care because of limits on free services and inflexibility in some service delivery which may have prevented the supply of additional services financed by fund pool reimbursement.
5. Financial flexibility and accountability focused on client need	Financial discretion of CMs may reduce client choice or replace access based on objective eligibility criteria.	Financial discretion exercised by some CCs appeared to enhance choice of care by some Linked Care participants.
6. Efficient financial management	Impact on cost of care. Total costs may increase, rather than decrease, with CM.	Cost of care to participants and the fund pool did not appear to change due to care coordination. The data on cost of care to participants were insufficiently complete to make conclusive statements, but some participants reported their costs decreased.

General results and difficulties experienced in the Linked Care model of care coordination are presented in Table 3.29.

Table 3.29: Results from the Care Coordination Mechanisms

Intervention	Results
1. Subcontracted CCs	Full-time CCs were more likely to fulfil obligations (see the remainder of the table for details). The goal of supplementing existing service provision through subcontracting was weakened by some non-GP CCs having no former relationship with participants, due to agency practices such as the method of allocating participants, staff turnover and the appointment of full-time CCs.
2. Care coordination process	Having a CC was associated with increased participant access to and use of services. This seemed to be dependent on the initiative of the CC and access to the fund pool rather than the preparation of a care plan.
3. Care plans	Some participants found it useful to have the list of services on the care plan e.g. to give to other providers, listing medications. Neither CCs nor Linked Care fulfilled their tasks in a prompt manner. The IT system hindered the process. Participants were not always involved in preparing care plans or received a copy of them.
4. Peer Support Groups	Attendance was poor. CCs with fewer participants were less likely to attend. The multidisciplinary forum was effective for information exchange.
5. Assessment	Existing common records and referral systems could not be accessed or were not effectively used. Prior assessments did not appear to be accessed by CCs. Inadequate service provider infrastructure (e.g. incompatible information or computer systems) and a restricted culture of written information exchange may be explanations for this.
6. Participant Category Care Protocols	The protocol system did not usefully add to the care coordination process because it was insufficiently flexible to track changes in categories or predict service use and CC time.
7. Quality assurance activities	The complaints handling process appeared effective to improve practice. The interpretation of the subcontracting relationship prevented enforcement of and professional support for care coordination tasks.

Procedural suggestions to improve the model of care coordination identified by CCs included the following.[60]

? Not all participants needed quarterly care plan reviews. A stand-by category with telephone support to check their stability and to wait for their calls about changed needs would be sufficient for some participants. They described these participants as those who knew where to go for help once they have been informed; were alert and assertive; had a GP knowledgable about community services; may have come through a crisis and were now stable; and may still receive maintenance services that appear to be meeting their needs.

? A neutral, community location for CCs may overcome some of the professional misunderstandings between providers e.g. Community Health Centres.

? Mindful of the critical role of GPs, effective relationships with GPs could be improved by allocating CCs to an area with a certain number of GPs. This could encourage GPs to refer to the CC and build up an understanding of each other's role and interaction with a broader range of services.

? An alternative to paperwork would be direct access to an interactive computer system to maximise the likelihood of up to date service usage data; eliminate the care plan data entry delay; and provide detailed information resources.

[60] Full-time CCs interview, 6 May 1999.

3.5 Service Substitution

In addition to the major components of the trial, care coordination and fund pool mechanisms, Linked Care also developed specific service substitution strategies. The strategies are summarised in Table 3.30. Service usage results (last column) are presented in Section 5.4.

Table 3.30: Service Substitution Strategies

Strategy	Expected impact on service usage	Result
1. Quarterly care plan reviews, service utilisation reports, and Peer Support Group meetings	Improve appropriate service provision; reduce unneeded services; replace high cost with lower cost services.	Little measured change. Some participants and some CCs reported improved access to HACC services.
2. Hospital notification	Facilitate early inpatient discharge; prepare for appropriate service changes after discharge.	Data incomplete.
3. Greater access to community care and equipment e.g. personal care, respite, therapies, and social activities	Reduce acute care.	No measured change. Some participants and some CCs reported improved access to HACC services.
4. Patient Medical Management System (PMMS)	Reduce medication use and drug related problems e.g. emergency presentations, inpatient admissions, and unnecessary prescribing.	No measured change due to PMMS. Perhaps reduced total PBS use.
5. Hospital Issues Working Party	Flexible provision of rehabilitation services; prevent rehabilitation inpatient service admission or reduce length of stay.	Data incomplete.
6. Influenza immunisation	Reduce acute care admissions.	No measured change.
7. GP medication peer review	Reduce medication use and drug related problems.	Not measured by GPs.
8. GP reminder lists – Clinical Advisory Group	Flexible management in acute care; reduce use of medications, GP attendance and diagnostic services.	Not distributed.
9. Hip protectors	Reduce falls related injuries.	Not measured.

The major substitution strategy was the quarterly review of care plans and feedback and training of CCs through PSGs. With such intensive information mechanisms, the intermediate goal of this strategy according to Linked Care was to educate CCs on the full range of care available to participants.

The supplementary strategies focused on reducing disability or slowing the rate of deterioration or exacerbation of chronic and acute diseases. These strategies are explained in further detail in the following section.

Other less global strategies were of course implemented by individual CCs and participants through the care coordination process, such as changing to more suitable providers or swapping types of care.

Although measured results were not necessarily achieved for each of these strategies, they provided useful opportunities for Linked Care to develop the initiatives, experience the barriers to implementation and gain lessons for further development in Phase II of the trial.

3.6 Linked Care Initiatives

Linked Care was not specifically designed as a clinical intervention to address the needs of participants with particular diagnoses. Rather participants were recruited according to the complexity of their care. Nevertheless, in the context of this general trial, some specific initiatives were planned to enhance participant well-being, prevent deterioration in their health and to facilitate the service substitution strategies listed in the previous section. These included: use of clinical reminder lists; reviews of medication; changes to hospital admission communication; the convening of a working party to explore flexible ways of providing hospital services; and the use of hip protectors.

The development of specific Linked Care initiatives was for a large part, the result of initiatives discussed with the local Division of General Practice. In February 1999, after the election of new board members and new nominations to Linked Care working parties, the Board gave its strongest statement of support for Linked Care. A Clinical Advisory Group of five GPs and a Liaison Committee to inform the board were established, supported by a Division project officer. Unfortunately it was probably too late in the trial to make significant progress with the initiatives discussed below. Other important initiatives were instigated by Linked Care management following encouragement by a range of stakeholders, as discussed below.

3.6a Clinical and Service Delivery Prompt Sheets

When the Coordinated Care Trials were being established, it was envisaged that trials would develop protocols for managing the care of groups of participants with similar needs. Linked Care contracted the Family Medicine Research Unit at the University of Sydney to derive and analyse a clinical profile for the enrolled participants based on the medical and pharmaceutical data from HIC. The morbidity profile was formed from the data on the first 381 Intervention participants.

Six target diagnosis groups based on the pharmaceutical data were identified as having a high cost and a high frequency.

1. Cardiovascular disease – hypertension and heart failure
2. Psychological – insomnia, depression and anxiety
3. Upper Gastrointestinal disease – GORD and ulcers
4. Musculoskeletal disease – arthritis and osteoarthritis
5. Respiratory – asthma, COPD, emphysema and chronic bronchitis
6. Diabetes

The data did not identify diabetes as significant in this group of participants but the researchers and trial management agreed that it was likely to be significant given the participant demographic profile.[61]

[61] Analysing medication data also failed to identify other groups such as dementia as being significant, presumably because medication use is low for these diagnosis groups.

It was planned that the profile would be used at the baseline by Linked Care administration and the Division of General Practice to split the Intervention group into subgroups and to design intervention strategies as prompts to CCs and GPs.

From the experience of the Division and other trials, the success of prompt sheets and protocols seems to rely on local input into their design. With this in mind, Linked Care considered adopting the protocols designed by the local Division of General Practice. These included diabetes and heart disease protocols. A draft diabetes prompt sheet prepared by the Division and Linked Care was distributed for consultation with GPs through the Division of General Practice.

However, CCs and GPs at the mid-trial workshop were wary of developing best practice protocols in the context of Linked Care. Complexities they saw were the multiple diagnoses of most participants, the emphasis on community-based care rather than medical interventions and the relevance to the local context.

Linked Care reported that the Clinical Advisory Group (Section 3.6b) considered protocols were still a useful tool by if they were locally developed.[62] The Group developed eight one-page reminder lists for use in general practice and by other service providers for patients with or at risk of particular diagnoses. They would be distributed to GPs for participants with care plans that included the diagnosis or were at risk of acquiring it. The first two completed were cognitive impairment and impaired mobility. The lists not completed related to depression and anxiety, and cardiovascular disease.

The potential use of these sheets was discussed in PSG meetings. There was general concern about adding more paperwork to Linked Care. The evaluator observed contrasting reactions from GPs. Some GPs thought the sheets might be useful reminders but they might not result in any changes to current practice. Other GPs were less positive saying that they would be affronted to receive such material because it was information GPs should already know. Some non-GP CCs agreed. They said they already had enough difficulty communicating with the GPs about their participants. By handing over a reminder list to which the GP might take offence they might potentially aggravate the relationship further. On the other hand, a non-GP CC noted that they found it helpful to use similar sheets to orient new staff. The Clinical Advisory Group agreed that for the strategy to be successfully received an extensive prior explanation to GPs would be required.

The CCs thought that booklets given to patients and already produced by government organisations on subjects such as falls (booklet provided at meeting) were potentially more useful. They queried whether producing information sheets was the best use of Linked Care's resources.

3.6b Clinical Advisory Group

The second focus of the Linked Care initiatives was the development of methods of promoting quality practice and reducing costs through the Division of General Practice. GP and Linked Care reservations about drafting best practice guidelines were discussed above. In the second half of the trial, the Division and Linked Care shifted from the development of

[62] Linked Care report, March 2000.

prompt sheets and protocols toward more general methods of reinforcing quality practice among GPs through the newly formed Clinical Advisory Group. Areas of interest included diagnoses, admissions to public hospitals, drugs dispensed, consultations provided and patterns of diagnostic tests ordered and provided.

The Clinical Advisory Group was requested to assist Linked Care to identify:

? the best method of reinforcing quality practice among the Division's GPs (and other service providers) in the management of those conditions seen most frequently within the Linked Care cohort;

? admissions which had the best potential for management at home and which could be avoided; they were asked to advise Linked Care on the mechanisms that could be used to avoid these admissions;

? mechanisms that could minimise the cost of pharmaceuticals to Linked Care; and

? strategies for dealing with frequent presentation and delayed presentation for review, and the frequency of home visits relative to surgery visits and justification on the basis of cost efficiency.

The operational objectives of the Group differed from this list. While the Group did not find answers to these questions during the life of Linked Care, it generated considerable debate in a number of clinical areas among GPs, improved the working relationship with Linked Care and completed the clinical reminder sheets discussed above.

The second group convened by the Division, the Liaison Committee, met as needed to discuss liaison and policy issues, and project initiatives proposed by Linked Care relevant to the Division. Its aim was to facilitate better information flow to the Division Board and consultation about the future of Linked Care. Most issues submitted to this working group were successfully resolved over time according to Linked Care.[63]

Several of the process lessons from Linked Care concerned liaison with the Division of General Practice. The Division appeared slow to engage in the opportunity to improve service delivery through mechanisms offered by Linked Care. Their participation on working groups was sporadic and did not appear to be consistently relayed to other members of the Division. As a result it seemed difficult to reach decisions or to pilot suggestions. Consequently initiatives largely remained at the discussion level.

3.6c Medication Review

Linked Care adopted a model of medication review, Patient Medication Management Service (PMMS), developed for two other trials in collaboration with the Faculty of Pharmacy, University of Sydney and the Pharmacy Guild of Australia.[64]

Goals of introducing the PMMS were to reduce PBS costs, better manage medical needs and reduce the risk of illness from inappropriate or over-medication. Initial tracking data analysis in Linked Care revealed that less than six per cent of participants consumed 21 per

[63] Linked Care report, March 2000.

[64] The Guild received a grant from CDHAC as part of the coordinated care program. The Guild provided Linked Care with a small grant to undertake reviews.

cent of PBS resources from the fund pool. Linked Care administration identified 80 participants who were high users of medication according to agreed criteria for PMMS (over four medications and high PBS expenditure) and a review was to be undertaken by an accredited pharmacist, with the consent of the GP and the participant.

At the request of the Division of General Practice, GPs planned to review half the participants identified for medication reviews.[65] The Division specified that it would undertake what it called 'peer reviews of medication', not PMMS (a particular process) or medication reviews. They finalised how they would conduct the peer reviews mid-way through 1999. They completed 12 reviews but did not evaluate the outcomes.

The PMMS enrolment process was to contact the GP and ask permission to conduct the review on their patient. Permission was sought from the participant, who was then allocated to a pharmacist specially trained to conduct PMMS. The PMMS consisted of three parts. An initial interview with the patient was written up as a report and sent to University of Sydney to be checked, then a copy was sent to the GP. A second interview was then conducted with the patient after two weeks to see if any changes occurred. A three-month follow up interview completed the process.

With additional funding from the Pharmacy Guild, Linked Care aimed to complete 150 PMMS and 60 GP Peer Reviews, but fell short of this target, as summarised in Table 3.31. Some participants did not feel comfortable in having their medications reviewed and felt that the doctor would be under scrutiny. More participants than doctors denied consent for this process to take place. Due to length of the process and the fact that pharmacists had other large workloads the completion rate was small compared to the number of participants identified.

Table 3.31: Medication Reviews Summary

Status of the medication review	Participants	Total
GP denied permission to proceed	17	
Participant denied permission to proceed	39	
Participant exited before completion	19	
Allocated to pharmacist but not completed	38	
Allocated to GP Peer Review but not completed	49	
Total unable to complete		162
PMMS completed	57	
GP Peer Review completed	12	
Total completed		69

The Faculty of Pharmacy analysed the outcomes of the PMMS only for the reviews that were completed (all three interviews). No significant changes were observed. The Faculty of Pharmacy had hoped to analyse the GP peer reviews too, but the proposed design by the GPs became too divergent from the PMMS.

[65] This was then revised to 50 participants.

Results from the Faculty of Pharmacy analysis are included in the following box. They relate to the three Coordinated Care Trials that adopted PMMS (completed PMMS numbers were Linked Care = 57, Care 21 = 65 and Care Plus = 16).

Summary of the PMMS Analysis

Clinical benefits

The most common clinical findings made by pharmacist conducting the PMMS in CCTs were: no diagnosis for a particular medication documented in the care plan, side effects or adverse drug reactions, lack of or low therapeutic response, drug/drug or drug/food interactions, sub optimal medication for a particular condition, the patient having ceased a medication or altered the regime, missing therapy for a documented condition, over use of medications, the patient forgetting to take medications, and sub optimal dosage time for a particular medication.

Pharmacists made recommendations related to each of these findings. In Linked Care 181 recommendations were made by the pharmacists. Of those, 16% (29) were accepted by the GPs. Clinical outcomes flowing from those recommendations were: 16.6% of patients experienced improvement in symptoms associated with pharmacist recommendations, 3.6% experienced an improvement in side effects and adverse drug reactions, and less than 3% experienced no change or worsening of symptoms over the trial period.

Use of the health care system

MBS data were used to assess the number of health care system contacts per patient per month. Health care system contacts included all items with an MBS code, covering such things as GP visits, pathology tests, scans, and outpatient treatments for example. This data showed a trend to decreased health care system contacts after the PMMS service, but this trend did not reach statistical significance. The values decreased from a mean of 5.32 ? 0.61 health care contacts per month to a mean of 4.94 ? 0.33 health care contacts per month.

Due to the unavailability of data, a trial set of patients was selected for the purposes of analysing GP visit changes. A random selection of trial site & PMMS patients within that trial site was made. There was a trend towards reduction in the frequency of GP visits post service, but this trend did not reach significance. The decrease in GP visits per month was from a mean of 2.72 ? 0.33 to a monthly mean of 2.41 ? 0.33 GP visits.

While there is a trend for reduction in MBS costs, it does not reach statistical significance. The over all range in monthly MBS costs before the PMMS service is $49.28 to $2,069,30, and post service the range is from $28.07 to $5,055.80, while total sample size was 49 patients.

Medication use

Prescribed medication numbers in each individual site do show a trend towards reduction after the PMMS service, but this reduction is not statistically significant. The over all prescribed medications decreased from a pre-PMMS mean of 10.61 ? 0.58 to a post PMMS mean of 10.47 ? 0.55 per patient. The decrease in prescribed medications is closest to reaching statistical significance at the Linked Card site (P 0.070,33 df). The man number of OTC medications remains steady throughout the service at all sites.

An over all trend for reduction in the number of total medications can be seen, and while the change between pre service and post service values is approaching significance, it does not reach it (in paired-sample t-test, P 0.085, 103 df).

Changes in medication cost were classified into changes resulting from pharmacist recommendations, and other changes. Pharmacist initiated changes, showed a statistically significant reduction in monthly medication costs (prescription and OTC) over the course of the PMMS (P 0.018,87 df).

Over the course of the PMMS, the cost of medications dropped from a mean of $236.91 to a mean of $221.57 per patient per month, which is a saving of $15.34 on average per patient per month. Pharmacist recommendations and actions achieved an annual decrease in medication costs of $25,403.04 across the 138 patients receiving a PMMS in the Coordinated Care trials. This was equal to an annual saving of $184.08 per patient.

The changes in monthly total medication cost (prescription and OTC) unrelated to pharmacist recommendations or actions showed a trend to increase which did not reach statistical significance. The means changed from $229.13 ? $35.32 per patient per month before the PMMS, to $235.61 ? $36.51 per patient per month after the PMMS.

(Benrimoj et al, 1999)

The implementation process was slower than expected, partly due to a lack of available pharmacists. Nineteen accredited community pharmacists in the area undertook reviews and six actually completed them. Linked Care management explored ways to improve the review rate for the second half of Linked Care, including a higher payment to the pharmacist. Linked Care appointed a Pharmacist Liaison Officer one day per week to improve the functioning of the process (e.g. formalised agreements between each of the parties, re-enrolled pharmacists and arranged clinical support for the pharmacists from the University of Sydney).

At the mid-trial GP focus group, some GPs reported they had experienced difficulty with the PMMS, with their patients finding them intrusive and confusing. Most of the GPs felt that these should be conducted by GPs only. This result should probably be read with caution given that less than 20 PMMS had actually been conducted at that stage and only eleven GPs attended the focus group.

It would be useful in future to assess whether a secondary intervention such as medication reviews, paid for through the fund pool, were successfully adopted by CCs and medical practitioners and whether they produced any significant cost savings to the fund pool and improved health outcomes for participants.

The model of the Coordinated Care Trials constrains the degree of intervention available to Linked Care management in relation to any findings from the PMMS, other models of pharmaceutical review or from other analysis of medication data. Irrespective of the findings, Linked Care is only ever in a position to present the information to the prescribing practitioners, rather than having the jurisdiction to compel any change in medical practice. Similarly, Linked Care must abide by Medicare rules to pay for all treatments claimed by medical practitioners.

Irrespective of the effectiveness of these formal medication review mechanisms, the fund pool results indicate that perhaps indirectly Linked Care had the effect of decreasing the use of PBS services in the Intervention area (Section 3.3e. Service usage analysis did not show a significant change relative to the Control group; Section 5.4b and Appendix 5). An explanation could be that GPs were aware that the PBS levels were being monitored by Linked Care through the medical care plans and service usage data collection.

Other opportunities for Linked Care feedback to GPs and the Division about pharmaceutical service usage patterns were introduced by the administration at an elementary level during the trial. The potential efficacy of these broader information mechanisms were planned to be acted on in Phase II of the trial.

3.6d Hospitals Notification System

Linked Care established a system of communication for when a participant was admitted to the public hospitals Hornsby Ku-ring-gai, Royal North Shore or Ryde, and one private hospital, Sydney Adventist Hospital (SAH). The hospitals informed Linked Care staff, who notified the CCs of any admissions. CCs commented favourably about this process because it enabled them to plan and cancel other services, facilitate discharge, as well as potentially reduce the length of stay and organise additional services if required.

The SAH, like the two private health insurers in Linked Care, was interested in exploring new partnerships and ways of managing inpatient admissions. It is a large private hospital with an accident and emergency service, so it receives unplanned admissions.

CCs also suggested enhancements to improve the hospital notification practice, that were not implemented during this trial. They suggested that: Linked Care negotiate similar arrangements with other hospitals especially the other large public hospital, Westmead; the hospitals inform CCs about imminent discharge; and the CCs fax a copy of the care plan to the hospital.

Linked Care also intended to develop a priority list of participants so that they could check that the CCs had acted on the admission notification. This was rejected as too ambitious for the timeframe of this trial. Therefore whether CCs acted on the notification information was independent of any Linked Care scrutiny. CCs were reported to be inconsistent as to whether they did act on it; as were the discharge planners in notifying the CCs as to discharge plans.[66] Greater development work with the hospital staff would be required to make the strategy more effective in Phase II of the trial.

CC involvement in discharge planning was seen as an effective strategy in the experience of full-time CCs because they knew the participant and family as well as the range of community-based services to assist in the discharge. On admission, they faxed the care plan to the discharge planner. The discharge planner was reported as often not responsive, maybe because they were more focused on tasks such as finding alternative beds, tending to make them more impersonal in their dealings with participants. There was sometimes a better response from the NUM or Social Worker who were more likely to know the participant.[67]

3.6e Hospital Issues Working Party

A more general initiative was the formation of the Hospital Issues Working Party.[68] This working party was formed to examine if improvements could be made to the admission, length of stay and separation of persons admitted to the rehabilitation ward of HKHCHS. Admission for AN-DRG 941 (rehabilitation) was the most frequent reason for admission for Linked Care participants.[69] The experience with the Control group was reported to be the same.

In recognition of the limitations the AN-DRG coding for sub-acute and non-acute episodes of care, HKHCHS was one of the pilot sites for testing SNAP. However the data were only provided to Linked Care as AN-DRG. It would appear that the participants within this rehabilitation group had a wide range of diagnoses and disabilities. It was hoped that with

[66] PSG Summary May 1999.

[67] Full-time CCs interview 6 May 1999.

[68] Initially the Rehabilitation Working Group.

[69] An analysis by Linked Care of the inpatient episodes of trial participants showed that between January and October 1998 the most frequent inpatient event was 'Rehabilitation' AN-DRG 941, accounting for $566400 of inpatient care, more than ten times the cost of the next most expensive DRG.

alternative and flexible use of available funds available in Linked Care some of these participants could have been cared for differently.

The Working Party was formed to examine the diagnoses and disabilities of this group, if appropriate identify sub-groups within the DRG and recommend good practice guidelines. The terms of reference were to:

1. examine the participant inpatient events which have been coded as 'rehabilitation' and identify sub-groups within this DRG where possible;
2. select, sub-groups where opportunities may exist to provide improved care, substitute care or more appropriate care either as an inpatient or non-inpatient;
3. examine opportunities for reducing length of stay for the group as a whole or one of the sub-groups;
4. canvass the views of the Rehabilitation and Aged Care Service on what aspects of the health and community care services could be substituted or improved for this group;
5. pursue other lines of inquiry that may result in reduced length of inpatient stay or avoid hospital admission; and
6. make recommendations to the management of Linked Care.

Data obtained from the NSAHS suggested that participants in the Intervention group were more likely to be discharged home and less likely to be transferred to a nursing home than all other patients admitted for rehabilitation in the NSAHS (five hospitals).

An incidental goal from the hospital notification described above was to avoid last minute discharges, such as on Fridays. If the hospital notification strategies were effective, arrangements for services after discharge would already have been made in advance. CCs also had authority to purchase additional services until other arrangements can be made if an unexpected discharge is made.[70] The working party also addressed the adequacy of hospital discharge planning on Friday afternoons for participants who require community support that may wait until Monday to be put into place. If community support had not been arranged, one strategy discussed was to leave Friday discharges to Sunday, which would see only a one-day delay in implementing services.

No strategies emerged from the working party that were acted upon. While a number of initiatives may be useful (such as more resources in the rehabilitation discharge team, improved accident and emergency-community interface, and early discharge programs), none of these strategies would have been cost effective for the number of participants in Linked Care and the frequency with which they were admitted. Such strategies would only be cost effective if they were introduced for all patients in the hospitals. It is dubious then as to whether these types of strategies are relevant to a coordinated care trial, unless the participant population is a significant proportion of the total service population.

[70] Management Committee minutes 5 March 1999.

3.6f Hip Protectors

An additional service substitution strategy was added near the end of the trial (August 1999): the use of hip protectors to prevent hip fractures due to falls. The strategy was reported by Linked Care staff to have been received well by CCs at PSG meetings because of the evidence presented about lower fracture rates in users. Nearly half the participants (189) were identified as being at high risk of sustaining a fractured hip. Sixteen participants consented to referral and five participants had good compliance. There were no reported falls or fractures among the 16 participants.

3.6g Results from the Specific Linked Care Initiatives

The evaluation of the implementation of these initiatives remained one of examining the process rather than outcomes. Their achievements appeared to be to reach recommendations for future practice. With such a short period between the implementation of the strategies and end of the trial it was not possible to observe any measurable impact on health and well-being or financial outcomes. Outcomes as were observed were summarised in Section 3.5. Other process results are summarised in Table 3.32.

Table 3.32: Results from Specific Linked Care Initiatives

Intervention	Results
1. Prompt sheets	GPs and CCs rejected best practice guidelines as inappropriate to clients with complex care needs and patronising to professional practitioners. Draft prompt sheets were greeted with ambivalence by GPs and CCs.
2. Clinical Advisory Group	Division representatives met regularly and developed prompt sheets.
3. Medication review	68 PMMS (29 per cent) were completed. The PMMS process was hampered by resistance from GPs and participants and insufficient incentives to pharmacists to participate until financial returns were increased. No significant changes to pharmaceutical use were measured. The Division did not design a GP peer review that from which outcomes could be evaluated and too few were undertaken to evaluate the process.
4. Liaison with hospitals	CCs and hospitals embraced the process as positive. Incremental changes to increase its effectiveness were identified. Limitations were that the system relied on cooperation between discharge planners and CCs, which was not achieved in all cases. Some CCs acted on the admission data to adjust care arrangements and some admissions did not need follow up by CCs.
5. Hospital Issues Working Party	Issues about appropriate rehabilitation care and discharge were discussed but the number of Linked Care participant admissions was too small to justify resource investment.
6. Hip protectors	The initiative was implemented in the last quarter of the trial, too late to measure the impact (few referrals and the number of participants was too small to observe fall-related injury prevention).

4. Impact on Clients

This chapter describes the clients and their experiences of Linked Care. Clients 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.

Linked Care did not produce a negative effect on outcomes for clients 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 worsened. It appears clients not involved as participants in Linked Care may have been disadvantaged but the evidence is ambiguous.

The chapter begins with a background to the client focus of Linked Care (Section 4.1). Next a description of the participants and the match between the Intervention and geographical Control groups (Section 4.2) is provided. Client outcomes from the perspective of the participants, service providers and Linked Care administration are presented in Section 4.3. The impact on carers and clients not in Linked Care are discussed separately in Sections 4.4 and 4.5, followed by a conclusion at the end of the chapter.

Further participant tables are presented in Appendix 6 and participant experience tables in Appendix 7. Methodology associated with the evaluation of participant experiences is described in Appendix 4.

4.1 Background to the Client Focus

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.[71] 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).

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.

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

‘Consumer’ was used in the trials to mean those with complex care needs and users of multiple health and community services.[72]

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.[73]

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 their participants 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 throughout this report, particularly in Sections 3.1c, 3.4 and 4.3.

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

> 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: data reported from service providers (e.g. exits, measure of disease control, participant profile); and participant reported data (e.g. SF-36, participants perceptions and explanations of their experiences)

---

[72] 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.

[73] Local Evaluation emphasis; Centre for Health Advancement and KPMG Management Consulting, 1997:6.

through participant questionnaires and qualitative interviews. Methodology in relation to participant reported data is described in Appendix 4.

It is in this context that the remainder of the chapter examines the profile of the participants in Linked Care and the impact of the model on their experiences as users of health and community services.

4.2 Description of the Participants

A summary of the participant groups referred to throughout this report is listed in Table 4.1.

Table 4.1: Descriptions for All Participants and Participant Samples

Participant group name	Description	Participant group		
		Intervention	Control	Total
All participants in Linked Care	All those participants in Intervention and Control groups.	722	423	1 145
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

4.2a Baseline Characteristics of the Linked Care Participants

Final consents were obtained from 722 Intervention and 423 Control participants.[74] When participants were recruited to Linked Care, their recruiter or CC was expected to complete a participant profile with them. This 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 identified and corrected data entry errors and gaps in the data.[75]

[74] 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.

[75] The participant profile form was redrafted in the second year of the trail 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.

Table 4.2 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.

Table 4.2: 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 4.2 (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).

The sample can be described as consisting of mainly 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 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 DVA clients. Data on household income were dropped from the analysis due to missing data (participants did not respond).

4.2b Comparison of Intervention and Control Groups

Although the participants in both the Intervention and Control groups were fairly similar overall, some large differences were 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 with the equivalent.

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 must be taken into account (Sections 4.3 and 5.4). Logistic regression analysis was carried out to estimate to what extent personal and other characteristics change the odds of being in the Intervention group, while at the same time controlling for the influence of all other characteristics. The results are presented in Appendix 6, Table A6.1. 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, while participants who did not speak English at home were significantly less likely to be in the Intervention group. These results suggest 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. Intervention participants were less likely to be renters rather than owners.

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 A6.1 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 (Sections 4.3 and 5.4).

4.2c Comparison of Participant Samples to all Linked Care Participants

Two primary methods of evaluation of the participant experiences were repeated participant questionnaires and participant interviews. The methodology is described in Appendix 4. 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 A7.1, Appendix 7.

There were some differences within the effective participant questionnaire sample (participants that 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 participant groups who had not exited at the end of the trial (Section 4.2b; Table A7.1 and A7.5). 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 (Appendix 4). 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, strokes and Parkinson's disease or had conditions such as leukemia, angina problems, continuing eye problems and paralysis. Most interview participants had a carer (usually a daughter or spouse) and one participant from each group, while in poor condition themselves, were also the main carer for another person (Table A7.3, Appendix 7).

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 and four from Intervention groups 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 included throughout this report. All names used in the report are pseudonyms.

4.2d Diseases at the Baseline

Information on participants' diseases was provided by GPs as part of the medical care plan. Table 4.3 summarises this information by grouping it into disease categories and presenting mean nominations for each group.[76] 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.

Table 4.3: 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).

[76] Data has been classified according to ICD-9.

Leaving aside category 14, which had very small numbers 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.[77]

Columns three and four show that circulatory diseases were most common in both groups, followed by musculoskeletal and nervous system diseases. Overall, significantly more circulatory disease was evident among the Control group, while for the Intervention group, nervous system diseases, skin and ill-defined diseases were more common.[78]

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.

[77] Digestive diseases ($t=2.0$, $p<0.05$); musculoskeletal diseases ($t=2.1$, $p<0.04$).

[78] 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 disseases ($t=2.0$, $p=<.05$).

4.3 Client Outcomes

The results about outcomes for Linked Care participants were ambiguous. Linked Care did not appear to 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.

This section discusses the results in relation to exits, health and well-being, satisfaction and the measure of disease control. The perspectives of participants, service providers, CCs and the Linked Care administration are included. Separate analysis of changes in service usage and access to services is presented in Section 5.4.

Further analysis of outcomes by participant type and CC type is recommended in future.

4.3a 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.

This section examines that characteristics of those participants who exited compared to those who stayed in Linked Care. Second, it presents the analysis on reasons for exit. Comparison to the exit rate in the Control group is made throughout the section.[79]

Socio-demographic Characteristics of Participants who Exited

The socio-demographic differences of exiting and non-exiting participants within the Intervention and Control groups and between the two groups were analysed to examine patterns of exiting (Table 4.4). In the Intervention group a larger proportion of participants with private insurance exited than participants without insurance, as did participants who described their occupation as home duties. Amongst the Control participants, smaller proportions of 70 to 79 year olds and participants from non-English-speaking backgrounds exited, compared to the proportions who remained in Linked Care. A slightly larger proportion of single participants was also evident among the non-exiting Control participants.

[79] An administrative limitation of managing a geographic Control arose in the collection of Control group exit data. There was no system in place to specifically inform Linked Care of exits from the Control group. Linked Care decided it was unrealistic to collect it through regular contact with service providers. Instead, they relied primarily on an occasional survey of the recruiting agencies. In addition the administration of participant questionnaires generated exit information. This had possible drawbacks: the first method relied on the records and memory of the recruiting agencies; and the second could be an insensitive way of approaching participants and their carers. Both methods were not as timely as the collection of exit data from the Intervention group and some of the information about reasons for exit may have been lost.

Table 4.4: Selected Baseline Characteristics of Participant Groups by Exit Status

	Participant Group			
	Intervention[a]		Control	
	Not Exited %[b] (n=)	Exited %[b] (n=)	Not Exited %[b] (n=)	Exited %[b] (n=)
Participant Characteristics				
Age				
<50	6.3	4.6	1.9	2.3
50-59	4.8	2.5	2.9	2.3
60-69	9.1	6.4	9.0	9.4
70-79	29.8	25.8	36.7	24.4
80-89	42.7	46.9	45.2	46.9
90 and over	7.3	13.8	4.3	14.1
	100.0	100.0	100.0	100.0
	(396)	(326)	(210)	(212)
Gender				
Male	33.3	36.5	22.9	29.6
Female	66.7	63.5	77.1	70.4
	100.0	100.0	100.0	100.0
	(396)	(326)	(210)	(213)
Marital status[c]				
Single	54.8	57.8	72.4	66.2
Couple	45.2	42.2	27.6	33.8
	100.0	100.0	100.0	100.0
	(396)	(308)	(210)	(213)
Country of birth				
Australia	77.3	78.2	77.6	75.1
Other	22.7	21.8	22.4	24.9
	100.0	100.0	100.0	100.0
	(396)	(321)	(210)	(213)
Language spoken at home				
English	97.2	98.4	86.2	93.0
Other	2.8	1.6	13.8	7.0
	100.0	100.0	100.0	100.0
	(396)	(317)	(210)	(213)
Participant's accommodation				
House, unit, apartment, flat	90.1	91.5	93.8	95.3
Independent living unit, hostel	9.9	8.5	6.2	4.7
	100.0	100.0	100.0	100.0
	(395)	(316)	(210)	(212)
Tenancy[d]				
Owner	81.3	85.3	72.4	72.0
Renter	18.7	14.7	27.6	28.0
	100.0	100.0	100.0	100.0
	(396)	(299)	(210)	(211)
Shares home				
Does not share	37.1	41.7	57.6	50.7
Shares with spouse	43.4	39.0	26.2	31.5
Shares with other	19.4	19.3	16.2	17.8
	100.0	100.0	100.0	100.0
	(396)	(326)	(210)	(213)
Carer status				
Carer not needed	18.4	8.5	30.0	18.5
Has a carer	57.1	72.2	34.3	46.0
Needs a carer	24.5	19.2	35.7	35.5
	100.0	100.0	100.0	100.0

	(396)	(317)	(210)	(211)

Table 4.4 (continued): Selected Baseline Characteristics of Participant Groups by Exit Status

	Participant Group			
	Intervention		Control	
	Not Exited	Exited	Not Exited	Exited
Participant Characteristics	%[b] (n=)	%[b] (n=)	%[b] (n=)	%[b] (n=)
Private assistance				
Has help	64.9	69.9	67.6	76.1
No help	35.1	30.1	32.4	23.9
	100.0	100.0	100.0	100.0
	(396)	(326)	(210)	(213)
Employment status[e]				
Retired	88.6	92.7	94.8	92.5
Not retired	11.4	7.3	5.2	7.5
	100.0	100.0	100.0	100.0
	(395)	(326)	(210)	(212)
Health insurance				
Some private insurance	48.7	55.6	35.2	30.0
No insurance	51.3	44.4	64.8	70.0
	100.0	100.0	100.0	100.0
	(396)	(324)	(210)	(213)
DVA status				
DVA card	19.9	14.4	19.0	18.8
No DVA card	80.1	85.6	81.0	81.2
	100.0	100.0	100.0	100.0
	(396)	(326)	(210)	(213)
Cards status				
Has card	88.6	82.5	95.7	94.8
No card	11.4	17.5	4.3	5.2
	100.0	100.0	100.0	100.0
	(396)	(325)	(210)	(213)
Education level				
Primary	13.1	13.2	21.4	20.2
Secondary	53.3	56.8	71.4	70.9
Tertiary	33.6	30.0	7.1	8.9
	100.0	100.0	100.0	100.0
	(396)	(317)	(210)	(213)
Occupation				
Professional	32.6	32.0	21.9	21.1
Trade	48.5	39.2	58.6	60.1
Home duties	18.9	28.8	19.5	18.8
	100.0	100.0	100.0	100.0
	(396)	(316)	(210)	(213)

Notes:

a)Exited Intervention participants include 3 participants who exited on the 31 December 1999 and 2 participants who exited in January 2000.

b) Percentages may not add to 100 due to rounding.

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

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

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

Comparison between the Intervention and Control Groups

Of more immediate interest however, were differences between the characteristics of the participants who exited from the Intervention and Control groups. Table 4.4 shows that a larger proportion of participants who exited from the Intervention group had a carer (just over 72 per cent) compared to only around 46 per cent for exiting Control participants. Similar patterns can be found with regard to marital status, private health insurance and occupation.

Table A6.2 in Appendix 6 shows the number of participants who exited the trial each month. Both groups show a steady decrease in participants over the observation period, with the Control group losing a slightly higher proportion overall (almost 51 per cent compared to just over 44 per cent in the Intervention group). This is probably due to the re-consenting process in the last year of Linked Care.[80]

Reasons for Exit

Reasons for exit from the Intervention group are summarised in Table 4.5 and Tables A6.3a and A6.3b in Appendix 6.[81] 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.

Table 4.5: Proportion of Exits by Participant Group

	Participant Group			
	Intervention		Control	
	n	%	n	%
Remained in Linked Care	396	54.8	210	50.0
Admission to a nursing home or hostel	132	18.2	44	10.4
Related death	87	12.0	53	12.5
Administrative	47	6.5	30	6.9
Participant decision	36	5.0	78	18.4
Unrelated death	24	3.3	8	1.9
Total	722	100.0	423	100.0

[80] Comparisons between the groups from Table A6.2 are limited because recruitment continued until April 1998 so entry and exits overlapped to some extent. As Table A6.2 only refers to the exit process, it gives no indication of the number of active participants in the groups each month.

[81] Exit categories used in this section were derived from the national data set 'Reason for exit' variable and were aggregated in the following way: 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).

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). Tables A6.3a and A6.3b in Appendix 6 describe characteristics of the participants who exited from the Intervention and Control groups according to reasons for exit.

Of particular interest is whether, after taking socio-demographic characteristics into account, there was a difference in exiting between Intervention and Control participants (Tables A6.4a to A6.4d, Appendix 6).[82] Model 1 shows that the odds of exiting were slightly less for Intervention participants (0.94) compared to the Control. When baseline characteristics were taken into account (model 2), this difference increased significantly to 0.75. Overall, decreased risk related to Intervention participant status, having a non-English speaking background, living with another person, paying for private domestic help, holding a pensioner concession or health care card, and participants whose current or past occupation was at the trade or professional level. Greater risk was associated with having or needing a carer, single status, being male and increasing age.

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.

4.3b Health and Well-being

Administration of the SF-36

The SF-36 was selected by the National Evaluation Reference Group (NERG) as the standard instrument across the national Coordinated Care Trials to assess changes health and well-being. At the time of the selection, the limitations to its suitability for predominantly older clients with complex care needs were acknowledged: insensitivity to change, difficult to administer (CHA and KPMG, 1997a). These were balanced against the benefits of a validated instrument with Australian scales. The procedures for administration were dictated by the national evaluators (CHA and KPMG, 1997b).

In Linked Care the baseline SF-36 was administered within three weeks of consent to the trial. Consent was taken as the activation date, and this ranged from November 1997 to August 1998. The second administration was within 12 months of the first plus or minus four

[82] Because only some participants exited during the trial, the survival analysis technique used was Cox proportional hazard analysis. The event or dependant variable was defined as exit from the trial (1=exit, 0=remained in trial). Tables A6.4a to A6.4d in Appendix 6 summarise results from this analysis and all have the following format. Model 1, the base model, shows the risk of exit by group membership without adjusting for any other variables which might affect the risk of exit. Model 2 adjusts risk ratios after taking into account the influence of participant characteristics at baseline. Intervention and Control group participants were then analysed separately (models 3 and 4) to examine differences in their respective risk profiles.
A risk ratio estimates the risk of exit among participants with the specified characteristic in relation to the risk for the corresponding reference category. For example, in Table A6.4a risk of exit was 2.6 times greater for those participants with a carer and almost 50 per cent higher for those who needed a carer than those participants who did not need or have a carer. A ratio over one indicates a higher hazard or risk, while below one indicates a decreased risk.

weeks. The final administration was conducted in November 1999 at the end of the trial. The timing of the second administration might have been problematic especially for those participants for whom the second administration was quickly followed by the final one.

The administration was contracted out. To assure quality in the contracting out of the SF-36, the evaluators conducted training with the field manager and interviewers, inspected the field management systems for the administration of the questionnaire, attended the contractor's offices to check interviewer compliance with the instructions, liaised regularly between the contractor and Linked Care administration, and attended to any administration and instrument problems. Having been reassured as to the quality of the administration, the local evaluators arranged that the second and third administrations were to be contracted directly between Linked Care administration and the external contractor, without the middle position of the local evaluators.

The contractor was thorough in providing feedback to Linked Care staff about participant needs and corrections to the database information. By contracting out the administration, confidentiality standards were observed as the evaluators do not have access to the participants' identifying details. The SF-36 contractor completed a summary about how many and for what reasons participants have not completed the SF-36.

Few respondents required a face to face interview or interpreter. The national requirement of having the same proportion of interview and mail administered questionnaires in the Control and Intervention groups meant that extra interviews were conducted in the Intervention area that would otherwise not have been necessary. As most respondents completed the questionnaire by mail, the prompts in the guidelines for telephone or face to face interviews could not be used. This may have reduced the accuracy of responses compared to trials that used a higher proportion of other methods of administration.

The participant questionnaire included three health and well-being questions to supplement and check the SF-36 results for those participants who completed the SF-36 and to act as a substitute for those who did not complete the SF-36.

In the first administration of the SF-36, eight participants specified the SF-36 as the reason for withdrawing from Linked Care. They could not be dissuaded from withdrawing from Linked Care, even if the SF-36 was not administered. About one-third of participants objected to doing the questionnaire, but most went on to complete it. It was more difficult to get the Control participants to answer because many claimed to have never heard of Linked Care or they were not motivated to complete the questionnaire. All missing data were checked with a telephone call. Approximately 30 per cent of participants had missing data before telephone follow up.

Results of the Health and Well-being Questionnaire

Response rates for the three administrations of the SF-36 are summarised in Table A6.5 in Appendix 6.[83] . The Control group had a slightly lower response rate at both the baseline and end of trial administrations. Given that non-response may cause bias or distortion of results, the characteristics of responding and non-responding participants at each administration were examined. The results of this comparison are shown in Tables A6.6a to A6.6b. While there is considerable detail in these tables, the distribution of characteristics remained more or less the same throughout the period for both Intervention and Control groups.

Table 4.6 presents mean scores for each administration of the SF-36. A higher score indicates better health and well-being. These results show little change overall (that is from baseline to end of trial) on any of the items measured. Similarly, there were no major differences between the Intervention and Control groups at each administration. What differences there were, were only moderately significant. At the baseline, emotional role was significantly higher among the Intervention group, while at the mid-trial physical functioning and social functioning were significantly lower among the Intervention group participants. By the end of trial Intervention participants had significantly higher scores on the bodily pain measure. [84]

[83] A number of questionnaires were found to have administration dates after exit dates. Only where this discrepancy was greater than three months were the questionnaires dropped from the analysis (10 cases dropped). Ninety-two questionnaires were also found to be missing all data, although they did have an administration date and participant identification. These were also dropped from the analysis.

[84] Emotional role ($t=2.24$, $p<0.03$); physical function ($t=2.26$, $p<0.02$); social function ($t=2.18$, $p<0.03$); bodily pain ($t=2.36$, $p<0.02$). Similar results were obtained from the Mann-Whitney test – at baseline scores for emotional role were higher among the Intervention group ($z=-2.21$, $p<0.03$); at mid-trial both physical function and social function scores were lower among the Intervention group ($z=-2.497$; $p<0.02$) and ($z=-2.22$, $p=<.03$) respectively; and by the end of trial bodily pain was higher for the Intervention group ($z=-2.33$, $p=.02$).

Table 4.6: SF-36 Mean Scores by Participant Group for Three Administrations during the Trial

	Mean Scores					
	Baseline		**Mid-trial**		**End of trial**	
	Intervention	**Control**	**Intervention**	**Control**	**Intervention**	**Control**
SF-36 Item	Mean (n =)	Mean (n =)	Mean (n =)	Mean (n =)	Mean (n =)	Mean (n =)
Physical function	24.9 (651)	24.1 (376)	22.6 (419)	27.2* (266)	23.1 (388)	25.6 (200)
Physical role	20.3 (648)	17.1 (375)	19.2 (418)	22.2 (264)	22.4 (384)	19.5 (199)
Bodily pain	49.7 (652)	47.3 (375)	48.5 (419)	44.4 (266)	49.7 (387)	43.7* (198)
General health	44.7 (648)	43.3 (376)	45.8 (420)	45.1 (265)	44.4 (387)	43.8 (200)
Vitality	38.7 (652)	38.2 (375)	40.5 (420)	39.5 (266)	37.7 (386)	39.6 (200)
Social function	48.6 (653)	49.3 (376)	49.1 (420)	54.5* (264)	50.4 (388)	51.8 (200)
Emotional role	51.1 (645)	44.5 * (373)	49.2 (416)	47.00 (261)	49.5 (383)	43.9 (199)
Mental health	69.8 (653)	68.7 (374)	70.2 (419)	70.9 (266)	69.9 (386)	69.2 (200)
PCS	27.9 (636)	27.3 (371)	27.3 (413)	27.9 (260)	27.9 (382)	27.3 (197)
MCS	45.9 (636)	45.2 (371)	46.6 (413)	46.6 (260)	46.0 (382)	45.8 (197)

* $p<0.05$

Table A6.7 provides background information regarding 'floor' and 'ceiling' effects. This table shows the proportions of participants who scored either the minimum or the maximum possible score for an item. For instance, given that all Linked Care participants by definition had complex medical needs and problems, it is not surprising to find that for physical role at the baseline over 60 per cent scored the lowest possible score. When comparing their scores with the end of trial score they could only improve or remain the same. It should also be noted that for the dimension of emotional role, around 80 per cent in both the Intervention and Control groups scored either the maximum or the minimum at the baseline, again limiting possible changes in scores.

Changes in scores between the baseline and end of trial administrations of the SF-36 are presented in Table A6.8 in Appendix 6 as proportions of each group who were better, the same or worse over the period. These scores were calculated for each participant end of trial score less baseline score. Where participants responded to the baseline SF-36 but

exited due to a related death or entered residential care before the end of trial administration, they have been included in the calculations and have been categorised as worse off over the period and given a score of zero.[85]

The first two columns of Table A6.8 exclude exited participants – only those who responded at both the baseline and end of trial are included. For each item it can be seen that relatively large proportions of the Intervention groups have worse scores at the end of the trial except for items physical role and emotional role. Similar patterns were also evident among Control participants. When exited participants were included, the proportion of participants whose score worsened increased on most dimensions.

Logistic regression was used to analyse these changes across the Intervention and Control groups.[86] Table A6.9 shows that after controlling for baseline differences, only emotional role is significantly different. Being in the Intervention group increased the odds of having a better score, compared to scoring the same, by around 73 per cent. However, Intervention group membership also meant that the odds of having a worse score, compared to scoring the same, were also significantly higher (by a factor of 2.7).

Preliminary analysis of changes in scores when exiting participants are included reproduces those patterns identified previously. Participants whose score for emotional role worsened were twice as likely to be an Intervention participant (significant at the 10 per cent level). In addition, however, those whose bodily pain score worsened were 40 per cent less likely to be an Intervention participant (significant at the 5 per cent level).

In summary, as expected, there was very little change in participants' health and well-being as measured throughout the trial, comparing a baseline, mid-trial and end of trial score. 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

[85] The analysis presented in this report is relatively simple. A more sophisticated analysis might adopt some of the methods utilised by Ware et al. (1996) where, for instance confidence intervals were incorporated into calculations when estimating changes in item scores.

[86] Logistic regression was performed with Intervention group membership as dependent variable (outcome) and a number of socio-demographic variables as background variables (Section 4.1b). The regression predicts that with a given outcome and controlling for background differences, the participant was or was not from the Intervention group. More specifically, it provides the odds of being an Intervention participant for a particular variable, holding all other variables constant.

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.

The effect of CC type on changes to participant health and well-being as measured by the SF-36 scores were examined using OLS regression procedures. Preliminary analysis found no significant differences in health and well-being outcomes between participants with different types of CCs.

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 4). 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 4.7). 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 4.7).

Table 4.7: Self-assessed Health and Well-being by Participant Type

	Participant group					
	All baseline responses		Effective Sample[(a)]			
	Intervention	Control	Intervention		Control	
			baseline	end trial	baseline	end trial
	% (n=)	%(n=)	% (n=)	% (n=)	% (n=)	% (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[(d)]	***	***	**		**	
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.

4.3c Satisfaction

The participant questionnaire asked eight questions about various aspects of care coordination to gauge client satisfaction levels and to observe change over time. However there are a number of problems associated with investigating client satisfaction. Studies have revealed that older clients in particular are unlikely to criticise or rate poorly services they receive in satisfaction surveys (Draper and Hill, 1995: 67). Other studies have found satisfaction surveys can be usefully employed to improve specific aspects to 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 more concretely rate 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, service providers responded to changed needs.

The results showed that there was little difference between Intervention and Control participants in their satisfaction levels. Significance 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 4.8).

Analysis of changes in satisfaction over time was also conducted (Table 4.9). When comparing the scores for change, only costs of care was shown to be significantly different. This was discussed in Section 3.3f. 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 client satisfaction with aspects of care coordination are presented in Table A7.6, Appendix 7. Future research could explore the significance of change between administrations at the baseline and mid-trial.

When analysed by CC type, some additional areas of significant improvements in satisfaction in 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 A7.8). 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 (TableA7.8). 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 4.8: Client Satisfaction with Organisation of Care 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=)
Unnecessarily repeated tests/assessments[b]						
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[d]						
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[e]						
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[f]				*		*
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[j]						
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[c]						
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[i]	***	***	***		***	
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
Notes: (a)Effective sample: participants who responded to both the baseline and end trial questionnaires.

Table 4.9: Changes in Client Satisfaction with Organisation of Care by Participant Group

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

The qualitative interviews explored client satisfaction in further detail, revealed a complex picture. It suggested that it may be difficult for clients to untangle the differences between care coordination and the services they receive. This was discussed in greater detail in

Section 3.4.[87] Despite the differences in the levels of services received by interviewed participants, satisfaction was similar between Intervention and Control groups (Table A7.7, Appendix 7). 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.

4.3d Measure of Disease Control

An additional health outcome measure was included in the review of the medical care plan for each participant, a measure of disease control. The measure of disease control was included in the Linked Care evaluation at the instigation of GPs on the Evaluation Working Party who wanted a clinical outcome measure to supplement the SF-36. It was developed by Professor Mark Harris specifically for the purposes of the evaluation. The measure of disease control was a rating by GPs of how successfully they considered a patient's chronic condition to be, on a scale from 1 (well controlled) to 3 (not well controlled), with 4 meaning 'not applicable'. It was filled out by GPs when they provided Linked Care with a list of diagnoses for the patient, and was collected in both Intervention and Control groups.

Since it was not part of the original evaluation, the measure was introduced after the beginning of the trial. It was filled out between November 1998 and December 1999.

Methods

The measure of disease control scores were collected and entered into a database by Linked Care. The data were then transferred to the evaluators and analysed using SPSS. The earliest and latest rating was taken for each diagnosis for each participant[88] for which the measure was used and data analysed only for patient diagnoses for whom two ratings between one and three were available, ignoring those for whom the measure was deemed not applicable. A variable was computed which measured whether the rating for a patient diagnosis stayed the same across the two measurements, improved or worsened.

Results

There were 237 patients (20.7 per cent of patients in the trial) with 210 separate diagnoses between them. Table 4.10 shows the number of diagnoses per patient.

[87] 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).

[88] Hereinafter referred to as 'patient diagnosis'

Table 4.10: Measure of Disease Control: Number of Diagnoses by Patient

Number of diagnoses	Number of patients	Percent of patients
12	1	0.4
11	1	0.4
10	1	0.4
9	4	1.7
8	5	2.1
7	8	3.4
6	11	4.6
5	28	11.8
4	23	9.7
3	46	19.4
2	66	27.8
1	43	18.1
Total	237	99.8

The ten most common diagnoses are shown in table 4.11.

Table 4.11: Measure of Disease Control: Most Common Diagnoses

Diagnosis	No of patients	% of patients
Essential (primary) hypertension	98	41.4
Polyarthrosis unspecified	43	18.1
Chronic IHD unspecified	43	18.1
Congestive heart failure	27	11.4
NIDDM (diabetes) without complications not stated as uncontrolled	27	11.4
Unspecified osteoporosis site NOS	26	10.9
Glaucoma unspecified	22	9.3
Asthma unspecified	19	8.0
Gastro-oesoph reflux disease with oesophagitis	17	7.2
Atrial fibrillation and flutter	16	6.8

Table 4.12 shows the classifications of each diagnosis for each patient from Intervention and Control groups on their first rating for each diagnosis.

Table 4.12: Measure of Disease Control: First Rating of Control for Each Diagnosis

Measure of disease control	Intervention		Control		Total	
	n	%	n	%	n	%
Well controlled	249	47.7	145	58.5	394	51.2
Somewhat controlled	245	46.9	78	31.5	323	41.9
Not well controlled	28	5.4	25	10.1	53	6.9
Total	522	100.0	248	100.1	770	100

Overall the two groups were significantly different at first measurement, with the Control group having fewer patient diagnoses 'somewhat controlled' and more at either extreme ('well controlled' or 'not well controlled').

Table 4.13 shows how the measure of disease control of each diagnoses of each patient in the Intervention and Control group changed between the two measurements.[89]

Table 4.13: Measure of Disease Control: Change Between the Two Measurements

Measure of disease control	Intervention		Control		Total	
	n	%	n	%	n	%
Improved	40	7.7	45	18.1	85	11.0
Stayed same	432	82.8	178	71.8	610	79.1
Became worse	50	9.6	25	10.1	75	9.7
Total	522	100.1	248	100	770	99.8

In both groups most patient diagnoses remained the same across the two measurement points, and a similar percentage became worse (9.6 per cent and 10.2 per cent). However Control group patients were more likely to improve their measure of disease control than Intervention group patients.[90]

The results were then analysed by groups of diagnoses. Because of the small numbers involved the 'stayed same' and 'became worse' categories were collapsed and compared with the number who improved in the Intervention and Control groups, using the Fisher exact two tailed test. The results are shown in Table 4.14.

Table 4.14: Measure of Disease Control: Change Between the Two Measurements Intervention and Control Groups by Diagnosis Groups

Change in measure of disease control	Intervention		Control		Total		p
	n	%	n	%	n	%	
Hypertension and hypercholesterolaemia							
Improved	10	15.4	6	13.0	16	14.4	0.79
Did not improve	55	84.6	40	87.0	95	85.6	
Total	65	100.0	46	100.0	111	100.0	
Heart disease							
Improved	2	4.3	6	25.0	8	11.3	0.015*
Did not improve	45	95.7	18	75.0	63	88.7	
Total	47	100.0	24	100.0	71	100.0	
Diabetes and other endocrine disorders							
Improved	0	0	5	25.0	5	11.4	0.014*
Did not improve	24	100.0	15	75.0	39	88.6	
Total	24	100.0	20	100.0	44	100.0	
Asthma/COPD							
Improved	2	6.9	4	30.8	6	14.3	0.06
Did not improve	27	93.1	9	69.2	36	85.7	
Total	29	100.0	13	100.0	42	100.0	

[89] Chi square = 18.851 df=2 p<0.001.

[90] Chi square = 19.339 df=3 p>0.001.

There was significantly greater improvement in the Control patients for heart disease and diabetes and other endocrine disorders (p= 0.015 and p=0.014 respectively).

Discussion

These results should be used with caution. Only a fifth of Linked Care participants had the measure taken twice and the measures were taken at different times with differing intervals between them. Participant numbers become particularly small when the data are analysed by diagnosis group. The measure itself was checked for face validity with GPs but was not tested further. There are no other data on which to assess the similarity of Intervention and Control group patients, no independent ratings of their diagnosis related health status, and there are no comparisons of the characteristics of the different GPs who assessed the patients.

The 'not applicable' rating was excluded from the evaluation because it was difficult to interpret. For example, a patient might move from 'well controlled' to 'not applicable' because the condition was in remission, in which case it would represent an improvement, or because although the patient's condition had deteriorated, the effects were overshadowed by other health problems.

The results show that Control group patients were more likely to improve their measure of disease control, overall and for heart disease and diabetes and other endocrine disorders. This was true even though they had a larger proportion of patients who were 'well controlled' at baseline and therefore had no scope at all for improvement on the scale. This may be offset to some extent by their having more patients 'not well controlled' who perhaps had the greatest scope for improvement.

The results for specific diagnosis groups are consistent with the overall results, and reflect the potential impact of care coordination on management of the condition. There was no significant difference for hypertension and hypercholesterolaemia, which were generally managed by the GP alone, while there were significant changes for heart disease and diabetes and other endocrine disorders, where the GP was more likely to be collaborating with others in the care of the patient.

Although this is where significant changes might be expected, there is no easy explanation of why improvements came about for Control patients rather than Intervention patients. Patients or GPs might have been different in the two groups. Services might have been more available in one area than the other. Intervention GPs might have developed higher expectations through their involvement in Linked Care, and so applied harsher standards in their second rating.

Overall it would be unsafe to draw any specific conclusions from the 'measure of disease control' results. However the measure does have some intuitive appeal as a clinically relevant measure across different diagnosis groups. In the second round of Coordinated Care Trials it would be worth developing the measure further and considering it for use from the beginning of trials.

Finally, the experience with using this measure emphasises the disadvantage of working with a geographical rather than a randomised control group. With a randomised group it would

have been much easier to interpret the results of these analyses, particularly where numbers were small.

4.3e Service Provider and Care Coordinator Experiences of Client Outcomes

At the start of Linked Care, on balance managers from both health and community care service providers seemed to be of the view that participants would benefit from Linked Care. The possible threats to participants were short-term administrative issues, such as recruitment, that had already been resolved by Linked Care. They identified a potential negative impact on access to care by clients outside Linked Care because of capped budgets.[91]

Half the CCs (51.1 per cent) reported more benefits than disadvantages for their participants. Only one-third (32.6 per cent) reported improvements in the health and well-being of the participants although over half (56.8 per cent) thought Linked Care was more beneficial for some participants that others, particularly those with complex care needs or those who, for a variety of reasons, had not been able to negotiate access to care (Table A8.1).[92]

CCs were asked about the balance of benefits and disadvantages of Linked Care to their service or practice (Table 4.15).

Table 4.15: Care Coordinator Views: Linked Care has More Benefits than Disadvantages, November 1998 and November 1999

	n	1 Strongly agree %	2 Agree %	3 Neutral %	4 Disagree %	5 Strongly disagree %	Median
1998							
For my participants	44	18.2	31.8	36.4	13.6	0.0	2.5
For my other clients	42	2.3	11.4	52.3	18.2	11.4	3.0
For my service or practice	43	9.1	25.0	36.4	20.5	6.8	3.0
1999							
For my participants	45	11.1	40.0	28.9	8.9	11.1	2.0
For my other clients	45	2.2	11.1	35.6	26.7	24.4	4.0
For my service or practice	45	6.7	17.8	37.8	15.6	22.2	3.0

Source: CCs mid-trial and end of trial questionnaires November 1998 and November 1999.

By the end of the trial a greater proportion of CCs surveyed strongly disagreed that Linked Care had more benefits than disadvantages for their Linked Care participants, their other clients, and their service or practice. However, examination of the median suggests that it was only in reference to clients not in Linked Care and that opinions of CCs has shifted from neutrality to disagreement. This is discussed further in Section 4.4. Analysis revealed significant variation by CC type for impact on other clients and impact on the service or practice. Non-GP CCs were more likely to disagree about the balance of benefits and

[91] Service provider manager baseline interviews, December 1997.

[92] CC mid-trial and end trial questionnaires.

disadvantages to other clients and similarly disagree about the balance of benefits to their service than GP CCs.[93]

4.3f Client Experiences of Benefits of Having a Care Coordinator

The participant interviews revealed information about how participants experienced the relationship with CCs (Section 3.4i). 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 to avoid the burdensome and time consuming processes and to negotiate their case; and

? 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 sense of security 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, them 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 hospital[94] or something like that,

[93] p=0.042 and p=0.029, Pearsons Chi-Square.

> somebody's got to look after my husband and Linked Care is the first one I'd ring 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 to know where to turn without the entire responsibility of making the arrangements themselves. However, their expectation that CCs could respond to crises contradicts the Linked Care model. 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.[95]

Facilitator and Advocate

CCs were also seen by participants to facilitate access to services. In the past accessing care had been seen by some respondents as difficult. Interviewee, 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. His 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 respondents appreciated the more active role of CCs organising service provision, such as negotiating on behalf of the participant with services 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.[96]

---

[94] This contradicts Linked Care policy of not being an emergency service, including no out of business contact numbers and subcontracting CC to agencies that do not always replace CCs on leave.

[95] A CC indicated participants should not expect immediate community service provision since most participants need to wait for assessments and for timetabling of staff; CC interview, September 1999.

[96] 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.

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 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 valued.[97] Mrs Nancy Burke appreciated the telephone calls from her CC while she was in hospital since she provided cheerful company.[98] Mrs Alice Norton noticed the family GP CC became more concerned about how she, as a carer, was managing emotionally and had longer appointments with 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 interviewees 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.[99] 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 is very important:

---

[97] 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.

[98] 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.

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

> 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 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.

> One of the main advantages … is that we now have the information of knowing where to go if we want something. Before, you get 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)

4.3g Further Analysis

The results presented in this section represent only a preliminary examination of the rich data available about client outcomes. Further analysis could include exploration by participant type or CC type, use of proxies for disease severity and complexity, and greater use of the three administrations of the SF-36. Specific suggestions were included throughout the section.

4.4 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.[100] 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.[101]

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.[102] Participants reported a high rate of reliance on informal support for everyday activities, including: shopping, transport, home maintenance, meal preparation, ongoing supervision and nursing (Table 5.5). Both Table 4.16 and Table 4.17 show that family members, particularly spouses and children, were most likely to be relied upon. Table 4.15 also shows a high incidence of reliance on a combination of informal support. Table 4.16 identifies that informal supports were often relied upon to provide assistance and provided major support for shopping, transport, home maintenance, meal preparation, ongoing supervision and nursing.

[100] Carer interviews.

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

[102] Participant questionnaire.

Table 4.16: 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
	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)
			**	**	**	**
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
	100.0	100.0	100.0	100.0	100.0	100.0
Total	(164)	(146)	(109)	(137)	(88)	(115)

** $p<0.05$

Source: Participant questionnaire, 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.

Table 4.17: 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
	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)	% (n=)
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	(348)	(317)	(237)	(230)	(187)	(207)

Source: Participant questionnaire, November 1998 and 1999.

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, 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.[103] 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. 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.
>
> [So does your daughter talk about it with you afterwards?]

[103] Participant interviews.

> 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 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 Sheilds, 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 it was like 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 don'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 do it. So I don't want to press it.

The carers involved in daily support of a family member reported 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.[104] 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 and care for her husband, as well as maintaining her husband's and her own 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 … I'm sure I wouldn't have got the … respite hours without [name CC] who

[104] In the third case, Mears, while primarily involved in her husbands care found the Aged Care Unit at Hornsby Hospital very helpful in organising care.

> 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, grab 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 to great), having an impact on their reliance on a carer or a more formal mechanism such as the CC.

In summary, the Linked Care model appeared to complement the carer relationship in several ways:

? supplementing rather than replacing the role of the carer or other client networks;

? providing another choice to the client seeking assistance to change care needs;

? providing another source of information for the CC in the care planning process;

? carers gained assistance and support from the CC for coordination decisions;

? acknowledging the expertise/experience of families in managing care needs of the person; and

? if the carer was no longer available, providing a back-up and therefore a sense of security for the client and carer.

4.5 Impact on Clients not in Linked Care

One of the objectives of the trials was to implement the intervention without disadvantaging non-participants. There appeared to be four ways that clients outside Linked Care could have been 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.[105] 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 because HCS personal care was reportedly capped since August 1998, reducing the care available to non-participants.[106]

At the baseline, all 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.[107]

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 A8.1). Comments supporting this result described the negative impact on access to services for non-participants because of capped resources.[108]

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).

---

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

[106] This is consistent with the increase in waiting list numbers for HCS and other service providers; Table A8.8a and A8.8b.

[107] Service provider baseline interviews, December 1997.

[108] Service provider managers and CC mid-trial questionnaires; Table 4.14.

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.[109]

The evidence about the impact on non-participants was only 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.

[109] Service provider manager baseline interviews.

4.6 Conclusion about the Impact on Clients

Findings about participant experiences have been included throughout Part B of this report (Chapters 3 – 5). Some preliminary conclusions can be drawn about the impact of Linked Care on clients from their experience of the model, summarised in Table 4.18

Table 4.18: Participant Experiences of Linked Care

Intervention	Results
1. Client outcomes	Client outcomes did not change in terms of health and well-being or rate of death. There was a slight increase in nursing home admission compared to the Control group.
2. Client satisfaction	Participants chose to remain in the trial. They started and remained highly satisfied with organisation of their care and only slightly less satisfied with the quality of care. There was some evidence that having a full-time CC was more likely to improve their perception of receiving the care they needed.
3. Carer outcomes	Carers reported a positive experience from participating in Linked Care. Participants continued to largely rely on informal care, both in terms of organising formal services and preventing the need to use formal services.
4. Client involvement	Client involvement in the care coordination process was dependent on CC skills and experience and the perspective of the CC (e.g. their strengths in knowledge of the range of services and holistic approach, and their attitude to client focus). There was no effective measure to assess levels of client involvement.
5. Care coordinators	Most participants were pleased to have a CC for a sense of security and ease of access to care. However 26.1 per cent were unaware of having a CC or how to contact them.
6. Care coordination process	Participants were not always involved in preparing care plans or received a copy of them. Only 56.5 per cent of CCs reported using strategies to involve participants in care planning.[(a)] Participants continued to rely on existing networks of services and caregivers to access care.
7. Care plans	Some participants found it useful to have the list of services on the care plan e.g. to give to other providers, listing medications. They complained about the paperwork.

Table 4.18 (continued): Client Experiences of Linked Care

Intervention	Results
8. Service usage and access to care	Having a CC was associated with increased participant access to and use of services. This seemed to rely on the initiative of the CC and access to the fund pool rather than the preparation of a care plan. Participants had high satisfaction with services provided, not dissimilar to the Control group. Gaps in service delivery continued to be experienced by participants: respite, transport, advocates and a quick way through the processes to access care.
9. Cost	Client contributions to cost decreased according to the Intervention participants.
10. Organisation of Linked Care	Consumer representatives provided a general consumer perspective to the management of Linked Care rather than direct contact with participants. Complaints appeared to be acted upon and were used to inform improvements in practice.

Note: (a) A significant decrease from the mid-trial, when 65.1 per cent reported using strategies; CC questionnaires, Table A8.1.

5. Service Delivery

5.1 Service Provider Profile

As the base for the *Local Evaluation Final Report* and thematic reports concerning service delivery, information about service providers and GPs during the Establishment Phase was collected and analysed. For the purposes of the description, three groups of service providers were examined: hospital-based services; home and community care services; and GPs. There were three parts to the investigation: data profile surveys of service providers, interviews with managers of the service providers and written surveys to all GPs practising in the Hornsby Ku-ring-gai area. In addition, HIC provided information on patterns of local GP test ordering and consultations in the Intervention and Control areas.

The profile on service providers describes the extent of service availability in the Hornsby Ku-ring-gai area in terms of clients, finances, staffing and range of services. Despite the gaps in the data available, the tables provide a useful measure of service provision at the commencement and end of the trial. The tables are presented in Appendix 8. The *Service Provider Experience Report* has a more detailed discussion of the profile changes, and the *Whole of System Report* further discusses the implication of the changes.

The picture of the service system is one of interrelated service delivery. Agencies include public, private and voluntary services. Their care ranges from specialised medical intervention to personal care in the community. Of interest in Linked Care was not only the range of services, but also how these services interrelated, through referrals and other information exchange. Potentially, Linked Care could have changed both the assistance provided and the links between the providers.

5.1a Hospital-based Services

The first service group to be explored is hospital-based services. Public hospital services are administered by the NSAHS. Hornsby Ku-ring-gai Hospital and Community Health Services (HKHCHS) is the regional public hospital in the Intervention area and Royal North Shore Hospital the major teaching hospital. In addition, many private hospitals supplement the public services and are accessed by the population in the trial area.

Hospital-based Client Profile

Client use of hospital services can be measured in terms of where clients accessed the services; what type of services they used and how often; and the demographics of the users. Data on these three categories were collected from the hospitals and Area Health Service. Little information was available about the second category of the types of services they accessed.

Information on hospital use was available in the form of hospital separations data, as opposed to admissions data. This included information on which hospital facilities were accessed and whether the length of stay was greater than one day. Tables A8.11a and A8.11b present comparative data on hospital separations for residents aged 65 years and older in the Hornsby Ku-ring-gai and Ryde Hunters Hill Local Government Areas (the Intervention and Control areas) at the beginning and end of the trial.

The data show that Hornsby Ku-ring-gai residents used inpatient services from a large number of facilities, although most of the use was concentrated in public and private facilities in the local area. In the 1996-97 year, Hornsby Ku-ring-gai residents were recorded as using 72 public hospitals; and Ryde Hunters Hill residents used 65 public hospitals. Women and men had similar patterns of hospital use in both areas.

There was a high use of private health care, especially by the Intervention group and by people from an English-speaking background. In the Intervention area (Hornsby Ku-ring-gai), over the period of the trial, private hospital use rose from 43 per cent of total multi-day hospital separations in 1997 to 53 per cent in 1999. As was observed at the baseline, Control area residents (Ryde Hunters Hill) continued to use fewer private hospital services than the Intervention group. Over the period of the trial, private hospital use actually decreased slightly for Ryde Hunters Hill residents. In 1997, 21 per cent of total multi-day hospital separations involved private hospital usage, whereas by 1999 it was 18 per cent. However, it should be noted that some private hospital data were not available to the evaluators at the end of the trial, and the noted decrease may be in part due to the incomplete data set.

HKHCHS is the regional public hospital in the Intervention area. It contributed to the Linked Care fund pool and subcontracted care coordination services to Linked Care through the Aged Care assessment Team (ACAT). For these reasons, HKHCHS was included in the baseline data survey to collect additional client profile data (Table A8.9). End of trial data were not available to the evaluators.

The entire local population can potentially access public hospital services. In the baseline data survey, according to HKHCHS managers, almost 50,000 clients received services from HKHCHS in 1996-97 (48 849), most of these receiving non-inpatient services (31 600). New referrals amounted to only 54 per cent of clients serviced, suggesting a slow turnover of clients. One-third of all occasions of service were provided to clients aged over 65 years (33 per cent). This may be compared to the general Hornsby Ku-ring-gai population where 14 per cent are aged over 65 years. More than half the HKHCHS clients were women (60 per cent).

Few clients were from a non-English-speaking background (5 per cent) or were Aboriginal or Torres Strait Islanders (none reported). This contrasts with the general Hornsby Ku-ring-gai community where 15 per cent were from a non-English-speaking background. It also contrasts with NSAHS reported hospital separations in Table A8.11a, where 14 per cent of HKHCHS clients were reported to be from a non-English-speaking background.

Hospital-based Financial Profile

As well as client service use, financial data is a significant baseline measurement of hospital-based service use. NSAHS expenditure data in the program category most relevant to this trial, Rehabilitation and Extended Care, were compared in the two major public hospitals, Hornsby Ku-ring-gai and Royal North Shore. According to financial data from the annual reports the proportions spent in each category of hospital expenses in the NSAHS and hospitals, although broadly comparable, appear to have some variation (*Service Provider Experience Report*, Section 3.1). As expected, the majority of costs were associated with human resources. The NSAHS spent 44 per cent of its budget on wages. Similarly, 63 per cent of Royal North Shore Hospital expenses were spent on human resources compared to

the slightly higher proportion of 70 per cent at Hornsby Ku-ring-gai Hospital, probably reflecting the different activities of a teaching and a regional hospital.

Hospital-based Staffing Profile

From the financial data above, it is clear that human resources are a significant aspect of hospital management. To generate data to further dissect this part of the baseline position of the hospital service provision, HKHCHS completed the baseline data survey questions on staffing (Table A8.10). End of trial data were not available to the evaluators.

The hospital reported that it had more part-time staff and volunteers (860) than full-time staff (700) but the total staff hours of the former were less than total full-time staff hours. This is a different profile to the community service agencies (Tables A8.6a and A8.6b). Volunteers were more likely to be engaged in direct care tasks (60 per cent) than paid staff (35 per cent).

The hospital-based staffing profile indicated that a significant proportion of paid staff time was already spent organising care (25 per cent); and even volunteers were reported as being involved in organising care 10 per cent of their time. Care coordination by Linked Care could have changed these patterns of care provision if the model had replaced, rather than supplemented existing organisational processes; or on the other hand, if they had encouraged greater internal coordination by HKHCHS staff. The hospital notification communication strategy and Hospital Issues Working Party attempted to build on these existing coordination functions within the HKHCHS inpatient service (Section 3.6). Unfortunately, end of trial data were not available regarding hospital-based staffing and so it is not possible to comment on whether a change occurred as a result of Linked Care. Given the small number of Linked Care participants using HKHCHS services it is unlikely that it had a measurable effect.

Linked Care participants and their associated hospital costs were a small proportion of total hospital patients and budget. Any impact of Linked Care on hospital services was therefore likely to be measurable mainly in terms of changes in client outcomes (Chapter 4) and possibly hospital substitution costs (Section 5.4).

Implications for the Linked Care model from these client hospital use data were that the provision of the costly inpatient services was likely to be spread among many facilities, both public and private. If it was intended that Linked Care should have had an impact on the use and cost of inpatient services there seem to be two possibilities. Either CCs needed to have some influence over where clients received these services or Linked Care needed to negotiate with multiple facilities to establish processes to control the use of inpatient services. Again, given the scope of Linked Care, neither of these strategies occurred.

5.1b Community-based Services

The second group of service providers to be explored is the community-based agencies. To describe community-based services in the Linked Care area, six organisations were asked to complete the data surveys and interviews during the trial. They were agencies that either provided community-based services or coordinated their delivery. These were:

? the Rehabilitation and Aged Care Service, including the ACAT, at the HKHCHS;

? Hornsby Meals on Wheels;

? Northern Sydney Home Nursing Service;

? Hornsby Ku-ring-gai Home Care Service;

? Mercy Family Centre; and

? Neighbour Aid, as an example of a voluntary HACC agency.

The first three of these services were administered by the NSAHS or hospital; and the last three were at least partly funded under the HACC program through Ageing and Disability Department (ADD) or directly from the Commonwealth.

Community-based services are delivered by multiple agencies and can vary in availability and type, and by location. To compare total HACC service provision in the Intervention and Control areas over the period of the trial, ADD Area Reports in two sample months were examined. This ADD data includes care provided by the six organisations surveyed for the baseline and end of trial reports and numerous other smaller community-based agencies, such as Ku-ring-gai Meals on Wheels (MOW) and voluntary organisations like Easy Care Gardening.

Community-based Client Profile

The profile of community-based services was one of many agencies serving nearly 3000 clients each month; the most frequently provided services in Hornsby Ku-ring-gai were food services, transport, home nursing, and home help. This varied slightly from the Control area, Ryde Hunters Hill, where home help was the service type provided to the most people. A comparison of the 1997 and 1999 ADD reports (Tables A8.12a and A8.12b) indicate that Intervention and Control areas continued to show a similar pattern of service usage over the period of the trial.

Total numbers of people assisted increased in the Intervention area and dropped in the Control area over the period of the trial, but these changes were not marked e.g. small increases in food services, particularly centre meals; and a decrease in home nursing services. The number of people receiving home help almost doubled in the Intervention area over the period of the trial but there was not a proportional increase in the hours spent assisting these people, perhaps due to a policy of broadening access to care by restricting hours per client.

Most significantly to Linked Care, the number of people receiving personal care services increased by four times during the course of the trial in the Intervention area. No similar increase was noted in the Control area over the period of the trial. In August 1998 Home Care Services capped personal care budgets. The large increase in the Intervention area could perhaps be due to the activities of Linked Care.

Additional data about client access to HACC services were collected by the evaluation (Tables A8.4a and A8.4b). The profile of clients using HACC services is divided into the number of clients who received assistance and the demographics of these clients. Some caution should be taken interpreting these figures. The data were collected retrospectively

from the agencies, and the definition of clients and referrals may not be consistent between agencies.

Over 8000 clients in the 1996-97 period were reported to have received services from the community-based providers who completed the baseline data survey. This number had risen by almost a quarter to 9 993 for the 1998-99 period (Table A8.4b). Similar increases were noted in total number of referrals and number of clients in a typical week. The total number of clients served would be less than these numbers because some clients received services from more than one service provider.

Consistent with the HACC area report data above, large increases in the number of clients receiving help were recorded by Home Care Service and Mercy Family Centre, the first increasing client numbers by almost half and the second doubling client numbers over the trial period. The client demographics of the agencies surveyed did not change markedly over the course of the trial.

These agencies served a large and stable client base over the trial period, new referrals were reported to have replaced less than 50 per cent of clients at the beginning of the trial. This number had risen to a little over 50 per cent by the end of the trial. This could have presented several opportunities for Linked Care, including assisting agencies to refine processes to facilitate turnover of clients when their needs were satisfied, and to efficiently meet the needs of new referrals either through prioritising demands or referring to other agencies. No evidence of these changes were available to the evaluators.

Community-based Staffing Profile

Another dimension of community-based service provision in Hornsby Ku-ring-gai is the staffing profile. The data presented here were self-reported from the service provider baseline and end of trial surveys. They are divided into the characteristics of the employment relationship and the tasks in which the staff were involved (Tables A8.6a and A8.6b)

Unlike the hospital-based services, most agencies reported relying on more part-time and volunteer staff than full-time staff both in terms of the number of staff and the hours of care over the period of the trial. Total numbers of full and part-time staff and volunteers rose over the course of the trial, most significantly for total numbers of part-time workers which almost doubled. Similar increases were noted in total staff hours worked per week for full- and part-time staff, again, part-time staff hours almost doubling over the course of the trial. This was not the case, however, for volunteers. Total hours worked per week halved over the course of the trial for volunteers.

Staff tasks also changed across all agencies over the period of the trial. Notably, organising care dropped during the course of the trial from 28 per cent to eight per cent (a similar trend was not noted for volunteer workers). This is probably due to changes in reporting between the two questionnaires rather than changes in practice. The decrease is in part due to two smaller agencies reporting they spent no time on organising care at the end of the trial. Even when considering only larger agencies that had subcontracted CCs to Linked Care, there was still a reported decrease in time spent organising care.

Community-based Financial Profile

The final way of describing the community-based service providers is in relation to the financial management of the services. Most community-based services are funded in one of three ways. The ADD administers the joint Commonwealth and State funded HACC program. Most HACC agencies receive this funding directly through ADD. A second group of agencies receive their HACC funding indirectly, through the NSAHS or hospital. A third, smaller group of agencies receives funding directly through the Commonwealth Department of Health and Aged Care. These include funding packages such as CACPs.

In the Hornsby Ku-ring-gai area the first group included Neighbour Aid and the Home Care Service; Mercy Family Centre received funding both through ADD and through packages; and Hornsby Meals on Wheels, Northern Sydney Home Nursing Service and the Aged Care Assessment Team received their funding though the NSAHS and hospital structures.

Only very general financial data were available from the service providers through the baseline and end of trial data surveys. Most revenue was reported to have been received from the Commonwealth and State HACC program, supplemented by other State funding over the period of the trial (Tables A8.5a and A8.5b).

In the 1996-97 period Commonwealth and State (HACC) funding for Hornsby Ku-ring-gai based agencies dropped from 67 per cent of the total operating budget for all agencies to 47 per cent in the 1998-99 period. Conversely, other state funding increased from 19 per cent of the total operating budget of all agencies in 1996-97 to 36 per cent in 1998-99. Client fees, co-payments and donations remained at 12-14 per cent, despite expected changes due to HACC client contribution policies.

Mercy Family Centre experienced the largest increases in government funding and client fees (nearly tripling government funding and increasing client fees by 10 times). Similarly, they experienced a 100 per cent increase in client numbers for the same period. It would appear that Mercy Family Centre had taken on a new focus in service provision over the period of the trial, probably due to attracting a higher number of aged care packages. Other services also attracted significant increases in funding (NSHNS, ACAT). Comparison data were not available from the HCS as their areas amalgamated during the trial.

5.1c General Practitioners

The third type of service is the primary health care provided by GPs. The results of two questionnaires of GPs within the Linked Care trial evaluation are presented here. The questionnaires were almost identical, the first being a baseline questionnaire conducted in December 1997 and the second an end of trial follow up in November 1999.

Results from the questionnaires are discussed throughout this report. The full reports and summaries are available from Linked Care, *Baseline Survey of General Practitioners in Hornsby Ku-ring-gai, Report for the local evaluation of the Linked Care Trial* (May 1998) and *Survey of General Practitioners in Hornsby Ku-ring-gai, Report for the local evaluation of the Linked Care Trial* (February 2000).

Demographic information of GPs responding to the 1997 and 1999 questionnaires are summarised in Table A8.13. Most GPs in the area appeared to serve a general population of all age groups throughout the period of the trial; only 28 per cent of GPs reported having more than one-third of their patients aged 65 years and over.

The evaluators also requested comparative health insurance data on consultation and test ordering from the Health Insurance Commission (HIC) for all GPs in the Intervention and Control areas from 1997 to 1999. The aim was to examine HIC data for all patients (Linked Care participants and others) seen by comparative groups of GPs during the June quarters of 1997, 1998, and 1999 in order to:

? compare differences between GP CCs; GPs who were not CCs but who had some patients in Linked Care (both in the Intervention area and Control area); and GPs with no patients in Linked Care (both in Intervention and Control areas); and

? analyse differences between these groups and change over time in GP consultation rates and ordering of imaging and pathology tests.

The hypothesis was that participating in Linked Care may have global effects on how GPs managed all the patients. For example, Linked Care could affect the frequency with which GP's ordered tests or asked patients to attend tests, even for patients who were not included in Linked Care. It also provided an opportunity in the Intervention area to examine whether at the baseline there were differences between the types of GPs who volunteered to become CCs and others.

The findings are presented in Appendix 8. The global effect in the Intervention area was a reduction in GP consultations whether GPs had patients who were trial participants or not (Tables A8.14 to A8.17). The reason for this change, and whether it was related to Linked Care, was unclear. Changes in rates of ordering imaging and tests did not appear to be associated with Linked Care (Table A8.16) although the data did reveal some differences, both between the groups and over time. The reasons for those differences will be explored further and taken into account by the evaluators when drawing conclusions about both service usage patterns and the role of GPs in Linked Care. See Appendix 8 for more details.

5.2 Service Delivery Processes

Service profiles can be described in terms of the processes of service delivery in the area. This was explored through the service managers and GPs' perceptions. These were used at the end of the trial to identify change over the period attributable to Linked Care itself or to other external influences.

The discussion is made in the context of the multiple providers and types of care. The providers each served a similar client base, but without explicit coordination mechanisms. Within the network of service provision, providers both rationed care to match clients to resources, and also spread referrals between the various services to meet the most urgent client needs. It seems that once clients received care, there were limited processes for changing the type or amount of care clients received.

Health and community care services delivered in the Hornsby Ku-ring-gai area appeared to operate in a highly developed, complex system of interrelated service delivery. Players included public, private and voluntary services. They ranged from specialised medical interventions to personal care in the community.

The existing range of care and service providers in the health and community service sectors in Hornsby Ku-ring-gai was broad. Their client base had more diverse needs than those of the Linked Care target group. The target group itself used services from providers both in and outside the Intervention area. This breadth of service provision presented challenges to clients attempting to access appropriate care and challenges to coordination of services for those who had access.

The health and community service sectors had already identified these complexities and in various ways were coping with the multiplicity of service types and service providers. Linked Care was therefore operating in a context of larger changes, with similar goals to those of Linked Care, aiming to improve service delivery.

Service delivery processes were described by the managers from the point of entry into the sectors, through allocation of services, review and client turnover. In addition links between services including care coordination were discussed. The processes were as reported by the service provider managers and GPs. Opportunities to verify the information from other sources were not available to the evaluators.

The providers each served a similar client base, with only informal coordination mechanisms. Perhaps because of the intricate network of service provision, providers managed to both ration services in an attempt to maximise client access to the limited resources, and also spread referrals between the various services to meet the most urgent client needs. Once clients received care, there seemed to be few processes for changing the type or amount of care clients received, particularly reducing service levels. Observation of the effectiveness of the informal links between services suggests that the current processes work reasonably well to match need with services.

5.2a Entry to Services

To enter health and community care services potential clients must first gain access, satisfying providers of their need through some form of assessment, and negotiating the referral and allocation processes until they are matched with available care.

In the context of frequent referral between service providers, the question of sharing assessment data was investigated. Assessment processes were reported as being sometimes duplicated and not consistent between agencies. It appears that some service providers were attempting to reform assessment processes to improve integration and efficiency. Trends indicating this were: the conduct of joint assessments; sharing assessment information when referrals were made; adoption of a shared client record (CIARR); and using simpler assessments, such as telephone assessments, in standard referral situations.

Access to most services was reported to be flexible, through mechanisms ranging from direct contact by potential clients to referrals from other service providers. It appears that entry to services could be haphazard, depending on where a potential client tried to enter the system. The multiple points of entry and referral no doubt worked to the advantage of the persistent and articulate clients and those supported by knowledgable service providers. However, it is probable that others fell between the gaps and only managed effective entry at a later crisis point.

The potential drawback of relying on this type of critical management of clients' health and community service needs is that it may not be the most effective from the perspective of the client or the health and community care sectors. It may indicate an inappropriate use of resources such as missed opportunities for prevention or less interventionist care.

Such conclusions can only be hinted at as possibilities because of the absence of data on these issues. Without consistent assessment procedures it is not possible to quantify the needs, let alone the response to alternative assistance. Indeed, observation of the apparent effectiveness of the links between services suggests they worked reasonably well to match need and services.

5.2b Managing Demand

Processes to cope with the demand for new or more services from clients were one of the major management concerns raised. The strategies used by service providers to manage demand were: only providing assistance to existing clients; allocating available services at internal coordination meetings; referring clients to alternative agencies; placing clients on waiting lists; and providing less care per client. Data in Tables A8.12a and A8.12b show that allocating less care per client did occur in some services during the trial period.

Analysis of waiting list data collected for the evaluation (Tables A8.8a and A8.8b) showed large increases in numbers of clients on waiting lists over the trial period, and higher percentages of people waiting for longer periods at the end of the trial, compared to the beginning, for two of the three agencies which responded (HCS, MFC). The third agency on which information was gathered, the Aged Care Assessment Team, did not operate a formal client waiting list at the beginning of Linked Care but had 50 clients waiting for service by the end of the trial.

Linked Care appeared to facilitate more rapid entry to services, as two service personnel commented at the end of the trial.[110]

Because community service providers operated within fixed budgets, they appeared to act informally as gatekeepers to the limited resources by balancing the best interests of one client against multiple client needs. They reported that it was not in the providers' interest to over-service one client since it meant that other potential clients may receive no assistance. Managers claimed that demand was generally managed through prioritising demand rather than by maintaining waiting lists.

5.2c Duration of Service Delivery

The next steps in the management of service delivery are procedures for review and exits. Exit processes described by the service managers seemed to be almost self-managed by clients. Except for the hospital-based services, duration of service appeared to be long, turnover of clients low, and few providers reported formalised review mechanisms. Once a client received some level of care it appeared that they generally had priority over persons outside the service until they no longer needed or wanted care. Tables A8.7a and A8.7b show the estimated duration of service provision for current clients in the Intervention area.

Single client visits or events decreased over the trial period from 13 per cent of total client numbers across all agencies surveyed in 1997 to five per cent in 1999. All agencies surveyed except ACAT reported increased percentages of clients receiving service for over six months. These data support the view that agencies were prioritising service for existing clients and taking on fewer new clients over the trial period. Linked Care clients were also prioritised, as one service provider commented at the end of the trial 'the participants on the Linked Care trial appeared to receive a greater range of services and for a more realistic amount of time'.

It is possible that some of these issues could have been taken up by Linked Care as opportunities for incrementally improving the processes of health and community service delivery. These opportunities included: integrated access and assessment processes; information about the range and cost of services; and review and discharge planning. No evidence of these changes were available to the evaluators (*Whole of System Report*, Section 5.2).

5.2d Cost and Charges

Integral to Linked Care intervention was the management of the cost of services and of the total health and community service funds held by service providers or contributed by clients. The evaluation attempted, with only limited success, to collect cost data from service providers.

[110] 'Immediate service provision, no delays due to branch budgets' and 'Those in the Linked Care trial received services more promptly e.g. HCS for which others have had to wait and one still waiting'.

The first question to address in relation to funding is the cost of care, particularly comparative costs for similar services. Different service providers in the trial area apparently provided similar forms of assistance. Duplication of services may have been appropriate in this context with the possible drawback of distorting demand, access or cost. The investigation seemed to reveal that there was some distortion through differential service availability to clients, possibly affecting the level of care clients received, the mix of services available to them and the stability of that care.

Implications for Linked Care related to the variable cost to the fund pool of accessing potentially similar care from different providers. Linked Care was restricted in its ability to address these anomalies by pre-existing relationships between clients and providers, and the 'preferred provider' status of fund pool contributors.

A second cost issue is the affordability of the care to the client due to the charging practices of each provider. In this respect the spectrum of client cost varied greatly from medical and nursing care to community and social services. Despite this variation, it appeared that under the baseline charging processes affordability was not an issue for clients because co-payments were means tested or were set so low that they were unlikely to affect demand for services.

In the context of Linked Care, the expectations of participants for cost contribution may be shaped by their prior contact with service providers' charging mechanisms. If, for example, they were only familiar with accessing free NSAHS services, they may be reluctant to change to a HACC provider that expected some level of co-payment. Some participants made these comments to CCs during the trial. Overall, client contribution to costs decreased in Linked Care.[111]

[111] Participant questionnaires, November 1998 and November 1999; *Client Experience Report*.

5.3 Impact on Care Coordination and Service Integration

The effectiveness of service delivery depends not only on processes within an organisation, but also on the strength of the links between agencies and service types. The concept of linkages are examined at three levels:

? at a micro-level, through care coordination or care planning for individual clients;

? at an internal organisational level, through the use of multi-disciplinary teams and service types; and

? at a macro-level, in working relationships between agencies.

At the beginning of Linked Care, the managers' description of an existing culture of coordination, their constructive relationships and predilection for increased cooperation was a positive base from which to achieve the goals of Linked Care.[112]

Service provider managers used the language of care coordination in a very broad sense to include at various times all three ways of linking services. The analysis tried to divide the types of interrelationships into the three levels to more fully understand the comparison to Linked Care goals and the extent of service interrelationships in the Hornsby Ku-ring-gai area.

This section discusses the influence of Linked Care on service delivery practices relating to care coordination and service integration. The experiences of service providers specifically in relation to the organisation of the Linked Care model of care coordination are explored more fully in Section 3.4.

5.3a Care Coordination or Referrals?

Care coordination or care planning for individual clients can be described as the micro-level where the impact of the two other levels of integration can be tested. Effective links between agencies or within a range of care types in one agency should be conducive to successful care coordination.

For the purpose of this discussion, care coordination is taken to mean case management for clients; that is, assessing their needs, arranging the services and monitoring any changes in need. Other references made by the service providers to more general coordination such as information sharing and referral (discussed later in this section) are taken to mean ways that practitioners and agencies communicate and operate together in the same health and community service environment.

All the health and community service providers, including most GPs, said they coordinated the care needs of their clients. This ranged from informal coordination when a client approached them to provide advice and make referrals, to formal care coordination through funded packages such as COPs and CACPs. GPs tended to emphasise coordination of clinical needs.

[112] Service managers baseline interviews, December 1997.

It appears that the distribution of limited resources to clients was moderated by service providers linked through referrals to other service providers. While clients could potentially enter at any part of the health and community service sectors, they seemed to rely on a series of referrals to become aware of other services. Managers reported that most clients got some service and that most urgent needs were met.

This form of access and service allocation was dependent on the autonomous decision-making of service providers to meet the most critical needs of most clients. It represents a basic level of coordination, with information sharing through referral and sector meetings. Some service delivery benefited from additional client-focused management, such as packaged care, case management or discharge planning. Other clients, though, struggled without adequate assistance until a crisis, only then presenting in the health care sector.

Except for case management of packaged care, care coordination appeared to be reactive in nature after the initial care arrangements were established, relying on the client or direct carers to indicate a need to review the care arrangements.

The cost advantage of the baseline service delivery coordination was that it had a minimal infrastructure cost, because service providers needed to only manage their own budget, staff and client base. Perhaps that was only a short-term gain. Conversely, without addressing issues such as equity between clients and preventative early intervention, opportunities for improvements in service delivery and allocation could be missed.

At the baseline most service provider managers saw the Linked Care model of care coordination as an opportunity to formalise and improve on existing types of care coordination in the health and community care sectors.[113] They hoped it would improve outcomes for clients and relieve providers of the unpaid, time-consuming task of coordination. They proposed incremental improvement of the existing system by Linked Care rather than imposing a new regime. This could be achieved through: more thoroughly arranging care delivery provided by other agencies; being a single point of contact; and preventing wasted service use.

They raised cautions about the need to minimise financial cost and bureaucracy, and the need for training and guidance to ensure informed performance from CCs cognisant of accessing care from the full breadth of the health and community services.

The CCs views of the Linked Care model were explored through mid- and end of trial questionnaires.[114] The results are presented in Appendix 8, Table A8.1. Section 3.4 discusses the results in more detail. The findings from the mid-trial GP focus group and comments on questionnaires summarise the views expressed by many of the CCs. Some CCs of all types (GP, non-GP and full-time) reported that Linked Care had improved their role as CC and advocate for the client. However, some found it difficult to make contact with other CCs, GPs and other services, resulting in wasted time on the telephone. Some CCs and service providers, including GPs, reported little impact other than being expected to complete forms. Most GPs reported some improved communication and referral with other services. However there was now some duplication of communication required around

[113] Service managers baseline interviews, December 1997.

[114] CC mid-trial and end of trial questionnaires, November 1998 and November 1999.

referral (e.g. to the CC and to the service being referred to). Some non-CC GPs felt 'out of the loop', being asked to provide information but not being informed of the outcomes.

Overall, the service manager and CC expectations about improvements to existing care coordination appeared unfulfilled by the end of the trial. Linked Care at times duplicated existing coordination, especially if a formal case manager already existed (Section 3.4b). Rather than complementing their existing roles, 42.2 per cent of CCs reported a conflict between their role as CC and their other work (Table A8.1). Feedback from CCs to providers was patchy and there was no evidence of reducing wasted service use. In some cases, managers and staff appeared angered at the apparent wastage and inequity created by Linked Care participant access to services, such as care from the Home Care Service (see also Section 4.4).

5.3b Internal Organisational Coordination

The second level of integration may be described as internal organisational coordination. Within a broad-based agency clients may benefit from access to multiple service types and professions, without needing to initiate links with other agencies. Breadth of service orientation was observed in service delivery in the forms of a range of service types, multiple professions or co-location with a larger service provider. Generally this broad service range appeared to be present in some of the community-based agencies (MFC, RACS), and it also seemed to be developing in the HKHCHS due to the shift of some hospital services away from on-campus delivery toward community delivery.

As part of the trend towards integration of care, some service providers were integrating services internally by broadening the types of care they provide, the skills of the care staff or co-locating with other providers. The health and community service agencies observed in this area included instances of this integration that often transcended the distinctions given to health and community care, especially if they were associated with the HKHCHS.

The second type of internal integration is focusing on the coordination of the service delivery processes within an organisation. At both the beginning and end of the trial some service personnel remarked that their service was already well coordinated with adequate communication, implying that there was no room for Linked Care to have an impact on internal coordination. This was in contrast to the quantitative results (Table 5.1). Comments that service delivery from service provider's own programs remained unchanged, except for the increase in paperwork, were repeated many times throughout the trial by GPs, CCs, service managers and service personnel alike.

The most positive change over the life of the trial reported by service personnel was in relation to internal communication.[115] Over the period of the trial there was a significant decrease from one quarter of respondents (24.4 per cent) reporting that staff knew little about each other's work in their organisation to only 8.2 per cent reporting the same lack of coordination at the end of the trial. This corresponded with an increase in staff working

[115] Service personnel and CCs were asked to rate their personal knowledge of, and their organisation's mechanisms for, integration (Appendix 8, Tables A8.1 – A8.3 and A8.18 – A8.24).

closely together occasionally. Interestingly CCs, in contrast to other staff, reported that staff worked closely together most of the time both at the beginning and end of the trial, with no significant change (69.6 per cent and 64.7 per cent).

Table 5.1: Service Personnel Views of Service Integration: Description of Care Provided to Clients, 1998 and 1999

	Total		Care Coordinators			Other Staff	
			Non-GP	Non-GP	GP		
	1998	1999	1998	1999	1999	1998	1999
	% (n=45)	% (n=75)	% (n=24)	% (n=17)	% (n=29)	% (n=20)	% (n=26)
		**			*		*
Staff work closely together most of time	46.7	39.7	69.6	64.7	30.8	16.7	34.6
Staff work closely together occasionally	28.9	52.1	17.4	29.4	61.5	44.4	53.8
Staff know little about each other's work	24.4	8.2	13.0	5.9	7.7	38.9	11.5

Source: Service personnel questionnaires, May 1998 and November 1999.
** $p<0.05$ * $p<0.10$

5.3c Inter-Service Integration

More generally, service providers also raised issues surrounding interrelationships between service types and between service providers. They extolled the benefits of both working with different professionals within the one organisation, and of having cooperative relationships with other complementary and similar health and community service providers.

Links with other providers, such as through telephone referrals, were reasonably effective according to many of the service providers interviewed. They surmised that Linked Care may have the effect of further improving these links because it provided an opportunity for greater contact, including the potential gain of increasing GP involvement in the community sector (UNSW Evaluation Consortium, 1999b).

As expected, Linked Care did in fact facilitate many opportunities for managers and staff to discuss service delivery processes in the trial, and more generally. They thought this provided an opportunity for better care for clients.

Both health and community service managers said that links between service providers strengthened through the establishment period. The managers reported that existing relationships between the providers were enhanced by constant contact through Linked Care and it was an opportunity to establish relationships with other providers.

The increased contact developed more of a team spirit and a greater understanding of each service. The hospital manager particularly noted the benefits to his organisation from this. The Division of General Practice did not seem to similarly benefit, perhaps because of the ambiguity over the duties of GP representation. On a more individual level, GPs felt that

Linked Care had improved awareness of and referral to GPs.[116] GPs also felt Linked Care had improved some of their patients' access to services and their own awareness of other services (Tables A8.21 and A8.22).

At the beginning of the trial a number of HACC services feared that Linked Care involvement might, through competition, cause division between services that before Linked Care had worked collaboratively. During the trial, this situation was avoided through the preferred provider status of agencies contributing to the fund pool, rather than the adoption of a competitive contracting model.

In relation to their experiences on service integration, summarised in Table 5.2, service managers were positive about the opportunities for working together created by organising Linked Care. However, Linked Care did not appear to be able to change the responsiveness of service delivery processes to address specific integration shortcomings in the existing system.

Table 5.2: Expectations and Impact of Linked Care on Service Integration

Expectation	Service providers' experience
Better working relationships	Linked Care facilitated many opportunities for managers and staff to discuss service delivery processes in the trial and more generally, improve care and develop more of a team spirit, a greater understanding of each service and a greater ownership of the larger system. The hospital manager particularly noted the benefits to his organisation from this. The Division of General Practice did not seem to similarly benefit.
Improvement in existing care coordination	Linked Care at times duplicated existing coordination, especially when a formal case manager already existed. Feedback to providers was patchy. There was no evidence of reducing wasted service use.
Streamlined referral processes	No evidence of change in practice e.g. CIARR not extensively used, care plan not widely distributed to providers

This was also reflected in the reported changes to service integration made by service personnel and CCs (Appendix 8, Tables A8.1 – A8.3 and A8.18 – A8.24). Respondents were asked to rate their personal knowledge of, and their organisation's mechanisms for, coordinating with other service providers.

The contrast between the two administrations of each instrument was a general trend of little change in the 'needs to be improved' category, but a tendency away from rating integration as excellent toward satisfactory (Table A8.2). Examples of this decline were knowledge of assistance provided by services; referral processes to and from services including

[116] GP mid-trial focus group.

community services, other health and hospital services and GPs; and clients involvement in choosing level of care.

The decline may have reflected an actual decrease in service integration by the end of the trial as a result of changes in the wider context of health and community services sector (see Section 5.5). However, more likely explanations relate to the change in context of responding to the questionnaire. Baseline questions were asked when service personnel would have limited knowledge about Linked Care beyond its goals. Responses at the end of the trial would be much more likely to be based on service personnel's experience of Linked Care with a more accurate assessment of the shortcomings of the sector's integration and Linked Care's achievements. Specific comments supporting an improvement in inter-agency integration were made by these same respondents such as improved networking generally or in relation to community services and improved cooperation and communication between the services.

On a more positive note, in relation to the Linked Care model CCs reported that the trial had had a positive effect or no impact on links with other services (50.0 per cent and 45.7 per cent) and by the end of the trial only 17.8 per cent had problems persuading services to cooperate in the care coordination process (Table A8.1).

5.3d Medical and Community Service Cooperation

A notable aspect of the descriptions of care coordination in its various forms was the limited extent of integration between health and community service sectors. Providers appeared to focus on either community services, perhaps incorporating referrals to medical services; or they coordinated medical needs, sometimes referring also to community services.[117] For example, almost all GPs reported that their patients see them as coordinating their clinical care (81 per cent) and only a smaller proportion reported they were seen as coordinating their patients' community care (45 per cent). If this is what had evolved in the sector, it could be that it was a realistic limitation on a working care coordination model: the professional expertise of the CC might determine which parts of a client's care were most successfully integrated.

The division between GPs and community-based service providers did not appear to dissipate during the trial. Although both groups expressed their support for an interdisciplinary coordinated care approach there were criticisms about lack of communication between CCs, GPs and community agencies about care available to clients.

Several evaluation instruments attempted to measure the integration of medical and other services: the GP, service personnel, CC and service manager questionnaires, interviews and focus groups.[118] Tables of results are presented in Appendix 8.

A positive outcome of Linked Care was that GPs who answered both the baseline and end of trial GP questionnaires gave a significantly higher rating to communication with community

[117] Similar results were found in a baseline questionnaire to staff and volunteers of the key service providers to canvass their views on existing care coordination and referral (May 1998).

[118] See Appendix 2 Evaluation data sets.

services in the second questionnaire than in the first (Table A8.19).[119] This is in contrast to the more general survey of all service provider personnel, where they reported their referral processes to community care had declined in excellence. This difference was due to the GP responses (Tables A8.2 and A8.3).

Referral processes to GPs were reported as significantly improved over the course of the trial (36 per cent of other service personnel reported them as excellent; Table A8.3). Staff were the most negative about referral processes from GPs (44 per cent reported the processes needed improving, although this was an improvement, but not statistically significant, from 57 per cent at the beginning of the trial; Table A8.3). GPs and other service staff reported a two-way improvement; their own awareness of other services and an awareness of and referral to GPs.[120]

How to implement processes to improve the quality of the medical aspects of the care plan proved to be a continuing issue for the Quality and Complaints Working Party. GPs themselves were reluctant to be reviewed, as evidenced by the reaction to the Patient Medication Management System (PMMS) initiative (Section 4.4). Agency CCs also expressed a reluctance to broach the professional divide of raising questions about medical care and expressed resentment at spending time at PSG meetings 'educating GPs about how to use services and fill out care plans.'[121] One PSG discussed this issue directly and a GP expressed the opinion that the PSG meeting was an appropriate place to discuss medical management.

[119] chi square = 5.63, df=1, $p<0.05$; the changes for other respondent GPs were not significant.

[120] GP mid-trial focus group, November 1998; Service personnel questionnaire comments, November 1999.

[121] Care coordinator interviews, May 1998.

5.4 Service Usage Patterns

5.4a Data Collection Limitations

The evaluators maintained a close watch on the data collection process because of the implications for the evaluability of the service usage data. Choices were made by Linked Care administration to prioritise some data collection. Potentially therefore, there could be significant gaps in the data collected.

Linked Care restricted data collection to those agencies from which data were necessary, collectable and affordable. Data supplied by the fund pool contributors to establish an operational fund pool were the priority for Linked Care. The choice not to collect some service data appeared to be based on a combination of the following grounds:

? the data would need to be collected manually so the data might not be accurate and would have required intensive effort from Linked Care or service providers;

? the proportion of the fund pool that the service usage would represent was too small to warrant the investment in data collection; or

? the services were outside the fund pool or free.

Table 3.15 above summarised the service usage data collection methods in the Intervention and Control areas and the limitations to the data collected. The gaps in the service usage data areas included: inpatient services from private hospitals and other public hospitals outside the NSAHS (except data provided for MBF and HCF clients); non-inpatient services; accident and emergency services; other HACC services, client paid services and informal care.

Linked Care initially identified a wide range of agencies from which to collect data. These included small HACC agencies whose data management systems were not highly developed. Early in the development phase Linked Care decided to exclude small HACC agencies from fund pooling following a review by the North-East Metropolitan HACC Services Forum (Beatty, 1997). Data collection from these agencies then held a lower priority.

Electronic records were provided by the Health Insurance Commission; Department of Veteran Affairs; NSAHS; Northern Sydney Home Nursing Services; Home Care Services; Medical Benefits Fund (MBF); and Hospitals Contribution Fund (HCF).

Obtaining records from other health care providers was labour intensive and required the health services to be recorded in a hard copy format and entered manually into the Linked Care information system. Hard copy records were provided by: Mercy Family Centre; Wesley Gardens; and various smaller and private providers (Community Support Program; Home Help and Monitoring Program, Macquarie Nursing Agency, Epping Nursing Agency, TLC Nursing Agency, Kincare, Silver Circle, Elder Care, Baptist Community Services, private podiatry services, private physiotherapy services and PADP (equipment hire and purchase).

The quality of data manually collected and transferred was inconsistent. Of particular concern to the sponsor, the NSAHS, was public non-inpatient hospital services. It was anticipated by the sponsor that one of the outcomes from Linked Care would be substitution

away from inpatient services towards other community-based hospital services. To account for that substitution, services would need to be appropriately costed and measured during Linked Care. However, neither function adequately occurred during the trial.

From the point of view of evaluating the fund pool, this compromise was accommodated because these services represented only a small draw on the fund pool; or they are free or outside the fund pool. The lack of data was more problematic in analysing the substitution effects. Although these service providers were generally smaller than the fund pool contributors or were voluntary services, the cost to the fund pool, if the pool were to pay for or substitute this care, could be significant. A change in payments from the fund pool might have reflected an unmeasured change in use of free services or services paid for outside the fund pool.

A second limitation for evaluation of the data collection was the uneven collection between the participant groups. The most thorough collection was in relation to the Intervention participants because of the financial link to the fund pool. In contrast, services used by the geographical Control group were less thoroughly collected because of the lack of financial incentive for these organisations.

The third limitation was that the data collected might have been distorted because of possible differences associated with the geographical Control. The largest inconsistency between the participant groups was likely to be public inpatient hospital use outside the three NSAHS hospitals. It appears from initial examination of the inpatient data, that there was significant difference in inpatient service use that could be attributable to Control participants using out of area public hospitals and private hospital services.

There are many other specific limitations to the service usage and cost data set provided by Linked Care.

? Data lag of up to three months was known for some of the providers throughout the trial. For this reason the analysis was conducted on data up to the end of September 1999. Similarly, analysis begins for data from May 1998 when data collection was first adequately finalised for most service groups.[122]

? Data capture for some participants was absent. For example, it is known that no data were received from HIC for at least 71 participants – affecting three service groups.[123]

For further discussion see also Section 3.4g Service Usage Data.

Supplementing Service Usage Data

The evaluation plan included multiple checks of the service usage data because of the evaluators' concerns about the completeness of the data collection. The evaluators planned

[122] These data were subsequently updated for the national evaluation data set, completing a reasonably reliable data set to December 1999. Further analysis at the local level could include data from these valuable additional three months.

[123] Future analysis could include examination of the characteristics and exit status of these participants to determine the implications of the missing data.

to compare care plan data and participant questionnaire data with the service usage data collected by Linked Care.

Unfortunately the comprehensiveness of the care plans did not appear to be thorough enough to support the evaluation to the extent anticipated. The range of services and needs addressed by the care plans varied considerably between different CCs, for example as to whether they included medical needs, paid and voluntary community services, client paid services and caregiver tasks. As a comprehensive record of existing or likely future service use, the care plans were not accurate.

For the purposes of the evaluation, service data were also supplemented and checked for accuracy through the participant questionnaire and telephone interviews. A questionnaire rather than diary was chosen for reliability because of the characteristics of the participants.[124]

The qualitative data were also needed to measure the impact of Linked Care on unpaid formal and informal care.[125] Service usage data on these types of care were not consistently included as part of the care plan or at all for financial management.

5.4b 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. Descriptions of service use and cost during the trial are presented in chart format in Appendix 5.

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 (a catch all other category, mainly private providers).[126]

Mean use and mean cost per month per participant in Linked Care were calculated for the period May 1998 to September 1999.[127] 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).

---

[124] The Control area service providers were also resistant to a diary because of the confusion it would cause with the existing diary type systems in place in the area.

[125] Unpaid formal care included that provided by volunteers, voluntary agencies and self-help groups. Informal care included care by friends, relatives and household members.

[126] 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.

[127] 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.

As discussed in Chapter 4, Linked Care did not appear to change the measured health outcomes of participants enrolled in Linked Care. Similarly, this chapter discusses the 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.

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.[128] Tables 5.3 and 5.4 show that increased use of medical 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 (Chart A5.24). 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. Suggestions about the areas for further examination are included in the discussion below.

[128] 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 differences (largely demographic, Section 4.2b) 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.

Table 5.3: 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 5.4: 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.

Hospital Inpatient Services

Hospital inpatient services included all private and public admissions to three of the public hospitals in the NSAHS: Ryde, Hornsby Ku-ring-gai and Royal North Shore. It did not include other public or private hospital admissions except as it related to the clients of the two contributing private health insurers, MBF and HCF.[129] Costs are 75 per cent of AN-DRG costs as supplied by the NSAHS (Section 3.3).[130]

The pattern of average hospital inpatient service use and cost per participant in Linked Care began with higher recorded use and cost for the Intervention participants at the beginning of the trial (Charts A5.1a and A5.1b, Appendix 5). This relative position remained throughout the trial, although the trends converged towards the end of the trial (the convergence could have been a trial effect or due to incomplete data collection in the last months). The higher baseline might be explained by either the impact of the geographical Control described above (Section 5.1a) or unmeasured differences in the severity and complexity of the health conditions of the participants.

Mean use and cost per participant decreased over time for both Intervention and Control group participants. Unlike the convergence between the Intervention and Control clients mentioned above, this appears to be due to an actual decrease in use (rather than a data capture problem), most likely explained by the survivor effect of the reducing participant groups over time.

The regression described above, revealed no significant difference in hospital inpatient service use or cost between Intervention and Control participants (Tables 5.3 and 5.4). Further analysis could examine length of stay patterns of usage.

Two of the substitution goals in Linked Care were to prevent hospitalisation and reduce length of hospital stay. Specific hospital service substitution strategies were implemented and others were explored by Linked Care, including the hospital notification system (Section 3.6d) and the convening of the Hospital Issues Working Party (Section 3.6e). Participants and CCs related stories of early discharge through intense home-based care arrangements. Other examples of avoiding admission, especially to hospital-based palliative care, were also reported. According to the full-time CCs, Linked Care seemed to be effective at providing services in the home to keep participants out of hospital or get them out early.[131] Palliative care was a good example of this, reportedly effective because it also coincided with the goals of those specialist care facilities, such as Neringah, a private palliative care hospital. However, the full-time CCs noted that it would take longer than two years to assess the

[129] Seventy-six records were dropped from the HIC and MBF/HCF data as duplicate private hospital admissions. They are included in the private insurance graphs.

[130] This was the fund pool contribution cost negotiated with the NSAHS. Hospital inpatient costs were estimated on 75 per cent AN-DRG, weighted by the three NSAHS hospitals included in the Trial, Hornsby Ku-ring-gai, Royal North Shore and Ryde Hospitals. AN-DRGs are one part of the total resource formula for calculating NSAHS resources. The NSAHS is funded on 80 per cent of AN-DRGs, and 20 per cent is retained by the Department of Health for capital grants and special purposes. A further discount of five per cent was agreed upon with the Trial to minimise the NSAHS exposure and to reflect their expected loss on substitution away from the NSAHS.

[131] Full-time CCs interview 6 May 1999.

effect on hospital admissions and health outcomes of earlier intervention of services, aids and equipment.

Two case studies were recorded by Linked Care staff as examples of successful early discharge and avoiding admission through the actions of the CC, in the words of Linked Care administration.

> 1. The participant was a 98 year old woman who lived with her grand daughter. She was alert and independent, engaging in social activities.
>
> She was hospitalised in a private hospital following a fall in which she had fractured her pelvis. She was insistent that she be allowed to return home as early as possible and told the nursing staff that her CC would help. The hospital staff were concerned that she may be unsafe in her activities of daily living. She would require a walking frame, which she had used before the fall, but her balance was not as good as it had been before the fall.
>
> The CC was able to organise nursing services, seven days a week, for personal care, to be reviewed once she was fully recovered. These arrangements enabled her to go home safely to where she wished to be. It is estimated that these services reduced her hospital stay by seven days.
>
> 2. Linked Care office received an anxious call from the brother of a participant to report that he had found him on the floor at 9.30 am and believed that he had been in that position all night. The participant is an 89 year old widower, a fiercely independent man who had refused to let his brother call either his doctor or an ambulance, but insisted that his Linked Care CC be called.
>
> The CC was notified and able to visit soon after the telephone call. She persuaded him to be seen by his doctor. Although his GP would have preferred a hospital admission for investigations, he would not agree. It was advised that he should not be left alone overnight, so overnight emergency respite through Community Options was organised by the CC.

Hospital Non-inpatient Services

The data for non-inpatient services were manually collected and entered only for the purpose of the Linked Care trial. It was incomplete. Data were not available for the Control group. The charts of average non-inpatient service use and cost per Intervention participant show a decrease in service use and cost for the first eight months before it stabilises for the remainder of the trial (Chart A5.2a and A5.2b). It is unlikely that the data reflect much beyond the adequacy of the data recording, as there is no explanation for a decrease or stabilisation in service use and cost.

Home and Community Care Services (HACC)

The data included in the HACC service group included that from all HACC fund pool contributors (Home Care Service, Northern Sydney Home Nursing Services, Mercy Family Centre), sample data from Meals on Wheels and Easy Care Gardening and other miscellaneous services provided by HACC agencies.

The Home Care Service data appeared to be a reasonably accurate reflection of service use and comparison between the Intervention and Control areas because they were extracted from the head office financial application. To achieve this, each branch of Home Care Services was required to ensure that each service record relating to a Linked Care participant was assigned to the Linked Care account number.

Throughout the trial, Linked Care and the Northern Sydney Home Nursing Service (NSHNS) invested considerable effort to overcome difficulties in transferring reliable data about service use due to a number of information technology changes at the NSNHS (new IT systems and personnel and an office relocation). It appears that by the end of the trial most of the problems were solved.[132]

Mercy Family Centre (MFC) service data related to packages of care (COPs, CACP). No equivalent data were available from the Control area. Similarly the sample data for Meals on Wheels and Easy Care Gardening were only available for the Intervention area. These differences in the data set contribute to the difference in both the use and cost per participant between the Intervention and Control area, but the effect would be approximately constant.

The charts of average HACC service use and cost per Intervention participant show little change throughout the trial (Charts A5.3a and A5.3b). This was also reflected in the regression analysis (Tables 5.3 and 5.4). The Intervention participants entered the trial with a considerably higher mean cost per participant (I=$285, C=$93) and roughly maintained that relative position during the trial (end of trial I=$311, C=$73). This is similar to the geographical differences in total use of HACC described in Section 5.1a (Tables A8.12a and A8.12b, Appendix 8).

Although as a group HACC service use and cost did not vary significantly, the service usage patterns were different for particular service providers. Charts of the service use and cost relating to the HACC fund pool partners to Linked Care (HCS, NSHNS, MFC) and the sample data from Meals on Wheels and Easy Care Gardening are included in Appendix 5 (Charts A5.4a to A5.8b).[133]

The HCS chart shows a distinct increasing trend in cost and service use for the Intervention participants, relative to their baseline position and relative to the Control participants (Charts A5.4a and A5.4b). This was also reflected in participant and CC reports that Linked Care enabled them to use greater amounts of HCS care, both in terms of initially accessing care and increasing the amount and type of care they needed. Future analysis could include changes in the use of HCS home help and personal care, given the constraints on non-participants.

The NSHNS charts reveal the opposite trend (Charts A5.5a and A5.5b). Participant service use and cost reduced throughout the trial, this time for both Intervention and Control participants. Like the inpatient service use, this might reflect a survivor effect, where the higher users of NSHNS care left the trial. The lack of relative change between the

[132] Linked Care developed a program in Microsoft Access to extract data from the NSHNS information system. Linked Care discovered in the middle of the trial that the data extract software was missing data when performing monthly extracts. All efforts to modify the program failed to solve the problem.

[133] The MFC, MOW and Easy Care Gardening data are presented as an average per participant who used the service rather than an average per Linked Care participant.

Intervention and Control groups would tend to support this conclusion. A similar explanation might apply to the MFC and Easy Care Gardening charts (Charts A5.6a to A5.7b), which decreased in average use and cost over the trial.

Further analysis could exclude HACC services that were not comparable between the Intervention and Control group data sets, such as the MFC data.

Diagnostic and Investigational Services

Intervention participants' diagnostic and investigational services (MBS categories 2, 5 and 6) use and cost did not appear to change either in relation to the baseline or relative to the Control participants (Charts A5.9a and A5.9b). This might indicate that the application of care coordination did not spawn a proliferation of additional assessments, a risk of intensive case management.

Pharmaceutical Services

There were several idiosyncrasies with the PBS data transfer. They included HIC changes to the management of MBS and PBS data relating to participants who withdraw; the effect of the household safety net level; and a consistently low match on Medicare numbers.[134]

The analysis of the use and cost of pharmaceutical services revealed little change between the Intervention and Control group participants over the life of the trial (Charts A5.10a and A5.10b). Initial analysis of service usage data did not reveal any significant changes in either use or cost of PBS (Tables 5.3 and 5.4).

The pharmaceutical services group would be a particularly interesting data set to examine further given this was one of the few service groups with an apparent surplus after balancing contributions and payments from the fund pool.

Future analysis could also include examination by ATC code and the most frequently prescribed pharmaceuticals, to investigate changes in patterns of use over time. The sample of participants with diagnostic data (803) could be further examined in combination with the PBS data.

Linked Care implemented specific service substitution strategies to reduce pharmaceutical use (e.g. PMMS, medication reviews, reporting PBS data analysis to the Division of General Practice; Section 3.5). The lessons from designing and piloting these strategies might result in measurable changes in service use when applied more widely in future models of service substitution.

Medical and Specialist Services

The remaining MBS items, medical practitioner and specialist services (MBS Categories 1, 3, 4 and other) was the only service group that showed a significant difference in change of service use and cost between the Intervention and Control group participants (Charts A5.11a and A5.11b, Tables 5.3 and 5.4). After controlling for demographic and other characteristics, it was found that increased use of services and increased costs were both more likely among the Intervention group than were decreased costs. More detailed analysis is required to further analyse the size of these effects and to determine if it was the

[134] This was despite Linked Care recording the participants' Medicare number with their usual pharmacist.

result of seasonal variation of the particular months chosen for the analysis. Further analysis could also separate the GP services from other medical and specialist services.

Although disappointing, this result was probably not unexpected. Several parts of the care coordination process encouraged an increase in medical and specialist service use. Participants were required to visit their GPs for care planning or to complete medical care plans on a regular basis and quarterly monitoring by a CC could be expected to precipitate early recognition of changes in medical need. Yet there were limited opportunities for Linked Care in a short trial with few and reducing numbers of participants to effectively implement strategies to counter this increase or reduce medical and specialist service use. A longer, more widespread trial, with continuing recruitment would be more likely to be able to design and implement service substitution strategies to address this opportunity for service reduction. The Phase II development for Linked Care is attempting to do that.

Other Goods and Services (Private Providers)

Data from multiple sources were included in this last catch all service group. Primarily the group included equipment, private providers and individual professionals such as private physiotherapy and podiatry services. Additional services approved by Linked Care to be paid from the fund pool were also generally included in this category (Section 3.3h). It does not include other private services paid for by participants. Nor is it an accurate collection of data from the Control participants.

The analysis of other goods and services shows an increase in use and cost toward the last third of the trial (Charts A5.12a and A5.12b). Possible explanations could be that Linked Care exercised conservative financial management of the fund pool during the first year and that CCs were less familiar with making requests for additional services or using private providers until the end of the trial.

Future analysis could include breakdown of the type of services included in this category e.g. range of services, cost, frequency, type of participant, type of CC.

Private Health Insurance Clients (MBF and HCF)

Service usage data of clients of the two private health insurance companies, MBF and HCF is presented separately in Charts A5.13a to A5.14b.

Department of Veterans' Affairs Clients

Analysis to differentiate between DVA inpatient and non-DVA inpatient services is presented in Charts A5.15a to A5.20b. The DVA data could not be interpreted in the same way as the other inpatient hospital data. DVA data were collected as per patient hospital day (bed day) records, compared to admission event data regardless of the number of days for other participants. The cost data also differed. The cost only included the accommodation or bed day costs, not the medical costs such as theatre, which were all included for non-DVA clients.

Further analysis could test the relative change between DVA clients and other Linked Care participants and between DVA clients in the Intervention and Control groups.

Impact of Care Coordinator Type

Analysis was conducted by CC type to explore if CCs had different influences on the type and cost of services participants used during the trial, particularly any patterns of change. The analysis used the allocation of the last CC.[135] CC types were divided into GP, non-GP part-time and full-time CCs, using data about the 614 participants who had an allocated CC during the May 1998 to September 1999 period. The analysis separated inpatient services from all other service groups because of the infrequency and high cost of inpatient services. DVA inpatient services were treated separately because of the difference in the nature of the data (see above).

Analysis showed mean use and mean cost of services varied according to CC type (Charts A5.21a to A5.23b). Cost and use was higher for participants with non-GP part-time CCs. This could either be due to the characteristics of the participants or the CCs. There was no evidence to suggest a difference in the characteristics of participants allocated to the various CC types, but this should be confirmed through statistical analysis. Further analysis is needed to explore this apparent difference between CC types.

5.4c Participant Reported Data

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.[136]

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 5.5). 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.

---

[135] Further analysis could include longitudinal analysis by CC, taking point-of-time-allocated-CC, to account for the effects of CC reassignment on service use and cost.

[136] 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.

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).

Table 5.5: 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 5.5 (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 5.6). 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.[137]

Table 5.6: 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

[137] Participant interviews.

	(196)	(182)	(135)	(132)	(113)	(113)

* 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.[138] 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 here 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 bustled. All the oldies go to Graham. (Mrs Turner, Intervention, carer)

Mrs Gleeson found her relationship with the GP very supportive to assist 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.

[138] 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 was 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 Mrs Newman 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.

5.4d Service Provider Experiences of Service Usage Patterns

Service provider managers were asked throughout the trial about their expectations and experience of Linked Care.[139] In relation to their experiences on service usage, summarised in Table 5.7, the experiences were generally not as negative as they initially feared at the start of the trial. They were critical however of apparent wastage of resources where Linked Care participants were given access to care when they would not have been assessed as

[139] Appendix 2 Evaluation Data Sets.

meeting the priority needs for a HACC service. As discussed further in Chapter 7, this suggested that the system may not have been sustainable if extended to all clients.

There was agreement from the service provider managers that participants benefited from extra access to services, but that this also could have been having a negative impact on clients outside Linked Care, because of capped resources and difficulty recruiting staff (Section 4.5). They did not consider that the additional access to care could be maintained if all clients had access to the same level of service.

GPs felt that some patients had improved access to some services, such as respite care, and that it had enabled some patients to be managed at home and delayed (rather than prevented) admission to nursing homes. However, others had patients whose access to care had been limited, for example, to Home Care Services.[140]

Table 5.7: Expectations and Impact of Linked Care on Service Usage

Expectations	Service providers' experience
Loss of resources to other providers	Usage by service type did not decrease except perhaps MBS and PBS services. Payments were greater than contributions for all local services.
Reduced access to services by clients outside Linked Care	Inconclusive. Service managers and staff reported reduced access that they attributed to the inequity between clients in and out of Linked Care. It could equally have been due to other competing pressures on budgets and increased demand for services.
Cost shifting from residential care	Decisions were made by CCs in Peer Support Groups to keep participants at home despite the higher cost because of participant preference.
Inefficient use of resources or over-servicing compared to existing priorities	Some managers reported a lack of understanding of the need to manage care costs by a number of CCs who prescribed services that ordinarily would not have been a priority for that participant or participant group.

[140] GP mid-trial focus group.

5.5 External Changes

Many structural changes were underway in the health and community service sectors in Hornsby Ku-ring-gai and they were likely to dominate the immediate concerns of the service providers throughout the trial period. Fortunately, in the main, the goals appeared to be similar to those of Linked Care. The changes included shifting hospital-based service delivery off campus; new HACC funding arrangements; and internal restructuring to meet financial constraints.

In the baseline interviews, all managers discussed the climate of change and uncertainty in which they were operating, involving broad changes to the delivery of health and community care or internal restructuring in response to these wider changes. GPs were not asked about external changes.

The direction of the changes appeared to be similar to the goals of Linked Care. However, in many cases the implications of external changes were probably of greater significance to the service providers than Linked Care.

The HKHCHS manager described the context of change for hospital care: inpatient stays were shortening; budget restraints were in place; budgets were moving between Area Health Services; and the mix of staff was changing. He described the emphasis as being on the core business of patient care, with a cost efficiency priority for all other services, such as food services which were contracted out. He foresaw a future where patients would travel for specialist care, hospital stays would be brief and community care would increase.

The hospital director laid the claim that the HKHCHS had priority over other agencies in Linked Care to provide care in the community because HKHCHS staff needed replacement positions in community care when they were told to move from hospital-based positions. It was impossible for the evaluation to test whether this possibility eventuated because non-inpatient data were inadequately collected. Observations suggest, however, that additional staff were not recruited to non-inpatient services to meet demand from Linked Care. This could be explained by the short, temporary nature of Linked Care, and the fact that the care coordination model delegated care planning discretion to CCs, who had no incentive to direct demand toward non-inpatient HKHCHS care.

The second set of external changes described were those by the NSAHS manager in relation to pressures on Area Health Service budgets. These included the impact of Medicare Agreement renegotiations and the relatively higher salary costs in NSW compared to other states; the relative needs of Area Health Services; and the decrease in the number of patients covered by private health insurance. He feared that during the life of the trial, this could mean significant changes to service provision and organisational structure. The two-year timeframe of Linked Care in fact was not long enough to witness such structural changes in the NSAHS, except the absorption of the home nursing service (NSHNS) into the NSAHS infrastructure.

The NSHNS reported that during the trial period it would be designing and implementing long-term changes to overcome expected budget deficits; yet these measures were in a time of increasing need for community nursing care. The effect of these changes was reflected in the decrease in home nursing delivered in terms of both number of hours and number of participants (Table A8.6a and A8.6).

HACC-funded agencies also listed the many changes happening in the community care delivery. They included: competitive tendering in HACC growth funding; a new round of CACP funding; supplementing HACC funded care; changes to on-line data collection due to ADD taking over the management role from DOCS; and other concurrent research such as case management and the NSW Demonstration Projects in Integrated Community Care. An effect of these changes can be seen in the doubling of the size of the Mercy Family Centre community program (Tables A8.4a – A8.6b).

HACC providers reported increasing pressure on community care from policies such as decreased nursing home beds, preference for hostels and preference for care in the participant's home. One manager described the bitter irony of how successful the government strategies to care for older people in the community had been yet they had not been matched with increased resources to provide care to those people.[141] This dilemma was directly relevant to Linked Care, which had similar goals to these strategies. If the budgets at the field staff level were not adequately supplemented by the fund pool, the result may have been to only further increase demand and pressure on the already stretched budgets (see Chapter 3 for discussion on these organisational difficulties for service providers).

Smaller voluntary agencies, such as Neighbour Aid, described their vulnerability to HACC funding changes because all their financial support was from the narrow base of HACC funding or fundraising.

The individual local service managers were important to the success of Linked Care because of their critical role in the establishment and operation of care coordination, the fund pool and other management processes. For these reasons their personal knowledge of, and commitment to, Linked Care was important. Unfortunately many of the service providers restructured or their directors were replaced during the first year of Linked Care (Section 3.2c), perhaps in response to some of the external pressures described earlier in this section. This probably had the impact of delaying Linked Care processes and negotiations with providers.

It appears that most service providers were preoccupied with larger external changes in service delivery occurring simultaneously to Linked Care. They help to explain the changes in service profile described in Section 5.1. Many of these changes related to funding structures and highlighted the perceived vulnerability of smaller agencies to State or Commonwealth policy movements.

5.6 Service Delivery Conclusions

This chapter has examined the lasting impact of participation in Linked Care on the availability of services and the process and integration of service delivery. It seems that Linked Care had few direct effects on the profile of services and the system of service delivery. This could be explained by several factors expected at the beginning of Linked Care. First, the Linked Care population was small in comparison to other client numbers for

[141] Service Managers meeting 18 March 1999.

most providers except the Home Care Service. Second, providers and participants knew that Linked Care was a temporary initiative.

It is clear that the influence of the many other significant changes in the sector may have been larger than the impact of participating in Linked Care. Nevertheless, participation provided an opportunity for service provider managers, staff and volunteers to meet with a common goal and discuss issues such as whether their service delivery processes needed reform and how integration could assist in improving outcomes for clients.

Part C Conclusions

6. How the Linked Care Model Performed: a Synthesis of Results

This section summarises the findings in terms of the national and local hypotheses. A complete list of the hypotheses are listed in Appendix 1, national hypotheses (1 - 11) and local hypotheses and objectives (12 - 27). Appendix 2 is a list of the evaluation data sets.

In each sub-section, the national hypothesis is presented, along with any related local hypotheses. Data sets used for analysing the hypothesis are then listed, followed by a summary of the findings.

6.1 Support for the Primary Research Hypothesis

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 well being* within existing resources.

Related local objectives:
? health status (Local 17);
? social well-being (Local 12).

Analysed with data sets

? Exit data
? SF-36 Health and well-being
? Care plan and medical care plan
? Measure of disease control
? Participant questionnaire and interviews
? CC questionnaire and interviews
? Service provider and organisation questionnaires and interviews

Findings

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

Care plans were introduced for all participants. There was considerable delay in producing the first care plan for some participants. Care plans did not work as effectively as had been envisaged for some participants, in that their care arrangements did not change significantly and they were not always consulted in the preparation of the care plans. It would thus be an exaggeration to claim that care was generally accessed through care plans.

Funds were pooled from ten service providers. This was supplemented by an infrastructure grant from CDHAC. Given the inconsistency between the findings of the service usage analysis and the financial analysis, it is difficult for the evaluation to conclusively state whether or not care was paid for from existing resources. There was an apparent surplus in the

operation of the fund pool, when analysed both for all costs and income and for only ongoing costs and income. However, this result is ambiguous, as discussed in Section 3.3e of this report, because of questions about the accuracy of the capitation rates, the collection of service usage data, the division of administrative costs between establishment and ongoing costs, and the impact of a small number of participants with a high exit rate and no continuous recruitment.

In summary, the primary evaluation hypothesis was not fully testable because of the lack of appropriately sensitive data. Key components of the intervention were not able to be implemented with full success. For those items for which data is available, the hypothesis is not supported.

6.2 Secondary Hypotheses

The primary national hypothesis was supplemented by a number of qualifying secondary hypotheses. They stated that the success of coordinated care, as tested in the primary hypothesis, will be affected by the secondary hypotheses.

Hypotheses 2 and 3

The success of coordinated care will be affected by … the *extent of substitution* between services within the trial pool and the *range of services* included in the trial and the *size of the pool*

Related local objectives and hypotheses:

? a system of care planning for participants receiving care from *a range of providers* including funded services and *informal caregivers* (Local 14);

? services will be funded with *greater flexibility* and with a *closer match to participant needs* (Local 18);

? a *service mix* that better meets the needs of frail aged people, people with severe disabilities ... and people with complex chronic medical problems (Local 19);

? *substitute high cost, high dependency* support services with lower cost lower dependency services where appropriate to maintain participants in the most *appropriate environment* (Local 20);

? *substitute inappropriate service usage* by more appropriate service usage by the introduction of *new funding* arrangements (Local 21).

Analysed with data sets

? Change in service usage
? Service usage prior to exit
? Care plan
? Trial financial records
? Participant questionnaire and interviews
? CC questionnaire and interviews
? Service provider and organisation questionnaires and interviews

Findings

Funds were pooled from ten service providers across the range of hospital-based, community-based and GP-related services. This provided potential for substitution across the range of stakeholder services. While there was evidence of a high level of utilisation of community care services amongst the Intervention group, there was little evidence of significant substitution, changes in service mix or significant shift in the range or type of services used. CCs who adopted a creative advocacy role appeared to access more free services or make requests for additional financial expenditure.

The size of the fund pool did not inhibit care planning. Virtually all requests for additional financial expenditure were granted.

Care plans prepared by full-time CCs were more likely to acknowledge the care provided by informal carers.

Hypothesis 4

The success of coordinated care will be affected by … the *characteristics of the clients* to whom services are provided.

Related national hypothesis:
? people with multiple service needs (National 1)

Analysed with data sets

? Demographics and diagnoses
? Exits
? SF-36 Health and well-being
? Service usage
? Participant questionnaire and interviews
? CC questionnaire and interviews
? Service provider and organisation questionnaires and interviews

Findings

Complexity and severity of 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.

CCs provided considerable assistance to family carers. This was reported to be highly valued by the recipients.

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.

Hypothesis 5

The success of coordinated care will be affected by … the *quality* of the clinical and service delivery protocols.

Analysed with data sets

? Participant care protocol categories

? Service provider and organisation questionnaire and interviews

Findings

Specific protocols were not developed in Linked Care. The participant care protocol categories, which attempted to categorise participants by service use, were not sufficiently accurate to predict service cost or care coordination time.

Reminder lists, drafted as an alternative to best practice guidelines, were not distributed during this phase of Linked Care.

Hypothesis 6

The success of coordinated care will be affected by … the *characteristics of the care coordination* function

Related local objectives and hypotheses:

? *identify the characteristics of coordinated care* which contribute to the improvement in participants health and social well being (Local 13);

? test *different approaches to care management* (Local 22).

Analysed with data sets

? Service usage by CC type

? Care plan

? CC questionnaire and interviews

? Service provider and organisation questionnaire and interviews

Findings

Care coordination services were subcontracted from service provider agencies and GPs. Responsibilities ranged from those of full-time CCs to GPs with less than five participants. GPs prepared the least expensive care plans, but care plans did not reflect actual service costs because they were an incomplete list of care. Evidence over the course of the trial showed the position of full-time CC to be most efficient and effective.

Care plans were incomplete in terms of content and regular quarterly review. All types of CCs reported finding the care planning process burdensome and bureaucratic.

Peer Support Groups for CCs appeared to be a useful multidisciplinary model of training, but attendance was difficult for all CCs except full-time CCs.

The evaluation results also highlight the success of the Control group in achieving comparable outcomes. Evidence shows that many services in this region provided relatively successful care coordination arrangements from within existing service budgets.

Hypothesis 7

The success of coordinated care will be affected by … the particular types of administrative arrangements.

Related local objectives and hypotheses:

? whether coordinated care can be provided ... in a way which demonstrates *cost-effectiveness* (Local 15)

? pool of funds for the trial groups from which access to included services is funded *in accordance with the care plan* (Local 26)

? *funding participating agencies* according to an *agreed schedule of fees* (Local 27)

Analysed with data sets

? Service usage
? Care plan
? Service provider and organisation questionnaire and interviews

Findings

The operation of the fund pool appeared to adequately recompense providers for services delivered to participants. Difficulties in the transfer of accurate and timely service usage data were not overcome for some providers.

The fund pool facilitated access to services for participants with active CCs. The care coordination process was hampered by requirements for a detailed computer-generated care plan and service usage reports, which the information technology system never fully delivered.

Linked Care staff relations with CCs were reported to be both constructive and supportive.

Hypothesis 8

The success of coordinated care will be affected by … *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.

Related local objectives and hypotheses:

? while maximising their *ability to exercise choice* and *live independently* in the community (Local 12)

? client satisfaction (Local 17)

Analysed with data sets

? Participant questionnaire and interviews

? Service provider and organisation questionnaire and interviews

Findings

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 did not often leave a copy of the care plan with the participant. Twenty per cent of participants reported they were still unaware they had a CC at the end of the trial.

Intervention participants were more likely to enter a nursing home, but there was no evidence to link inappropriate actions of CCs and decisions by participants to enter residential care. Satisfaction with service delivery and care coordination was similarly high for both Intervention and Control participants.

Hypothesis 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.

Related local objectives and hypotheses:

? Operate the trial in a manner which has no detrimental effect on access to care or privacy (Local 16)

Analysed with data sets

? Participant questionnaire and interviews

? Service provider and organisation questionnaire and interviews

Findings

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 confirmed cases in which access by other clients was detrimentally affected by the operation of Linked Care. 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 as inequitable. Structural barriers within agencies might have disadvantaged non-participant clients. First, they might 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 (Section 4.5).

Hypothesis 10

The success of coordinated care will be affected by … 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.

Related local objectives and hypotheses:

? *provider satisfaction*, the *management model* (structure and process), carer satisfaction (Local 17)

Analysed with data sets

? Participant questionnaire and interviews

? Service provider and organisation questionnaire and interviews

Findings

Linked Care provided an opportunity for providers to meet face to face in management and CC meetings. The hospital liaison process to notify Linked Care of participants admitted to hospital improved communication. Whether CCs acted on the notification was not evaluated, nor did the hospitals expand the process to notifying other service providers. Anecdotal and evaluator observations indicated that there was some improved collaboration between service providers. Service manager, staff and CC questionnaires indicated no effect or detrimental effects.

The Linked Care geographic area was subject to other collaborative initiatives, particularly between HACC services, that also had potential to improve the integration of care e.g. CIARR, formalised waiting lists.

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.

Hypothesis 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.

Related local objectives and hypotheses:

? a *closer match to participant needs* (Local 18)

? *integrated, multidisciplinary assessment* services (Local 23)

Analysed with data sets

? Participant service and satisfaction questionnaire and interviews
? Service usage and care plan
? Service provider and organisation questionnaire and interviews

Findings

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.

CCs reported being able to arrange care quicker through mechanisms such as avoiding waiting lists and using private care until public care could be arranged. They complained about the repetitive paperwork generated by the care coordination process. Evidence-based guidelines were thought by CCs and service providers to be inappropriate for care coordination of chronic complex care participants with multiple needs.

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.

7. Conclusion

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.

Delays were experienced in a number of aspects of Linked Care's operation. These had important implications for the evaluation as well as for the trial. Perhaps the most enduring problem concerned difficulties in the availability of reliable data from different sources. This created difficulties for comparisons of the participants in the Intervention and Control groups. It also made it difficult to document trends in participant use of services of various kinds. Other problems experienced at local level also had an impact on the operation of the trial and on the final evaluation. An instance of these was the need to develop a fully functioning funding model that included elements such as the capitation-based fund pool calculations, and which had no precedent in the Australia health care system. These delays can be attributed, for a large part, to the national administration of the Coordinated Care Trials, which clearly underestimated the complexity of the information technology and funding models required for the trials.

It could be argued, in retrospect, that leaving development of each of these fundamental building blocks of the system of coordinated care to local trials with limited resources was a strategic decision that caused significant difficulties for the trial and the evaluation. A number of other difficulties encountered in Linked Care can also be sourced to the national administration of the trial, such as the deadlines imposed on the recruitment of participants and the subsequent administrative problems that arose as a result of the reduction of participant numbers over time.

As the results presented earlier in the report have shown, many aspects of the operation of Linked Care were successful. However, there were also a number of elements of the model of care coordination utilised by Linked Care that were not demonstrated to be any more effective than the pre-existing service provision arrangements, despite the increased costs associated with their introduction. Conclusions about these aspects of the model are summarised in Table 7.1. Drawing out the lessons of the evaluation can help disentangle some of the less successful elements of the intervention from those that were effective and cost-efficient. For other parts of the model, any conclusions would only be determined with

the opportunity for greater analysis than has been provided for in the commissioning of this evaluation.

In this conclusion we review the implications of a number of the main findings of the evaluation. We consider first the constraints that need to be borne in mind when addressing the evaluation of such an evolving trial. We then 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.

7.2 Cautions Interpreting the Findings

A properly constituted evaluation is designed to provide a rigorous test of the efficacy of a particular intervention. When interpreting the findings it is equally important to be aware of the limitations of the research results. In drawing conclusions from the evaluation findings presented in this report, there are at least three reasons to exercise caution. These are set out below.

7.2a Difficulties Arising from the Trial Approach

Conducting careful, well-constructed trials and evaluations of major system changes, such as that envisaged in the original Council of Australian Governments (COAG) proposals for a new approach to the funding of health and social services across Australia, provides unique opportunities to learn about the delivery of human services. It is, however, important to be aware that a trial approach differs from a full scale implementation. The use of a trial approach runs the risk that what is developed and evaluated could, in important ways, be different from that which might have operated had the project or program been implemented under different, perhaps more natural circumstances. In turn, the results of an evaluation may be less than a full representation of the outcomes had the intervention not been introduced under trial circumstances. The results may also be overly favourable or unfavourable, or, more commonly, less definitive than those hoped for by the intervention's supporters.

Some of the issues affecting the interpretation and generalisation of findings include:

? *The scale of the trial*, and the extent to which participating services change their mode of operation, or continue to operate as part of the existing system of service provision.

Although the initial sample of Intervention group participants was large, with over 700 individuals recruited, for many of the services involved (such as the hospitals) as well as for individual primary care providers (including GPs), the Intervention participants formed less than five per cent of the total numbers of service users. Under these conditions it is possible that direct care practices directed to trial participants would not differ dramatically from that provided to non-participants.

? *Recruitment selection effects*, resulting from the recruitment of a sample of participants that is, in some way, less than fully representative.

In Linked Care, the pressure to quickly fill the quota of Intervention group participants was considerable. Some participants entered the program with significant backlogs of unmet need and others seemed to have relatively low needs, or to have had only short-term

requirements for supportive care following an episode of hospitalisation. Whilst a spread of participants with diverse levels of need may be argued to provide a realistic context, a different and perhaps more time-consuming selection procedure could have resulted in a different sample being selected. In this case, had the sample been constituted solely of highly dependent (nursing home level) clients, it may have been possible to demonstrate that case management and care planning had clear economic benefits. Amongst a more diverse small sample, the benefits are likely to be less apparent. In turn, a different sample may also have responded less favourably to aspects of the intervention.

A closely related issue concerns the possibility that features could be introduced in the trial model that would not be replicated in a full-scale implementation of the program. In this instance, it is clear that there were significant differences in the original model of coordinated care proposed by COAG (COAG, 1995) and that finally implemented in Linked Care. In this regard, it is of note that the Linked Care trial developed a collaborative approach to participation, which relied on the voluntary surrendering of a portion of the operational funds of many of the key stakeholders. In return there was an agreement that funds contributors would be 'preferred providers'. Given the circumstances of the local trial there was probably no feasible alternative to such a collaborative approach. It would have been irresponsible of service providers to commit scarce, dedicated funds to a fund pool that would then be used to undermine their own agencies and, perhaps, put their clients at risk.

The premise of the original COAG proposal is that competition between providers would drive down the price of provision and thereby create savings for funders equal to or greater than the transaction costs of case management/care coordination and administration while maintaining or improving service quality. This premise remains unproven in the field of health services. It was certainly hotly contested by trial stakeholders at the commencement of preparations for Linked Care in 1996 and 1997. The proposal to divert existing payments to a fund that would introduce competition between providers faced a degree of opposition that was widespread and passionately argued. GPs and other private medical practitioners likely to be affected expressed deeply held opposition, as did a number of the voluntary agencies and other opinion makers in the local community.

It could be claimed that the proposed competitive approach was unsuitable for conditions in Australia or New South Wales at the time. Or that the approach was incapable of being implemented in any local context involving a mixed economy of service provision that includes private practitioners and services, government-owned public enterprises and a range of non-profit and volunteer-based agencies. To implement Linked Care required a working compromise be found. That resulted in absence of competition between providers in Linked Care, which contrasts with the emphasis placed on competitive mechanisms in the original COAG proposal.

Similarly, Linked Care was not able to implement the devolved budgetary management by CC (or case managers) on which the original COAG scheme appeared to be premised. This should require a diligent rethinking of the premise by its proponents in the Australian health care system. However, it could be argued that the failure to achieve devolved budgetary responsibility is an artefact of the trial, insofar as pre-existing mechanisms for accessing services in the public and private systems continued to operate.

7.2b Difficulties Arising from the Implementation Process

In reviewing the progress of Linked Care it is important to emphasise that, in hindsight, the complexity of the multiple tasks involved in the establishment of a trial appear to have been underestimated by the national and many local administrators at the time of commencement. The Linked Care management attempted to adhere as closely as possible to the program's national schedules, but difficulties arising from the pioneering nature of many of the trial's undertakings were formidable. Difficulties were experienced obtaining data from different sources, and in linking these data with information obtained directly from participants and carers who filled in forms incorrectly or incompletely. In addition, financial and organisational problems arose from the need to bring together as working partners, a wide range of otherwise independent services. These problems were in addition to others discussed elsewhere in this report, such as: recruiting the sample of participants; establishing the Control group and information collection arrangements for them; selecting and training CCs; developing care plans; calculating and revising fund pool capitation rates; appointing a local evaluator; and consulting with stakeholders and gaining their commitment to proceed with agreed courses of action.

Finding cost-effective, workable solutions to these problems required more time than the trial sponsors, participating service providers or government managers had envisaged. In most cases workable solutions were found, but there was little opportunity to adjust the overall time-frame of the trial, which continued, by and large, to be managed according to its pre-determined schedule. Hence, the period of the Live Phase of the trial was shortened considerably. These delays and adjustments were of particular significance for the evaluation. Baseline information on service arrangements for the Intervention group, for example, was difficult to collect and, as discussed earlier, was compromised by the early arrangements to provide services to those recruited for the trial. Similarly, data to the end of the trial in December 1999 were not available at a time that would have enabled it to be analysed for this *Local Evaluation Final Report*.

7.2c Limitations of the Evaluation

Finally, in drawing conclusions from the results of the trial, it is necessary to revisit the constraints and limitations of the evaluation discussed earlier in Chapter 2. It is not necessary to repeat the methodological caveats here. Nonetheless, the resource limitations of the evaluation - the constrained capacity of evaluation staff to undertake in-depth analysis of a number of important issues and the time limits on the production of the final report - need to be understood.

Most importantly, the limited operational period of trial, and constraints on continuous recruitment, make final conclusions premature. In many instances the time remains too short for conclusive results. Had the evaluation team been appointed earlier, had there been more resources available to conduct the evaluation, had there been more time at the completion of the trial to prepare the final report, a more comprehensive and in-depth study would have been possible.

While it is appropriate to point to these constraints, it would be wrong to give the impression that the evaluation was not successful. As this report and the three accompanying thematic reports have shown, a considerable body of evidence was collected and the results have

enabled a great many of the research hypotheses to be successfully addressed. Considerable attention was also given in the design specifications of both the national and local evaluations and to the collection of a detailed data set. It is hoped that opportunities will subsequently be available to undertake further analyses of these data.

In summary, it is not clear whether the results would have been less favourable or more favourable either if the trial or the evaluation been conducted differently, or if a large scale implementation process had proceeded instead of a trial. It is not our intention in this conclusion to undermine the credibility of either the data collection process or the results presented as part of the evaluation. Rather, drawing attention to the limitations of the trial and of the evaluation is intended to remind readers that the conclusions need, for the moment at least, to be qualified.

7.3 Linked Care's Interventions in Review

With due regard for the cautions expressed above, a number of lessons can be confidently drawn from the evaluation. The Coordinated Care Trials provided a unique opportunity to examine the operational effectiveness in a live setting of both the overall coordinated care approach and a number of constituent interventions. Details of the results of the operation of the trial were examined in detail in Part B of this report. Further information regarding the extent of support for the research hypotheses was presented in Chapter 6. Readers seeking information on the outcomes for participants and services are referred there. Here, we briefly consider the findings of the evaluation concerning the component initiatives, before turning to the significance and implications of the evaluation findings.

While the results of the coordinated care approach could be seen to have been less positive than the advocates of the approach had hoped for, separate components of the trial performed well. As shown in Table 7.1, a number of these successful techniques appear to offer policy makers and service providers a valuable repertoire of approaches that might be deployed more widely as part of future service enhancement activities.

Table 7.1: Successful and Problematic Initiatives in Linked Care

Successful	Inconclusive	Problematic or rejected
? Collaborative approach (Management Committee, Working Parties, adoption of common protocols)	? Management of decisions affecting stakeholders	
? Full-time CCs	? Sub-contracted CCs (agency and GP CCs)	? Participant Care Category Protocols
? Fund pool operation and management	? Fund pool capitation rate calculation and revision	
? Patient Medication Management System (PMMS)	? Clinical Advisory Group	? GP Medication Peer Review
? IT data systems	? IT data quality	
? Evaluation	? Care reminder lists	? Best practice guidelines
? Use of external expertise to provide advice and data analysis, e.g. Family Medicine Research Centre, Faculty of Pharmacy, Public Health Unit NSAHS	? Service usage reports to CCs	
	? Service data collection system	
	? Hospital liaison system	
	? Hospital Working Party	
	? Hip protectors	
	? Peer Support Groups	
	? Care plans	

The results presented in Table 7.1 are based on the findings of the process component of the local evaluation. To simplify the presentation, these initiatives are presented as having been successful, problematic or rejected, or inconclusive results. Readers are cautioned, however, that the term 'successful' should not be regarded as implying absolute endorsement. Neither is the term 'problematic or rejected' intended to indicate a final refutation of the approach. It may indicate for example, that no result was available for analysis or indicate difficulties faced introducing and operating them as successful components of the trial. Capitation payments, for example, have functioned well for over fifty years as part of the British NHS and in many other health systems. Their implementation at the local level as part of this trial, however, was less conclusive. Each of these judgements therefore, needs to be seen as having been made in the context of a short trial, and cautious qualifications of these assessments are in order.

Seven initiatives may be seen as having been successfully introduced. These were: the adoption of a collaborative approach to the establishment of the trial and to decision making using the Management Committee and working parties; the contracting of full-time CCs; the operation and management of the fund pool; the introduction of the Patient Medication Management System (PMMS); some aspects of the information technology development; the evaluation process; and the use of external expertise to provide data analysis. Each of these may be considered to have been successfully introduced, and to have been shown to be at least a qualified success in operational terms. This is not to suggest that each of the initiatives was outstanding in every respect, or that the approach could be used

indiscriminately in future service delivery arrangements. It was clear, however, that each of these approaches performed at or above the level of expectation for at least some of the trial, with direct benefits for some of the participants. Full-time CCs, for example, were able to carry out their work to a level of satisfaction, as rated by participants, other service providers and Linked Care Managers that eluded CCs engaged on other bases. As is made clear elsewhere in this report, this is not to suggest that all care needs to be coordinated by full-time CCs.

7.4 Lessons from Linked Care

In this section we concentrate on the implications of the findings that are of relevance to readers seeking to improve local patterns of service provision and promote appropriate forms of care substitution.

? *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 (see below). 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.

? *Care coordination is not a viable method of cost control at present*

The evaluation evidence suggests that the CCs in Linked Care were not able to exercise devolved budgetary control for many if not most of the participants for whom they were responsible. Instead, they generally served as budget monitors, responsible for tracking expenses that were generated by the participant's self-referral activities, or by referrals initiated by others. This difficulty arises from the continuation of existing service access and payment arrangements in both the public and private sectors, alongside the introduction of Linked Care. To test the efficacy of devolved budgetary management, different spending authorisation arrangements, requiring approval by a CC before a service is accessed, may need to be introduced. This would arguably involve a diminution of existing consumer rights under Medicare for public patients and may prove difficult to test through a trial mechanism. For clients with private health insurance coverage, however, such an approach could provide a valuable mechanism for cost control and hence, prove an attractive proposition for the purposes of more extensive trials.

? *Fund pooling methodology is still developing*

Controversies surrounding the interpretation of the findings of this evaluation are likely to identify the fund pooling methodologies as still immature. Linked Care management achieved well beyond reasonable expectations in the development of the methods of calculating annual capitation fees for existing participants, but considerable doubt still remained at the conclusion of the trial, over the actual calculation processes. One of the difficulties identified was associated with predicting changes in costs in the final year of a person's life, as previous service use patterns do not provide much guidance in such cases. Difficulties were also experienced in calculating capitation rates for individual services, both hospitals and community services. Further, it is unclear whether a capitation method has yet been developed which would be acceptable to GPs or to Divisions of General Practice. As argued in Section 7.4, future trials of fund pooling may need to consider relying on centrally derived funding formulas.

? *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 clients 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.

? *Collaborative local approach to serving the population was valued*

One of the more positive findings of the evaluation was the extent to which the collaborative and systemic approach to servicing the local population was valued by participants and

stakeholders. Until the introduction of Linked Care there had been few opportunities for representatives from the different services and GPs to plan joint activities. The system of working parties and voluntary agreements entered into by the stakeholders was intended purely as an instrumental mechanism for Linked Care, but they appear to have produced considerable incidental benefits. Building on this experience, it may prove possible to adopt many of Linked Care's consultative, community-building methods in future locality-based initiatives for service development.

7.5 Concerns about Wider Introduction of the Model

Finally, we consider the potential implications of extending the principles of the coordinated care model to operating principles for the Australian health care system.

? *Operational viability*

Linked Care has demonstrated that it is possible to use the approach of coordinated care as the basic operational principle of a system of care. While the evidence from the evaluation presented earlier in this report shows the approach did not ensure a superior level of outcome for participants, neither is there any evidence of systematic disadvantage. Recipients of the care, family caregivers and health professionals from a range of disciplines rated the care provided positively. The evidence suggests that the approach was in general, comparable to and in some cases possibly preferred to the standard forms of care available to the participants.

? *Potential cost implications*

The coordinated care approach adopted by Linked Care appeared to be most questionable in terms of the cost of the operations. Considerable savings had been anticipated from the introduction of substitution strategies as part of Linked Care. There was no evidence of successful, cost-reducing substitution of services beyond that which was already evident in the standard care available to the Control group. Evident instead was the additional costs involved in operating the model.

The evidence presented in Section 3.3 and Appendix 5 of this report suggests that the trial operated within budget, and that over the period September 1997 to December 1999, a total surplus of $714 283 was achieved. However this figure included infrastructure grants and other monies. If the ongoing costs of infrastructure, other operational concerns and relevant service usage costs are analysed, the surplus is reduced to $294 599 still, apparently, a healthy financial result (Section 3.3e). How can it be that such a surplus was produced for the Intervention group while the level of expenditure, per participant exceeds that of the Control group on almost all items? The answer lies in the qualifications associated with this surplus calculation. The capitation rates used to calculate the contribution by stakeholder services, for example, appear to have been inaccurate. It is unlikely that such rates could be sustained on a population basis without considerable additional expenditure by government. Other financial data management difficulties appear to have contributed to the apparent surplus. These include the incomplete collection of service usage data (and, therefore not paid from the pool); decisions about the attribution of costs as either establishment, ongoing or trial-related costs, and the absence of continuous recruitment despite a high exit rate for a small number of clients.

Diligent administration by Linked Care management kept the additional costs of care coordination and project administration to a minimum. This was achieved by maintaining payments for care coordination at a low level and by increasing the productivity of many CCs through relatively large work loads. There were suggestions that this level of productivity and efficiency may not have been sustainable had Linked Care continued. CCs for example, complained that their case loads were high whilst their level of remuneration was too low for ongoing operation. But even if these relatively low levels of ongoing costs had been maintained, the results would still require expenditure additional to existing service usage costs for participants.

Taken together, the results suggest that the model did not offer a simple solution to the financial problems of providing public care through the existing system of services. Doubts about the viability of the fund pool suggest that the approach would not be affordable as the main principle for the Australian Health Care System. Even in a modified form, as a sub-system to be deployed for those needing complex care, it would require the injection of significant extra amounts of funding into the care system. Incomplete accounting records and other problems discussed above, however, point to the need for further work on this issue. This is also discussed further below.

? *Fund pooling methodology*

Linked Care demonstrated that it is possible to create a fund pool utilising contributions from participating services. However, as discussed above and noted earlier in the report, the extent to which such fund pools could serve as viable sources of funding for all care needs of clients in the future is less clear. Although incomplete records and other problems make definitive statements about the adequacy of the fund pool difficult, it would be imprudent to proceed with the approach without further financial research.

If fund pooling were to be favoured for further trials, the main question arising from the experience of Linked Care is: should fund pool calculations be carried out at the local level? The data from the evaluation to date suggest not. Not only was it a very resource intensive exercise, it was one requiring extensive professional expertise, well beyond the level of financial expertise available in most health and community care services. Further, the proliferation of local-level approaches to the calculation of fund pool contributions would, over time, tend to regional differences which would undermine inter-regional equity and may place the ongoing financial viability of some services at risk.

? *Excluded services*

One of the more interesting findings of the evaluation concerned the higher rate of admission of participants from the Intervention group to nursing home care when compared to the admission rate from the Control group. Under these circumstances, a suspicion arises, perhaps unfairly, that the funding arrangements may have created an incentive for placing high-need, high-cost participants off budget in such homes.

Given that a great many of the participating services, particularly those funded through the HACC program, had been developed as alternatives to such care, it was a major flaw in the national design of the trials that residential care services such as nursing homes were excluded from the stakeholders and contributors to the funds pool. It is recommended that residential care be included in any further trials.

7.6 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 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 were not 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 encouraging. 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.

References

Adamson, L. (1997), Discussion Paper on the Coordination of Care for the Hornsby Ku-ring-gai Coordinated Care Project, unpublished.

Ageing and Disability Department (ADD) and HACC (1998), *Community Care Assessment in NSW: A Framework for the Future,* Agency Printing, Sydney.

Applebaum, R. and P. Mayberry (1996), 'Long-term care case management: a look at alternative models', *The Gerontologist*, 36 (5), 701-5.

Australian Bureau of Statistics (1998), *Analysis of Home Care Service of NSW Customer Satisfaction Survey,* ABS Statistical Consultancy.

Baldwin, R. (2000), 'Roles, relationships and responsibilities in a coordinated care trial: observations of a manager', in Commonwealth Department of Health and Aged Care, *The Australian Coordinated Care Trials: Lessons from the Trials,* Publications Production Unit, Commonwealth Department of Health and Aged Care, Canberra, forthcoming.

Barnes, M., and A. Walker (1996), 'Consumerism versus empowerment: a principled approach to the involvement of older service users', *Policy and Politics*, 24 (4), 375-395.

Bates, E. and S. Linder-Pelz (1990), *Health Care Issues*, 2nd edition, Allen and Unwin, Sydney.

Beatty, D. (1997), Options for Pooling HACC Funds for the Hornsby Ku-ring-gai Coordinated Care Project, commissioned by the North-East Metropolitan Home and Community Care Forum (NMHACCF), unpublished report.

Benrimoj, S. I., L. Emerson, E. Kopecny, G. Peacocke and P. Whitehead (1999), *The Best Practice Alternative Pharmacy Arrangements Project, Final Report,* joint project between the University of Sydney and the Pharmacy Guild of Australia Faculty of Pharmacy, University of Sydney,.

Bernabei, R., F. Landi, G. Gambassi, A. Sgadari, G. Zuccala, V. Mor, L.Z. Rubenstein and P.U. Carbonin (1998) 'Randomised trial of impact of model of integrated care and case management for older people living in the community', *British Medical Journal*, May 316 (7141), 1348-51.

Booske, B., F. Sainfort, A. Hundt (1999), 'Eliciting consumer preferences for health plans', *Health Services Research*, 34(4), 839.

Carcagno, G.J., and P. Kemper, (1988), 'The evaluation of the national long term care demonstration: 1. an overview of the Channelling demonstration and its evaluation', *HRS: Health Services Research*, 23(1), April, 1-22.

Centre for Health Advancement and KPMG Management (1997), *National Evaluation of Coordinated Care Trials Evaluation Manual*, Commonwealth Department of Health and Family Services, Canberra.

Centre for Health Advancement and KPMG Management (1997a), Draft Discussion Paper of The Administration of the SF36, unpublished.

Centre for Health Advancement and KPMG Management (1997b), *National Evaluation of Coordinated Care Trials Administration of the SF36 Health Survey at the*

Local Trial Level, Guidelines and Protocols, Version 2, Commonwealth Department of Health and Family Services, Canberra.

Challis D. (1990), 'Case management: problems and possibilities', in *Care Managers and Care Management*, Isobel Allen (ed), ADAA/PSI Discussion Paper, Policy Studies Institute, London, 9-25.

Charlton, F., M. Arch, M. Carter, S. Humphries and M. Todd (1992), *Bendigo-Ballarat Linkages Study. A Comparison of Outcomes for Geriatric Assessment team Clients,* Aged and Community Care Service Development and Evaluation Series No. 5, AGPS, Canberra.

Client-Focused Evaluations Program (1998), *Final Report: Systematic Feedback from a Sample of Patients Seen by Registrars,* Outcomes Evaluation Unit of the Royal Australian College of General Practitioners, South Melbourne.

Commonwealth Department of Health and Aged Care (CDHAC) (1999), *The Australian Coordinated Care Trials. Interim National Evaluation, Volume 1*. Ausinfo, Canberra.

Commonwealth Department of Health and Family Services (CDHFS) (1996), *Evaluation of Coordinated Care Trials. Evaluation Guidelines. Draft 5, July 1996,* Commonwealth Department of Health and Family Services, Canberra.

Commonwealth Department of Health and Family Services (CDHFS) (1996), *Evaluation of the Coordinated Care Trials, Evaluation Framework,* June 1996, Commonwealth Department of Health and Family Services, Canberra.

Commonwealth Department of Human Services and Health (CDHSH) (September 1995), *Call for Expressions of Interest in Conducting Trials in Coordinated Care,* Commonwealth Department of Human Services and Health, Canberra.

Coopers and Lybrand (1997), *Evaluation Framework. Evaluation of Coordinated Care Trials,* Commonwealth Department of Health and Family Services, Canberra.

Council of Australian Governments (COAG) (1995), *Health and Community Services: Meeting People's Needs Better,* A Discussion Paper, Commonwealth Department of Human Services and Health, Canberra

Daniel, A. (1990), *Medicine and the State,* Allen and Unwin, North Sydney.

Davies, B. (1992), *Care Management, Equity and Efficiency: The International Experience,* Personal Social Services Research Unit, University of Kent, Canterbury.

Davies, B. (1994), 'Improving the case management process', in *Caring for Frail Elderly People: 1. New Direction in Care,* OECD Social Policy Studies No. 14, Paris, 111-43.

Davies, B. and D. Challis (1986), *Matching Resources to Needs in Community Care,* Gower, Aldershot

Davies, B., A. Bebbington and H. Charnley, with B. Baines, E. Ferlie, M. Hughes and J. Twigg (1990), *Resources, Needs and Outcomes in Community-Based Care. A Comparative Study of the Production of Welfare for Elderly People in Ten Local Authorities in England and Wales,* Avebury, Aldershot.

Day, A. T. (1985), *'We Can Manage': Expectations About Care and Varieties of Family Support Among People 75 Years and Over*, Institute of Family Studies, Melbourne.

Dockrell, J. (1995), 'Exploring users' views', in *Community Care: Asking the Users*, Gail Wilson ed., Chapman and Hall, London.

Dowson, S. (1997), 'Empowerment within services: a comfortable delusion', in P. Ramcharan, G. Roberts, G. Grant and J. Borland, eds., *Empowerment in Everyday Life: Learning Disability*, Jessica Kingsley Publishers, London.

Draper, M. (1997), *Involving Consumers in Improving Hospital Care: Lessons from Australian Hospitals*, Royal Melbourne Institute of Technology, Commonwealth of Australia, Canberra.

Draper, M. and S. Hill (1996), *The Role of Patient Satisfaction Surveys in a National Approach to Hospital Quality Management*, National Outcomes Program, AGPS, Canberra.

Eardley, T. and M. Thompson (1997), *Does Care Management Help Unemployed Job Seekers?*, SPRC Reports and Proceedings No. 132, Social Policy Research Centre, University of New South Wales, Sydney

Faculty of Health Sciences (1998), *Data Dictionary for National Database, Coordinated Care Data Management*, Release 2.0, for the Commonwealth Department of Health and Family Services National Evaluation of Coordinated Care Trials, La Trobe University, Melbourne.

Fine, M.D. (1995), 'Community-based services and the fragmentation of provision', *Australian Journal of Social Issues*, 30 (2): 143-161.

Fine, M.D. (1997), *Coordinating Health, Extended Care and Community Support Services: Issues for Policy Makers and Service Providers in Australia*, Discussion Paper No. 80, Social Policy Research Centre, University of New South Wales, Sydney.

Fine, M.D., K. Fisher, G. Powell Davies and M. Harris (1999), 'Linking care in Sydney's leafy northern suburbs: the evaluation of the Hornsby Ku-ring-gai Coordinated Care Trial', in Commonwealth Department of Health and Aged Care *The Australian Coordinated Care Trials: Methodological issues in trial design and evaluation*, Publications Production Unit Commonwealth Department of Health and Aged Care, Canberra.

Fine, M. D. and J. Stevens (1998), 'Innovation on the margins: age care policies since white settlement', in *Successful Ageing: Perspectives on Health and Social Construction*, Mosby, Sydney.

Fine M. D. and C. Thomson (1995), *Factors Affecting the Outcome of Community Care Service Intervention: A Literature Review*, Aged and Community Service Development and Evaluation Reports No. 20, AGPS, Canberra.

Fisher, K. (2000), 'Process lessons from establishing the Linked Care fund pool', in Commonwealth Department of Health and Aged Care, *The Australian Coordinated Care Trials: Lessons from the Trials*, Publications Production Unit, Commonwealth Department of Health and Aged Care, Canberra, forthcoming.

Fisher, K. and M.D. Fine (1999), 'The theory and practice of case management in coordinated care', in *The Australian Coordinated Care Trials*, Centre for Health Service Development Discussion Paper No. 1, University of Wollongong.

George, J. and A. Davis (1998), *States of Health: Health and Illness in Australia*, Longman, South Melbourne.

Gibson, D. (1998), *Aged Care: Old Policies, New Problems*, Cambridge University Press, Melbourne.

Graham, S. (1999), 'A discussion paper: the experiences of elderly people in hospital', presentation at Westmead Hospital 21 May.

Graham, S., R. Ross, T. Payne with G. Matheson (1992), *The Evaluation of Community Options in New South Wales*, SPRC Reports and Proceedings 103, Social Policy Research Centre, Social Policy Research Centre, University of New South Wales, Sydney.

Grant G. and B. Parry-Jones (1996), 'What practitioners least enjoy about care management', *CSPRD Research Update Number 1*, Assessment and Care Management Study, Centre for Social Policy Research and Development, University of Wales, Bangor.

Gray, L., N. Appleby, S. Farish and M. Sullivan (1995), *Bundoora Community Care Project. Evaluation Report*, Bundoora Centre for Applied Gerontology, Bundoora.

Harris, M. and G. Powell Davies (1998), Baseline Survey of General Practitioners in Hornsby Ku-ring-gai, Report for the Local Evaluation of the Linked Care Trial, unpublished.

Harris, M. and G. Powell Davies (2000), Survey of General Practitioners in Hornsby Ku-ring-gai, Report for the local evaluation of the Linked Care trial, unpublished.

Hornsby Ku-ring-gai Coordinated Care (HKCC) (1997), Proposal for the Live Phase of the Coordinated Care Trial, Linked Care, Hornsby Ku-ring-gai Coordinated Care Project, unpublished.

Hornsby Ku-ring-gai Coordinated Care (HKCC) (1997a), Framework of the Development of a Local Evaluation Plan, Budget and Tender, Hornsby Ku-ring-gai Coordinated Care Project, unpublished.

Howe, A.L. (1997), 'What does community care research tell us about community care in Australia?', *Australasian Journal on Ageing*, 16(3): 120-127

Huntt, D. and B. Growick (1997), 'Managed care for people with disabilities', *The Journal of Rehabilitation*, 63(3), 0-15.

Irvine, R. (1996), 'Losing patients: health care consumers, power and sociocultural change', in G. Grbich ed., *Health in Australia*, Prentice Hall Australia, Sydney.

Kane, R.A., J.D. Penrod, G. Davidson, R. Moscovice and E. Rich (1991), 'What cost case management in long-term care?', *Social Service Review*, 65(2), June, 280-303.

Kapp, M. (1989), 'Medical empowerment of the elderly', *The Hastings Centre Report*, 19(4), 5-7.

Kemper, P. (1990), 'Case management agency systems of administering long-term care: evidence from the Channelling demonstration', *The Gerontologist*, 30(6), 817-24.

Kendig, H. (1986), 'Perspectives on ageing and families' in Hal Kendig ed., *Ageing and Families: A Social Networks Perspective*, Allen and Unwin, Sydney.

Kendig, H. (1986a), 'Ageing, Families and Social Change' in Hal Kendig ed., *Ageing and Families: A Social Networks Perspective*, Allen and Unwin, Sydney.

Kendig, H. G. McVicar, A. Reynolds and A. O'Brien (1992), *Victorian Linkages Evaluation*, Department of Health, Housing and Community Services and Community Services Victoria.

Lazarus, I. R. (1996), 'Personal health management: with medical care centers as a keystone, personal health management adds value without additional cost, *Managed Healthcare*, June.

Leigh, J., D. Tyson, B. Pekarsky and C. Silargy (1999), 'The ACCT and their evaluation – an introduction', *The ACCT: Background and Trial Descriptions, Commonwealth Department of Health and Aged Care*, Canberra.

Marshall M. (1996), 'Case management: a dubious practice', *British Medical Journal*, 312 (7030), 523-4.

McGrath M. (1996), 'Care management and client groups', *CSPRD Research Update Number 3*, Assessment and Care Management Study, Centre for Social Policy Research and Development, University of Wales, Bangor.

Minichiello, V., R. Aroni, E. Timewell and L. Alexander (1995), *In-depth Interviewing*, 2nd edition, Longman, Melbourne.

Naleppa M.J. and W.J. Reid (1998), 'Task-centered case management for the elderly: developing a practice model', *Research on Social Work Practice*, 8 (1): 63-85.

Nettleton, S. (1995), *The Sociology of Health and Illness*, Polity Press, Cambridge.

Newcomer R., P. Arnsberger and X. Zhang (1997), 'Case management, client risk factors, and service use', *Health Care Financing Review*, 19(1) Fall, 105-20.

Northern Sydney Area Health Service (NSAHS) (1997), Hornsby Ku ring gai Coordinated Care Project. Framework of the Development of a Local Evaluation Plan, Budget and Tender, unpublished.

Northumberland Health Authority, *Health Today in Northumberland*, 20, Summer Edition, 3.

O'Connor, D.W., P.A. Pollitt, C.P.B. Brook, B.B. Reiss and M. Roth (1991), 'Does early intervention reduce the number of elderly with dementia admitted to institutions for long term care?', *British Medical Journal*, 302, April, 871-5.

Opie, A. (1998), '"Nobody's asked me for my view": user's empowerment by multidisciplinary health teams', *Qualitative Health Research*, 8(2), 188-206.

Phillips-Harris, C. (1998), 'Case management: high intensity care for frail patients with complex needs', *Geriatrics*, 53 (2), 62-5.

Pond, D, S. Knowlden and M. Harris (1996), 'News from the divisions: diabetes shared care', *Australian Family Physician*, 25(1), Supplement 1, S9-S10.

Quinn J. (1995), 'Care management in Home and Community Care', *Journal of Gerontological Social Work*, 24 (3,4), 233-48.

Reynolds A (1995), *Clients with Complex Needs: Effective Care at Home*, AGPS, Canberra.

Richards, T. (1998), 'Partnership with patients', *British Medical Journal*, 316(7125), 85-6.

Rodwin, M. (1997), 'The neglected remedy: strengthening consumer voice in managed care', *The American Prospect*, 34, 45-50.

Rowland, D.T. (1991), *Ageing in Australia*, Longman Cheshire, Melbourne.

Rubin A. (1992), 'Case management', in S. Rose ed., *Case Management and Social Work Practice*, Longman, New York, 5-20.

Rungie, M. (1990), 'Some effects on agencies which plan services around individuals' in A. Howe, E. Ozanne and C. Selby Smith eds *Community Care Policy and Practice. New Directions in Australia*, Public Sector Management Institute, Monash University, Clayton Victoria.

Sarantakos, S. (1993), *Social Research*: 2nd edition, Macmillan Education, South Yarra.

Scotton, D. (1995) 'Managed competition: issues for Australia', *Australian Health Review*, 17 (3), 82-104.

Shapiro, M. (1995), 'Doctors learning their trade: the reproduction of professional power', in G., Lupton and J. Najman eds., *Sociology of Health and Illness: Australian Readings*, 2nd edition, University of Queensland, South Melbourne.

Shepperd, S, D. Charnock and B. Gann (1999), 'Helping patients access high quality health information', *British Medical Journal*, 319(7212), 764.

Turner, B.S. (1987), *Medical Power and Social Knowledge*, Sage Publications, London.

Turvey, K. and M. Fine (1997), The Shared Care of Older People Project (SCOPP), Twelve Month Evaluation Report, prepared for the Eastern Sydney Area Division of General Practice, Sydney.

UNSW Evaluation Consortium (K. Fisher, M. Fine, S. Strazzari, J. Doyle, G. Powell Davies, M. Harris, T. O'Brien and P. Saunders) (1997-1999), various reports for the Hornsby Ku-ring-gai Coordinated Care Trial Evaluation, unpublished.

UNSW Evaluation Consortium (1997), Linked Care Hornsby Ku-ring-gai Coordinated Care Trial Local Evaluation Plan, unpublished.

UNSW Evaluation Consortium (1999a), Establishing the Fund Pool Local Evaluation Finance Report, unpublished.

UNSW Evaluation Consortium (1999b), Service Provider Baseline Report – Managers' Expectations of Linked Care, unpublished.

UNSW Evaluation Consortium (1999c), Service Provider Baseline Report – Service Delivery Description, unpublished.

Vaus, de D.A. (1990), *Surveys in Social Research*, 2nd edition, Allen and Unwin, Sydney.

Wallerstein, N. (1993), 'Empowerment and health: the theory and practice of community change', *Community Development Journal*, 28 (3), July, 218-27.

Ware, J., M. Bayliss, W. Rogers, M. Kosinski and A. Tarlor (1996) 'Differences in 4-year health outcomes for elderly and poor, chronically ill patients treated in HMO and fee-

for-service systems', *Journal of the American Medical Association*, 276 (13), 1039-47.

Wearing, B. (1996), 'Medical dominance and the division of labour in the health professions', in C. Grbich ed., *Health in Australia*, Prentice Hall Australia, Sydney.

Wells, Y., H. Swerissen and H. Kendig (1999), 'Client outcomes in case managed care: who benefits most?' *Australasian Journal of Ageing*, 18 (2),79-85.

Wilson, G. (1995), 'Introduction' in G. Wilson ed., *Community Care: Asking the Users*, Chapman and Hall, Melbourne.

Wilson, G. (1995), 'Future Developments', in G. Wilson ed., *Community Care: Asking the Users*, Chapman and Hall, London.

Young, A.F., J.E. Byles and A. J. Dobson (1998), 'Women's Satisfaction with General Practice Consultations', *Medical Journal of Australia*, 168, 386-9.

Zambada, C., P. Rivers and G. Munchus (1998), 'Obstacles to the application of total quality management in health-care organisations', *Total Quality Management*, 9(1), 57-66.

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 well-being* 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 well-being ...;

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 well-being*, *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 Data Sets

Data set	No. times administered	Data type quantitative	qualitative
Participants			
1. Participant Profile (demographics)	2	x	
2. SF-36 Health and Well-being Questionnaire	3	x	
3. Participant Telephone Interview	3		x
4. Participant Questionnaire (service usage, support and well-being)	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		x
3. Linked Care staff Focus Group	2		x
4. Trial minutes, reports and policies			x

A separate volume of evaluation instruments accompanies this report.

Appendix 3: Local Evaluation Financial Analysis

Table A3.1: Local Evaluation Financial Analysis September 1997 to December 1999

Table A3.2: Local Evaluation Financial Analysis September 1997 to December 1999 - Excluding Trial Related Costs and Infrastructure Grant

Appendix 4: Participant Experience Methodology

The participant perspective was sought in three main ways. Triangulation was employed to explore participant experiences from a number of angles to overcome the limitations of using only one method (Bryman, 1992: 75; Dockrell, 1995: 50; Sarantakos, 1993: 169). This was achieved by using a variety of methods, collecting longitudinal data, and of course integrating the research with other aspects of the evaluation.

First, a mailed questionnaire was administered to a random sample of Intervention and Control participants in November/December 1998 and re-administered in October/November 1999. Written comments made by questionnaire respondents also provide greater insight into some aspects of participant experiences. 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 sample of participants from each group in September 1998, April 1999 and October 1999. While the questionnaire provided an overall perspective with which to view the Trial, 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 third supplementary method for exploring participant experiences was with the extensive field experience and contacts made at Linked Care including: attending Linked Care staff meetings, peer support meetings for care coordinators, interviews and discussions with Linked Care staff, service providers and consumer representatives.

A supplementary method for exploring client experiences was the extensive field experience and contacts made by the evaluators 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 initially quantitative data from over 400 participants in the trial, and has longitudinal information from over 250 intervention and control participants.

The participant questionnaire was developed in three stages. Initially, published experiences of developing other similar questionnaires were drawn on. Then, discussions were held with people conducting other trials on their experiences with participant data collection. Lastly, the questionnaire was modified and adjusted through two pilots. Discussion with Linked Care staff and management and involved service providers including care coordinators continued throughout this process. The questionnaire was designed as far as possible not to be as simple and unrepetitive for participants since they were already complaining about the burden of paperwork. Identification numbers, which ensured confidentiality, linked questionnaire responses to data already collected from the 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 evaluation 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 random sample of 500, with equal numbers from intervention and control, was computer generated. The first administration had a 84 per cent response rate (after excluding participants who had exited from the trial). The questionnaire was readministered 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. The samples are summarised in Table A4.1.

Table A4.1: Descriptions for All Participants and Participant Samples

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 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 (23). The participants were selected via systematic sampling. The Intervention participants were randomly selected based on the three types of CC they might be allocated to:

? GP CCs;

? agency CCs; and

? full-time CCs.

The Control participants were matched based on the living arrangements of the Intervention sample (whether 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 who exited in the second round were not replaced.[142]

The small numbers involved in the interviews means their experiences cannot be generalised to all intervention and control. 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).

The interviews were usually conducted by telephone and recorded with the consent of the participant. Interviews varied from 15 minutes to two hours. The interviews were semi-structured and incorporated issues addressed in the questionnaire, but were responsive to issues the participants 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 particularly asked participants to comment on their experiences of Linked Care.

[142] 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 recently had an operation.

Appendix 5: Service Usage Charts

Appendix 6: Participant Profile and Outcomes Tables

These tables supplement the participant profile and outcomes tables in Chapter 4. Participant experience tables are listed in Appendix 6.

Table A6.1: 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 A6.2: 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 A6.3a: 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 A6.3a (continued): 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 A6.3b: Baseline Characteristics of Control 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 A6.3b (continued): 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 A6.4a: 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 A6.4b: 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 A6.4c: 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 A6.4d: 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 A6.5: 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 usable 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 A6.6a: Baseline Characteristics of Intervention Participants 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	16.9	25.7	17.1	24.7	19.1
	100.0	100.0	100.0	100.0	100.0	100.0

	(654)	(59)	(421)	(292)	(388)	(325)

Table A6.6a (continued): Baseline Characteristics of Intervention Participants 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=)
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	100.0	100.0	100.0	100.0	100.0
	(657)	(65)	(421)	(301)	(388)	(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	100.0	100.0	100.0	100.0	100.0
	(653)	(59)	(420)	(292)	(387)	(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	100.0	100.0	100.0	100.0	100.0
	(657)	(63)	(421)	(299)	(388)	(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	100.0	100.0	100.0	100.0	100.0
	(657)	(65)	(421)	(301)	(388)	(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	100.0	100.0	100.0	100.0	100.0
	(656)	(65)	(421)	(300)	(388)	(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	100.0	100.0	100.0	100.0	100.0
	(654)	(58)	(421)	(291)	(388)	(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 A6.6b: Baseline Characteristics of Control Participants 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
	100.0	100.0	100.0	100.0	100.0	100.0
	(376)	(47)	(266)	(157)	(201)	(222)

Table A6.6b (continued): Baseline Characteristics of Control Participants 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 A6.7: Proportional Change of Lowest and Highest Possible SF-36 Scores by Participant Group

	Baseline		End of Trial	
	Intervention	Control	Intervention	Control
	%	%	%	%
SF-36 Item	(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 A6.8: Change in SF-36 Scores from Baseline to End of Trial by Participant Group

	Excluding Exits		Including Exits	
	Intervention	Control	Intervention	Control
	%	%	%	%
SF-36 Item	(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
	100.0	100.0	100.0	100.0
	(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
	100.0	100.0	100.0	100.0
	(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
	100.0	100.0	100.0	100.0
	(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
	100.0	100.0	100.0	100.0
	(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
	100.0	100.0	100.0	100.0
	(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
	100.0	100.0	100.0	100.0
	(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
	100.0	100.0	100.0	100.0
	(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
	100.0	100.0	100.0	100.0
	(384)	(198)	(581)	(284)
PCS				
Better	48.9	49.7	32.0	34.4
Same	-	-	-	-
Worse	51.1	50.3	68.0	65.6
	100.0	100.0	100.0	100.0
	(372)	(193)	(569)	(279)

MCS				
Better	47.3	45.6	45.6	31.5
Same	-	-	-	-
Worse	52.7	54.4	54.5	68.5
	100.0	100.0	100.0	100.0
	(372)	(193)	(569)	(279)

Table A6.9: 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 A6.10: 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 7: Participant Experience Tables

Table A7.1: Comparison of 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	
Participant Characteristics	Baseline (n=) %	End trial (n=) %	Baseline (n=) %	Effective sample % (n=)[a]	Baseline (n=) %	End trial (n=) %	Baseline (n=) %	Effective sample[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 A7.1 (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<.01[143]

[143] All significance tests in Appendix 7 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 A7.2: Selected Characteristics of Participant Questionnaire Sample by Participant Group

	Participant group					
	All baseline responses		Effective Sample[(a)]			
	Intervention (213)	Control (208)	Intervention (143) baseline	Intervention (143) end trial	Control (122) baseline	Control (122) 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 A7.3: Self-reported Participant Characteristics in Qualitative Interviews

	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 A7.4: 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 A7.5: Comparison of Exit Status and Selected Characteristics of All Linked Care Participants and the Participant Questionnaire Sample

	Participant Group							
	Intervention				Control			
Participant characteristics	**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=)
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 (396)	100.0 (299)	100.0 (149)	100.0 (61)	100.0 (210)	100.0 (211)	100.0 (132)	100.0 (75)

Table A7.5 (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	
Participant characteristics	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)
SF36 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 A7.6: 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
Received type of services needed								
Gender								
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
Age								
<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
Living arrangements								
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
Housing arrangements								
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
Private insurance								
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
DVA client								
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
Pension/benefit recipient								
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
Language								
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								
Gender								
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
Age								
<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
Living arrangements								
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
Housing arrangements								
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
Private insurance								
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
DVA client								
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
Pension/benefit recipient								
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

Language								
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 A7.6 (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								
Gender								
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
Age								
<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
Living arrangements								
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
Housing arrangements								
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
Private insurance								
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
DVA client								
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
Pension/benefit recipient								
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
Language								
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								
Gender								
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
Age								
<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
Living arrangements								
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
Housing arrangements								
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
Private insurance								
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
DVA client								
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
Pension/benefit recipient								
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

Language								
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 A7.6 (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								
Gender								
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
Age								
<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
Living arrangements								
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
Housing arrangements								
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
Private insurance								
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
DVA client								
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
Pension/benefit recipient								
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
Language								
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 A7.7: 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**
Self-reported	6.7	11.5[(a)]
Care plan	-	7.1[(a)]

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

Table A7.8: Differences in 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 (26)	100.0 (33)	100.0 (59)

* $p<0.10$

Source: Participant questionnaires, November 1998 and 1999.

Appendix 8: Service Provider Evaluation Tables

1. Service Provider Views of Linked Care

Table A8.1: Care Coordinators Views of Linked Care, 1998 and 1999

	1998		1999		
	n	%	n	%	
Service					
Sydney Home Nursing Service	5	12.2	15	19.5	
Home Care Service	2	4.9	4	5.2	
Hornsby Hosp. Rehab. & Aged Care	6	14.6	11	14.3	
Mercy Family Centre	8	19.5	17	22.1	
Neighbour Aid	0	0.0	0	0.0	
Wesley Gardens	2	4.9	1	1.3	
Meals on Wheels	0	0.0	0	0.0	
GPs	18	43.9	29	37.7	
Position					
Field Staff/Volunteers	0	0.0	5	6.5	
Coordinator	13	31.7	14	18.2	
Nurse	6	14.6	15	19.5	
Occupational Therapist	3	7.3	3	3.9	
Social Worker	1	2.4	2	2.6	
Clinical Specialist	0	0.0	3	3.9	
Physiotherapist	0	0.0	6	7.8	
Medical Practitioner/Doctor	18	43.9	29	37.7	
No. of care coordinated participants					
0 to 24 participants	40	93.0	46	100.0	
25 to 49 participants	0	0.0	0	0.0	
50 to 74 participants	1	2.3	0	0.0	
Over 75 participants	2	4.7	0	0.0	
Other clients who are not your participants					
0 to 19	29	80.6	39	86.7	
20 to 39	7	19.4	3	6.7	
40 or more	0	0.0	3	6.7	
Trial created problems in coordinating and planning care					
Yes	7	15.9	9	19.6	
No	38	86.4	37	80.4	
Trial created problems in delivering care					
Yes	9	20.9	2	4.3	**
No	34	79.1	44	95.7	
Trial affected health and well-being of clients					
Positive change	15	34.1	15	32.6	*
Negative change	0	0.0	1	2.2	
No change	24	54.5	30	65.2	
Don't know	5	11.4	0	0.0	
Trial been more beneficial for some types of participants than others					
Yes	19	43.2	25	56.8	
No	9	20.5	8	18.2	
Don't know	15	34.1	11	25.0	

Conflict between care coordinator role and other work				
Yes	20	45.5	19	42.2
No	24	54.5	24	53.3
Don't know	0	0.0	2	4.4

Table A8.1 (continued): Care Coordinators Views of Linked Care, 1998 and 1999

	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	
Trial changed access to assistance or care					
Yes	12	28.6	11	23.9	
No	26	61.9	34	73.9	
Don't know	4	9.5	1	2.2	
Trial changed access or assistance provided by other services					
Yes	22	52.4	22	50.0	
No	11	26.2	18	40.9	
Don't know	9	21.4	4	9.1	
Trial had impact on links with other services					
Positive change	28	63.6	23	50.0	
Negative change	1	2.3	1	2.2	
No change	15	34.1	21	45.7	
Don't know	0	0.0	1	2.2	
Problems persuading services to cooperate					
Yes	12	28.6	8	17.8	
No	27	64.3	34	75.6	
Don't know	3	7.1	3	6.7	
Trial has more benefits than disadvantages for my participants					
Strongly agree	8	18.2	5	11.1	
Agree	14	31.8	18	40.0	
Neutral	16	36.4	13	28.9	
Disagree	6	13.6	4	8.9	
Strongly disagree	0	0.0	5	11.1	
Trial has more benefits than disadvantages for other clients					
Strongly agree	1	2.4	1	2.2	
Agree	5	11.9	5	11.1	
Neutral	23	54.8	16	35.6	
Disagree	8	19.0	12	26.7	
Strongly disagree	5	11.9	11	24.4	
Trial has more benefits than disadvantages for my service/practice					
Strongly agree	4	9.3	3	6.7	
Agree	11	25.6	8	17.8	
Neutral	16	37.2	17	37.8	
Disagree	9	20.9	7	15.6	
Strongly disagree	3	7.0	10	22.2	

Adequate administrative support for your role as care coordinator				
Yes	34	77.3	24	58.5
No	5	11.4	12	29.3
Don't know	5	11.4	5	12.2

Source: Care coordinators questionnaires, November 1998 and 1999.
*** p<0.01 ** p<0.05 * p<0.10

Table A8.2: Service Personnel Views of Service Integration, 1998 and 1999

	1998		1999		
	n	%	n	%	
Service					
Sydney Home Nursing Service	13	27.1	15	19.5	
Home Care Service	11	22.9	4	5.2	
Hornsby Hosp. Rehab. & aged Care	12	25.0	11	14.3	
Mercy Family Centre	7	14.6	17	22.1	
Neighbour Aid	5	10.4	0	0.0	
Wesley Gardens	0	0.0	1	1.3	
Meals on Wheels	0	0.0	0	0.0	
GPs	-	-	29	37.7	
Position					
Field Staff/Volunteers	12	25.0	5	6.5	
Coordinator	14	29.2	14	18.2	
Nurse	15	31.3	15	19.5	
Occupational Therapist	1	2.1	3	3.9	
Social Worker	4	8.3	2	2.6	
Manager	1	2.1	0	0.0	
Clinical Specialist	1	2.1	3	3.9	
Physiotherapist	0	0.0	6	7.8	
Medical Practitioner/Doctor	-	-	29	37.7	
Years working at service					
Less than 3 years	15	31.5	24	35.8	
3 to <7 years	16	33.6	15	22.4	
7 to 12 years	12	25.2	15	22.4	
Over 12 years	5	10.5	13	19.4	
Employment status					
Paid	43	89.6	73	96.1	
Other	5	10.4	3	3.9	
Care coordinator?					
Yes	24	54.5	46	63.9	
No	20	45.5	26	36.1	
Knowledge of assistance provided by other services					
Excellent	23	51.1	21	28.0	**
Satisfactory	17	37.8	43	57.3	
Needs to be improved	5	11.1	11	14.7	
Sharing of information within my area					
Excellent	9	20.5	16	21.3	
Satisfactory	22	50.0	42	56.0	
Needs to be improved	13	29.5	17	22.7	
Communication between services					

Excellent	5	11.6	7	9.3	
Satisfactory	23	53.5	44	58.7	
Needs to be improved	15	34.9	24	32.0	
Referral process to community services					
Excellent	17	40.5	18	24.0	*
Satisfactory	20	47.6	51	68.0	
Needs to be improved	5	11.9	6	8.0	
Referral process to GPs					
Excellent	6	16.7	16	26.7	
Satisfactory	23	63.9	40	66.7	
Needs to be improved	7	19.4	4	6.7	

Table A8.2 (continued): Service Personnel Views of Service Integration, 1998 and 1999

	1998		1999		
	n	%	n	%	
Referral process to other health and hospital services					
Excellent	19	46.3	20	26.7	*
Satisfactory	18	43.9	49	65.3	
Needs to be improved	4	9.8	6	8.0	
Referral process from community services					
Excellent	10	23.8	8	11.0	
Satisfactory	25	59.5	49	67.1	
Needs to be improved	7	16.7	16	21.9	
Referral process from GPs					
Excellent	5	12.8	3	5.0	
Satisfactory	15	38.5	33	55.0	
Needs to be improved	19	48.7	24	40.0	
Referral process from other health and hospital services					
Excellent	4	10.3	5	6.8	
Satisfactory	24	61.5	44	60.3	
Needs to be improved	11	28.2	24	32.9	
Clients' initial access to services					
Excellent	8	17.8	11	14.9	
Satisfactory	22	48.9	39	52.7	
Needs to be improved	15	33.3	24	32.4	
Clients' involvement in choosing level of care provided					
Excellent	14	32.6	18	24.3	
Satisfactory	22	51.2	46	62.2	
Needs to be improved	7	16.3	10	13.5	
Informed if clients receive assistance from other services					
Always or nearly always	5	11.4	9	12.0	
Often	8	18.2	25	33.3	
Sometimes	18	40.9	26	34.7	
Seldom or never	13	29.5	15	20.0	
Officially informed of outcome of referral					
Always or nearly always	5	11.9	8	10.7	
Often	3	7.1	17	22.7	
Sometimes	19	45.2	23	30.7	
Seldom or never	15	35.7	27	36.0	
Description of care provided to clients					
Staff work closely together most of time	21	46.7	29	39.7	**
Staff work closely together occasionally	13	28.9	38	52.1	
Staff know little about each other's work	11	24.4	6	8.2	
Description of relationship with other services					
Well coordinated team	14	31.8	22	29.3	
Partially coordinated team	25	56.8	46	61.3	
Series of separate uncoordinated services	5	11.4	7	9.3	

Source: Service personnel questionnaires, May 1998 and November 1999.
*** p<0.01 ** p<0.05 * p<0.10

Table A8.3: Service Personnel Views of Service Integration - Care Coordinators Compared to Non-Care Coordinators, 1998 and 1999

	Care Coordinators			Other Staff	
	Non-GP 1998 n (24)	Non-GP 1999 n (17)	GP 1999 n (29)	1998 n (20)	1999 n (26)
Service					
Sydney Home Nursing Service	12	3	-	1	11
Home Care Service	3	0	-	7	4
Hornsby Hosp. Rehab. & Aged Care	5	6	-	6	5
Mercy Family Centre	4	7	-	2	6
Neighbour Aid	0	0	-	4	0
Wesley Gardens	0	1	-	0	0
Meals on Wheels	0	0	-	0	0
GPs	-	-	29	-	0
Position					
Field Staff/Volunteers	0	0	-	9	1
Coordinator	7	8	-	7	6
Nurse	13	4	-	2	10
Occupational Therapist	0	3	-	0	0
Social Worker	2	2	-	2	0
Manager	1	0	-	0	0
Clinical Specialist	1	0	-	0	3
Physiotherapist	0	0	-	0	6
Medical Practitioner/Doctor	-	-	29	-	0
	%	%	%	%	%
Knowledge of assistance provided by other services					
Excellent	62.5	52.9	17.9 **	33.3	26.9
Satisfactory	37.5	47.1	64.3	44.4	50.0
Needs to be improved	0.0	0.0	17.9	22.2	23.1
Sharing of information within my area					
Excellent	25.0	35.3	7.1 *	17.6	30.8
Satisfactory	58.3	52.9	78.6	29.4	26.9
Needs to be improved	16.7	11.8	14.3	52.9	42.3
Communication between services					
Excellent	12.5	11.8	3.6	12.5	15.4
Satisfactory	62.5	70.6	71.4	37.5	30.8
Needs to be improved	25.0	17.6	25.0	50.0	53.8
Referral process to community services					
Excellent	50.0	41.2	3.6***	33.3	38.5
Satisfactory	45.8	52.9	85.7	40.0	53.8
Needs to be improved	4.2	5.9	10.7	26.7	7.7
Referral process to GPs					
Excellent	19.0	21.4	23.5	16.7	36.0 **
Satisfactory	71.4	78.6	64.7	50.0	60.0
Needs to be improved	9.5	0.0	11.8	33.3	4.0
Referral process to other health and hospital services					
Excellent	56.5	29.4 *	21.4	25.0	34.6
Satisfactory	43.5	70.6	71.4	50.0	57.7
Needs to be improved	0.0	0.0	7.1	25.0	7.7

Referral process from community services						
Excellent	29.2	23.5	7.7	*	13.3	7.7
Satisfactory	58.3	70.6	57.7		60.0	69.2
Needs to be improved	12.5	5.9	34.6		26.7	23.1

Table A8.3 (continued): Service Personnel Views of Service Integration - Care Coordinators Compared to Non-Care Coordinators, 1998 and 1999

	Care Coordinators				Other Staff	
	Non-GP 1998 %	Non-GP 1999 %	GP 1999 %		1998 %	1999 %	
Referral process from GPs							
Excellent	21.7	5.9	14.3		0.0	0.0	
Satisfactory	34.8	41.2	64.3		42.9	56.0	
Needs to be improved	43.5	52.9	21.4		57.1	44.0	
Referral process from other health and hospital services							
Excellent	13.0	5.9	11.1		7.7	3.8	
Satisfactory	60.9	76.5	59.3		53.8	46.2	
Needs to be improved	26.1	17.6	29.6		38.5	50.0	
Clients' initial access to services							
Excellent	25.0	17.6	10.7	*	5.6	19.2	
Satisfactory	45.8	35.3	67.9		50.0	42.3	
Needs to be improved	29.2	47.1	21.4		44.4	38.5	
Clients' involvement in choosing level of care provided							
Excellent	45.8	29.4	11.1		12.5	26.9	
Satisfactory	41.7	64.7	74.1		62.5	53.8	
Needs to be improved	12.5	5.9	14.8		25.0	19.2	
Informed if clients receive assistance from other services							
Always or nearly always	17.4	11.8	10.7		5.9	3.8	
Often	17.4	47.1	32.1		23.5	30.8	
Sometimes	47.8	41.2	28.6		29.4	42.3	
Seldom or never	17.4	0.0	28.6		41.2	23.1	
Officially informed of outcome of referral							
Always or nearly always	13.0	11.8	10.7		13.3	3.8	
Often	8.7	23.5	39.3		6.7	7.7	
Sometimes	56.5	35.3	25.0		26.7	38.5	
Seldom or never	21.7	29.4	25.0		53.3	50.0	
Description of care provided to clients							
Staff work closely together most of time	69.6	64.7	30.8	*	16.7	34.6	*
Staff work closely together occasionally	17.4	29.4	61.5		44.4	53.8	
Staff know little about each other's work	13.0	5.9	7.7		38.9	11.5	
Description of relationship with other services							
Well coordinated team	41.7	35.3	25.0		18.8	23.1	
Partially coordinated team	58.3	58.8	64.3		62.5	69.2	
Series of separate uncoordinated services	0.0	5.9	10.7		18.8	7.7	

Source: Service personnel questionnaires, May 1998 and November 1999.
*** p<0.01 ** p<0.05 * p<0.10

2. Service Provider Profile

Table A8.4a: Hornsby Ku-ring-gai Community-based Agencies Client Profile (estimates) 1996-97

		Total	MOW	NSHNS	Neigh-bour Aid	Home Care Service	Mercy Family Centre	ACAT
1. Number of clients								
No. clients receiving help		8018	475	2293	250	1085	439	3476
No. referrals		6226	185	1824	50	594	97	-
Referrals as a percentage of clients		43	39	80	20	55	22	-
No. clients in a typical week		1725	230	521	44	714	216	-
2. Client demographics	HK general population[(a)]	**Average**						
% clients over 65 years	14	88	90	81	95	83	83	95
% clients women	52	73	75	64	85	78	67	70
% clients NESB	15	6	1	0	4	9	12	7
% clients ATSI	0	0	0	0	0	0	0	0

Source: Baseline service data survey, December 1997.
Note: (a)ABS Census 1996, Hornsby Ku-ring-gai (HK) LGAs

Table A8.4b: Hornsby Ku-ring-gai Community-based Agencies Client Profile (estimates) 1998-99

		Total	MOW	NSHNS	Neigh-bour Aid	Home Care Service	Mercy Family Centre	ACAT
1. Number of clients								
No. clients receiving help		9993	450	2491	250	1555	883	4364
No. referrals		7980	0	2066	50	1080	420	4364
Referrals as a percentage of clients		53	0	83	20	69	48	100
No. clients in a typical week		2130	198	423	44	933	452	80
2. Client demographics	HK general population[(a)]	**Average**						
% clients over 65 years	14	86	80	79	95	85	80	94
% clients women	52	72	68	61	85	77	75	67
% clients NESB	15	7	1	0	4	13	8	13
% clients ATSI	0.2	0	0	0	0	0	0	0

Source: End of trial service data survey, November 1999.
Note: (a)ABS Census 1996, Hornsby Ku-ring-gai (HK) LGAs

Table A8.5a: Hornsby Ku-ring-gai Community-based Agencies Financial Data (estimates) 1996-97

	Total $	%	MOW	NSHNS	Neigh-bour Aid	Home Care Service	Mercy Family Centre	ACAT
1. Revenue								
Commonwealth & State (HACC)	4 746 769	67	-	1 818 770	44 818	2 215 360	330 821	337 000
Other State funding	1 325 135	19	121 844	265 502	-	-	776 789	161 000
Client fees, co-payments, donations	859 253	12	246 456	-	1 765	463 945	147 087	-
Other	127 737	2	1 762	125 000	-	975	-	-
Total operating budget	7 058 894	100	370 062	2 209 272	46 583	2 680 280	1 254 697	498 000
Other in-kind support				rent	rent			
2. Expenses								
Wages & on-costs	5 675 564	81	81 363	1 964 060	35 663	2 311 647	785 431	497 400
Expenses - non-wages	1 308 534	19	-	245 212	7 940	305 155	434 042	19 000
Total expenses	6 984 098	100	378 548	2 209 272	43 603	2 616 802	1 219 473	516 400

Source: Baseline service data survey, December 1997.

Table A8.5b: Hornsby Ku-ring-gai Community-based Agencies Financial Data (estimates) 1998-99

	Total $	%	MOW[(a)]	NSHNS	Neigh-bour Aid	Home Care Service[(b)]	Mercy Family Centre	ACAT
1. Revenue								
Commonwealth & State (HACC)	3 745 066	49	-	2 392 268	46 400	-	953 648	352 750
Other State funding	2 769 677	36	-	685 811	-	-	1 870 340	213 526
Client fees, co-payments, donations	1 094 423	14	-	-	2 050	-	1 092 373	-
Other	24 900	0	-	-	-	-	24 900	-
Total operating budget	7 609 166	100	-	3 078 079	48 450	-	3 916 361	566 276
Other in-kind support	-	-			rent		24 900	
2. Expenses								
Wages & on-costs	6 039 007	80	-	3 003 344	40 296	-	2 506 471	488 896
Expenses - non-wages	1 517 035	20	-	74 235	4 030	-	1 361 390	77 380
Total expenses	7 556 542	100	-	3 078 079	44 326	-	3 867 861	566 276

Source: End of trial service data survey, November 1999.

Notes (a)Data for this service are not available.

(b)Comparison of data is not possible as Hornsby Home Care Service amalgamated with the Ryde Home Care Service during the trial period.

Table A8.6a: Hornsby Ku-ring-gai Community-based Agencies Staff Profile (estimates) 1996-97

	Total	Average/ per cent	MOW	NSHNS	Neigh-bour Aid	Home Care Service	Mercy Family Centre	ACAT
1. Number of staff	n	Average	n	n	n	n	n	n
Paid full-time staff	56	9	1	38	0	5	5	7
Paid part-time staff	176	29	2	12	2	93	61	6
Volunteers	239	80	100	-	75	-	64	-
2. Staff hours per week								
Paid full-time staff	2117	353	40	1444	0	175	190	268
Paid part-time staff	3118	520	35	188	40	1925	831	99
Volunteers	490	163	300	-	165	-	25	-
3. Paid staff tasks		Average %	%	%	%	%	%	%
Direct care		47	50	65	-	77	43	-
Organising care		28	25	15	60	10	30	-
Administration and management		17	25	15	30	3	10	-
Travel, training & other		8	0	5	10	10	17	-
4. Volunteer tasks								
Direct care		85	100	-	75	-	80	-
Organising care		0	0	-	0	-	0	-
Administration and management		7	0	-	20	-	0	-
Travel, training & other		8	0	-	5	-	20	-

Source: Baseline service data survey, December 1997.

Table A8.6b: Hornsby Ku-ring-gai Community-based Agencies Staff Profile (estimates) 1998-99

	Total	Average/ per cent	MOW	NSHNS	Neigh-bour Aid	Home Care Service	Mercy Family Centre	ACAT
1. Number of staff		Average						
Paid full-time staff	63	13	2	34	0	5	12	11
Paid part-time staff	334	67	0	13	2	195	113	13
Volunteers	358	72	297	0	75	-	61	-
2. Staff hours per week								
Paid full-time staff	2251	450	76	1292	-	175	456	442
Paid part-time staff	5932	1483	0	211	35	3898	1808	226
Volunteers	241	48	100	0	165	-	141	-
3. Paid staff tasks		Average %	%	%	%	%	%	%
Direct care		55	50	65	55	61	60	50
Organising care		8	0	15	0	10	12	10
Administration and management		20	50	15	35	8	10	10
Travel, training & other		15	0	5	10	21	8	30
4. Volunteer tasks								
Direct care		75	60	0	75	-	90	-
Organising care		3	0	0	0	-	5	-
Administration and management		0	0	0	20	-	0	-
Travel, training & other		23	40	0	5	-	5	-

Source: End of trial service data survey, November 1999.

Table A8.7a: Estimated Duration of Service Provision for Current Clients, December 1997

	Average	MOW	NSHNS	Neigh-bour Aid	Home Care Service	Mercy Family Centre	ACAT	HKHCHS[a] Inpatient	HKHCHS[a] Non Inpatient
					Percentages				
Single visit or event	13	-	9	3	-	-	-	55	35
Less than 2 weeks	8	5	12	2	-	-	25	10	10
2 weeks to <1month	10	15	12	-	-	15	-	10	25
1 to 3 months	19	15	35	10	2	5	60	10	15
Over 3 to 6 months	9	15	17	-	13	10	-	10	5
Over 6 months	42	50	15	85	85	70	15	5	10
	100	100	100	100	100	100	100	100	100

Source: Baseline service data survey, December 1997.
Note: (a)Hornsby Ku-ring-gai Hospital and Community Health Services; excluding ACAT.

Table A8.7b: Estimated Duration of Service Provision for Current Clients, November 1999

	Average	MOW	NSHNS	Neigh-bour Aid	Home Care Service	Mercy Family Centre	ACAT	HKHCHS[a] Inpatient	HKHCHS[a] Non Inpatient
					Percentages				
Single visit or event	5	0	-	3	0	0	20		
Less than 2 weeks	8	5	-	0	0	0	25		
2 weeks to <1month	3	0	-	0	0	1	10		
1 to 3 months	6	0	-	7	2	2	20		
Over 3 to 6 months	7	10	-	0	0	4	15		
Over 6 months	71	85	-	90	98	93	10		
	100	100	100	100	100	100	100		

Source: End of trial service data survey, November 1999.
Note: (a) Data unavailable.

Table A8.8a: Size and Length of Waiting Lists (percentage, weeks), December 1997

	Home Care Service	Mercy Family Centre	Aged Care Assessment Team	HKHCHS Inpatient	HKHCHS Non Inpatient
Average no. on waiting list over the last 4 weeks	60	7	-	560	500
% Waiting less 1 week	-	-	-	10	5
% Waiting 1 to < 4 weeks	-	71	-	15	30
% Waiting 4 to < 12 weeks	40	29	-	50	50
% Waiting 12 weeks or more	60	-	-	25	15
	100	100	100	100	100

Source: Baseline service data survey, December 1997.

Table A8.8b: Size and Length of Waiting Lists (percentage, weeks), November 1999

	Home Care Service	Mercy Family Centre	Aged Care Assessment Team	HKHCHS[a] Inpatient	HKHCHS[a] Non Inpatient
Average no. on waiting list over the last 4 weeks	630	100	50		
%Waiting less 1 week	0	2	46		
% Waiting 1 to < 4 weeks	0	1	30		
% Waiting 4 to < 12 weeks	0	17	24		
% Waiting 12 weeks or more	100	80	0		
	100	100	100		

Source: End of trial service data survey, November 1999.
Note: (a) Data unavailable.

Table A8.9: Hornsby & Ku-ring-gai Hospital & Community Health Services Client Profile (estimates) 1996-97

		Total	Inpatient	Non Inpatient[a]
1. Number of clients				
Clients receiving help		48 849	17 249	31 600
Referrals		26 500	8 500	18 000
Referrals as a percentage of clients		54	49	57
Clients in a typical week		980	330	650
2. Client demographics	HK general population[b]	**Average (per cent)**		
% clients over 65 years	14	33	35	30
% clients women	52	60	57	62
% clients NESB	15	5	4	5
% clients ATSI	0	0	0	0

Source: Baseline service data survey, December 1997.
Notes: (a)Except ACAT & MOW services; included with community-based services in Table A8.4.
(b)ABS Census 1996, Hornsby Ku-ring-gai LGAs.

Table A8.10: Hornsby & Ku-ring-gai Hospital & Community Health Services Staff Profile (estimates) 1996-97

	Total staff	Staff hours per week
1. Staff numbers		
Paid full-time staff	700	26 000
Paid part-time staff	360	9 000
Volunteers	500	300
2. Staff tasks (% time spent)	**Paid staff**	**Volunteers**
Direct care	35	60
Organising care	25	10
Administration and management	20	10
Travel, training & other	20	20

Source: Baseline service data survey, December 1997.
Notes: Excludes ACAT & MOW; included with community-based services in Tables A8.4a and b.

Table A8.11a: Hospital Separations for Residents Aged 65 years and over, Hornsby Ku-ring-gai, 1997 and 1999

Hospital	Separations				Resident characteristics of inpatient clients							
	Multi-day	Day only	Total		English speaking		NESB		Male		Female	
	n	n	n	%	n	%	n	%	n	%	n	%
1997												
Private	49 636	7 697	13 677	56.2	13 493	58.5	184	14.1	5 712	52.7	7 961	59.0
Hornsby Ku-ring-gai	33 694	1 184	4 860	20.0	4 676	20.3	184	14.1	1 898	17.5	2 962	21.9
Royal North Shore	8 166	1 459	2 548	10.5	1 749	7.6	799	61.4	1 362	12.6	1 186	8.8
Concord Repatriation	2 211	929	1 197	4.9	1 165	5.1	32	2.5	875	8.1	322	2.4
Ryde	3 124	100	470	1.9	461	2.0	9	0.7	199	1.8	271	2.0
Neringah Home of Peace	9 046	10	444	1.8	431	1.9	13	1.0	176	1.6	268	2.0
Lady Davidson	5 003	3	232	1.0	231	1.0	1	0.1	139	1.3	93	0.7
Westmead	876	99	230	0.9	212	0.9	18	1.4	149	1.4	81	0.6
Royal Prince Alfred	1 033	61	203	0.8	176	0.8	27	2.1	107	1.0	96	0.7
Sydney Hospital	297	21	106	0.4	91	0.4	15	1.2	43	0.4	63	0.5
ALL	116 460	11 680	24 353	100.0	23 051	94.7	1302	5.3	10 849	44.5	13 500	55.4
1999												
Private	63 153	9 070	16 182	62.1	15 751	60.4	431	1.7	6 994	26.8	9 188	35.2
Hornsby Ku-ring-gai	33 212	1 334	4 711	18.1	4 546	17.4	165	0.6	1 977	7.6	2 734	10.5
Royal North Shore	7 515	1 798	2 819	10.8	1 999	7.7	820	3.1	1 344	5.2	1 475	5.7
Concord Repatriation	1 744	507	717	2.8	682	2.6	35	0.1	529	2.0	188	0.7
Ryde	2 347	116	408	1.6	387	1.5	21	0.1	163	0.6	245	0.9
Neringah Home of Peace	3 297	9	215	0.8	205	0.8	10	0.0	103	0.4	112	0.4
Lady Davidson	-	-	-	-	-	-	-	-	-	-	-	-
Westmead	1 537	145	305	1.2	278	1.1	27	0.1	167	0.6	138	0.5
Royal Prince Alfred	993	86	221	0.8	205	0.8	16	0.1	46	0.2	45	0.2
Sydney Hospital	242	37	91	0.3	74	0.3	17	0.1	46	0.2	45	0.2
All	118 901	13 222	26 071	100.0	24 492	93.9	1 579	6.1	11 614	44.5	14 457	55.5

Source: Northern Sydney Area Health Service (NSAHS) June 1998 and February 2000.

Note: The data set for 1999 is incomplete. Data for some private hospitals were not available at the time of compilation.

Table A8.11b: Hospital Separations for Residents Aged 65 years and over, Ryde Hunters Hill, 1997 and 1999

Hospital	Separations				Resident characteristics of inpatient clients							
	Multi day	Day only	Total		English speaking		NESB		Male		Female	
	n	n	n	%	n	%	n	%	n	%	n	%
1997												
Private	16 600	1 498	3 435	28.6	3 300	29.8	135	14.2	1 541	28.4	1 890	28.6
Ryde	20 518	624	3 008	25.0	2 911	26.3	97	10.2	1 221	22.5	1 787	27.1
Concord Repatriation	8 354	1 452	2 494	20.7	2 225	20.1	269	28.3	1 382	25.5	1 112	16.9
Royal North Shore	5 618	1 193	1 884	15.7	1 570	14.2	314	33.1	710	13.1	1 174	17.8
Royal Prince Alfred	1 340	66	242	2.0	205	1.9	37	3.9	129	2.4	113	1.7
CBJD	6 591	0	205	1.7	178	1.6	27	2.8	65	1.2	140	2.1
Hornsby Ku-ring-gai	576	38	97	0.8	85	0.8	12	1.3	43	0.8	54	0.8
Greenwich Home of Peace	2 107	2	90	0.7	82	0.7	8	0.8	34	0.6	56	0.8
Lady Davidson	1 913	0	87	0.7	87	0.8	0	0.0	59	1.1	28	0.4
Sydney Hospital	221	21	78	0.6	62	0.6	16	1.7	33	0.6	45	0.7
ALL	79 209	5 016	12 020	100.0	11 070	92.1	950	7.9	5 419	45.1	6 597	54.9
1999												
Private	13 798	2 252	3 973	29.7	3 707	27.7	266	2.0	13.9	1875	2 116	15.8
Ryde	2 347	116	408	3.0	387	2.9	21	0.2	163	1.2	245	1.8
Concord Repatriation	675	91	187	1.4	2 142	16.0	365	2.7	1 546	11.6	961	7.2
Royal North Shore	7 515	1 798	2 819	21.5	1 999	14.9	820	6.1	1 344	10.0	1 475	11.0
Royal Prince Alfred	993	86	221	1.7	205	1.5	16	0.1	121	0.9	100	0.7
CBJD	-	-	-	-	-	-	-	-	-	-	-	-
Hornsby Ku-ring-gai	33 212	1 334	4 711	35.2								
Greenwich Home of Peace	1 201	4	54	0.4	52	0.4	2	0.0	14	0.1	40	0.3
Lady Davidson	-	-	-	-	-	-	-	-	-	-	-	-
Sydney Hospital	242	37	91	0.7	74	0.6	17	0.1	46	0.3	45	0.3
All	77 917	6 525	13 378	100.0	11 975	89.5	1 403	10.5	6 573	49.1	6 805	50.9

Source: Northern Sydney Area Health Service (NSAHS) June 1998 and February 2000.

Note: The data set for 1999 is incomplete. Data for some private hospitals were not available at the time of compilation.

Table A8.12a: HACC Services in the Intervention and Control Areas, November 1997

	Hornsby Ku-ring-gai		Ryde Hunters Hill	
	persons assisted	hours/meals	persons assisted	hours/meals
Total	2 786	27 398	3 094	19 116
Total home help	549	3 111	993	3 525
- housekeeping	301	-	705	-
- shopping	139	-	69	-
- social support	255	-	250	-
- linen/laundry	31	-		-
Personal care	102	1 965	129	1 773
Home nursing	607	3 129	411	1 673
Paramedical services	105	108	92	46
Respite care	139	1 867	199	2 126
Centre day care services	155	4 100	145	3 673
Total food services	687	-	602	-
- home delivered meals	585	10 615	290	5 018
- centre meals	129	599	275	646
- other food services	3	15	54	172
Total home maintenance and modification	171	1 138	113	-
- home maintenance	164	-	81	-
- home modification	7	-	32	-
Transport services	667	-	626	-
Other	248	711	192	464

Source: ADD Area Reports by LGA, November 1997.

Table A8.12b: HACC Services in the Intervention and Control Areas May 1999

	Hornsby Ku-ring-gai		Ryde Hunters Hill	
	persons assisted	hours/meals	persons assisted	hours/meals
Total	3 387	29 936	2 806	19 380
Total home help	931	4 747	980	3 056
- housekeeping	691	-	694	-
- shopping	136	-	87	-
- social support	285	-	209	-
- linen/laundry	34	-	22	16
Personal care	483	4 492	138	2 105
Home nursing	423	1 475	338	1 260
Paramedical services	58	115	14	261
Respite care	164	2 268	169	1 461
Centre day care services	218	3 993	186	3 909
Total food services	797	-	529	-
- home delivered meals	632	10 164	295	5 726
- centre meals	164	1 020	236	754
- other food services	1	7	36	86
Total home maintenance and modification	196	1 343	80	145
- home maintenance	159	-	52	-
- home modification	37	-	28	-
Transport services	679	-	662	-
Other	96	312	249	601

Source: ADD Area Reports by LGA, May 1999.

Note: End of Trial Data (November 1999) were not available at publication.

Table A8.13: Summary of Demographic Information of GPs, 1997 and 1999

Demographic information		**1997** (n=197)		**1999** (n=210)
Sex	Male	55%	Male	50%
	Female	45%	Female	50%
Year of graduation	Earliest	1947	Earliest	1928
	Median	1978	Median	1978
	Latest	1992	Latest	1998
Years practising as a GP	Least	1	Least	1
	Median	15	Median	15
	Most	50	Most	50
Years practising in Hornsby Ku-ring-gai	Least	1	Least	1
	Median	10	Median	10
	Most	49	Most	49
Estimated percentage of patients aged 65 or over	0-5	10	0-5	10
	6-10	20	6-10	20
	11-20	22	11-20	22
	21-30	21	21-30	21
	31-50	19	31-50	19
	51-80	9	51-80	9

3. Comparative Consultation and Test Ordering by GPs

In the June 1997 quarter, GPs who had patients in Linked Care, had a higher number of patient contacts than those who had no patients in Linked Care. This was apparent for both the GPs in the intervention and control areas (Table A8.14).

The average number of patient contacts decreased for GPs in the intervention area (whether or not they had patients in the control) except for GPs who were CCs (the number of GPs who were CCs was small reducing from 82 in 1998 to 34 in 1999). There was no significant change for GPs in the control area or all GPs in NSW over the period.

Table A8.14: Average Consultations per GP in the Quarter, Hornsby Ku-ring-gai and Ryde Hunters Hill, 1997 to 1999

	June 1997	June 1998	June 1999
Intervention area			
Care coordinator GP	1236	1206	1244
Non CC with patients in trial	1386	1354	1233
No patients in trial	1107	1085	1003
Control area			
Patients in trial	1409	1293	1359
No patients in trial	1121	1263	1324
Total NSW	1374	1334	1333

GPs with patients in Linked Care in the intervention area tended to have more patient contacts than those with no patients in Linked Care (Table A8.15). Intervention area GPs

with patients in Linked Care who were not CCs and those with no patients in Linked Care tended to have fewer contacts in 1999 than in 1997 whereas this did not change for CCs.

Table A8.15: GPs with less than 1000 Patient Contacts per Quarter, Hornsby Ku-ring-gai and Ryde Hunters Hill, 1997 to 1999

	June 1997	June 1998	June 1999
Intervention area			
Care coordinator GP	35	38	32
Non-CC with patients in trial	33	36	40
No patients in trial	51	53	57
Control area			
Patients in trial	27	34	34
No patients in trial	54	44	49

At baseline, GPs who had patients in Linked Care (in both intervention and control areas) had lower rates of ordering imaging than those who did not have patients in Linked Care or who were CCs (Table A8.16). Over the three years the rate of ordering increased for GPs in the intervention area (except for CCs), for those with patients in Linked Care in the control area and for all GPs in NSW. The only group whose rate of ordering decreased were GPs with no patients in Linked Care in the control areas.

Table A8.16: Rate of Imaging Ordered in Quarter per 100 Patient Contacts, Hornsby Ku-ring-gai and Ryde Hunters Hill, 1997 to 1999

	June 1997	June 1998	June 1999
Intervention area			
Care coordinator GP	7.0	6.9	6.8
Non-CC with patients in trial	6.0	6.4	7.1
No patients in trial	7.0	7.1	7.6
Control area			
Patients in trial	6.1	6.3	7.0
No patients in trial	7.2	7.4	6.2
Total NSW	7.1	7.6	7.8

In the June 1999 quarter, GPs in the control area with no patients in Linked Care had lower rates of ordering CT scans and Xrays of the shoulders and pelvis than other groups. GPs in the intervention area with patients in Linked Care had higher rates of ordering CT scans than those in the control area. Those in the intervention area with no patients in Linked Care had higher rates of ordering ultrasound and Xrays of the extremities.

There appears to have been an increase in imaging ordering by GPs in the intervention area and those with patients in Linked Care in the control area (Table A8.16). In the intervention

areas this appears to have been largely due to increased rates of ordering ultrasound, examinations, CT scans and Xrays of the extremities (unpublished data).

Table A8.17: Rate of Pathology Ordered in Quarter per 100 Patient Contacts

	June 1997	June 1998	June 1999
Intervention area			
Care coordinator GP	45.7	46.0	46.1
Non CC with patients in trial	40.9	41.2	45.2
No patients in trial	39.3	40.2	43.3
Control area			
Patients in trial	39.9	43.1	42.7
No patients in trial	36.1	35.1	34.6
Total NSW	37.7	38.5	39.1

In June 1997 GPs who were CCs had higher and GPs in the control areas with no patients in trial had lower rates of pathology test ordering respectively than the other groups (Table A8.17).

Rates for GPs in the intervention area (except care coordinators who were already higher) for GPs in the control areas with patients in Linked Care, and NSW GPs as a whole, increased over the three years. The greatest increase was for GPs with patients in Linked Care who were not care coordinators. Only for GPs in the control area with no patients in Linked Care did rates decrease.

In the June 1999 quarter, rates of ordering chemistry tests were higher for GPs in the intervention area with patients in Linked Care and lower for GPs in the control areas with no patients in Linked Care. Rates of microbiological and cytological tests were higher for GPs in the intervention area with no patients in Linked Care.

Pathology test ordering rates increased for all groups except for GPs in the control area with no patients in Linked Care with the greatest increase being for GPs in the intervention area with patients in Linked Care. This appears largely due to increased rates of chemistry ordering and to a lesser extent rates of microbiological and cytological tests. The reasons for this are unclear but may be partially explained by increasing screening for diseases and complication (e.g. for diabetes).

The HIC data about the various groups of GPs in the control and intervention areas reveal some differences in both consultations and test ordering patterns, both between the groups and over time.

4. GP Questionnaire Results

The GP questionnaires were carried out with GPs working in the Hornsby Ku-ring-gai area, the first between December 1997 and March 1998 and the second between November 1999 and January 2000. They were sent to all GPs on the list maintained by the Division of General Practice at the time of the questionnaire and achieved response rates of 62 and 57.7 per cent respectively. The main findings of the questionnaires are as follows:

? the overwhelming majority of GPs were aware of the trial;

? most GPs had only a few patients in the trial - the median number was two. Just over a third of GPs reported acting as care coordinators and the vast majority of these had done this for only one or two patients;

? few GPs reported that the Trial had caused any problems for their patients;

? a minority of GPs reported difficulties in referring patients to, or communicating with, other services. More reported difficulties with community services than with nursing and allied health services, and fewest with specialists. The level of difficulties did not change significantly through the trial;

? almost all GPs reported that their patients saw them as coordinating their clinical care, but significantly fewer thought this applied to community care. This did not change through the trial;

? GPs were generally satisfied with the quality of care that they could provide and believed that they were able to act as effective advocates for their patients. These attitudes did not change through the Trial.

? in the first questionnaire most GPs found organising and coordinating care satisfying but thought that they were not adequately remunerated for it, while more than a third thought it took too much time. In the second questionnaire more GPs thought they were adequately remunerated for coordinating care but fewer found it satisfying;

? in both questionnaires the largest proportion of GPs was non-committal about the likely balance of benefits and disadvantages of the trial. However by the end of the trial significantly more thought that the trials would not, on balance, benefit GPs; and

? although there were some favourable remarks, the main thrust of GPs' comments was that they found the trial added little to the care they normally provided, and involved too much time and paperwork.

Table A8.18: Ease of Referral to Selected Types of Service - Percentage of GPs Agreeing that Referral is Easy, 1997 and 1999

Service type	Strength of agreement	1997	1999
		Percentages	
Specialist services	agree/strongly agree	72.4	69.0
(n = 203 (1997) and 213 (1999))	neutral	20.2	18.8
	disagree/strongly disagree	7.4	12.2
Nursing & allied health services	agree/strongly agree	43.6	49.8
(n = 202 (1997) and 213 (1999))	neutral	34.2	32.2
	disagree/strongly disagree	22.3	17.4
Community services	agree/strongly agree	34.5	30.8
(n = 203 (1997) and 211 (1999))	neutral	33.5	38.4
	disagree/strongly disagree	32.0	30.8

Table A8.19: : Percentage of GPs Agreeing that Communication with Selected Types of Service is Satisfactory, 1997 and 1999

Service type	Strength of agreement	1997	1999
		Percentages	
Specialist services	agree/strongly agree	75.7	73.7
(n = 203 (1997) and 213 (1999))	neutral	17.3	21.6
	disagree/strongly disagree	7.0	4.7
Nursing & allied health services	agree/strongly agree	36.5	45.1
(n=202 (1997) and 213 (1999))	neutral	34.5	34.7
	disagree/strongly disagree	29.0	20.2
Community services	agree/strongly agree	27.7	30.8
(n=203 (1997) and 211 (1999))	neutral	34.7	38.4
	disagree/strongly disagree	37.6	30.8

Table A8.20: Percentage of GPs Agreeing that Patients See them Coordinating their Clinical and Community Care, 1997 and 1999

Type of care	Strength of agreement	1997	1999
		Percentages	
Clinical	agree/strongly agree	83.1	81.0
(n=201 (1997) and 211(1999)	neutral	9.5	11.8
	disagree/strongly disagree	7.5	7.1
Community	agree/strongly agree	49.3	45.5
(n=201 (1997) and 211 (1999)	neutral	32.8	35.5
	disagree/strongly disagree	17.9	18.0

Table A8.21: GP Satisfaction with Aspects of Providing Care for Patients with Complex Care Needs, 1997 and 1999

Aspect of providing care	Strength of agreement	1997	1999
		%	%
Organising care takes too much time	agree/strongly agree	36.8	42.5
(n=201 (1997) and 212 (1999))	neutral	36.3	31.6
	disagree/strongly disagree	26.9	26.0
Satisfied with quality of care I am able to provide	agree/strongly agree	70.9	66.5
	neutral	24.1	26.4
	disagree/strongly disagree	4.9	7.1
(n=203 (1997) and 212 (1999))			
Find organising /coordinating care for	agree/strongly agree	59.9	48.8
patients satisfying	neutral	26.2	32.4
(n=202 (1997)and 213 (1999))	disagree/strongly disagree	13.9	18.8
Adequately remunerated for time spent	agree/strongly agree	4.5	11.3
coordinating care	neutral	15.1	20.4
(n=199 (1997) and 211 (1999))	disagree/strongly disagree	80.4	68.3
Able to act as effective advocate for	agree/strongly agree	58.4	57.4
patients	neutral	28.2	29.4
(n=202 (1997) and 211 (1999))	disagree/strongly disagree	13.5	13.2

Table A8.22: Self Reported Levels of Involvement with Patients in the Linked Care Trial for GPs Aware of the Trial, 1997 and 1999

Type of involvement	No. of patients	1997	1999
		Percentages	
Having patients who are involved in Trial	None	38.5	26.6
(n=174 (1997) and 177 (1999)	1	19.5	19.2
	2-4	27.6	37.3
	5-9	12.6	10.2
	10+	1.7	6.8
Acting as care coordinator (n=171 (1997) and 168 (1999))	None	74.9	64.3
	1	9.4	12.5
	2-4	9.4	17.3
	5-9	5.3	4.2
	10+	1.2	1.8
Writing medical plans	None	73.4	36.3
(n=173 (1997) and 171 (1999))	1	9.8	17.0
	2-4	10.4	32.7
	5-9	5.8	9.4
	10+	0.6	4.7
Providing clinical care (only)	None	59.8	48.4
(n=164 (1997) and 161 (1999))	1	12.8	18.0
	2-4	17.7	23.6
	5-9	6.1	5.0
	10+	3.7	5.0

Table A8.23: GPs Aware of the Trial Reporting Problems for Patients Arising from the Trial, 1997 and 1999

Type of problem	GPs reporting a problem	
	Percentages	
	1997	1998
Coordinating care (n=127)	8.7	10.6
Planning medical care (n=122)	2.5	5.6
Providing clinical care (n=125)	3.2	2.8

Table A8.24: GPs Aware of the Trial who Agree that the Benefits of the Trial Outweigh the Disadvantages for Selected Groups, 1997 and 1999

Group who may benefit	Strength of agreement	1997	1999
		%	%
		(166)	(153)
Patients	agree/strongly agree	41.0	31.4
	neutral	47.6	49.0
	disagree/strongly disagree	11.4	19.6
GPs	agree/strongly agree	26.5	14.4
	neutral	53.0	54.2
	disagree/strongly disagree	20.4	31.4