

# ***CHERE***

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**Out of hours: An evaluation of the Continuing  
Community Cancer Care Program in Western Sydney**

**Mike Aristides, Alan Shiell, Jane Hall  
Sue Cameron, Jenny Madeline**

**Centre for Health Economics Research and Evaluation  
Department of Community Medicine,  
Department of Public Health, University of Sydney**

**CHERE  
LEVEL 6  
Bldg. F  
88 Mallett St.,  
Camperdown 2050**

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**Mike Aristides<sup>1</sup>, Alan Shiell<sup>1</sup>, Jane Hall<sup>1</sup>,  
Sue Cameron<sup>1</sup> and Jenny Madeline<sup>2</sup>**

**<sup>1</sup>Centre for Health Economics Research and Evaluation  
Department of Community Medicine  
Westmead Hospital**

**<sup>2</sup>Department of Medical Oncology and Palliative Care  
Westmead Hospital**

**Correspondence to:**

**Centre for Health Economics Research and Evaluation**

**CHERE**

**Level 6**

**Bldg. F**

**88, Mallett St.,**

**Camperdown 2050**

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The views expressed are those of the authors alone. We accept responsibility for any errors or omissions.

## ABSTRACT

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## ABSTRACT

The domiciliary after hours nursing service (AHNS) of the 4C (Continuing Community Cancer Care) Program in Western Sydney is registering approximately 550 people per year. In this discussion paper, the results of an evaluation of the AHNS are reported.

The service caters for clients with a variety of needs, providing emotional support as well as physical nursing care. Carer satisfaction with the service is high. The availability of the service alone (irrespective of whether it is used) is a source of satisfaction for many carers. However, the service has not succeeded in reducing admissions to hospital or length of stay. The cost of the program is therefore only partially offset by savings in hospital resources.

Only a small reduction in hospital use is needed to make the 4C program cost neutral. Improvements in program reach, and increased awareness of the program among GPs will increase utilisation and reduce the average cost of the program. A new drugs policy, allowing better out-of-hours access to anti-emetic and pain killing drugs, will also improve the effectiveness of the service and its efficiency.

## 1. INTRODUCTION

The Continuing Community Cancer Care Program (4C) was funded under the Medicare Agreement Incentive Package (MIP). This provided funds for innovative schemes designed to achieve more cost effective use of scarce hospital resources. A condition of funding was that the cost-effectiveness of projects be evaluated with continued funding dependent on successful results.

The 4C Program included capital funds to establish a day care centre, the provision of additional home care services and the establishment of a new consultative medical service. These services were integrated with those previously provided by general practitioners, specialists, hospitals, hospices and community health services. A key element of the 4C program was the After Hours Nursing Service (AHNS) which supplemented existing community nursing services and provided after hours and weekend domiciliary nursing care in the Western Sydney area for cancer and palliative care patients.

The aims of the 4C Program were;

- a) to provide cancer and palliative care patients and their carers with increased support and domiciliary care.
- b) to reduce hospital admissions and lengths of stay.
- c) to improve the quality of life of patients and carers.

In this discussion paper, selected results from the evaluation of the 4C program and the AHNS are presented. A report of the full evaluation is available. (Aristides et al 1992)

In section 2, the structure of the AHNS is described and in section 3, the methods adopted in the study are explained. The study comprised an analysis of both registrations and occasions of service data for all patients registered with the AHNS plus two additional surveys; a survey of carer satisfaction and an

assessment of the costs of the 4C program. The results from each of the four components of the study are presented in section 4. Conclusions and some discussion of the results are reported in section 5. The results of a sensitivity analysis, a brief review of the evaluative literature and an outline of the revised drugs policy introduced since the evaluation are contained in appendices.

## 2. STRUCTURE OF THE AHNS SERVICE

The AHNS commenced in the local government areas (LGAs) of Holroyd (Merrylands Community Health Centre) and Baulkham Hills (The Hills Community Health Centre) in September 1989, Blacktown (Blacktown and Mount Druitt Community Health Centres) in October 1989, Parramatta (Sydney Home Nursing Service, Parramatta) in November 1989 and Auburn (Sydney Home Nursing Service, Auburn) in February 1990. The AHNS supplemented the general community nursing service and provided out of hours support to cancer and palliative care patients in their own homes.

At any one time during the course of the study, between fourteen and eighteen registered nurses were employed by the Program (on a permanent, part-time basis). Most of these had community nursing and/or oncology/palliative care experience.

In addition to an initial orientation and training program, regular in-service days have been held to provide training and support in areas of need identified by community clinical nurse consultants, nursing unit managers and the after-hours nurses.

The actual hours covered by the AHNS differed in each of the LGAs but each sought to provide out of hours support to patients requiring palliative care. Staff were generally on-duty during weekday evenings and on-call at night and weekends.

Referral and discharge policies of the different community health centres also differed slightly. In general, patients were referred first to the General Community Nursing Service (GCN) which would then refer patients on to the AHNS if deemed appropriate.



### 3. METHODS

#### Overview

As noted, the evaluation comprised four distinct elements; analyses of registrations and occasions of service for all patients registered with the 4C program in 1991, plus two separate surveys, one of carer satisfaction and one of costs.

#### Data Collection

##### *Registrations data*

A registration form was developed by the coordinator of the 4C Project in association with members of the evaluation team, and medical and nursing staff to obtain a profile of the patients being referred to the after-hours nursing service.

The registration form recorded demographic information, diagnosis, current treatment, symptoms, medications, performance status, quality of life measures, household membership and support, client and carer preference regarding dying at home and discharge information such as reason for discharge and place of death. Two health status measures were recorded at the time of registration. First, the Eastern Cooperative Oncology Group (ECOG) functional performance scale which classifies individuals to one of five possible functional states (Oken et al 1982). Second, the Spitzer QL index in which scores of 0, 1, or 2 are assigned to each of five dimensions of health (functional activity, dependence in daily living, physical health, social support and emotional outlook) (Spitzer et al 1981). A total score can be derived from this measure by summing the individual dimensions (scores ranging from 0 to 10). Higher scores reflect a better state of health.

##### *Occasions of Service*

The occasions-of-service form recorded the numbers and nature of nurse-patient contacts. An occasion of service was defined as either a home visit or a phone call (initiated by the patient or by nurse). The form included information on the type

of shift being worked (whether on-duty or on-call), time of on-call occasions of service, type of patient, travelling time, services provided, contact with GP or specialist, administration of parenteral medication, outcome of visit/phone call and time spent with clients.

One form was used by each nurse for each shift and on-call period in each centre. Only phone calls with a "significant therapeutic content" were recorded. This proved difficult to define and despite efforts to encourage uniformity on this issue, there was variation in the way this criterion was interpreted.

#### *Carer satisfaction*

The carer satisfaction survey was set up to assess whether the aims of the program were being met from the client's point of view. Ideally, this would have involved surveying the patient as well as the carer. However, to avoid the possibility of further distressing patients who were already seriously ill, it was decided to survey carers only. The survey asked about the carer's satisfaction with the service as carers are as much clients of the AHNS as the patient. Carers' views cannot be used as a proxy for patients' views (Higginson et al 1990).

Patients who died between April and November 1991 and who had lived within the boundaries of the Western Sydney Area Health Service were identified from the Department of Medical Oncology database. The carers of these patients (n = 66) were traced through hospital records and community health centres. A letter explaining the study was sent to each carer by the former patient's doctor, between 4 and 6 months after the patient had died. One of two interviewers followed up this letter with a telephone call requesting an interview appointment. The interviews lasted about half an hour and were done in the carer's home.

Carers who declined a full interview were requested on the telephone to answer three questions; one general question about satisfaction with the service, one on the importance of the availability of the service, and one on the extent of physical fatigue caused by caring for a dying person.

The interview questionnaire had three parts. The first part contained questions about the employment of the carer and the patient prior to the patient's illness; the patient's age at time of death; the number of people living in the household and their relationship to the carer and the approximate number of visits made by the after-hours nurses.

The second part was modelled on a questionnaire developed by Wiggers et al (1990), from work by Cockburn et al (1991), Risser (1975), and Ware and Snyder (1975). This had twenty six statements which covered four topic areas: convenience and accessibility of the service, staff interpersonal skills, information transfer between staff and client, and perceived competence of staff. Statements were paired, with one phrased in the positive and one phrased in the negative, to enable testing for internal consistency. The carers were asked how much they agreed with each statement and were offered a choice of the following responses: strongly agree, agree, undecided, disagree, or strongly disagree. Then they were asked how important to them was the issue raised by the statement. This time four possible responses were offered; very important, moderately important, slightly important, not at all important. For this part of the questionnaire, the statement was always phrased in the positive. In piloting, it was found that alternate use of positive and negative phrasing easily confused respondents.

The third part of the questionnaire was designed to gauge the carers' attitude towards the service overall. The three questions mentioned above for the telephone interviews were repeated and the carer's comments on the service, including suggestions for improving it, were solicited in an open-ended question.

### *Costs*

The evaluation of costs sought to compare the costs of running the 4C program with the value of hospital resources released because of the prevention of admissions or the reductions in lengths of stay. The use of hospital bed days and hospital costs incurred by patients during the last ninety days of their life were compared before and after the introduction of 4C.

Patients included in the cost study had been treated in the Department of Medical Oncology, Westmead Hospital which is the main tertiary referral centre for cancer care in the Western Sydney Area. The 'before' group consisted of 153 patients who were referred to the Department of Medical Oncology and who died during 1987 and 1988. The absence of a comprehensive cancer register meant that these patients had to be selected from inpatient records. Therefore, all patients in the 'before' group had at least one admission to Westmead Hospital at some time during their illness though this was not necessarily during the last ninety days of their life. The impact that this bias in patient selection has on final results is discussed later. Patients in the 'after' group were selected from a newly compiled clinical database. Between May 1990 and April 1991, there were 123 recorded deaths of patients of the Department of Medical Oncology who were eligible for 4C services. However, not all of these patients received 4C services. For example, patients with colon cancer were excluded because of a change in treatment (the introduction of adjuvant chemotherapy) between 1987/88 and 1990/91.

The dependent variables for the study were the number of days in public hospitals during the last ninety days of life and their costs. Details of the number of admissions and lengths of stay for patients in the before and after groups were obtained from all six public hospitals in the Western Sydney Area.

The cost of hospitalisation was estimated for four wards in two representative hospitals. A top-down method was adopted in which the annual expenditure of the hospital was apportioned to ward level. The costs included staff time, consumable costs, overheads and capital (Drummond et al 1987). Costs of medical staff time were based on an estimate of the proportion of time each clinician spent on the oncology wards. Nursing costs were based on the staffing establishment of each of the wards. Overhead costs were allocated according to appropriate "rules of thumb". Thus, laundry costs were allocated pro rata to the number of items of laundry sent from the oncology wards.

The estimates reflect the economic value of an inpatient day on the assumption

that resources released by preventing admissions or reducing lengths of stay are made available to other patients. The cost estimates do not reflect the financial savings that would be realised if inpatient days were reduced and beds closed down. Financial savings will be lower than the estimates of economic costs because of the existence of fixed costs.

The annual expenditure of the 4C program in Western Sydney in 1991/92 was \$580,000. The net cost of the program therefore is the difference between the annual expenditure and the value of the bed days released.

### **Statistical analysis**

Simple frequency counts of the registration and occasions of service data and the results of the carer satisfaction survey are reported.

A chi-squared test was used to test for differences in the proportions of patients who were admitted to hospital before and after 4C. The distribution of the length of stay data for patients who were admitted was highly skewed and so a non-parametric test (Mann-Whitney) was used to test for differences in inpatient days and costs. A one-tailed test was used in the comparison of inpatient days because the introduction of 4C was not expected to increase lengths of stay. Costs, however, are influenced both by the number of days in hospital and by any shift between high cost and low cost hospitals. The direction of any change in costs following the introduction of the 4C program was uncertain and so a two-tailed test was used to compare costs.

## 4. RESULTS

### Registration data

#### *Number of registrations*

Over the course of the study, 412 registration forms were sent to the study team but reporting by CHCs to the NSW Department of Health indicate 544 registrations over the same period. The discrepancy arises partly because of missing data but also because some patients did not consent to having their registration details disclosed to the study team. Over 90% of registrations are new or initial registrations.

The main sources of referral to 4C were from the discharge planner (62%) or the GP (8%).

#### *Demographic details*

Fifty four percent of clients were males. The median ages of clients were 66 years for men and 65 years for women. Seventy percent of the client group were aged over 54 years (table 1). Most clients (70%) were born in Australia and a further 9% originated from the United Kingdom. Two thirds of clients were married or in a de facto relationship, 24% were widowed, 7% were single and 1% were divorced or separated.

#### *Carer support*

Almost one-third of clients (31%) were totally dependent on others for activities of daily living. One fifth of clients could care for themselves and the remainder needed some support from others.

#### *Duration on 4C program*

Duration on the 4C program is shown in table 2. The median length of stay on 4C was 60 days. Not surprisingly, the main reason for discharge was death (70% of discharges). Next in importance was admission to hospital and to hospice (approximately 8% of discharges each).

**Table 1: Demographic characteristics of clients**

<u>Age</u>	<u>Number of Clients (%)</u>		
	<u>Male</u>	<u>Female</u>	<u>Total</u>
0-14	2 (1)	1 (-)	3 (-)
15-24	4 (2)	1 (-)	5 (1)
25-34	7 (3)	9 (5)	16 (4)
35-44	12 (5)	24 (13)	36 (9)
45-54	21 (10)	25 (13)	46 (11)
55-64	48 (22)	30 (16)	78 (19)
65-74	76 (34)	54 (29)	130 (32)
75-84	44 (20)	28 (15)	72 (18)
85+	1 (-)	9 (5)	10 (2)
<b>TOTAL</b>	<b>221(100)</b>	<b>188(100)</b>	<b>409 (100)</b>

**Table 2: Duration on 4C program**

<u>Duration</u>	<u>Number of Clients (%)</u>	
< 1 week	34	(9.9)
1-2 week	28	(8.2)
2-4 week	46	(13.4)
1-2 month	65	(19.0)
2-4 month	86	(25.1)
4 months	84	(24.5)

*Diagnosis and health status*

Diagnosis is shown in table 3. The most commonly experienced symptoms were weakness (60%), pain (54%) and nausea, constipation and anorexia (25%).

<b>Type of Cancer</b>	<b>Male n (%)</b>	<b>Female n (%)</b>	<b>TOTAL n (%)</b>
Breast	(-)	57 (31)	57 (14)
Small cell lung	24 (11)	15 (8)	39 (10)
Melanoma	7 (3)	3 (2)	10 (2)
Colorectal	23 (11)	19 (10)	42 (10)
Non-small cell lung	22 (10)	7 (4)	29 (7)
Stomach	8 (4)	4 (2)	12 (3)
Adenocarcinoma	10 (5)	9 (5)	19 (5)
Prostate	21 (10)	0 (0)	21 (5)
Other	87 (40)	57 (31)	144 (35)
Other disease	15 (7)	17 (9)	32 (8)
<b>TOTAL</b>	<b>219(100)</b>	<b>187(100)</b>	<b>406(100)</b>

According to responses to the ECOG questions, 39% of clients were confined to bed or to a chair, or were totally disabled. Responses to the Spitzer QL index indicated a range of severity of illness rather than a high proportion of people in the poorest health states.

### *Outcome*

28% of clients died at home, 49% of clients in a hospice, 20% of clients in hospital and 1% of clients in nursing homes. Some 75% of the information on client and carer wishes on place of death was missing because nurses experienced difficulties in asking this question. Of those who were asked and who answered the question, 83% of clients wished to die at home. This corresponded with 75% of carers who wished for death to be at home. It would appear that client and carer wishes are closely related. However, only 32% of clients and carers who expressed a preference for death to be at home, had their wishes met.



## Occasions of Service Data

There were 5225 (88%) occasions of service performed during on-duty hours and 734 (12%) performed whilst on-call (table 4).

**Table 4: Services provided by type of shift**

Service Provided	On-duty (% of occasions of service) <sup>1</sup>	On-call
Routine check	38	6
Physical Nursing Care	40	23
Treatment	25	37
- Pain	8	7
- constipation	3	11
- dyspnoea	9	18
- nausea	21	37
- other		
Diagnosis or clinical decision- making	17	33
Emotional/social support of client	66	41
Emotional/social support of carer/s	51	48
Information or education	20	21
Other services	8	10

1. More than one outcome per occasion of service. Therefore totals do not add up to 100.

Eighty per cent of occasions of service performed whilst on-duty were visits by a single nurse, 13% were phone calls by a nurse, and only 6% were phone calls by the client/carer. Sixty per cent of occasions whilst on-call took the form of a phone call from the client/carer (only 10% were phone calls from the nurse) and 30% took the form of a visit by a nurse.

The average number of occasions of service per shift for the four centres which regularly operated four-hour shifts was estimated to be 2.7. In a typical four-hour

shift, about 45% of time was spent in direct patient contact, 20% of time was spent travelling to and from patient's homes and 35% of time was spent on staff-handover, administration, self education and unrecorded phone contacts.

The most frequent types of service provided whilst on-duty were; emotional support for the client (66%) and for the carer (51%), physical nursing care (40%), a routine check (38%) and treatment for pain (25%). The most frequent services provided whilst on-call were emotional support for the carer (48%) and for the client (41%), treatment for pain (37%), diagnosis or clinical decision-making (33%) and physical nursing care (23%).

Nurse-reported outcomes of the occasions of service are presented in table 5. Each occasion can have more than one outcome. On-duty, the most frequently reported outcomes were; the reassurance of client or carer (80%), meeting the physical needs of clients (35%) and the control of symptoms (21%). Clients were admitted to hospital in 1% of the occasions of service and in 5% of occasions, a hospital admission was said to be averted. On-call, the most frequently reported outcomes were the reassurance of client or carer (60%), the control of symptoms (26%) and a home visit (24%). Clients were admitted to hospital in 6% of the occasions of service, and in 16% of nurse contacts an admission was reportedly averted.

On-duty activity therefore involved a high proportion of emotional support, physical nursing care and routine checks rather than treatment for symptoms. In contrast, on-call activity involved relatively more symptom treatment and clinical decision-making.

**Table 5: Nurse-reported outcomes by type of shift**

<b>Outcome</b>	<b>On-duty (% of occasions)<sup>1</sup> of service</b>	<b>On-call</b>
A home visit	5	24
Physical needs met	35	18
Client/carer reassured	80	60
Symptoms controlled	21	26
Hospital admission	1	6
Hospital admission averted	5	16
Unable to meet client needs over symptom control	4	7
Unable to meet client needs other than symptom control	1	1
Recommended referral to other services	<1	1

1. More than one outcome per occasion of service. Therefore totals do not add up to 100.

## **Carer Satisfaction Survey**

### *Demographics*

Of the 66 patients identified, 21 had not received AHNS, 3 lived outside of the area and 3 had no carer. Thirty nine carers were approached, of whom, 30 agreed to be interviewed in person, 3 answered the telephone questions only and 2 refused. Four carers could not be contacted.

Twenty four of the respondents cared for their spouse, five cared for a parent, and one cared for a daughter. The patients they cared for were aged between 34 and 79 years when they died. Nine carers lived with their spouse-patient only, sixteen lived with their spouse-patient and children or other relatives and two carers lived separately from their parent patients but one of those lived in an adjoining granny flat. The remaining three carers had assistance from other family members who lived in the household.

Twenty five of the carers were in paid employment prior to the patient's illness. Twelve of these took time off work to care for the patient and five shared the care with other family members while remaining employed. Thirteen of the carers were retired or otherwise not employed outside the home. The number of visits by the nurses to each patient ranged from just one or two visits, to about eighty.

#### *Reliability and validity*

Close agreement in the distribution of responses between pairs of statements relating to the same issue indicated good internal consistency. One exception to this was the following pair of statements: "I would have liked more help to deal with the emotional and other non-medical problems caused by cancer" and "The nurses helped me to feel more able to cope with my life". Some carers interpreted the extra "help" as coming from family and other supportive people, rather than the nurses. Another carer wanted practical assistance in the home, eg. for meal preparation, so she would not have to leave the patient's bedside, but obviously did not expect the nurses to do this.

When asked how important each issue was, 73% of carers replied that three quarters of the issues were very important to them. The fact that nurses were available to provide counselling support for carers after the death of the patient, was not covered by the questionnaire, but this was the only outstanding issue mentioned by a few carers in the comment section. This suggests that the questionnaire had good content validity, covering most of the important dimensions of patient satisfaction.

#### *Results (Satisfaction / Importance)*

Satisfaction was measured in four areas: convenience and accessibility of the service, staff interpersonal skills, information transfer between staff and client, and perceived competence of staff.

(a) *Convenience and accessibility of the service*

A very high level of satisfaction was indicated in all responses by a large majority of carers (table 6). For clarity, the categories of "strongly agree" and "agree" are combined, as are "strongly disagree" and "disagree". Note that there was a total of 30 carers and some statements were deliberately stated in the negative.

**Table 6:**

**Convenience and accessibility of nursing service**

STATEMENT	NUMBER OF CARERS		
	who agreed with statement	who disagreed with statement	who regarded aspect as very important
I felt I had to wait far too long for the nurse to come	0	29	25
The nurses seemed to hurry through their visits	1	29	24
There was no unnecessary delay in starting the nursing care	29	0	27
I found the nurses did not call at a convenient time	1	27	17
I am sure that the organisation of the nursing service was as good as it could be	28	1	27
The hours the nurses were available were convenient	28	2	27
I think the Nursing Service could be run much more efficiently	2	27	23

(b) *Information transfer*

The level of satisfaction indicated by responses to statements about information transfer was not quite as high as the previous category, but was still rated very positively by the majority of carers (table 7). Two statements produced the greatest range of response: "dealing with the

emotional and non-medical problems caused by cancer" and "dealing with the spiritual issues in cancer care". The responses to the first statement sometimes related to practical issues, such as knowing about home-help or other hiring services. The responses to the second were more controversial, as some carers felt that this was not the role of the nurses. Some reported that only one of the visiting nurses "touched on it" and another nurse refrained from discussing the issue because she respected the family's decision not to inform the patient he was dying. Five carers were undecided on this question and three thought it irrelevant.

**Table 7:**

**Information transfer between nurse and carer**

STATEMENT	NUMBER OF CARERS		
	who agreed with statement	who disagreed with statement	who regarded aspect as very important
The nurses taught me how to manage the symptoms	19	8	23
The nurses used words that were hard to understand	0	28	27
I would have liked more help to deal with the emotional and other non-medical problems caused by cancer	10	17	22
The nurses helped me to adjust to some of the changes caring for a cancer patient have caused in my life	21	4	22
The nurses told me all I wanted to know about what could be expected next	23	4	27
The nurses neglected spiritual issues in cancer care	4	16	13

(c) *Staff interpersonal skills*

There was a very high level of satisfaction with staff interpersonal skills (table 8). Two statements were clearly of less importance than the others. These were: "The nurses helped me to feel more able to cope with my life" and "It was difficult having different nurses providing the after hours care". Three carers disagreed with the first statement and another five were undecided or thought it irrelevant, because they expected that support from family members, the priest or the daytime palliative care nurses only. Five carers who agreed with the second statement found it difficult to relate to more than one nurse, while eight carers found the statement irrelevant for them because they had only one nurse visiting. Only one carer did not feel at ease communicating with the nurses.

**Table 8:**  
**Staff interpersonal skills**

STATEMENT	NUMBERS OF CARERS		
	who agreed with statement	who disagreed with statement	who regarded aspect as very important
I felt free to ask the nurses questions I wanted to ask	29	1	29
The nurses could have done more to make me feel reassured about the treatment they provided	1	27	25
The nurses seemed to understand how it felt to have cancer	25	1	28
I feel I had the chance to speak freely to the nurses	29	0	28
The nurses helped me to feel more able to cope with my life	22	3	18
It was difficult having different nurses providing the After Hours care	5	17	15

(d) *Perceived competence of staff*

There were some negative responses to the statements in this topic area though an overwhelming majority of carers was still very satisfied with the competence of the nurses who visited (table 9). Of the four carers who agreed with the statement: "The nurses did not know how to keep the cancer symptoms under control", one felt there was nothing anyone could have done about the symptoms; another complained about a relief nurse who did not seem fully briefed about the patient, did not advise adequately over the telephone and was not able to provide any stronger medication to control the patient's pain. Another carer thought symptom control was the responsibility of the doctor, rather than the nurse.

**Table 9:**

**Perceived competence of staff**

<b>STATEMENT</b>	<b><u>NUMBERS OF CARERS</u></b>		
	<b>who agreed with statement</b>	<b>who disagreed with statement</b>	<b>who regard aspect as very important</b>
The nurses did not know how to keep the cancer symptoms under control	4	23	29
I was very satisfied with the care received from the nurses	29	1	30
I felt confident that the nurses knew their jobs well	28	1	29
The service provided by the nurses was much worse than I expected	1	29	25
I would hesitate to recommend this service to a friend who needed after hours nursing	2	28	29
I could not find any faults in the nursing service provided	27	3	26
The nurses always seemed to know what they were doing	26	3	28



In response to the statement: "The nurses always seemed to know what they were doing", one carer felt one nurse demonstrated insensitivity when offering home aids to the patient who was still denying his illness. Another carer complained that a catheter could not be re-inserted at midnight without the patient being hospitalised, and another carer thought the night nurses were not as well informed as the daytime nurses about their patients.

(e) *Overall satisfaction*

Overall satisfaction with the AHNS was very high; 23 of the 30 carers were very satisfied and only 2 cases were dissatisfied or worse. One was the daughter of a man who deteriorated markedly and died after being taken to hospital at midnight to have his catheter replaced. It was the carer's belief that After Hours nurses were not allowed to re-catheterise males though there is no such rule. The carer complained of a lack of support for relatives both prior to and after the death of the patient; and a lack of information about other available services, eg. linen services, bed hire and special allowances.

The second dissatisfied carer complained that the relief nurse did not know the background to the patient's illness when the family rang for advice after 10pm. The available medication was ineffective to relieve the patient's pain and the family felt they did not receive enough help.

All the other comments were very positive. All respondents agreed that the after hours nursing service was very important in allowing the care for the patient at home even though it did little to alleviate carer fatigue. The support and reassurance provided simply by the availability of the service were identified as important contributors to carer satisfaction.

Some suggestions were made to enhance the service: more publicity aimed at informing GPs and hospitals as well as the public, more access to pain-

relief, more contact with ministers of religion, more home-help, and better supply of respite beds.

## Cost evaluation

### *Characteristics of the two groups of patients*

The proportion of males to females was higher in the 'before' group though the mean age and age range are similar to each other in both groups (table 10). Clinical advice indicated that site of cancer was not relevant to the need for palliative inpatient care and so subsequent analysis compares the whole groups without further reference to cancer site. Of the 123 patients in the study group, only 86 (72%) received after hours nursing care.

Table 10

### Demographic characteristics of patients in costing study

	Before Group (n = 153)		After Group (n = 123)	
	Males	Females	Males	Females
Number (%)	84 (55)	69 (45)	60 (49)	63 (51)
Age (years)				
- mean	65	58	62	55
- range	25-86	18-78	18-87	33-82

### *Hospital use*

A higher proportion of patients was admitted before the introduction of 4C than afterwards but the difference is not statistically significant at conventional levels. There was also a shift in admissions away from the tertiary centre to non-tertiary hospitals (table 11).

The average number of days spent in hospital (not necessarily in a single admission) by a patient once he or she had been admitted fell slightly following the introduction of 4C from 23.8 days to 22.9 days. The difference is not statistically significant at conventional levels indicating that 4C was not successful

in reducing length of stay once a patient had been admitted to hospital.

**Table 11**

**Effects on hospital use**

<u>Proportion admitted to hospital</u>	<u>Before (%)</u>	<u>After (%)</u>
Tertiary	92%	82%
Non-tertiary	10%	27%
All	93%	90%

<u>Number of days in hospital (if admitted)</u>	<u>Before (days)</u>	<u>After (days)</u>
Tertiary	22.7	20.6
Non-tertiary	13.9	14.8
All	23.8	22.9

<u>Mean number of days in hospital (all patients)</u>	<u>Before (days)</u>	<u>After (days)</u>
Tertiary	20.8	16.7
Non-tertiary	1.5	4.0
All	22.2	20.8

Average bed-day use for the groups as a whole (including both admissions and non-admissions) fell from 22.2 days to 20.8 days, though once again, the difference is not significant at conventional levels.

*Costs*

The 4C program reduced average hospital costs per patient by some \$300, but the difference in cost before and after the introduction of 4C was not statistically significant (table 12). Over 550 patients registered with 4C AHNS during the 1991/92 financial year, which, with annual expenditure of \$580,000 translates into an approximate average cost per patient of \$1000. Therefore, the net cost of the 4C program (average cost of the program minus the value of hospital resources freed for other uses), is approximately \$700 per patient.

Table 12

Mean costs per patient

	<u>Before (\$)</u>	<u>After (\$)</u>
Hospitalisation	5075	4745
4c program	-	1000 <sup>1</sup>
<b>TOTAL</b>	<b>5075</b>	<b>5745</b>

<sup>1</sup> Approximation based on the annual costs of 4C divided by the number of patients registered in first year.

*Sensitivity analysis*

Sensitivity analysis is used to assess the effect of changes in key parameters to results. In this way, the potential for 4C to save resources can be estimated. An analysis was undertaken to determine the reduction in hospital bed-days which would be needed to make the program cost neutral (appendix 1).

The results of the analysis suggest that the program could be made cost neutral if hospital use could be reduced by 4 days per patient.

## 5. CONCLUSIONS AND DISCUSSION

The after hours nursing component of the 4C program is registering approximately 550 people per year distributed reasonably evenly across CHCs. A small proportion of these are likely to be re-registrations. There are about 1000 deaths from cancer in Western Sydney each year and so, as a crude estimate, the 4C program is reaching about 50% of its potential clients. The number of new cases of cancer each year exceeds 1500 and so the potential demand for 4C services is large.

As expected, the hospital discharge planner was the most frequent source of referral. The proportion of patients referred by GPs was very low. This may indicate a need to promote the service further to GPs, a view reinforced by some of the comments of the carers who complained about the lack of information on the availability of the service. Improved information to GPs may also serve to improve program reach.

Differences have emerged among CHCs with respect to time of referral. Some patients are not being referred (either by GCNs or externally until their disease is relatively advanced. Given that 4C aims for early referral, further consideration might be given to the reasons why this is occurring.

On-duty activity by the nurses involved a high proportion of emotional support, physical nursing care and routine checks rather than treatment for symptoms whereas on-call activity involved relatively more symptom treatment and diagnosis/clinical decision-making.

There is a very high level of carer satisfaction in three out of four topic areas covered in this survey. In the fourth area, that of information transfer, the response was still very positive, although not as strong. The large majority of carers was very satisfied with the service overall, and all of those carers who responded thought it was very important that the service was available. Not

surprisingly, the AHNS does not alleviate fatigue in carers. However, the reassurance in knowing the service was available was valued highly by carers including those who did not make use of the service but felt comforted by its availability should they have needed help.

The level of complaints is also minimal particularly when compared with the amount of negative feedback about the hospital service from the same group of people. However, the explanation of this may lie outside differences in the quality of care and may be due to unresolved grief reactions or misunderstanding of medical procedures. Therefore it is essential to ensure that sufficient grief counselling is available from nurses or other professionals, that channels of communication such as inter-shift meetings and charts in patients' homes are maintained between staff, and that careful and repeated explanations are given to patients and carers about treatment.

The impression of the After Hours Nursing Service from this part of the study is that it is working extremely well, but that it could be more widely publicised by making printed information about 4C available to the community at large, to patients and carers prior to hospital discharge, and in GPs' surgeries. This may cause the service to be used more extensively and its benefits spread to more people. The efficiency of the program, in terms of enhancing the quality of life of terminally ill people and preventing unnecessary hospital admissions, could be improved by the nurses having more access to pain/symptom-relieving drugs.

Following the introduction of the domiciliary palliative care nursing service, there has also been a switch in admissions away from the tertiary centre and towards other hospitals. However this is not necessarily related to the 4C after hours service. The total demand on public hospital beds and inpatient costs incurred by patients formerly treated in the Department of Medical Oncology have also fallen. However, the difference in resource use and cost before and after the introduction of the 4C program was not sufficient to reach statistical significance.

Unavoidable limitations in the design of the cost study may have introduced bias. Patients in the before group were known to have had at least one admission to hospital at some time during the course of their illness though not necessarily during the last ninety days of their life. If this had any effect, it was to inflate the number of inpatient days and costs in the before group. This bias, if it occurred, therefore favoured the 4C program and so the conclusion that there was no difference in costs before and after the introduction of 4C is reinforced.

The second source of bias arises from temporal trends in length of stay. Average lengths of stay for many diagnoses are falling over time for reasons other than early discharge schemes (Clavarino and Gibberd 1991). If there has been any downward shift in the length of stay of patients in the terminal stage of their illness over the two years studied then this will also have distorted the comparison of hospital use before and after the introduction of 4C. However, this source of bias also favours the 4C program further reinforcing the conclusion that the program did not reduce demand on hospital beds.

Finally, it was not possible to examine admissions to any private hospital or to public hospitals outside of the Western Sydney Area. The possibility that patients may have received inpatient care in other public hospitals or in private hospitals means that total bed-day use both before and after the introduction of the 4C program may be underestimated. The extent of this underestimate and the direction of any bias so introduced is unknown.

The finding that the 4C program has not resulted in net cost savings means that its continued funding depends on the value of any benefits of the program or on the scope to reduce costs in the future. Previous evaluations of palliative care have not shown convincingly that programs improve the quality of life of patient or carer (appendix 2). However, the 4C program supplemented existing services for patients in the terminal stages of illness and so it is difficult to see how patients could be any worse off than before. It was not possible to measure client quality of life during the terminal stages of illness but the results of the carer satisfaction

survey indicate strong support for the program. Neither was it possible to evaluate the effects of other aspects of the 4C program apart from the after hours nursing service.

Therefore, the benefits of the program cannot be specified in terms comparable with costs. Policy makers must decide whether the improvement in carer satisfaction (plus the unknown impact on client welfare) is sufficient to justify the program's costs of approximately \$700 per patient.

Increased utilisation will reduce the average cost of the program. Alternatively, to make the program cost neutral, reductions in hospitalisation of about 4 days per patient are required. The ability of the nursing staff to reduce admissions over the period of the study was limited by a drugs policy which hindered their access to anti-emetic and pain controlling drugs outside of normal working hours should a change in prescription be necessary. The policy has now been changed to allow after-hours nurses to carry such drugs (appendix 3). This may lead to better control of symptoms and therefore reduce the need for crisis admissions to hospital.

As there is potential for both improved health benefits and cost savings it is recommended that the funding of the program should continue subject to continued monitoring of bed-day use and, if possible, assessment of client health.



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## Appendix 1

### SENSITIVITY ANALYSIS OF RESOURCE CONSEQUENCES FOR 4C.

Sensitivity analysis is used to assess the effect of changes in key parameters to results. In this way, the potential for 4C to save resources can be estimated. The annual running costs of 4C are likely to be synonymous with the net costs of the program because no differences in hospital costs were detected. An analysis was therefore undertaken to determine the levels of bed-day saving necessary to make the net costs of the program zero.

The parameters of interest and prone to measurement error in this context are; bed-day costs, the number of bed-days saved by 4C and the expected number of annual registrations to 4C. Four estimates of bed-day cost were used, ranging from \$180 to \$280. Four measures of the number of expected registrations (throughput) for Western Sydney were also used; the number of initial registration forms received (412), the number reported by the CHCs themselves (544), also 500 and 600 as hypothetical values.

The number of bed-days saved is either generated or is specified within the analyses and the average expected length of stay per admission is assumed to be 10 days. The annual costs of the program are taken to be stable at a real cost of \$580,000 in today's prices.

The analysis answered the question, how many days and admissions need to be saved per patient registered with 4C for the program to release as many resources as it costs?

For the low estimate of throughput and lowest estimate of cost (the most pessimistic), it is estimated that 7.7 hospital days would need to be saved per patient for 4C to be cost saving. For the highest estimate of throughput and highest estimate of bed-day cost (the most optimistic) only 3.4 days need to be saved per patient.

All results are illustrated in figure 1 where for a given cost schedule, points on the line indicate the combination of throughput and the number of bed-days saved per patient that lead to a total cost saving. Points above these lines indicate combinations where there are positive savings generated. The current location of 4C in this space is identified by the box '4C'.

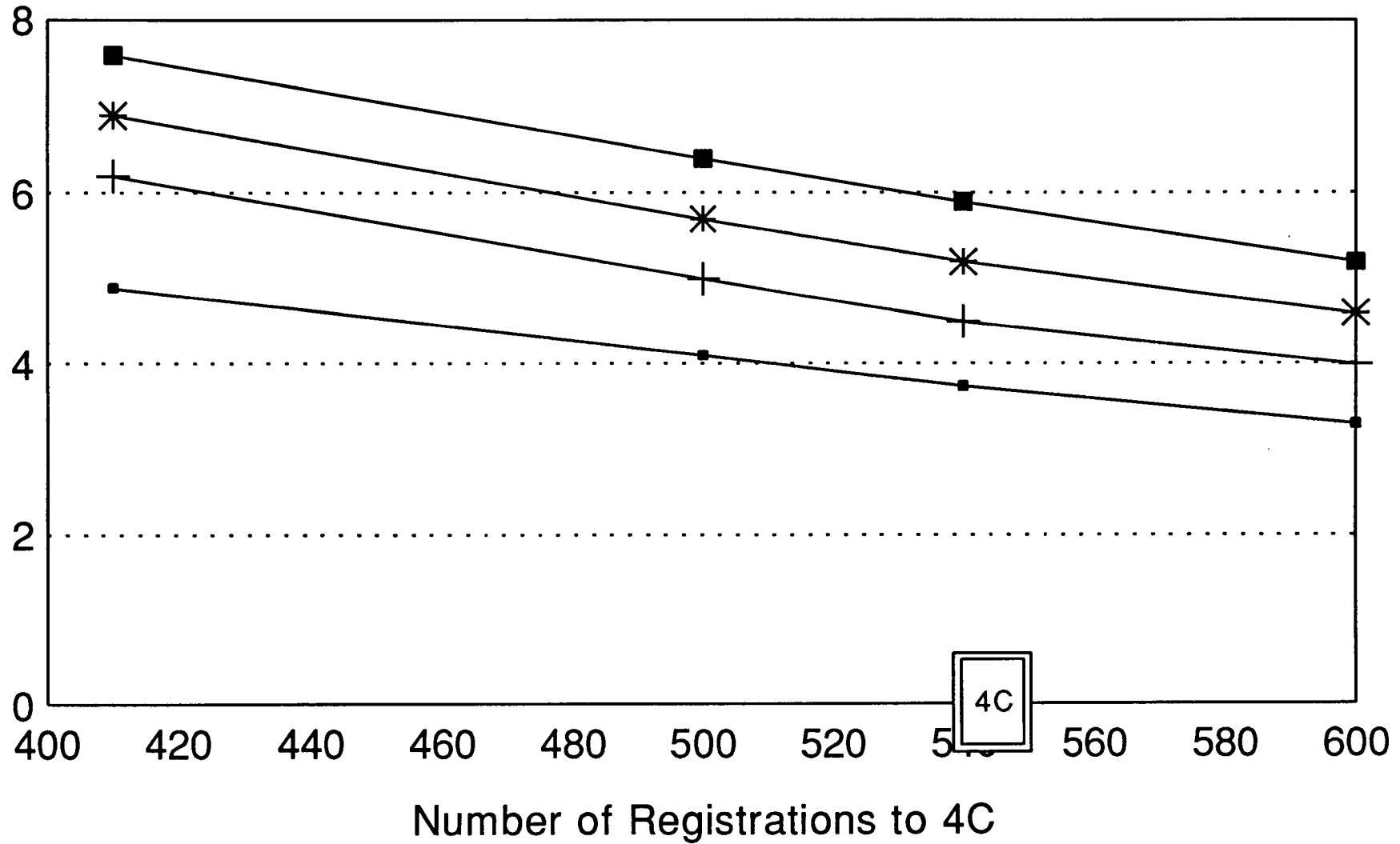
It is felt that the most realistic scenarios consider throughput to be at least at the level self reported by the CHCs (544 patients per year). For the range of costs approximated, this scenario suggests between 3.8 and 4.6 days need to be saved per patient: Where throughput increases to 600 patients per year within Western Sydney (an increase of roughly 10%), between 3.4 and 4.2 days need to be saved per patient. The extremes from these last two ranges will, it is felt, best reflect

the required range of bed-day savings to make 4C cost saving in resource terms is between 3.4 and 4.6 days.

This is a relatively narrow range and hence makes for a reasonably confident forecast that the program can be cost saving if it manages to prevent these numbers of days in hospital per registration.

Figure 1

### Number of Bed Days



32

■ cost=\$181 + cost=\$204 \* cost=\$232 ■ cost=\$282

note: 4C currently located on X axis



## Appendix 2

### LITERATURE REVIEW

Seven studies published during the 1980s analysed the costs and/or the benefits of palliative care services. Two of the programs (Gray et al, 1985 and Hannan and O'Donnell 1984) concern domiciliary palliative care services; the remaining five concern institutional hospice programs.

Hannan and O'Donnell (1984) evaluated three types of palliative care services in the U.S (one community based and two institution based) in terms of costs and patient satisfaction. There is little description of the structure and content of the services and consequently it is difficult to draw inferences from their results to 4C. The cost of the community program was lower than the two institutional programs and the costs for each of these were lower than the costs of conventional care. Patient satisfaction, as assessed by proxy with an interview with the principal care giver, was high for all three programs. Satisfaction for the community program was lower than the others because of difficulties in coordinating inpatient episodes with the visiting service.

Gray, et al. compared the cost of a domiciliary palliative care service with that of conventional care in Western Australia. Two matched groups were compared in terms of hospital use during the last 90 days of life. This program is similar to 4C. It differs in that medical oncology services were not expanded (as with 4C) and nursing staff were headed by a medical officer attached to the program rather than by CHC nursing unit managers. Also, special night nurses were employed to be with the patient throughout the night if the patient would otherwise have gone to hospital.

Ninety eight patients were matched on age, sex and site of cancer. Control patients were selected from the same locality as program patients and the distribution of cancers for the study group was compared with all cancer deaths in the Perth region. The authors found no differences in the costs of management per day but patients receiving the domiciliary service lived longer.

Five studies have considered institutional based palliative care. Four concluded that hospice care costs were the same as or more expensive than conventional care. (Gray, 1982, Greer et al, 1986, Kane et al, 1984, Dunt et al, 1986). One study found hospice costs to be lower (Davidson, Evans et al 1981). Three of the studies looked at the benefits of the services. Quality of life assessments performed by interviewing spouses or principal care givers, suggested no differences (Greer et al, 1986, Kane et al 1984 and Dunt et al, 1986). Dunt et al. (1986) found that hospice patients in Victoria tended to suffer less shortness of breath, had less severe and less frequent pain and had more contact with health workers. Satisfaction levels with the programs were shown to be high for patients. For carers, extra fatigue led to lower satisfaction scores than the comparison group. In the other two studies the carers experienced greater satisfaction with hospice care (Greer et al, 1986, Kane et al, 1984).

The results show palliative care services to be at least as costly as conventional care. In terms of the benefits, there are doubts as to whether the quality of remaining life is improved but satisfaction with the programs tends to be high. The results of these studies cannot easily be applied to 4C because they concern different types of programs and the descriptions of program content and structure are vague.

## Appendix 3

### 4C Program Drug Policy

The drug policy was developed over a two-year period in consultation with GPs, community and hospital nursing and medical personnel, the Pharmaceutical Services Branch of the NSW Department of Health and the Drug Committees of Westmead and Mt Druitt Hospitals, and implemented late in 1991. Its aim is to provide patients being cared for in the community with better access to drugs after hours to enable relief of symptoms and reduce unnecessary visits to hospital.

Before, GPs and specialists were encouraged to provide drugs and/or scripts in anticipation of changes in their patient's condition, but situations invariably arose where patients required antiemetics, a stronger analgesic or a change from oral to subcutaneous analgesia etc. after hours. As GPs and specialists (and pharmacists) were usually unavailable after hours, access to the necessary drugs was often difficult.

The new Drugs Policy provides for the following:

- a) Accreditation of after-hours nurses, following training and assessment in the appropriate medication for pain, nausea and other symptoms;
- b) a "Medical Practitioner's Authority for Administration of Medication" (signed by the patient's GP or specialist);
- c) Drug Kits containing small quantities of Schedule 4 drugs (carried by the after-hours nurses) and;
- d) a 4C Program drug cupboard containing small quantities of Schedule 8 drugs (located in the Accident and Emergency Departments of Westmead and Mt Druitt Hospitals).

Once a "Medical Practitioner's Authority" has been signed, a copy is sent to the Westmead or Mt Druitt Accident & Emergency Department and the original placed in the patient's home. If an after-hours nurse feels that it is necessary to act on the policy and administer a drug, she/he must first attempt to contact the patient's medical practitioner. If she/he is unavailable, then the Medical Oncologist on call from Westmead Hospital must be contacted to provide authorisation. Ethical, legislative and administrative obstacles prevented implementation until December 1991, which was after the period covered by the evaluation.



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