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This report is part of the final evaluation report on Care Net Illawarra, one of the Australian Coordinated Care Trials based in the Illawarra. Each of the national trials addressed the same primary hypothesis:

Coordination of care of people with multiple service needs, where care is accessed through individual care plans, and funds pooled from existing Commonwealth, State and joint programs, will result in improved client health and well being within existing resources.

A summary of the key elements of the Care Net Trial is contained in Appendix 1 of this report.

There are 10 reports in this evaluation series:

Report Number 1	The Care Net Trial – What it was and How it was Managed
Report Number 2	The Care Net Intervention
Report Number 3	Care Coordination in the Care net Trial
Report Number 4	The Use of IT in the Care Net Trial
Report Number 5	<i>Client Experiences in the Care Net Trial (this report)</i>
Report Number 6	The Care Net Trial – Impact on General Practitioners
Report Number 7	The Care Net Trial – Impact on Health and Community Care Providers
Report Number 8	The Care Net Trial – Impact on the Wider System
Report Number 9	The Care Net Trial – Value for Money?
Report Number 10	The Care Net Trial – The Evaluators Conclusions

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Report Number 5

Client Experiences in the Care Net Trial

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5.1 Introduction

5.1.1 Care Net Illawarra as a trial of coordinated care

This report is part of the final evaluation report on Care Net, one of the Australian Coordinated Care Trials based in the Illawarra region of NSW. Each of the national trials addresses the same primary hypothesis:

..coordination of care of people with multiple service needs, where care is accessed through individual care plans, and funds pooled from existing Commonwealth, State and joint programs, will result in improved client health and well being within existing resources.

The Illawarra Coordinated Care (Care Net) Trial primarily attempted to establish whether better, or similar, health outcomes for people with multiple service needs could be achieved within the same overall budget, using pooled funds. This trial of 'coordinated care' anticipated a new model which would address program boundaries and the perceived lack of coordination for people with multiple service needs, through:

- funds pooling;
- a free-standing care coordination unit and independent care coordinators with purchasing control;
- general practitioner participation as co-agents in care planning; and
- budget neutrality.

A description of the trial can be found in Appendix 1. The trial consisted of an intervention (client) group (those who received care coordination) and a control group (those against whose experience the intervention group was compared). A randomised control selection procedure was used.

Care Net Illawarra as an organisation is reported upon in Report Number 1. Within that organisation, the care coordination functions and the roles of the care coordinators – planning, coordination and purchase of services to clients in the trial - formed the engine room of the new model and were expected to drive the changes to be achieved within budget neutrality.

This report focuses on:

- outcomes for clients of the trial;
- the perspective of clients on the processes and procedures adopted by the trial;
- the nature of the partnership between the trial and clients; and
- issues of access and equity.

These broad issues were first canvassed by the National Evaluation Team in a set of hypotheses (see page 41). This report also addresses client themes raised by the National Evaluators (see page 41).

5.1.2 Data sources

The principal sources of data for this report are:

- quantitative analysis of Care Net assessments and the SF-36 quality-of-life assessment;
- semi-structured in depth interviews conducted with participants at regular intervals during the trial points in the trial (24);
- one-off interviews with specific clients (5); and
- documentary material from the trial eg. minutes from focus groups, compliments and complaints letters.

5.1.2.1 Quantitative analysis

The statistical or quantitative data are derived, for the most part, from the Care Net Client Assessment Data and from the application of the SF-36 quality-of-life assessment. These two instruments were applied to all participants (clients and intervention group). These instruments are described in detail in Appendix 4.

This trial featured a randomised control selection. Whilst the selection of participants was random, contamination of results may have occurred due to the following factors:

- Most general practitioners had patients in both the control and intervention groups. Any trial intervention involving these general practitioners could therefore have an impact upon both control and intervention participants. For example, general practitioners had the capacity to use their computers and the program *Medical Director* with both groups of patients.
- All participants were assessed and this would have provided opportunities for assessors to give information, primarily on the availability of community services, to participants in the control cohort. It is to be expected that this may occur in a trial with human subjects in difficult circumstances.

5.1.2.2 Semi-structured interviews

The main source of qualitative data for this report is a series of client interviews of 24 participants - 16 intervention clients and 6 control - at three regular intervals during live phase of the trial. The clients were selected using a theoretical sampling approach by a sampling frame, structured on the basis of age, whether the client lived alone or with a carer, and whether s/he was from an English or non-English speaking background. The interviews were conducted about three months after the commencement (around March 1998) at the mid-point of the trial (around October 1998) and at the beginning of the wind-down phase of the trial (from May 1999).

Care coordinators were asked to identify a minimum of 16 clients who they felt would be representative of clients of the service and were appropriate to the theoretical sampling frame of the research team. Sixteen clients were selected and agreed to interviews with members of the research team.

The original intention of the research team was to interview clients with multiple service needs and the researchers made an early assumption that most, if not all, clients of the trial would necessarily meet these criteria. It became clear after the first round of interviews that this was not an

assumption that could be made of trial participants. The majority of clients in the trial did not have multiple service needs.

As well, care coordinators had not necessarily chosen clients for interview who required the coordination of multiple services. Some care coordinators felt that clients with no current service needs comprised a significant proportion of their overall caseload and, further, were legitimate clients of a trial testing a preventative intervention approach (see care coordinator interviews in Report Number 3).

The researchers returned to the care coordinators with a further request to identify individuals receiving multiple services and whose experiences would demonstrate the range of Care Net interventions. A further 3 clients were interviewed on the basis of their need for the coordination of multiple services or recent hospitalisation.

Table 1 Sample profile for interviews

	Client interview	Control interviews	Total interviews
Sex			
Men	3	3	6
Women	13	3	16
Age			
< 75	8	2	10
75+	8	4	12
Marital Status			
Married	6	3	9
Widowed	10	3	13
Living arrangements			
Alone	8	3	11
With spouse	6	3	9
With adult child	2		2
Level of informal support			
None	1	1	2
General (eg. emergency contact and companionship)	5	3	8
Practical care (eg. pension collection, shopping and changing beds)	6	2	8
Practical and personal care (eg washing, dressing, toileting and live-in care)	4	-	4
Language background			
Non-English speaking	8	2	10
English	8	4	12

The 16 intervention clients interviewed were rated for need by the evaluators using an assessment rating analysis developed by the evaluators (see below and in Appendix 4). Table 2 shows the needs level for interviewed clients. Although it appears that a number of clients progressed from a lower level of need to a higher level, one client actually improved over time, following her discharge from hospital.

Table 2 Needs levels for client interviewees

Needs rating (evaluators)	Beginning of trial	End of trial
High	3	4 + 1 death
Medium	6	8
Low	7	3

Surveys with an older population are likely to return a high satisfaction rating irrespective of the service used (Draper and Hill 1995). The evaluators choose instead to explore the detailed experiences of a small number of clients to gain snapshots over time of the consumer experience in detail.

5.1.2.3 *Documentary material from the trial*

The trial established a database for consumer feedback. The aim of this database was to encourage consumer feedback from participants receiving coordinated care, and to ensure that information received is acknowledged and registered on a database used to provide information to monitor complaints in an endeavour to improve the quality of services purchased by Care Net.

5.1.3 Terminology

Clients

Participants in the trial who were in the intervention group. Also known as active participants. This group received three applications of the SF-36 and, in the majority of cases, a minimum of three Care Net assessments.

Controls

Participants in the trial who were not in the intervention group. This group received three Care Net assessments and three SF-36 applications.

Interviewees

This was a group of sixteen clients and eight controls (24 participants) who were interviewed at three points throughout the trial. Where over 10 client interviewees concurred the researchers use the expression “the majority”. The evaluators also sought out two further clients for interview in the “high need” category and two further clients that had been hospitalised. These are also referred to as interviewees.

Participants

People participating in the trial either as clients or as controls.

5.2 The Trial Participants

Overall, 1,988 consumers participated in the trial. 1,301 were in the active group (ie were clients of Care Net Illawarra) and 687 were in the control group. Table 3 provides a description of the participants.

Table 3 Trial demographic data

Demographic data	Participants
Gender	Males: 36% (466) Females: 64% (836)
Age Overall 78	Mean age of 78 years
Language	96% spoke English at home 68% were born in Australia
Marital status	51% married 39% widowed 3% divorced 3% never married
Assessment of social disadvantage	93% socially disadvantaged
Health status	Participants as a group had a lower health status than the average person over 65 Participants had more functional ability than community health or hospital outpatient departments
Levels of need (1 st assessment)	14% high need 61% mild to moderate need 25% low need
Carer availability	55% carer not required 28% resident carer 10% non-resident carer 6% carer required but not available

The trial intervention and control participants were well matched (Eagar, Owen et al. 1998).

5.2.1 Levels of need in the client group

The local evaluation team developed a blended five level scale¹ designed to measure dependency and need for services among the trial clients. This measure is shown in Table 4.

Table 4 The blended dependency/need measure

Level	Description
level 1	Moderate to high cognition OR low physical function (FIM<78)
level 2	no carer AND with high IADL needs
level 3	no carer AND with moderate IADL needs OR a FIM score of 78 to 90 OR with carer AND high IADL needs
level 4	with carer AND with mid physical function (FIM 79 to 90) OR with carer AND with moderate IADL needs
level 5	FIM=91 AND requires nil or minimum IADL needs

¹ Participants were classified as being Level 1 if either they have moderate to high cognitive deficits OR low physical function (FIM<78). Availability of carer was not taken into account in determining allocation to Level 1. We expected this group to have the highest care needs.

Level 2 clients were those people rating 5 or 6 on the Carer Scale (Carer required but not available) and rated as having high IADL needs on the Lawtons Scale.

Level 3 clients were those people without a Carer and with moderate IADL needs or medium FIM scores (78 to 90) as well as those people with a Carer and with high IADL needs.

Level 4 clients were those people with a Carer and with either moderate physical or moderate IADL function.

Level 5 clients were those people with a perfect FIM Motor Score of 91 and with nil or minimum requirements for IADL assistance. We expected this group to have the lowest care needs.

Analysis of the data showed that levels 2 and 4 were very low volume. In consequence, levels 1 and 2 were amalgamated together to form a 'High Need Group' and levels 3 and 4 to form a 'Mild to Moderate Needs Group'. The result of each client's first and last assessment can be seen in Table 5.

Table 5 Overall need assessment of clients in the intervention group

Level	1st assessment	last assessment	1st assessment	last assessment
High need	162	162	13.1%	14.0%
Mild to moderate need	704	704	57.1%	61.0%
Low need	366	288	29.7%	25.0%
Total	1232	1154	100.0%	100.0%

It will be seen that:

- Only 13% of the intervention group had high needs;
- Around 60% had either mild or moderate needs; and
- 30% of the intervention group had low needs at the beginning of the trial, although this had decreased to 25% by the end of the trial.

The trial also conducted its own reviews of need based using a variety of tools and instruments and without reference to the data base assessments. During 1998 the trial assessed clients using the Residential Classification Scale (RCS). On the basis of this assessment, the trial calculated that these clients formed 10% of the total trial population (Foulstone 1999)². This figure is similar to the numbers classified by the evaluators as being high need.

In September 1999 as the trial entered its wind-down phase, trial management was requested on behalf of HACC providers and those managing the transitional arrangements, to provide a profile of current trial participants and their utilisation of services. This could not be generated with confidence from the trial's information system and in any case it was felt the information would not be current. To answer this request the trial assessed clients again using a proforma approach to rank their levels of need. In November 1999, one month before the close of the trial, this exercise estimated that 79 individuals would require intensive support. Many of the 79 were on waiting lists for CACP and residential care options (Foulstone 1999).

The trial partners subsequently completed formal assessments at the end of the trial to determine the ongoing care needs of active clients and to arrange for ongoing services to be provided to those in need³. The results for the 994 intervention clients still in the trial at its end are shown in Table 6. Significantly, 707 (71%) trial clients were assessed as not needing ongoing community care services. 287 (29%) were assessed as requiring ongoing community care. Of the 287 clients requiring ongoing care, 86 (30%) had been previously clients of the Home Care Service and they transferred back to Home Care requiring the same level of service as they had before the trial.

Table 6 Client need for ongoing care as assessed at trial end

Active client situation at trial end	number	percentage
Did not require ongoing community care	707	71.1%
Previous Home Care client returned to same level of service as before trial	86	8.7%
Previous Home Care client needing more services than before trial	43	4.3%
Transferred as new client to Home Care	154	15.5%
Transferred to CACP	4	0.4%
Total number in intervention group at trial end	994	100.0%

² In November 1998 the trial unsuccessfully submitted a request for the inclusion of residential care funds for these participants.

³ Information on clients reported at January 2000 Management Committee.

Of the 283 transfers to Home Care, 43 (4.3%) were previous Home Care clients and they returned to Home Care needing more services than they had been receiving at the beginning of the trial while 154 (15.5%) were new to Home Care. 4 clients were transferred to other agencies to receive Community Aged Care Packages (CACP).

The group still in the trial at its end was no doubt healthier than those who had died or transferred to residential care during the course of the trial (see Report 9). Nevertheless, these outcomes further support the conclusion that only a small proportion of the trial cohort was in high need.

5.2.2 Medical status

The trial could not systematically collect diagnostic data from general practitioners⁴. Diagnostic information was recorded by recruiters or care coordinators (who did not necessarily have any clinical training) based on various information provided by the participant, their carer and perhaps the general practitioner. This information was then entered as text into the information system. There were no systems in place to check the accuracy or the completeness of the information recorded and no standards for recording the information as text.

The local evaluators had this diagnostic information coded using the International Classification of Primary Care (ICPC) classification⁵.

Up to ten ICPC codes could be recorded for each person⁶. Table 7 shows the number of diagnoses recorded for both the intervention and the control groups. The significant majority of both groups had multiple medical conditions. 81% of clients (active) had three or more conditions whilst 66% of controls had three or more conditions. On average, 4 diagnoses were recorded for participants in both the intervention and the control groups.

Table 7 Number of recorded diagnoses

Number of diagnoses	Active	Control	All
No diagnosis	0	2	2
1 diagnosis	69	34	103
2 diagnoses	177	93	270
3 diagnoses	288	148	436
4 diagnoses	289	161	450
5 diagnoses	213	111	324
6 diagnoses	137	71	208
7 diagnoses	78	25	103
8 diagnoses	16	27	43
9 diagnoses	17	8	25
10 diagnoses	14	6	20
All	1298	686	1984

Table 8 shows the top fifteen diagnoses by volume. The top 15 conditions were the same for both groups. 60% of participants in both the intervention and the control groups were recorded as having at least one of these 15 conditions. Uncomplicated hypertension was the most common diagnosis for both the intervention and the control groups, with 9.4% of the intervention group and 11.5% of the control group having this condition. The second most common condition was

⁴ General practitioners had the option to enter diagnostic information, as text, into *Medical Director*. Some doctors used this function whilst others chose to use *Medical Director* primarily for writing prescriptions. Of those who entered data into the field in *Medical Director* few entered diagnoses or differential diagnoses – many only entered the tests ordered. None entered data using a data dictionary. There were no systems in place to check the accuracy or the completeness of the information recorded and no standards for recording the information as text.

⁵ While it is likely that there are problems with both the accuracy and comprehensiveness of the data, it was decided that, on balance, it was better to analyse the available data rather than to ignore this source of information altogether.

⁶ A total of 191 different ICPC codes were recorded out of the 2,332 codes available in ICPC.

diabetes mellitus, which was recorded for 7% of the intervention group and 6.1% of the control group.

Table 8 Top 15 diagnoses by volume

Diagnosis rank	Diagnosis	ICPC code	Client Group	Control Group
1	Uncomplicated Hypertension	K86	122	79
2	Diabetes Mellitus	T90	91	42
3	Symptom/complaint Multiple Joints	L20	87	45
4	Stroke/cerebrovascular accident	K90	71	35
5	Repair/fixate-suture/cast/prosth device (Appl/rem)	L54	55	24
6	Angina Pectoris	K74	45	21
7	Accident/injury, Nos	A80	44	20
8	Osteoporosis	L95	40	27
9	Cataract	F92	38	14
10	Other Symptom/complaint Heart/Circ Syst (Excl R93)	K29	37	17
11	Acute Myocardial Infarction	K75	37	26
12	Asthma	R96	34	19
13	Repair/fixate-suture/cast/prosth device (Appl/rem)	K54	32	17
14	Other Osteoarth & Allied Cond (Excl L84,89,90,92*)	L91	32	10
15	Emphysema/Chronic Obstructive Pulmonary Disease	R95	23	19

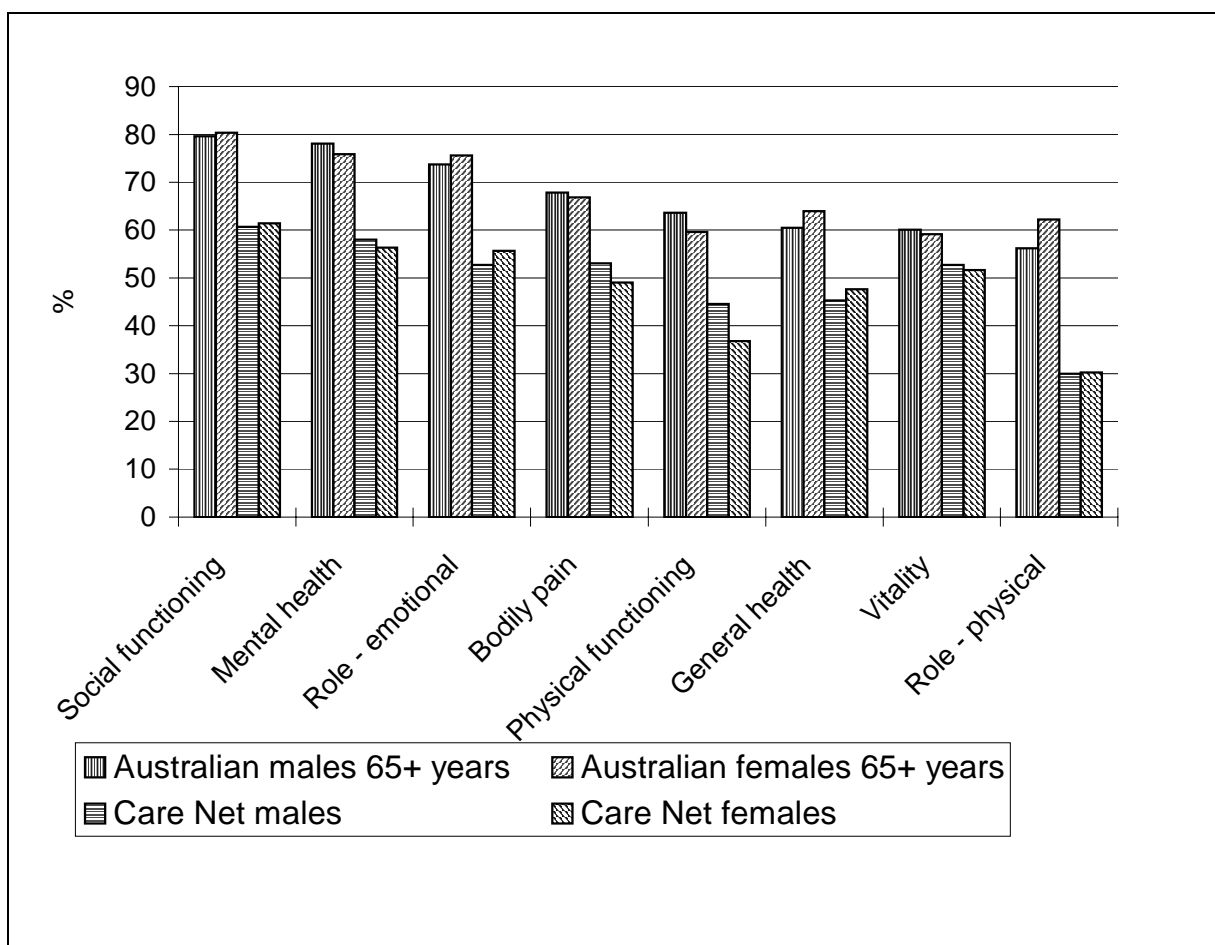
In addition to the diagnostic data recorded by the care coordinators, diagnostic data were collected for each hospital admission. Consistent with the national standard, hospitals coded these data using ICD-9-CM and, in the latter part of the trial, ICD-10.

5.2.3 A comparison with the Australian aged population

Trial participants, as a group, had a lower health status than the average person aged over 65 years. However, they had better health status than, for example, people of a similar age with a serious medical condition or people with serious psychiatric illness.

Figure 1 shows the results of the first health status and quality of life assessment (measured by the use of the SF-36 instrument (Ware 1993)). The figure shows transformed or standardised SF-36 scores. For all scales, the highest possible score of 100 is achieved when no disabilities or limitations are reported. Figure 1 compares the trial cohort with the Australian general population data for people aged 65 plus.

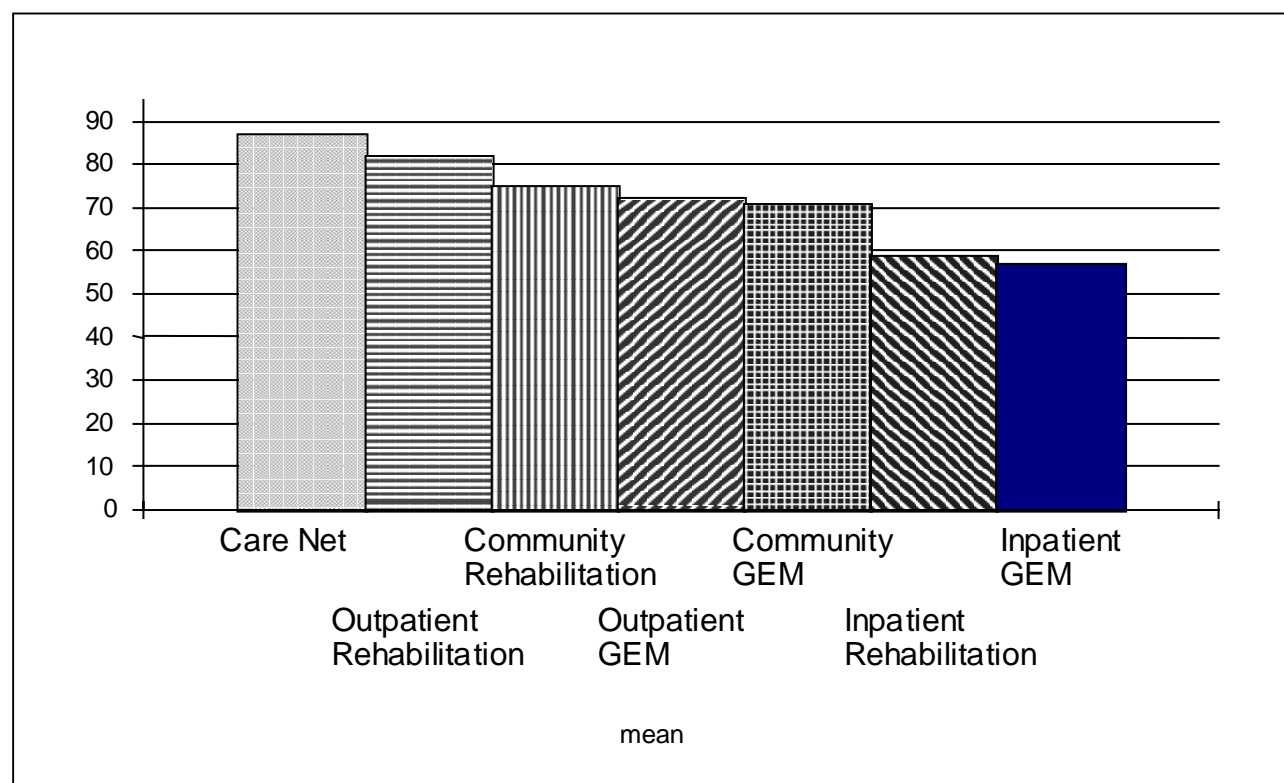
Figure 1 SF-36 results - first assessment



5.2.4 A comparison with hospital and community health patients

Figure 2 shows how Care Net clients compared with hospital and community health patients in relation to physical function as measured by the Functional Independence Measure (FIM). The comparative data reported here are from a national sample of over 30,000 patients (Eagar et.al 1997). The FIM range is 91 (fully independent in all aspects of activities of daily living) to 13 (two person physical assist). There are 13 items, each with a range of 1 to 7.

Figure 2 The functional status of trial clients compared to patients treated in the general health system (FIM Motor Scores)



The Care Net population had better physical function than either Rehabilitation or Geriatric Evaluation and Management (GEM) patients (typically Aged Care Assessment Team, ACAT, patients), whether treated in hospital, in outpatients or in the community. Inpatients had the lowest scores, followed by community patients, followed by outpatients followed by trial participants.

This suggests that the trial participants had more functional ability (ie were healthier) than patients seen either by community health or by hospital outpatient departments.

The overall conclusion is that the trial cohort were not as healthy as the general population of older people but were healthier than the population of older people using community health centres, outpatients and hospital inpatient services⁷.

In conclusion, trial participants were selected on the basis of identification by general practitioners (see Report Number 2). The population chosen, however, may not have fully reflected the intention of the Australian Coordinated Care Trials. That was to develop and test different service delivery and funding arrangements for “*people who required a mix of services for a long period of time and who would benefit from having their overall care managed by a care manager*” (Leigh, Tyson et al. 1999).

⁷ Both of these scales have excellent psychometric properties and the authors are confident of the results.

5.3 Findings: Clients and their outcomes

The evaluators measured the overall impact of the trial on participants' health and well-being in three ways:

- The destinational outcomes of trial participants;
- Assessing the participants at the beginning, mid-point and end of the trial using SF-36 data and data from the trial assessments; and
- Comparing the trial clients (the intervention group) with the trial controls using SF-36 data and data from the trial assessments.

5.3.1.1 The outcomes of care coordination

5.3.1.1 Destinational outcomes

Table 9 indicates destinational outcomes for trial participants. More control participants left the trial than did clients, most probably because there were few tangible benefits of participation for control participants (see Report Number 9). Approximately 10% of participants died during the course of the trial, with no significant difference between the intervention and control groups. A further 6% were admitted to a residential care facility. More than twice as many in the intervention group were admitted to residential care than in the control group (7.5% versus 3.3%), a statistically significant difference.

Table 9 Destinational outcomes

Location	Clients (intervention)	Control
Continued in the trial	75.8%	65.3%
Entered residential care	7.5%	3.3%
Dead	9.9%	9.5%
Left trial for other reason	6.8%	21.9%

The Care Net Trial was not designed to specifically address nursing home placements. There was no specific hypothesis concerning the impact of coordinated care on residential placement and residential care was not included in the funds pool. Nevertheless, the Project Manager argued that about 10% of the trial population would have been eligible for nursing home placement (Foulstone 1999).

Care Net Illawarra may have been less successful than mainstream community and acute care services at avoiding nursing home placement for clients. Certainly the two cohorts seemed functionally (FIM) well matched at the commencement of the trial (Eagar and Woods 1999).

On the other hand, Care Net Illawarra may have been more successful in identifying clients at risk, and in advocating for appropriate referral and placement. This latter interpretation is supported by the examination of one case study of a control participant:

Mrs DHP was a confused older woman living alone in her family home. Her only son was unemployed and was living at some distance from his mother. At the first visit the interviewer (and interpreter) found it difficult to conduct the interview. During the second interview the interviewer determined that through a review of documents in the house that the participant was receiving a Community Aged Care Package which was providing home help. The client was cooking for herself and the interviewer and interpreter turned off a burning pan on the stove during the interview. At the conclusion of the third interview the

interviewer undertook to contact the client's general practitioner and the client's son in order to seek a review of the client's health and well-being. At that time the client was receiving home help for two hours a week and yet, to the interviewer, was clearly at risk of self-injury.

Whatever the reason, it can be concluded that the Care Net intervention had no measurable impact on death rates. Yet under the Care Net intervention, twice as many people ended up in residential care, a result which was both significant and unexpected.

5.3.1.2 Health and well-being outcomes for clients over the course of the trial

The SF-36 quality-of-life instrument was selected by the Commonwealth as the standardised measure of health and well-being to be used in all Trials. At baseline, results indicated that Care Net trial population had poorer health status than the general Australian population, as measured by the SF-36 instrument (Eagar, Owen et al. 1998). Between baseline and the end of the trial, care coordination did not result in any improvements in health status⁸ for clients of Care Net. Table 10 gives details of the SF-36 analysis.

Table 10 1st, 2nd and 3rd applications of SF- 36 for Care Net clients

Clients	Average PCS*	Average MCS**	Number of Clients
1 st application	33.76 (S.D. 11.41)	44.01 (S.D.8.17)	1221
2 nd application	33.59 (S.D. 11.15)	47.15 (S.D.12.00)	990
3 rd application	32.17 (S.D. 10.73)	45.65 (S.D.11.66)	871

* PCS Physical Component Summary

**MCS Mental Component Summary

This analysis is confirmed by examination of the assessment data using the battery of instruments selected specifically for the Care Net Trial⁹. Table 11 summarises the changing health and well-being status of Care Net clients (intervention group)¹⁰ over the length of the trial.

Table 11 Changes from 1st to last assessment – clients (intervention group)

Measure	Number				Percentage			
	worse	no change	better	total	worse	no change	better	total
Motor (self-care) function	466	506	207	1179	39.5%	42.9%	17.6%	100.0%
Instrumental (domestic) function	425	537	216	1178	36.1%	45.6%	18.3%	100.0%
Social functioning	269	805	98	1172	23.0%	68.7%	8.4%	100.0%
Overall need (blended index)	185	928	119	1232	15.0%	75.3%	9.7%	100.0%
Carer situation	135	899	117	1141	11.8%	78.8%	10.3%	100.0%
Cognitive function	273	522	384	1179	23.2%	44.3%	32.6%	100.0%
Self reported health status	167	434	391	992	16.8%	43.8%	39.4%	100.0%

About half of the intervention group did not change between their first and last assessments. This could be seen as an achievement for Care Net – with a frail population it would be unlikely for there to be much, if any, improvement in a measurement of health over time. It also needs to be remembered when interpreting the data that only 14% of the total client population were assessed as in high need at the beginning of the trial.

In its detail, this analysis of the assessment data reveals some important differences between the dimensions.

40% of clients experienced a decline in their physical functioning and 36% of clients experienced an increase in their need for assistance with activities of daily living over the course of the trial. On both measures, more clients reported a decline than recorded an improvement in their health and well-being. Less than 20% of the cohort improved on these two measures.

⁸ Report 9 has further information on this analysis

⁹ See Report 9

¹⁰ See Report 9

In relation to the availability of a carer, 12% of active clients were in a worse position at the end of the trial than they had been at the start. Little can be inferred from this finding about the impact of the Care Net intervention per se – however, it could be imagined that such a change would have an impact on both the client's perception of their health and well-being and its objective rating.

15% of clients experienced increased overall dependency by the end of the trial (as expressed in the blended index of overall need). About 75% of participants recorded the same level at the last assessment as they did at the first one. The majority of clients also experienced stability in their level of social functioning. Nearly 70% of participants recorded the same score at the last assessment as they did at the first one. It should be noted however that the same trend occurred – more people experienced a decline in this measure over the course of the trial than experienced an improvement.

The pattern for self-reported health status and cognitive functioning differed from that of the physical measures. Nearly 40% self-reported an improvement in their health status while only 17% reported a decline.

This is a significant result for Care Net since several studies have indicated that an older person's self-rating of health status is a better predictor of mortality than medical assessment (Eagar and Woods 1999). The finding is reinforced by the opinions of clients interviewed by the evaluators. The majority of interviewees had a very positive experience of the Care Net intervention and felt that it contributed significantly to their "peace of mind".

Over 30% of all participants showed an improvement in cognitive functioning and 16% a decline. Cognitive functioning is an important attribute in influencing health status and quality of life. Poor cognitive function is a recognised risk factor for falls and other accidents and injuries.

Some of the improvements in cognitive function may well be attributable to an effect of repeated testing. The same questions were repeated throughout the trial and, undoubtedly some learning would take place (some participants were tested more than 6 times).

Other data quality problems arose from the timing and methods of assessment. The problems with the figures shown above are that they include participants who were only in the trial for a short period and participants whose first and last assessments were very close together (in a few cases, only a matter of days). The greater number of times a person was assessed, the more opportunity there was for the measurement of changes.

Also, the control group were only assessed at three points – around November 1997 (trial start), around November 1998 (mid point) and after the end of the trial - whereas the intervention group were assessed more frequently. A valid comparison of the intervention and the control groups requires that the control group and the intervention group be compared at similar points in time.

5.3.1.3 Intervention group clients with 2 of more assessments at least one year apart

A better comparison can be made by using only the intervention group data in which the participant had their first assessment before September 1998 and their last assessment after June 1999.

440 intervention group members (34%) met these criteria and they are termed the 'long term cohort' in Table 12.

Table 12 Changes from 1st to last assessment – long-term cohort

Measure	Number				Percentage			
	worse	no change	better	total	worse	no change	better	total
Motor (self-care) function	196	162	82	440	44.5%	36.8%	18.6%	100.0%
Instrumental (domestic) function	189	160	90	439	43.1%	36.4%	20.5%	100.0%
Social functioning	125	266	45	436	28.7%	61.0%	10.3%	100.0%
Overall need (blended index)	66	354	20	440	15.0%	80.5%	4.5%	100.0%
Carer situation	69	293	58	420	16.4%	69.8%	13.8%	100.0%
Cognitive function	100	182	158	440	22.7%	41.4%	35.9%	100.0%
Self reported health status	66	116	188	370	17.8%	31.4%	50.8%	100.0%

This long-term cohort has a different profile than the total group described above. Over 60% of the long-term cohort changed in their self-reported health status or in their motor, instrumental and cognitive functioning during the two years of the trial. Instrumental (domestic) and motor function showed more decline but, importantly, self-reported health status and cognitive functioning showed more improvement.

The Care Net intervention clearly had a positive impact on client's own perception of their health and in their sense of well-being.

5.3.1.4 *How did the control and intervention groups differ by the end of the trial?*

The next issue to examine are the differences in outcomes, if any, between the control group and the active clients.

Using the SF-36 quality-of-life measure, differences between the client (intervention) cohort and the control group were tested at three points during the trial. Table 13 describes a similar cohort with similar health and well-being outcomes (see Report Number 9). The results here indicate that the Care Net intervention had no greater impact on the health and well-being of clients than mainstream care had on the control group.

Table 13 1st, 2nd, and 3rd SF- 36 for Care Net active clients and control group

	1 st application	2 nd application	3 rd application
Active Clients	PCS 33.76 (STD 11.41)	PCS 33.59 (STD 11.15)	PCS 32.17 (STD 10.73)
	MCS 44.01 (STD 8.71)	MCS 47.15 (STD 12.00)	MCS 45.65 (STD 11.66)
Controls	PCS 34.31 (STD 11.28)	PCS 32.97 (STD 11.04)	PCS 32.43 (STD 10.47)
	MCS 44.05 (STD 8.36)	MCS 47.91 (STD 11.39)	MCS 46.54 (STD 11.62)

5.3.1.5 *Summary of findings on clients and their outcomes*

In summary, just over half of the long-term participants in the trial reported that their health status had improved over the course of their involvement. However, more than 80% of clients either declined (approximately 35%) or did not change (approximately 45%) in their physical and social functioning.

There were no differences in death rates between the client and control groups. Significantly, more than twice as many clients were admitted to residential care than participants in the control group.

There was no difference in health and well-being outcomes, as measured by the SF-36 quality of life tool, between the client group and the controls. Neither was there any measurable difference in other outcomes over the course of the trial between the control and client groups (see Report 9).

5.3.2 Client perceptions of Care Net Illawarra

This section of the report relates primarily to the interviews with clients and control participants described in section 5.2 of this report.

5.3.2.1 Recruitment to the trial

All interviewees were recruited by their general practitioners. Some remembered that they were initially reluctant to join, however, their general practitioners convinced them it would be in their interests:

"I had to be talked into joining (Care Net) by the doctor". The client went on to say that he would not have sought out community services. He relied heavily on help provided by his daughter and her husband. He now feels that a burden has been lifted from their shoulders.(Mr JWU)

Mrs DWP's doctor had to persuade her to join Care Net as she feared she would lose her Medicare entitlement:

"I never ask for anything. I was avoiding being a nuisance. I get my pension and that's it."

"I don't know why I am in it (Care Net). I had an operation on my eyes – I had some fatty tissue under the eyes. I got Home Care in to clean fortnightly after my husband died. " (Mrs JWP)

"My doctor suggested I join in case I may need help in the future." (Mr CNF)

These comments indicate that some Care Net clients had no expectations of Care Net prior to the trial, while others saw it as a form of "insurance".

5.3.2.2 Assessment by Care Net¹¹

It is important for quality assurance to assess what service users' expectations are, and how they understand the assessment processes. This makes it essential to capture their experience in ways which allow an examination of how they understand the service, the roles of various individuals in the care coordination process, and what expectations of the service are reasonable. This latter dimension of their experience is particularly important for a population who may have grown used to their low status in relation to the professionals involved (Owens and Batchelor 1996).

Most interviewees had to be prompted on what constituted "the assessment". They remembered being asked a series of questions at the initial assessment, however, the details of those questions were vague. Interviewees did not necessarily distinguish the assessment process from the more informal interaction with their care coordinators.

When prompted, the majority of interviewees expressed no difficulties with any aspect of the assessment, either the length of the interview, or the nature of the questions. The majority did not know the "results" of their assessment.

Comments included:

"The care coordinator asked questions whether we wanted help." UC

¹¹ The assessment processes used in the trial are described in Report 2 and the assessment tools in Appendix 4 of this report.

“Just normal questions... not intrusive.” (Mrs FQU)

The cognition scale was the most memorable feature of the assessment from the interviewee’s perspective as it caused embarrassment to some clients and to some carers. Some interviewees still remembered the address they had to repeat for the cognition scale - a learning effect that would skew the results in a positive direction.

Interviewees did not perceive any conflict between their own goals and those goals that the care coordinator may develop on their behalf. In the minds of the majority of interviewees, it was a general chat with a friendly and caring professional.

The nomination of goals, however, was identified as an issue by individual care coordinators who were conscious of the possibility of tension between a ‘needs-led’ versus a ‘service-led’ assessment (Hughes 1995). These care coordinators felt that the completion of the ‘client goals’ entry in the assessment form was not a straightforward process.

The Project Manager had directed that all care coordinators literally transcribe the client’s goal. Examples of client goals included: “helping prolong our lives”; “visiting Italy”; “continue driving car”; “continue going to bingo” (see Report Number 3). Some care coordinators, however, felt that it was more appropriate to list short-term pragmatic goals as an aid to care planning. This issue has implications for the application of goal setting and planning in care coordination models.

The majority of interviewees receiving new services under Care Net were not aware that the trial assessment replaced another assessment by some service providers. They were not aware that Home Care, for example, would normally undertake an assessment of their need and their financial status.

These findings have implications for quality assurance and the quality of assessment in care coordination models. A major requirement for such activity is that it should measure something that has meaning for the client (Rea 1999). There are markers of quality that may assist in reviewing the processes of care coordination. The numbers of service users who are aware of their care plan, when their care plan was last reviewed, how frequently it is to be reviewed and under what circumstances, and whether they felt personally involved in the process, are all useful indicators that service provision meets established standards.

However, the initial results from a small sample of Care Net clients indicate that perhaps more sensitive measures will be needed if quality indicators and the views of users of care coordination services are to be built in. It appears from the interviews that clients may have an understanding of the role of assessment and of the review process that is different to that of the organisation. In their eyes, the formal structure and process of care coordination is less important than the quality of the relationship to the care coordinator and their general practitioner.

5.3.2.3 *Development of the care plan*

Interviewees were asked whether a care plan had been drawn up for them and whether they had been given the opportunity to participate in any decisions relating to their care.

These questions elicited little specific response. The majority of interviewees felt involved and informed during the discussion of what their needs were and how they felt they could be helped. The majority, however, did not know if they indeed had such a document called a ‘care plan’. Interviewees would often show the interviewers the Care Net folder where documentation was kept and invited the researchers to look through it to see if the ‘care plan’ was there.

All the interviewees however, appreciated the degree to which their views were sought and their needs discussed and anticipated. The lack of any written documentation was not of concern to them. Interviewee comments included:

"We just tell them what we need. We were offered other services but we felt we did not need them." (Mrs FQU)

Clients were obviously more impressed with the spirit of care coordination within the trial, and primarily their relationship with the individual care coordinator, rather than with any written form. Care Net had a well developed culture of giving priority to consumer needs and this was both recognised and appreciated by the interviewees.

Whether this meant, however, that clients were fully involved in the construction of their own care plans is questionable. Many interviewees, in common with the findings of many other studies, seemed to prefer to accept unquestioningly that the care coordinators knew what was best for them (Owens and Batchelor 1996).

The majority of interviewees were not familiar with the language of case management and were not comfortable with academic descriptions of the components of case management, namely, eligibility criteria, assessment, care planning and review. From their perspective, the various processes and components were seamlessly combined in the person of the care coordinator who, in many cases, developed into friend, informant and confidante.

There is some indication in the interviews that the high levels of satisfaction can be explained in part by the relationship of friendship between care coordinator and client and the level of dependency on Care Net. A majority of the interviewees viewed their care coordinator as their friend and the services provided as "saving their lives", for example:

"I couldn't live without Care Net. I would have to go into a nursing home. I couldn't stay at home...It's the next best thing to complete 24 hour care. There's nothing to criticise – it has got to be a saving (of money to the Government)." (Mrs LHN)

Even those interviewees who had no need for the coordination of acute or community care were fulsome in praise of the coordinator and Care Net as they could realise the future implications of "membership" of Care Net:

While I can do it, I'll do it. If I want it (Care Net) it's there (pointing to the fridge magnet). I know I can call on them if I need help. There will probably come a time when I need it." (Mr CNF)

Interviewees did not immediately accept the ideas put forward by the care coordinator:

"We needed to be talked into having services and encouraged to have help... (but) she did not pressure me into anything.." (Mrs JWU)

Mrs GBW was living alone in a flat. She suffered from irregular black-outs. She had fallen during these blackouts. Once she had to rely on banging on the walls to alert her neighbour. At the first interview, she mentioned that her care coordinator had suggested a telephone monitor system. Mrs GBW said that she didn't know whether it would "be any good". At the second interview she said "I think it would be good but I am not fussing about it." Her GP said she "must have one." At the third interview she had the system installed and was most keen to show the interviewer how it worked.

From the interviews conducted with the participants the results indicate overwhelming satisfaction with the care coordinators and with the organisation.

5.3.2.4 The Care Package

Packages of care could contain a variety of elements, from intensive personal care support, nursing, help with practical tasks and/or the simple 'one-off' provision of aids.

Table 14 illustrates the variety of responses Care Net made to active clients in the trial. As discussed in Report Number 3, care coordinators had considerable flexibility with the commissioning of care packages.

Table 14 Examples of care packages according to levels of need

Level of Need	Definition	Interviewee example	Community care services commissioned by Care Net	Other services* and costs
Low	EITHER people independent with respect of the main domestic tasks OR people unable to perform one or more domestic tasks or having some physical deficits who have a carer. 25% of the Care Net population.	A widower in his late 70s with a chronic heart condition. The condition was adequately managed by medications and he displayed a singular determination to 'manage'. When the interviewer spoke with him the first time he had just finished mowing his neighbour's lawn and was about to visit the travel agent to finalise his plans for an overseas holiday. Over the course of three interviews he remained fit and well and managed several overseas holidays. <i>Mr CNF</i>	No community care services	AE = \$307 GP = \$1,474 PH = \$708 DIAG = \$487 Total = \$3,039
		An older women living with her adult son. She suffers from osteoporosis and arthritis. Was hospitalised following a broken pelvic bone prior to the start of the trial. Her son does all the cooking, cleaning and shopping for the household. Mrs GBW can shower herself and is mobile with the aid of a walking stick. <i>Mrs GBW</i>	Care coordinator explained the availability of the Carer's Pension to son.	AE = \$121 GP = \$589 PH = \$2,433 DIAG = \$303 HOSP = \$1,723 Total = \$5,169
Medium	EITHER people with no carer and unable to perform one or more domestic tasks or having some physical deficits OR people with a carer and unable to perform many domestic tasks or having mid-level physical deficits. 61% of the Care Net population	Mr HTW came into the trial on discharge from hospital following a gall bladder operation. He is blind, in his early 80s and is a member of a local social club. He lives in a Housing Department unit. The care coordinator advocated to the Housing Department for rails to be installed and organised for a podiatrist and Home Care every fortnight. Financially he finds it a real struggle and probably won't continue to pay for the Home Care Service when Care Net finishes. He was using MOWs prior to Care Net and will continue with this service. "I think for people who are a bit backward it (Care Net) gets things done. We don't get anywhere by ourselves (referring to the installation of the ramp)." <i>Mr HTW</i>	Advocacy with Housing Department for rails. Home Care cleaning Podiatrist	GP = \$1,112 HC = \$ 820 PH = \$2,991 DIAG = \$443 HOSP = \$2,399 Total = \$7,765
		Mr and Mrs FQU both suffer cardiac conditions. During 1999 they both had hospitalisations – Mrs FQU had heart complications and Mr FQU had an infection. Mrs FQU has had multiple falls. They have a daughter who helps with the shopping. They live in a purpose-built retirement village which offers user-pays meals, a bus and fortnightly podiatry. Care Net provides cleaning services. When Mr FQU was discharged from hospital a nurse visited for wound dressing. <i>Mrs and Mrs FQU</i>	Home Care cleaning services. Nurse for limited period after discharge from hospital.	Mr FQU AE = \$121 GP = \$4,219 HC = \$1,757 PH = \$2,057 DIAG = \$3,646 HOSP = \$4,998 Total = \$16,797 Mrs FQU AE = \$166 DIAG = \$2,029 GP = \$1,583 HOSP = \$3,171 PH = \$245 Total = \$7,194

Level of Need	Definition	Interviewee example	Community care services commissioned by Care Net	Other services* and costs
High	EITHER people suffering confusion OR having multiple physical deficits OR people with no carer and unable to perform most domestic tasks. 14% of the Care Net population	Mrs G has had a stroke which has left her in a wheelchair with limited use of the right side of her body. She rises at 11.00 am and retires for the night in the early afternoon. She is being cared for by her husband in his eighties. Mrs G was receiving some community services prior to their introduction to Care Net – MOWs a bath three times a week and two hours of respite care. Since Care Net the respite has been doubled to 4 hours a week. Mr G uses the time to pay the bills and do grocery shopping. Mrs G also received a visit from a physiotherapist for thirteen weeks.	Respite care Home physiotherapy	GP = \$1213 PH = \$953 HC = \$10470 DIAG = \$267 Total = \$12,903
		Mrs GHT is in a wheelchair and living alone. She has fallen repeatedly the last time required hospitalisation for a nearly six weeks. She lives in a purpose-built unit with disabled access. The care coordinator provided Mrs GHT with a comprehensive package of services. Mrs GHT commented "The care coordinator hasn't missed out on anything. My daughter rings her from the country to find out how I am going. .. I didn't expect to get all I got .. she would say to me, what about your washing? .. I just can't do it ... I shouldn't be asking for this."	Laundry collected and cleaned by laundromat, Home Care cleaning and personal care MOWs Vital Call (purchase of phone) commode shower chair walker folding wheel chair Taxis for past neighbours to visit hair dresser to visit chemist to deliver	AE = \$869 GP = \$2255 HC = \$6021 PH = \$1473 DIAG = \$1529 HOSP = \$8910 Total = \$21057

* AE = Accident and emergency care; DIAG = Diagnostics; GP = General practitioner visits; PH = Pharmaceuticals; HOSP = Hospital stay/s; HC = Home and Community Care type services, including community nursing.

Over the course of the trial, individuals varied in their assessed levels of need. For example, Mrs GBW had just been discharged from hospital when she was first assessed as in "high" need by the trial. Eighteen months later she was assessed as having moderate need - her condition had stabilised and, with the help of her carer, she was able to complete all her daily personal and domestic tasks. Mr HQS on the other hand, had a moderate need level at the start of the trial. By the end of the trial his condition had deteriorated to such an extent that, despite the presence of a full-time carer, he was ranked as in high need.

Some interviewees did change in their expectations of the services over time. At the beginning of the trial, some indicated that they might have needs but could manage by themselves. Over the course of the trial, as either needs changed or expectations changed, several of the interviewees began to have the confidence to ask their care coordinators for more assistance.

"I did the best I possibly could and we got on ... our own way. We wouldn't have asked for help from nobody." (Mr JWU) By the end of the trial Mr and Mrs JWU were receiving the following services: bathing; cleaning; meals; physiotherapy; podiatry; lawn mowing. They had also received a commode chair and walking frame. A pharmacist had assessed their medications and organised a chart for the fridge and a dossette box. Mrs JWU felt that the services provided by Care Net had helped her stay out of a nursing home. They were very unclear what would happen post-trial. They had been working out the costs of meals and perhaps getting the family to help out again.

It has been difficult to ascertain the costs of different packages of care in the Care Net model. Capping of budgets was discussed in Report 3. From the perspective of interviewees, however, care coordinators rarely discussed finances with their clients. However there are some examples of services being withheld. One client who lived in her son's house wanted a hand rail in her son's toilet and a rail on the back steps of his house. This request was declined by the care coordinator. Other similar requests (for example rails in rented accommodation) were paid for by Care Net through different care coordinators.

5.3.2.5 Clients with low level needs

Approximately 30% of clients were assessed as having low needs at the beginning of the trial. As would be expected with the trial population, this had decreased to 25% by the end of the trial.

The local evaluators interviewed 7 clients who had low needs¹² assessed at the beginning of the trial. Some interviewees did not receive any identifiable package of care. Nevertheless, these clients identified positive features from their involvement. Examples from the interviewees included:

"If I am sick I call the doctor. If I need a pill I call the chemist. That is all. It is nice to know people are concerned about you. It (Care Net) gives you a feeling that someone is concerned. The system doesn't do anything for me." (Mrs GBW)

Interviewees also commented on the value of aids and appliances – sometimes as "simple" as a chair raiser. One interviewee commented that although the idea appeared simple they would never have thought of it themselves or known how to make the arrangements for modifications to their own furniture. The importance of one-off simple provision cannot be overstated (Caldock unknown). Personal alarm systems were of particular merit in the eyes of several interviewees who had experienced falls. This system enabled them to talk through a speaker phone even from the floor and call for assistance. Several interviewees commented that they were unaware of the availability of such assistance nor could they afford the initial set-up charge.

It was certainly not within the original ambit of the trial that coordination would be extended to individuals without multiple service needs. Participants in the control group, without a personal relationship to any care coordinator, were less concerned with the long term "investment" goals of the trial:

Mrs X lived alone in a house on two levels. She suffered from high blood pressure. She saw no need for community services and was managing, with the help of her general practitioner, to control her condition and live a productive and interesting life. She had become enrolled in the trial, "as a favour to my general practitioner when my hypertension was uncontrolled." She did not see any need for care coordination as she felt she could satisfactorily work out her own services.

5.3.2.6 Clients with mild to moderate needs

Approximately 57% percent of clients were assessed as having mild to moderate levels of need at the beginning of the trial. This had increased to 61% by the end.

The range of care packages for clients with mild to moderate needs was considerable and to a large extent depended on the personality, skills, resources and perceptions of the client.

¹² The people to be interviewed were selected by the care coordinators and consequently reflected their understanding that the trial would test the impact of preventative interventions, as well as coordinated care, for people with multiple service needs.

Mrs DWP was a 78 year old widow living by herself. The care coordinator had offered to provide her with cleaning services and other household assistance. Mrs DWP had declined the offer of assistance. "There is only me. One day I do something (in the house). The next day I do something else." The care coordinator felt that she should participate in social activities however Mrs DWP declined "I've got used to being on my own. The Women's Weekly, the bible. Sometime a neighbour will come in for half an hour. I've got used to this type of life." Care Net provided her with shopping assistance every fortnight and a lawn-mowing service.

"I was alright before Care Net and now I'm more alright. I really don't need much at the moment. I'm always busy." (Mrs GTF)

5.3.2.7 Clients with high needs

Overall, 14% percent of clients were assessed as having high needs. It was obvious that the interviewees meeting these criteria could not exist in the community without such intensive service-finding and commissioning activity. As well, with many out of pocket expenses needing to be met, the cost to the client of packages of care could well be prohibitive.

The care packages provided to clients with high needs demonstrated the impact uncapped funds could make on the delivery of services to maintain people in their own home.

Mr and Mrs JWU had relied on each other and their family to remain together in their own home. Mrs JWU's conditions included oosteoarthritis and sciatica. Whilst Mr JWU had had a couple of strokes and had recently suffered a heart attack. The care coordinator had to convince them to try community services. The initial care plan included: showering assistance, house cleaning, meals, physiotherapy, mobility equipment, installation of outside rails, podiatry and a commode chair. Mrs JWU commented 'It's been a load off my mind ... knowing that there's always a meal.' Mrs JWU also described a time when she was acutely unwell and was able to continue to live in her own home. She commented: "The services Care Net has organised has helped in keeping me out of hospital."

Additional services were organised for the JWUs later in the trial including lawn mowing, a review of medications by the community pharmacist and a dressing gown. Care Net assisted with an application to the Housing Department to relocate their daughter to a house within walking distance. After the relocation, the daughter and her husband were able to assist with many of the personal and domestic tasks, including showering.

Mrs FQU said "I'm more relaxed ... my blood pressure is under 200 ... the first time in a long time ... Initially we did not want anything, but (the care coordinator) helped us to see that we really needed help. We also had financial constraints, so we could not pay for all the services we needed."

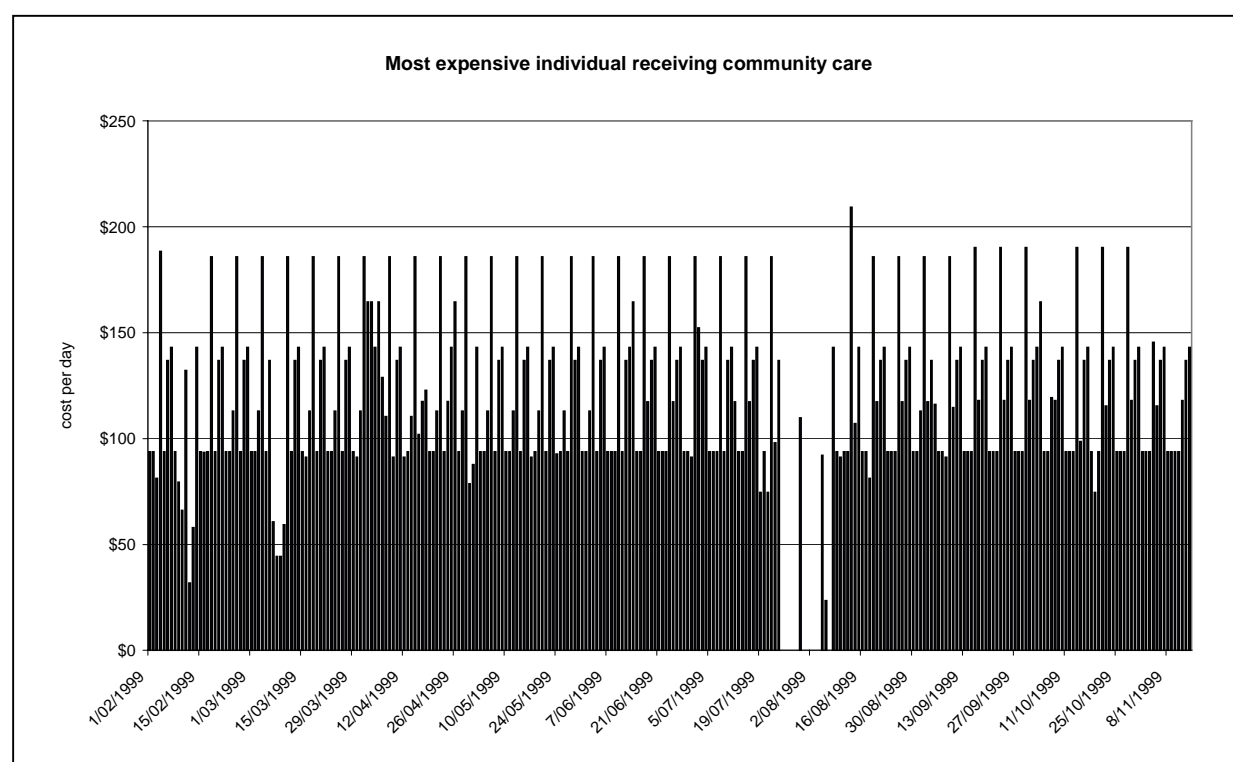
5.3.2.8 Highest cost client

The intervention client who consumed the most intensive community services in the last half of the trial was BS. His total community care costs were \$48,834 over his 16 months in the trial. According to the Care Net service utilisation database, BS had only 3 medical consultations during the period and was hospitalised twice. He rated as a High Need client on the Blended Need Index.

Table 15 An example of high cost community care – Mr BS

Service type	Number of services provided	Cost
Community care	1550	\$48,834
Hospital admissions	2	\$12,680
Accident and Emergency	1	\$272
Diagnostics	12	\$115
Medical Consultations	3	\$93
all	1568	\$61,995

The cost of his community care from 1 February 1999 until his admission into residential care in November 1999 is shown in Figure 3. This care was provided by just 3 community agencies, of which one provided nearly 90%. He had one period during this time when he did not receive community care because he was in hospital (August 1999).

Figure 3

As seen in Table 16, BS received mostly personal care. His records show separate bills for 5 to 6 items on many days. BS's care averaged \$121 a day of community care with the highest being \$209 for a single day. Despite being a high user of community care, BS had only 3 medical consultations during this period.

Table 16 Community care costs February 1999 until November 1999 – Mr BS

Service	Total cost
Personal Care	\$28,816
Respite Care	\$3,326
Domestic Assistance	\$793
Dressing of wound	\$307
Total Feb 99 to Nov 99	\$33,242

5.3.3 Client perceptions of care coordinators

The majority of clients did not use multiple community services. For those interviewed in this situation, the care coordinator was not so much a 'coordinator' of multiple services, rather a source of information and supplier of single services.

Interviewees certainly valued the care coordinator and frequently praised their diligence and responsiveness, and valued their opinions and actions.

"They are there to jog your memory, like your own family. You might be doing something wrong and the children don't want to upset you, and say you shouldn't do this or that – with a care coordinator ...you think. .oh yes, there's sense in that." (MacDonald and Boland 1999)

"I use her (the care coordinator) as a support, for the security of knowing she is there .. and to organise services. I call her when I want to go shopping. She arranges the transport. I get the house cleaned once a fortnight." (Mrs GBW)

During the course of the trial, a number of interviewees changed care coordinators. Whilst the trial management had originally anticipated that continuity of care would be an important attribute for clients, none of the interviewees commented adversely on the change. One client took the opportunity to make an observation about of her previous care coordinator:

"It's a big job.....Someone older would be more capable...I think a nurse would be more suitable for the job." (Mrs LHW)

Interviewees originally had few expectations of Care Net. It is not apparent to the evaluators whether this lack of concern about the change over in care coordinators reflected these low expectations, or a clients' understanding that the response from the service remained the same, regardless of the person who delivered that response.

5.3.4 Client perceptions of the GP role

The majority of interviewees did not have an impression that the general practitioner worked closely with the care coordinator. Their experience was that the general practitioner took care of their medical needs and the care coordinator took care of their needs in the house. However there were exceptions:

Mrs UTP's daughter informed the interviewers that she worked on the care plan with the care coordinator – "the GP contributed some ideas to the care plan and was consulted on the end result."

Some interviewees however had asked their care coordinators to 'have a talk' with their general practitioner about referrals to specialists.

The majority of interviewees felt that general practitioners did not have the time to take on the role of a care coordinator.

5.3.5 Carers' perspectives

The availability of a carer is thought to be an important influence on the package of care required to successfully maintain a frail older person in a community setting. Further, consistent with the desire to provide holistic care to trial participants, the care coordinators strove to see the needs of the person in the context of their environment (care coordinator interviews).

The trial could identify no valid measure of carer availability that would be suitable for the trial. It was agreed that it would be insufficient to simply ask whether the person lives alone. The basic dimension to be described was whether the client has a carer who was both willing and capable of undertaking tasks that would otherwise be undertaken by health and community care providers. It was agreed that a purposefully designed scale should be developed for this purpose. The resultant six level 'Carer Availability' scale was used to assess each person in the trial. Its six levels are shown in Table 17.

Table 17 Carer Availability

Carer Level	1st assessment	last assessment	1st assessment	last assessment
1 Carer not required	567	541	47.0%	44.6%
2 Carer not required, client is carer of another person	100	97	8.3%	8.0%
3 Resident carer	337	361	27.9%	29.7%
4 Non-resident carer	126	139	10.4%	11.4%
5 Carer not available	47	61	3.9%	5.0%
6 Carer not available, client is carer of another person	30	15	2.5%	1.2%
Total	1207	1214	100.0%	100.0%

Table 17 also shows the availability of carers for the participants in the intervention group over the course of the trial. Over half of all participants were assessed as needing no carer, whilst a quarter had a resident carer. 6% of participants required a carer but did not have one and nearly a half of these people cared for someone else. There was little change over the course of the trial.

Carers interviewed consistently praised the efforts of the care coordinators and the organisation.

“Wouldn't have known the services existed. The care coordinator orchestrated the set-up. She (the coordinator) organised it while she (the client) was still in hospital. When she went back in, the care coordinator put them on hold. Starts it all up again when she gets out. She ensures the success of it all by the way she coordinates it all. She is spot on.”

Mrs UTP required constant care to remain in the family home. Mr and Mrs UTP live with their daughter, her husband and two young children. The Care Net interventions have made it easier for the daughter to cope with caring for her mother. Mrs UTP's daughter commented that she was “100% better off” being part of Care Net. Showering services (6 days a week) organised through Care Net and weekly respite were seen to be the most important helps. The care coordinator also organised for the GP to do home visits.

5.4 Findings: positive features of Care Net from the client perspective

The Care Net Illawarra model of coordinated care had a number of key features that the interviewees identified as making a significant contribution to their health and well-being. The features were not common to all interviewees – they were obviously related to the contemporaneous needs of the client. These features are outlined in Table 18 and explained in the following section.

Table 18 Positive features of the Care Net Illawarra model

Feature	Components
Availability	Access to services
	Relieving carer strain
	Relieving family strain
Security	Telephone advice and assistance
	Availability of personal health information
Individualised approach	Commissioning services
	One friendly 'face'
	Information when needed
	Permission to experiment with novel therapies
	Better solutions
Affordability	No means testing
	Free community services
Advocacy	With service providers
	With other 'sectors'

5.4.1 Availability

5.4.1.1 Access to services

Interviewees viewed the timely provision of community care services through the trial as of paramount importance to their health and well-being. Interviewees receiving services commented positively on the effect of those services on their quality of life. These services could be for as little as two hours of cleaning services once a fortnight or, for those with high needs, to the provision of daily personal care.

Mrs GBW didn't know about the availability of services before Care Net. "I'm (now) getting my meals properly (through MOWs). I'm eating properly. When you are sick you don't feel like cooking."

"Care coordinator is probably better than my family. I know whatever I need can be arranged for me." (Mrs GNC)

5.4.1.2 Relieving carer strain

Interviewees were often conscious of the strain experienced by their live-in carers and were appreciative of the role of Care Net in relieving this pressure.

"It couldn't be any better. (My wife) only has to ring up and they are there for you. I'd give them 100%." (Mr JWU)

Mrs G had suffered a stroke and was barely able to communicate with the interviewer. Nevertheless she conveyed her concerns for her husband and for herself, if anything should happen to him. The coordinator had organised respite care for the husband. Even with this

service the husband was still near tears with the interviewer when describing his life as a carer for his wife.

5.4.1.3 Relieving family strain

Another feature of the trial which interviewees commented on was the positive impact on non-resident family members.

The majority of interviewees had family members who provided some assistance on a regular basis. Care Net relieved these family members of certain regular duties, and, from the perspective of the interviewees, eased their own feelings of being a 'burden' on their children. Examples include:

- The care coordinator would act as a telephone link for an independent view on how the parent was coping and to discuss care needs (particularly when the family member was not resident in the Illawarra).
- Easing of the burden of physical caring tasks such as shopping, lawn-mowing and laundry.
- Easing of the pressure on working daughters or daughters with child-rearing responsibilities for example, with house cleaning and meal preparation.

5.4.2 Security

5.4.2.1 Telephone advice and assistance

The availability of someone 'on the end of the phone' was a positive feature of the trial for many interviewees. This availability conferred a sense of security for the client. Even clients who perceived that they were not receiving any services or assistance through Care Net were impressed with this aspect of the trial.

Interviewees also felt that the care coordinators acted as 'sounding boards' in that they could be contacted to talk about issues without bothering either their general practitioner or their family. Overall the interviewees felt that the care coordinator would be available on the end of the telephone should the need arise.

Interviewees with few or no limitations in activities of daily living were still very supportive of the concept of Care Net. From their perspective they could contact a person – not an anonymous worker – and gain an immediate and individualised package of care should the need arise. This contributed greatly to their peace of mind.

5.4.2.2 Availability of personal health information

Despite initial concern over the privacy implications for sharing client data between health and community services professionals, interviewees saw the pooling of information as a positive step. It gave them the security of knowing that important health information was available in case of emergency.

Interviewees often commented that they were pleased that someone had their personal medical and community care needs on a computer and that this information could be shared between professionals.

Some interviewees were unaware that any discussions took place between their general practitioner and care coordinator. Where the interviewee was aware of such discussions, they were in favour of such interaction.

Significantly, no interviewee complained of either a real misuse of confidential information, or the potential for such misuse. These findings reflect a broader finding – nearly 2000 people signed up to participate in the trial and no one refused consent to their personal and health information being shared between the care providers. Quite clearly, the perceived benefits of continuity of care outweighed any potential concerns about privacy.

5.4.3 Individualised approach

Interviewees felt that the Care Net approach treated them as individuals with specific needs and requirements. This approach was evidenced through the commissioning of services, personalised attention through the care coordinator and information supplied when needed.

5.4.3.1 Commissioning

A significant feature of Care Net was the ability to commission a package of care. The concept of commissioning is receiving more recognition in the care management literature and refers, in the case of this trial, to the ability of the care coordinator to both design and order an individualised care package for clients.

In practice this contributed to the greater use of private services on the grounds of their increased flexibility and responsiveness to individual needs and timetables. Thus a personal care assistant could be scheduled to shower a client at the time the client wished rather than, through publicly provided services, at a time determined on the basis of clinical need. The personal care assistant could also perform a number of different duties for the same client such as showering, bed making and meal preparation. The public system would have more difficulty in meeting these functions through the one person. Community Health, for example, does not employ assistants-in-nursing (AINs) and the job description of a registered nurse would not include the performance of domestic tasks.

From the perspective of the interviewees, this practice did not lead to a decline in standards or the substitution of staff with lesser skills and expertise.

5.4.3.2 One ‘friendly face’

Care coordinators had visited and assessed all their clients. All interviewees commented on how impressed they were with the individual care coordinator. For many this person had become a friend and confidante.

“It’s good to know you can ring someone up and talk to them.”

5.4.3.3 Information when needed

Interviewees commented that the information provided by the care coordinators was timely. They were given extraneous information – it was provided when needed and directed at their specific situation.

“I didn’t know about services. A lot of people mustn’t know.” (Mrs GBW)

5.4.3.4 **Permission to experiment with novel therapies**

Some interviewees had tried and appreciated, what were to them, novel therapies. Their reluctance to pursue such options prior to the trial related to either a lack of information or knowledge about the therapy or a lack of ability to pay for such services.

“It (hydrotherapy) really brightens me up – that someone cares and really look after older people. It’s a good idea.”

5.4.3.5 **Better solutions**

Interviewees suggested that the care coordinator was able to establish the most cost-efficient path to meeting a client’s needs, without being bound to a particular service type. Examples included:

Mrs LHW had a nurse assess her showering. The nurse suggested the use of the Life Guard system (telephone monitoring system). Care Net paid for its installation (\$300) and Mrs LHW pays the quarterly rent.

Mr CSB lives in an area not well serviced by public transport and has mobility problems. The care coordinator organised for a physiotherapist to visit him in his home. Apparently the physiotherapist had never conducted a home visit before and was most interested in the approach of Care Net “Even our doctor was surprised that the physiotherapist had come out.”

“Care Net paid for half the dentures – it was too much for us to pay for the lot.” Mr JUC feels that she can go out and socialise more now.

It should be noted that the many of the interviewees commented that the availability of transport (either taxis or community transport) was a very positive service provided by the trial.

5.4.4 **Affordability**

5.4.4.1 **Free services**

A key feature of the trial from the client’s perspective was the commissioning and purchase of community care services, aids, appliances and home modifications free of charge. For the most part, where a service was commissioned by Care Net, the client did not contribute to the cost. This also appeared to be the case for the majority of smaller aids and appliances purchased. There were certainly no protocols at the beginning of the trial to guide such purchases. Towards the end of the trial there was a more rigorous vetting of the purchases of items over a certain limit through discussion in care coordinator’s teams. By the wind-down phase of the trial no one-off expenditures on home modifications were approved by the trial management.

It has been established that 93% of the trial participants could be described as socially disadvantaged (Silagy, Fagg et al. 1999). Many of the interviewees were on the basic pension. Some had suffered ill health for many years and this had had an impact on their savings, and hence their hedge against destitution. The financial costs of ill health also proved to be a continuing drain on low incomes.

Finances are a worry for Mr G. In his early eighties and caring for his wife, he estimated that he spent \$30 a week on continence pads. Before the start of Care Net the district nurse had asked if he had more than \$1,000 in the bank – apparently to see if she could provide assistance with aids. Mr G replied “Of course, I have to provide for my funeral. I don’t want to be carried out in a cardboard box. We manage. We don’t want to whinge.”

Mrs DWP has been a pensioner since her husband died. She has been on the pension for 31 years and recently her fridge, stove and hot water system have required replacement. She finds it increasingly difficult to maintain her standard of living. Although she receives concessions on most medications the total she spends is considerable. She produced all her medicines and described the reasons she needed each and the cost of each. She pointed out that some medicines were not subsidised through the PBS eg Mylanta at \$10.10 and Surmontil at \$17.73. "It's nothing for me to pay \$45-\$50 for medicines."

Mr and Mrs FQU reside in a purpose-built retirement village. Mr and Mrs FQU both suffer cardiac conditions. They receive Home Care services on a weekly basis through Care Net. They were not aware before the trial that the Home Care Service offered such cleaning services and probably would not have purchased such service, although they now see that such services would probably prevent falls around the house. They were interviewed prior to the close of the trial and commented that it would depend on how much the cleaning costs as to whether they would continue with the service. They "were grateful for the two years of free cleaning."

"I would not have been able to afford the alarm (Life Guard) especially with the phone costing \$250. That's a big bundle out of my little savings."

5.4.4.2 No means test

Care coordinators never had to ask clients about their personal finances, although when they felt it was appropriate to purchase expensive one-off items, some negotiation did take place with the client. For example, with the purchase of personal telephone monitors, the usual arrangement was for Care Net to purchase the telephone and pay the set-up costs and the client to meet the recurrent monthly charges.

As well as the provision of free services, interviewees were conscious that they were trusted to make decisions about their need for services, regardless of their financial position. Interviewees commented that they did not feel that they abused this position of trust.

5.4.5 Advocacy

5.4.5.1 Advocacy with service providers

The care coordinator was an advocate for the individual within the community care sector and, to a certain extent, within the health and social services sectors. Such advocacy could extend to ensuring personal preferences for time or personnel were met.

Mrs LHW was initially reluctant to have MOWs. She had heard that the quality of the food was poor. Her care coordinator contacted MOWs and "had a talk with the people in charge." They indicated that they had changed cooks. Mrs LHW then tried the meals and found that the quality of the food was "excellent."

5.4.5.2 Advocacy with other sectors

A number of interviewees were impressed with the capacity for the care coordinator to gain a response from the Housing Department in particular. This was particularly important for those interviewees requiring rails. Through the intervention of the care coordinator the Housing Department took action that benefited not only the client but also other residents in the apartment blocks.

5.4.6 Perceptions of 'substitution' initiatives

The design of the trial anticipated that Care Net would systematically introduce changes to health and community care interventions to take advantage of the flexibility for individualised care packages inherent in the pooled funding arrangements. These interventions were broadly called 'substitution' initiatives within the context of the Coordinated Care Trials. It was anticipated that such initiatives would lead to improvements in client outcomes within an overall framework of budget neutrality.

At the beginning of the trial, the Research and Development Officer identified a number of chronic conditions that were likely to lead to emergency hospital admissions (MacDonald and Hand Undated). These conditions included Diabetes, Chronic Obstructive Pulmonary Disease, Congestive Cardiac Failure and Depression. Falls were also identified as precipitating emergency hospital admission and were the focus of a structured intervention by the trial.

The concepts of 'funds pooling' and 'substitution' were not easily grasped by the majority of interviewees. These people had little background information on the trial and its hypotheses. They did, however, understand that the trial needed to demonstrate success and many felt that the 'bottom line' would determine whether Care Net continued or would finish in 1999.

Interviewees needed to be prompted to identify the impact of substitutions initiated by their care coordinator. Interviewees were specifically asked to comment on the impact of Care Net on the number of their visits to general practitioners, on their use of medications and on the likelihood of falls. They were also specifically asked about any other activity, other than community services, initiated through Care Net which could have had an impact on their health and well-being. Interviewees with Congestive Cardiac Failure (CCF) were asked to comment on their understanding of their role in the Care Net approach to this condition.

"My goal is to walk independently without sticks. I don't think I'm getting enough help. I want more physiotherapy and diet advice about losing weight." (Mrs GNC) By the next interview, Mrs GNC had been visited by a nutritionist from Care Net and a physiotherapist had attended.

The majority of interviewees did feel that they now saw their general practitioner less often. As mentioned above, there was a clear distinction in the minds of the interviewees between the role of the general practitioner and that of the care coordinator and Care Net services. Several interviewees with high care needs could clearly see that Care Net was substituting for residential aged care. One interviewee felt that the support of Care Net helped prevent her further hospitalisation.

5.5 Findings: Clients as partners in the trial

One intention of the Coordinated Care Trials was to assess the extent to which clients of trials were “partners in the planning of the trial, the development of care plans and empowered through the coordination process.

The Illawarra Care Net Trial was designed to accentuate the role of the client in decision-making processes, at both the macro and strategic level and also at the operational or micro level of individual users and carers (Hardy, Young et al. 1999). The evaluators are aware of concerted efforts by the trial management and individual care coordinators to involve consumers at both levels.

This section of the report examines consumer involvement in the trial at both the macro and micro levels.

5.5.1 Macro or strategic involvement of clients in the trial

The evaluators can clearly point to a culture supporting consumer input into the trial. A number of staff members devoted considerable effort to this endeavour and were keen to develop mechanisms appropriate to the client groups and support clients in participating at every level of decision-making in the trial.

5.5.1.1 Care Net Management Committee

The Care Net Management Committee was established to provide for the interests of the trial sponsors and key stakeholders in strategic planning (Care Net Illawarra 1997).

Two consumer representatives were included in the membership of this Committee. These individuals were nominated by individuals, health and consumer groups and peak consumer bodies and elected by the remaining members of the management.

One of these representatives commented:

The Care Net Trial was/is a great project. However, I feel that the consumers were not always given enough information. Often they felt “they” (whoever “they” are) was looking after them whilst not really understanding how the trial works.”

5.5.1.2 Active participant focus groups

In early 1998, four focus groups were held with trial clients to gain an understanding of consumer views on the trial and to seek input into the trial directions. The report of these focus groups concluded (MacDonald and Boland 1999):

“Given that the trial’s underlying philosophy is to establish a Primary Health Care model, using community development strategies, it is essential that consumer participation be taken into account when looking at the planning and development of interventions.... In rationalising this approach, empowerment and self determination are integral components of a Primary Health Care model and will be a driving force in the ongoing development of policy and intervention initiatives within the trial.”

Two groups of clients, called the Support and Information Groups, continued to meet on a monthly basis. Each group attracted approximately 20 people per session. The program was directed by the participants and included discussion on trial directions.

A Consumer Representative Training Course for trial clients was held in March 1999. Following this course, the Care Net Illawarra Consumer Communication Committee was established in April. The aim of this group was *“to enable trial participants to have more of an active say in the development and management of Care Net Illawarra and to ensure that the participation of Care Net trial participants is encouraged and maintained.”* This group was established during the wind down phase of the trial and discussed policy issues including; nursing home payment issues, contributions/copayments and the implications of the wind down of the trial. This committee reported to the Care Net Management Committee through the consumer representative. The group became very active in pressing for the continuation of the trial beyond its December deadline (Consumer Communication Committee 1999).

“You get to know what’s going on/ what’s happening as (Trial Manager) comes and talks ... the committee encourages people to have their say ..everyone can make up their own minds ... they do not follow blindly.”

“Going to the meetings is the best thing that has happened ... takes up your attention ... not thinking about yourself – it gets you in. I feel I could help them to run the country.”

The trial also conducted post-trial options discussion groups with clients in 4 locations in the Illawarra.

Considerable consumer effort was expended in an attempt to extend the life of the trial beyond the closure date. The Project Manager was particularly committed to the continuation and extension of the trial (Foulstone 1998). Clients were actively encouraged to petition relevant Federal and State ministers. Client input through the Consumer Communication Committees was perhaps focussed on strategies to prolong the life of the trial rather than seeking their input into the assistance clients might need when the trial closed. Hence the minutes of the final meetings of the Communication Committee and the focus groups on post-trial options are exclusively focused on variations of the trial to be run in the future.

5.5.1.3 Community development activities

The trial produced an irregular newsletter for clients. This included information and comment from the trial, service providers and consumers. It also was a way to provide information to clients on the range of services available through the trial. Consumers participated in the production of the newsletter.

The Support and Information Groups (see above) also ran activities such as bus outings, education sessions and mutual support groups.

5.5.1.4 Complaints handling

The complaint handling mechanism of the Illawarra Coordinated Care Trial was based upon the Australian Standard of Complaints Handling AS 4269-1995. Logs of complaints and compliments were sighted by the evaluators.

5.5.1.5 Being a trial participant

None of the interviewees had any concerns about being in a “trial”. Comments included:

“It feels like somebody’s looking after you and thinking about you. We’re definitely better off being part of Care Net.”

5.5.2 Micro or operational involvement of clients

A ‘good consumer’ has been defined as “*someone who can adequately assimilate information of the costs and quality of health care, and on the basis of such information, has an ability and a desire to make health care choices and is then prepared to search for the best ‘package’ of health care in terms of cost and quality*” (Shakely and Ryan 1994).

To some extent, then the very existence of the care coordination trial is evidence that this model of consumerism is likely to fail chronically ill individuals needing multiple services. They need help in 'navigating' the service system and choosing a package of services to meet their needs.

In the Care Net Illawarra Trial the majority of interviewees were keenly aware of their level of dependence on services provided free of charge. Many knew that they would not be able to afford, or would not consider paying for, services themselves. It is reasonable to conclude that in spite of the small-scale efforts at actively training some activist volunteers (representing less than 1% of participants) most clients relinquished their rights as consumers – albeit willingly – in terms of an evaluation of their care.

At each stage of the trial's assessment and care management process, clients were expected to make choices:

- about what services to receive (i.e. the type and range of support to be given);
- when to receive them (i.e. at what times and for what duration);
- from whom (i.e. which provider organisation, which individual worker);
- and the appropriate balance between individual effort (self-management) and formal and informal support.

The dimensions of choice in the assessment and care management processes within the trial are outlined in Table 19. This Table gives details of the different ‘what, when and from whom’ choices as they apply at each stage of the assessment and care management process (Clark, Becker et al. 1991). Evidence for the “evaluators’ comments” is drawn from the body of evidence in this and other Reports.

Table 19 Dimensions of choice in the assessment and care coordination process

Opportunities for client input:	Evaluators’ comments based on interviews with clients:
Assessment and definition of needs	
<i>Choices about services and sectors:</i>	
Choice between residential or hospital care and remaining at home with either informal or formal community support	Good input with care coordinators. Interviewees felt supported in their choice of location for care.
Choices over the type and range of support provided within the categories of residential, hospital or domiciliary care	Good input with care coordinators. Interviewees felt they contributed to the decision-making in care planning.
Choices about preventative, secondary and tertiary interventions	Variable input. Few interviewees understood the possibilities for preventative, secondary and tertiary interventions. Interviews with care coordinators indicated that the provision of choices to clients depended on the care coordinators training and interests. Only two protocols sighted by evaluators: falls prevention and CCF. The CCF intervention was inconsistent.

Opportunities for client input:	Evaluators' comments based on interviews with clients:
Care planning and implementation	
<i>Choices about what services and when to receive them:</i>	
Choice over the timing, duration and components of the care package	Interviewees reported that services provided through Care Net allowed for flexibility - they felt that they could ask care coordinators for a specific time for a service.
Choice over level and method of client contribution for different elements of formal support	Financial contributions were not required from Care Net although were sometimes sought for one-off items eg dentures, personal care phones.
<i>Choices about from whom to receive services:</i>	
Choice about private-for-profit provision and community not-for-profit sectors	Interviewees were not necessarily aware of 'sectors' however were pleased to receive services whichever services fitted in with their domestic timetable.
Choice between individual workers to deliver the different elements of the care plan	Interviewees did not necessarily want choice. However some did not complain about individual workers, even to the care coordinator.
Choice over the balance between the formal and informal support (paid and unpaid;	Interviewees felt that they had a good choice. The choice was not limited by financial considerations, nor was support imposed by the care coordinator.
Choice between individual providers of health services	To some extent clients were 'locked in' to the general practitioner if they wanted to remain in Care Net. No interviewee saw this as a problem.
<i>Choices about management of chronic conditions:</i>	
Choices about lifestyle changes	Offered to some interviewees – no consistent choices.
Choices about degrees of self-management	Offered to some interviewees eg CCF – no consistent choices.
Monitoring and review	
<i>Choices about what, when and from whom to receive services:</i>	
Choice over the nature of the response to changing user and carer needs	Interviewees felt that appropriate responses were made to their changing needs.
Choice in terms of when and how the case is reviewed	Interviewees felt that Care Net was very responsive to their changing needs. Good choice including case conferences if in hospital.
Choices about degrees of individual responsibility for self-monitoring.	This would apply to those clients involved in monitoring chronic conditions. As mentioned previously, there was no consistent Care Net intervention aimed at self-management of chronic conditions.

The above information is a limited attempt to address a significant issue for care coordination models based on a small sample of the active participants. The issue of consumer involvement in care coordination obviously depends on consumer expectations of the service and of their role in that service. Care coordinators and the Project Manager were emphatic that, given the culture of consumer sovereignty within the organisation, clients would feel comfortable with approaching their care coordinator or the service itself with a complaint. The in-depth interviews revealed that individuals did have complaints but were reluctant to raise them with the service. Examples include:

I'm glad they changed the care coordinator – this one is a bit more mature and I can discuss things with her – she understands The podiatrist they sent me cut my toe. It got infected and I've been laid up for weeks. I didn't complain to the care coordinator – no – they were very kind in sending me the podiatrist in the first place.” (Mrs LHW)

Mrs DWP felt that the podiatrist (through Care Net) had not cut her toenails in an appropriate way and does not want to use him again. She cuts her own toenails now. She does not want to cause trouble so she has not told the care coordinator the reason for stopping podiatry.

Analysis of the written complaints to Care Net show that the majority came from the control group and were concerned with their perceived lack of service.

5.6 Discussion: Access and Ethics

The last hypothesis formulated by the national evaluators identified issues of access and equity within the trial, namely:

“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.” (see Appendix 2)

5.6.1 Equity of access according to need

Care Net did not succeed in enrolling the neediest in the region's population. The trial then spent more than was within the funds pool on large numbers of individuals who, arguably, did not need or require care coordination in the first place. During the course of the trial, the Home Care Service closed its books at various points. In September 1999, the service had a waiting list of around 500 people (interview with program administrator). Waiting lists were long for other community services.

On the one hand, it is possible to dismiss concerns over equity of access by remonstrating that the project was a trial. On the other hand, Care Net did overspend its “budget” by an estimated \$1.8 million.

Care Net also never adequately addressed the issue of capped budgets for clients. The project proposal spelled out that: “Care coordinators will be allocated a budget for service provision dependent on the case types and base line needs of the clients” (Care Net Illawarra 1997). In reality, care coordinators were only given directions to address this issue in “teams” toward the end of the trial. Prior to that, only ‘expensive’ items or services were referred through to the trial executive for approval. The purchase of one-off items did not seem to be governed by any consistent policy. In the mid-term report the evaluators quoted the instance of one client receiving cruise control for their vehicle to enable them to commute to Newcastle to visit relatives. This had a clear goal of reducing social isolation. However, it did need to be reviewed in the context of the projected dual deficit and overall needs in the community.

The trial never had a policy of exiting a client from the service. Once a client of Care Net, always a client of Care Net. This meant that, despite some improvements in some clients, they would not be told that they would be “discharged” from the service. This meant that they could continue to receive reviews from the care coordinator – whether or not there was any indication that their service needs had changed. It should be noted that some care coordinators did not follow the policy of regularly spaced reviews but told their clients to ring them if their needs changed or they required any information.

The trial also adopted a policy of not requiring or requesting co-payments for services.

In response to a questionnaire, some care coordinators felt that asking clients for information on their finances would transgress the ‘culture’ of the Care Net Illawarra trial. A number of care coordinators did not attempt to assess how many of their clients had “limited financial resources”. The definition of ‘financial disadvantage’ was then entirely subjective with no protocols or policies in place in Care Net. Three care coordinators, for example, felt that less than 25% of their clients had limited financial means. Two care coordinators felt that over 75% of their clients had limited financial means.

The Project Manager explained this decision (Foulstone 1998):

“It should be noted that the provision of services without a co-payment is due to two principal reasons:

The Commonwealth requested that co-payments be collected by the trial to assess the extent participants contributed to their care. This raised issues related to the processing mechanisms and resources required to undertake this task.

During an early development meeting between the NSW based trial contenders, NSW Health and the Commonwealth in 1996, a serious problem arose. NSW Health representative demanded that no participant who was provided with services requiring a co-payment as a substitution for free hospital treatment was to be charged a co-payment for those substitution services.

These two issues together raised all sorts of questions about how we would be able to separate what service should include a co-payment, for how long a co-payment could be maintained and would we have systems and resources to separate them. A calculation was carried out on the number of PBS scripts ... As the main trial tasks were related to the effect of funds pooling, care coordination and substitution of services, it was decided not to collect co-payments. Further, those participants who had existing services with co-payments would continue to maintain them. Any new services (emphasis added) provided by the trial would be free of co-payment."

5.6.2 Equity of access by culture

The Proposal for the Live Phase of the Coordinated Care Trial (Care Net Illawarra 1997) outlined the arrangements that were made to ensure that people from non-English speaking backgrounds and Aboriginal and Torres Strait Islanders would have equitable access to the services offered by the trial from the start date.

The Aboriginal Health staff of the Illawarra Area Health Service and local community organisations were involved in identifying Aboriginal and Torres Strait Islander people eligible for the trial. The age requirements for this group were reduced from 65 years to 45 years as long as the person was suffering or experiencing an age-related condition. The project also employed a Recruitment Officer of Aboriginal descent.

A NESB sub-committee of the project's Advisory Committee provided guidance in the identification and recruitment of participants. Recruitment officers from non-English speaking backgrounds were employed and worked with interpreter services. Recruitment information was translated into the 12 most significant languages of the Illawarra.

Despite such efforts by the trial management, only 4% of the participants of the trial spoke a language other than English at home.

5.6.3 The ethics of a trial

It is sobering to view the endpoint of the trial from the perspective of the interviewees. The end of the trial was disturbing and upsetting for many of them.

Some interviewees had been assured during the earlier months that the trial was "successful" and would continue indefinitely.

"My GP has heard that there may be another Care Net coming." (Mrs GBW)

Interviewees on the pension were particularly concerned about the implications of the trial. Many had commenced on services because they were free of charge and had found that the services improved their quality of life considerably. In the last round of interviews by the evaluation team many interviewees were awaiting a visit from the care coordinator or some word from the trial about the "fate" of their particular package of services.

"I don't know what will happen when Care Net ends. The MOWs deliverer said that the meals cost \$6.00 each. I won't be able to afford that." Care Net also arranged taxis for Mrs GBW to go shopping. "I'll never be able to afford that on the pension."

*"We were going downhill when we first went on the it (the trial) but now we are more stable."
(Mr and Mrs FQU)*

Some had put off having structural alterations to their homes, unconvinced of the need and reluctant to order services simply because they were free of cost. They missed out when the trial stopped providing aids and appliances.

Mrs CTS had been assessed as needing rails on her back steps. She didn't feel that they were necessary at her first assessment. Later in the trial she decided that the time had come to put in the rails. There was a waiting list for the assessment by the occupational therapist and another waiting list for the installation and by the time the assessment had taken place, the trial management had decided to freeze all such 'one-off' expenditures. Mrs CTS had missed out on the installation of 'free' rails.

At some stage the trial changed its focus from a time-limited project to an ongoing and valued service. Understandably, this was in the interests of some of the employees both materially and psychologically. They also saw that it was in the interests of the clients. The evaluators, however, were disturbed by the comments from some participants who clearly felt that their care coordinators wanted the trial to continue and that it would continue if only the evaluation would demonstrate "success". This shift of focus unduly raised client expectations and made the trial closure (which was inevitability) a personal blow for many clients.

It is an important lesson for the wind-down phase of such trials. The design and implementation of community care services research must be mindful of the long term consequences for vulnerable individuals.

5.7 Conclusions

5.7.1 Doing worse...

The Illawarra Coordinated Care Trial did not result in improved client outcomes after 26 months of the Care Net intervention. Neither functioning nor activities of daily living showed consistent improvement in outcomes attributable to this redesign of the delivery of care.

Among the design limitations of the trial, three require particular emphasis. This intervention had been designed to target older people with chronic conditions requiring multiple services. It cannot be known whether the outcomes would have been different if the trial had initially succeeded in recruiting a majority of that population.

Second, the emphasis by the Trial Manager on demonstrating the effect of preventative investments in a 'healthier' population, such as the majority of Care Net clients, was overly optimistic.

Preventative investments need a longer time span to demonstrate pay-off. Perversely, older people have fewer remaining years of life to realise the benefits of preventative services. An older person may benefit substantially from a preventative intervention yet succumb sooner to another illness, lessening the measurable impact of the intervention (Pacala 1999).

Third, the design of the trial's preventative interventions and the evaluation of those interventions mitigated against detecting any discrete or measurable changes in health attributable to any particular preventative investment – diet, falls prevention, flu vaccinations, massage, podiatry, Terry towelling bath robes, etc, all were tried on different clients. The clients were not tagged, nor the interventions used consistently and according to established protocols.

Overall there was no difference in death rates between the intervention and control group but more than twice as many active clients were admitted to residential care than in the control group. There was also no statistical difference found between the clients of Care Net and the control group when assessed by the SF-36 quality of life measure or the trial's own measures.

Since 1997 when the trial first went live, there has been a growing body of international literature (see Report Number 3) demonstrating that the components of the intervention, ie who receives the intervention and specifically how it was delivered, are critical in the design of such trials. This is more important than good ideas implemented in a well-intended, yet random way.

So, there are no robust results in terms of client outcomes attributable to the specific Care Net interventions. However we do know a lot about the experience of clients, both individually through the in-depth interviews and collectively through the quantitative data.

5.7.2 ...But feeling better

The trial intervention succeeded in improving the self-reported health status of a majority of clients. Only 20% of clients reported that their health status had declined.

Intervention participants showed high levels of satisfaction with Care Net, suggesting that these clients highly valued a more comprehensive and flexible response to their perceived needs.

From the interviews conducted in the evaluation, it can be inferred that clients as a whole were more than satisfied with the services offered by Care Net Illawarra. Interviewees were either satisfied because the community care services they received were flexible and responsive to their

contemporaneous needs or because they could anticipate a time when they would need such services. This latter group had peace of mind because they knew the very name of the person they could ring to get timely and extensive help. Co-resident carers and non-resident carers alike were likewise very enthusiastic in their appraisal of Care Net. Many of the routine tasks of caring were lifted from their shoulders and they also had a person to help them share the emotional burden of caring.

These findings have particular significance for the design of care coordination initiatives and indeed for mainstream community care services. Clients with high and moderate levels of need in Care Net Illawarra valued a number of features of the trial, including individually designed packages of care which were then commissioned. They appreciated, and felt they needed, someone to “walk” them through the options and solutions available to help them, and their families, continue their independent living within the home. Secondly, they appreciated the financial assistance provided through:

- the purchase of one-off items, such as telephone monitors and home modifications; and
- the regular provision of assistance in the myriad of small tasks that led to independence in daily living.

Clients with low levels of need in the Care Net Illawarra Trial also saw benefits from their involvement. The most significant benefit from their perspective was the availability of a person to help them should the need arise for assistance or information. This was not an anonymous clerk but a person who both knew their circumstances and had met them in their home environment.

One aspect of the trial also has implications for further initiatives in coordinated care between the health and community care sectors. Despite initial concern over the privacy implications for sharing client data between health and community services professionals, interviewees saw the pooling of information as a positive step. It gave them the security of knowing that important personal and health information was available in case of emergency.

Care Net Illawarra was an undoubted success judging by the experiences of its clients. It is probably best expressed in the words of a client:

“It’s a very positive move by the government. We know that we are being taken care of and do not have to just rely on our families.” (Mrs GNC)

Appendix 1: An overview of the Illawarra Coordinated Care Trial

The Illawarra Coordinated Care Trial, or Care Net Illawarra, was established as part of a National series of demonstration projects that aimed to assess the benefits of coordinated care in the context of the Australian health care system. The primary hypothesis to be tested by the trials was that:

That coordination of care of people with multiple service needs, where care is accessed through individual care plans and funds pooled with existing Commonwealth, State and joint programs, will result in improved client health and well-being within existing resources.

Fund pooling was a key component of the coordinated care trials. The established, program-based organisation and funding of health care services was thought to be a principal factor in frustrating flexible service provision and service substitution. The way to overcome this issue was believed to be the pooling of funds from Commonwealth, State and joint Commonwealth-State programs (Pekarsky 1999). Trials would be allocated a budget from which they could purchase services for clients, with funds for the budget coming from the finances of existing service providers. But there would be no additional money. A key Commonwealth requirement was for trials to be cost-neutral.

The Illawarra trial encompassed three local government areas: Wollongong, Shellharbour and Kiama, the area being located south of Sydney, NSW. Its principal stakeholders were the Illawarra Area Health Service (IAHS), the Illawarra Division of General Practice (IDGP) and the NSW Home Care service.

The trial aimed to coordinate the care of people aged 65 years and over with either a risk of falling or who had complex medical or social problems that required multiple services from more than one health care service provider. During the 1997 planning phase of the trial, roughly 1800 eligible residents were referred to the trial by the 100 GPs participating. 1200 clients were allocated to an active group and would have their care coordinated by the trial, while the other 600 were allocated to a control group.

After the planning phase, the trial went live on 1 November 1997. It finished on 31 December 1999, a total period of 26 months over 3 financial years.

The coordination of care was undertaken by 15-16 care coordinators, in collaboration with the client's GP. The GP maintained control of the medical aspects of the client's treatment, while the care coordinator organised access to other services, purchasing services agreed to with the participant and GP. The care coordinators performed a systematic assessment of their clients initially every three months and subsequently in response to need. These assessments were intended to inform the creation of the clients' care plan that, among other things, included the goals of care for the client. Finally, a service plan was created that described the package of services to be bought by the trial in order to address the clients' goals was created.

Thus, the trial adopted a commissioning model of service provision. It secured services mainly from community care service providers, having access to both public services (those in the IAHS and the local HACC agencies) and private services. Medical (GP, specialist), pharmaceutical and hospital services were also within the funding pool, but these services were largely determined by GPs.

The trial used State and Commonwealth funds to develop an information system. Based on an intranet structure, the system supported email, client records, service utilisation, and financial data. This system did not support full communication between providers but significant steps included the increased use of computers by GPs.

Appendix 2: Hypotheses

The National Evaluation Reference Group established a primary hypothesis and a series of secondary hypotheses that represented the likely influences on whether that statement could be supported. The Care Net trial adapted that framework into a local set of hypotheses. The national and local hypotheses that are relevant to this report are listed below.

NH1 The primary hypotheses:

Local Illawarra adaptation

<p>National Hypothesis 1:</p> <p>“That coordination of care of people with multiple service needs, where care is accessed through individual care plans, and funds pooled from existing Commonwealth, State and joint programs, will result in improved client health and well being within existing resources”.</p>	<p>Care Net Hypothesis 1:</p> <p>“if improved individual client health and well-being can be achieved within existing resources where an individual’s multiple service needs are met through an individual care coordinator, a single care plan and a single pool of funds”.</p>
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The extent to which this is achieved, will be influenced by:

NH2 The extent of substitution of services within the pool

<p>National Hypothesis 2: “The extent of substitution between services within a trial pool”</p>	<p>Care Net Hypothesis 4: “If improved health outcomes can be achieved with service substitution”</p>
	<p>Care Net Hypothesis 6: “If injury prevention can be achieved with service substitution”</p>
	<p>Care Net Hypothesis 9: “If care coordination and the purchasing of services from a central fund can reduce expected bed days in hospital. This will apply to both lengths of stay and re-admissions”.</p>

NH4 The characteristics of clients selected

<p>National Hypothesis 4: “The characteristics of the clients to whom services are provided”.</p>	<p>No corresponding local adaptation</p>
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NH6 The characteristics of the care coordination function

<p>National Hypothesis 6: “The characteristics of the care coordination function”</p>	<p>Care Net Hypothesis 2: “If the allocation of care coordinators to general practice surgeries improves communication between GPs and other services available to provide necessary services for their patients”.</p>
	<p>Care Net Hypothesis 3: “If the care coordinator in a role of patient/client advocate increase the patient’s involvement in care planning processes”.</p>

NH7 Particular Types of Admin Arrangements

National Hypothesis 7: “The characteristics of trial administrative arrangements”	Care Net Hypothesis 7: “If an information system communication network containing the care plan and relevant clinical information can improve the cost-effectiveness of care coordination processes and outcomes”
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NH8 Consumer Involvement

National Hypothesis 8: “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”.	Care Net Hypothesis 5: “If consumer involvement in project management and policy development can improve the process and outcomes associated with care coordination”.
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NH9 Wider System

National 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”.	No corresponding local adaptation
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Appendix 3: Questions from the National Evaluators for the Client Thematic

The National Evaluators asked local evaluators to address a series of questions relating to consumer issues. The table below lists the questions and their corresponding reference point within the body of this Report.

Table A3.1: Client Themes

Themes to be addressed	Location within text
Specific consumer experiences relating to access, coordination, holism, understanding, explanation etc.	5.3.2 Client perceptions of Care Net Illawarra
Deficiencies associated with coordinated care generally.	5.6 Discussion: Access and Ethics
Deficiencies or problems associated with specific arrangements made by care coordinators for clients.	5.4 Findings: positive features of Care Net from the client perspective
The degree of consumer confidence in competence of care coordinators.	5.3.2.3 Development of the care plan
Adequacy of care plans from the client's perspective?	5.3.2.4 The Care Package
Perverse and other unintended effects of care coordination.	5.6 Discussion: Access and Ethics
Degree of consumer compliance with care plans.	5.5 Findings: Clients as partners in the trial
The level of comfort consumers experience in raising issues of concern re services and care plans.	5.5 Findings: Clients as partners in the trial
Client perceptions of being stigmatised or given 'special' treatment.	5.5 Findings: Clients as partners in the trial
Clients perceptions of changes to care plan and services over time.	5.3.2 Client perceptions of Care Net Illawarra
Analysis of client involvement in development of own care plans.	5.5 Findings: Clients as partners in the trial
Nature and extent of role of carers in care coordination processes.	5.3.5 Carers' perspectives

Appendix 4: Quantitative data sources for the evaluation

Quantitative data sources for the evaluation included:

- The Care Net Illawarra assessment tool;
- The SF-36 quality-of-life assessment.

The Care Net Illawarra assessment tool

The goal of the Care Net Illawarra assessment tool was to apply a comprehensive, systematic and validated assessment to all participants in the Care Net population. The assessment tool was applied three times to control participants and at least twice (but usually more often) to intervention participants (clients). The original intention of the trial was to apply the assessment tool at three monthly intervals to all clients of the trial. This was amended during the trial period in response to numbers of trial participants whose conditions were stable. The data, however, indicate that some clients only received two assessments. It is not known whether, in reality, this was the case or whether the absence of further records indicates data quality problems.

The Care Net assessment tool consisted of a battery of eight dimensions. The Clinical Issues Committee made decisions about inclusions in the assessment tool. The committee included representatives from general practice, rehabilitation medicine, geriatric medicine, nursing and occupational therapy. The eight dimensions and instruments were identified by the Committee as being those that, both individually and in combination, drive the need for coordinated care and are known to be predictive of the cost of care. After the relevant dimensions were identified, a measurement instrument was selected for each dimension.

As much as possible, instruments were selected that were already in routine clinical practice. Further, instruments were preferred if they were well validated, efficient and had demonstrated inter-rater reliability. In the event, tools were selected that met the technical criteria for all but one of the dimensions - carer availability.

The dimensions selected for assessment are shown in Table 20.

Table 20 Care Net assessment tools

Dimension	Instrument
health status	Medical practitioner assessment
self perception of health status	Self-report
self care ability (motor function)	Functional Independence Measure (FIM)
cognitive function	Short Orientation-Memory and Concentration Test (SOMCT)
instrumental (domestic function)	Lawtons IADL scale
social environment	Health of the Nation Outcome Scales, 2 items
physical environment	Care coordinator assessment
carer availability	Care Net Carer Availability Scale
Medications	Sighting and recording by the care coordinator

The tools and their rationale for inclusion were summarised in our interim report (Eagar, Owen et al. 1998) and described in more detail in a background paper to the evaluation (Eagar and Woods 1999). The initial assessment took about one hour and the subsequent review assessment forty five minutes. Care coordinators were given training in assessment at the beginning of their appointments.

All coordinators used the assessment protocol. There does, however, appear to be variation in how the protocol was applied in situ. For example, some coordinators spoke of using the tools as

'cues' for questions rather than strictly adhering to the specific question or the range of questions. Some coordinators were reluctant to use the cognitive function questions, particularly in review assessments or where its use caused some embarrassment to the client or their carer.

Thus, while a common assessment tool was used, the interpretation of that tool was in the hands of the care coordinator, and they varied in terms of their social and clinical backgrounds and experience. The collection of information on medications, for example, may have depended according to the clinical expertise of the assessor.

The Functional Independence Measure (FIM)

The 13 items that comprise the FIM Motor Sub-Scale are shown in Table 21. Both the current motor function and FIM goals were recorded during the assessment.

Table 21 FIM Motor Sub-scale

	Current	3 month goal	Guide to scoring the FIM Motor score
Eating			NO HELPER Score of 7 - Complete Independence Score of 6 - Modified Independence HELPER Score of 5 - Supervision or setup Score of 4 - Minimal contact assistance Score of 3 - Moderate contact assistance Score of 2 - Maximal contact assistance Score of 1 - Total contact assistance
Grooming			
Bathing			
Dressing Upper Body			
Dressing Lower Body			
Toileting			
Bladder Management			
Bowel Management			
Transfer - Bed/chair/wheelchair			
Transfer toilet			
Transfer Tub/shower			
Walk/Wheelchair			
Stairs			
MOTOR SUB-SCALE (total)			

The highest possible score of 91 is achieved when no disabilities or limitations are reported.

Motor function, or self-care ability, is an important attribute in influencing health status and quality of life. In addition, it has been demonstrated to be a good predictor of the cost of both inpatient and community care (Stineman, Escarce et al. 1994; Eagar and et.al 1997). This scale has been shown to have good technical properties (Granger, Hamilton et al. 1993; Ottenbacher, Mann et al. 1994) and international benchmarks are available through the Centre for Functional Assessment Research, University of Buffalo (Centre for Functional Assessment Research 1993). In addition, there is a large national data set collected as part of the Australian SNAP study that can be used to compare the functional status and outcomes of Care Net clients with patients using medical rehabilitation and geriatric services.

The Lawtons IADL Scale

Instrumental activities of daily living (IADL) tasks are more complex tasks than those measured in motor ADL scales. Deficits in IADL indicate a need for community care and home support services. Domestic function was measured by use of the Lawtons IADL scale. This scale is one of the oldest of its type, having been developed in 1969.

There are eight separate IADLs - use of telephone, shopping, food preparation, housekeeping, laundry, transportation, medications and finances. The scale has been demonstrated to have good technical properties in terms of construct validity and reliability. Care Net amended the scoring system as the original scale scored differently for men and women. It also increased the sensitivity of the scale by using a score of between 1 and 3 for 4 items, a score of between 1 and 4 for 3 items and a score of between 1 and 5 for 2 items. The final scale has a range of 8 to 31 with a score of 8 indicating that the person is IADL independent and a score of 31 indicating that the person is completely dependent on others for IADLs.

The Short Orientation-Memory and Concentration Test (SOMCT) of Cognitive Functioning

Like motor function, cognitive function is an important attribute in influencing health status and quality of life. Poor cognitive function is also a recognised risk factor for falls and other accidents and injuries. In addition, it has been demonstrated to have some predictive power in relation to the cost of both inpatient and community care, although cognitive function is less predictive than motor function (Stineman, Escarce et al. 1994). Cognitive status was measured by use of the Short Orientation-Memory and Concentration Test (SOMCT) (Katzman 1993). Where this initial screen indicated that there may be problems, a Mini Mental State Examination was also conducted.

A score of 0 to 14 on the SOMCT indicated no or mild cognitive impairment. A score of 15 to 28 indicates moderate to severe impairment.

Blended measure of dependency

A 5 level scale was developed by the evaluators to combine these various measures into a total scale designed to measure dependency/need for service. The scale is shown in Table 22.

Table 22 The blended dependency/need measure

Level	Description
level 1	moderate to high cognition OR low physical function (FIM<78)
level 2	no Carer AND with high IADL needs
level 3	no Carer AND with moderate IADL needs OR a FIM score of 78 to 90 OR with Carer AND high IADL needs
level 4	with Carer AND with mid physical function (FIM 79 to 90) OR with Carer AND with moderate IADL needs
level 5	FIM=91 AND requires nil or minimum IADL needs

Participants were classified as being Level 1 if either they have moderate to high cognitive deficits OR low physical function (FIM<78). Availability of Carer was not taken into account in determining allocation to Level 1. We expected this group to have the highest care needs.

Level 2 clients were those people rating 5 or 6 on the Carer Scale (Carer required but not available) and rating as having high IADL needs on the Lawtons Scale.

Level 3 clients were those people without a Carer and with moderate IADL needs or medium FIM scores (78 to 90) as well as those people with a Carer and with high IADL needs.

Level 4 clients were those people with a Carer and with either moderate physical or moderate IADL function.

Finally, Level 5 clients were those people with a perfect FIM Motor Score of 91 and with nil or minimum requirements for IADL assistance. We expected this group to have the lowest care needs.

SF –36 Multi-dimensional health status profile

The instrument selected for assessing quality of life in the national evaluation is the SF-36 quality-of-life measure. The SF-36 is a generic, subjective, health-related quality of life instrument, with questions that are designed to cover a broad range of disease groups of the general population. The eight scales measure both the positive and negative aspects of the following dimensions of a client's health: physical functioning; role limitations due to physical functioning; bodily pain; general health perceptions; mental health; social activities; limitations due to emotional difficulties; vitality. An additional item measures changes in the client's health over the past year (Kalucy, Hobbin et al. 1994).

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