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The First Year of The Care Continuum and Health Outcomes Project

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EXECUTIVE REPORT

This is the third report to the Commonwealth Department of Health and Family Services on the Care Continuum and Health Outcomes Project (CCHOP). It covers the first year of the study's operation, highlighting the broader context of the study in relation to the ACT Department of Health and Community Care; providing preliminary results on three months of data collection from the hospital interview questionnaire; and focusing on methodological issues arising from the research.

The main features of the report include an analysis of service use leading to a hospital admission, comparing low, moderate and high-end users of services on a number of socio-demographic and clinical indicators. Also, the report provides a preliminary investigation of the validity and reliability of the Medical Outcomes Study's SF-36 health status indicator, showing the diversity of correlates that influence the eight scales of the measure. Other features of the report include a description of the record linkage and electronic data storage aspects of the study, highlighting the complexities and size of the task over the next six months.

The CCHOP is rather unique in Australia because it is attempting to provide the ACT, and possibly Australia with an evidence base on which to build an outcome management approach to health care. Consequently, it has broad aims ranging from providing detailed profiles of patients service use and changing health status over the continuum, to identifying data requirements to achieve cost-effective decision making, to developing evidence-based clinical models of best practice. All this within the context of acute and ambulatory care.

With strong patient, clinical and economic foci, the expected outcomes of the project are starting to be recognised and wanted by clinicans and policy makers. Furthermore, the CCHOP methodology is generic, and consequently programs such as COAG's Co-Ordinated Care Trials, 'hospital in the home' initiatives, and palliative and ambulatory care reforms can be implemented and comprehensively evaluated from patient, carers, clinicans and policy perspectives using its methodology. Also, the project's rich data will allow us to examine from a longitudinal perspective existing data classifications systems, as well as, provide the ability to develop new ones.

The project's data collection phase is coming to an end in December 1996. Already other studies are using the CCHOP's methodology. These studies are being driven by clinicans, with interest from academic institutions like the Canberra Clinical School. Furthermore, the ACT Department of Health and Community Care is starting to orientate itself to adopt an outcomes management approach in which evidence-based decision making will be a major governing force in policy, planning and purchasing of services. Studies like the CCHOP will provide the pioneering research to achieve an ongoing scientific appraisal of our dynamic health system.

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Acknowledgments

The successful recruitment of patients into the study was mostly due to the hard and dedicated work of the interviewer team, while the central office staff provided efficient and exhaustive support. Special thanks must go to Mohan Singh and Maureen Bourne who superbly managed the project during their respective periods as Project Manager.

Staff at Woden Valley and Calvary Hospitals and other health professionals in the community have substantially contributed to the success of the project by enthusiastically co-operating with the demands of the study. Special thanks must go to the nurses on the wards and those working in Medical Records and IT areas.

The Reference Group have been very supportive and interested in the study, offering constructive comments. I look forward to their participation when more data are ready for analysis.

Staff at the Commonwealth Department of Health and Family Services have been extremely supportive of the study. Also, they have been very understanding of the problems faced doing innovative health services research.

Finally, special thanks must go to all the patients in the study who have given up valuable time and effort to participate in the project.

INTRODUCTION

The first year of the Care Continuum and Health Outcomes Project's post pilot work has been filled with new experiences and lessons, as well as a lot of hard work. The shear size of the project has often left us wondering why we ever started, and unfortunately I always get the blame. On the other hand, over the last year the presence of the project has created a real sense within the department that an outcomes approach to health care is achievable. Furthermore, the project has provided some early clues about the best way to reach such a goal.

In addition to providing some preliminary results, this report describes the operational side the project, highlighting the diversity and size of processes needed to achieve the project's broad aims:

- to provide detailed base-line profiles on health outcomes, care (including informal care), service-use and costs for a large part of the ACT health system. These profiles will be used by clinicans and administrators to improve continuity of care;
- to compare sub-groups in their service use and health outcomes. For instance, the study will examine the types of services and associated health outcomes of different socio-economic groups. Similarly, the outcomes of treatments for different groups, such as psychiatric and cancer patients, will be explored;
- to work with clinicans to improve clinical practice guidelines, both from health and cost perspectives;
- to test different methodologies of data collection, including patient-based instruments and data linkage. Furthermore, develop mechanisms for storing and analysing such data; and
- to revisit classification systems, such as DRGs, and determine the best types of classifications needed for the health system.

Putting the study into focus

When I first devised the Care Continuum and Health Outcomes Project (CCHOP) in 1993 there was little research of this type going on in Australia. As a result, research findings and discussions were not readily available to demonstrate the benefits of the CCHOP, making it difficult for me to convince the ACT government that a health outcomes program should be core business. Over the last two years, however, there has been a definite shift in Australia towards achieving evidence-based outcome focused management in health care. The National Health Information Agreement has a strong emphasis on outcomes, as well as the more recent Council of Australian Government's proposed trials on care co-ordination. The Commonwealth Department of Health and Family Services has an organisational structure that strongly supports an outcomes focus, and State health departments are developing infrastructures to address the quality aspects of care and reform.

Along with new members to the executive of the ACT Department of Health and Community Care, such as Mr Butt and Dr Zonta, this shift has replaced resistance with a nurturing environment for the project. In fact, CCHOP is now being perceived as the ideal base on which to develop an outcomes management process in the ACT. Although yet to be fully funded, Table 1 highlights a long-term plan to establish an ongoing outcomes focus. Basically, I see CCHOP providing a large part of the

Table 1: Implementation plan for an outcomes management approach

Developmental research	Infrastructure development	Ongoing data collection	Interventions (designed and imposed)
• Profiles • Sub-group comparisons • Data requirements • Test methods of data collection	• Data systems • Staff • Training • Analytical approach and model development	• Health indicators • Clinical status • Service use • Treatments/care • Costs • Special collections • Sample type/record linkage	• Study designs include: Observational Matching Split-half Historical Randomised trials • Multivariate analyses

- Based on a research infrastructure
- By relying on research, a sound methodology and data system that minimises strain on service providers can be introduced
- Responds to the dynamic nature of the health system
- The approach provides a mechanism for continuous evaluation

? Ownership
? Decision making

1995-97	1997-98	1998-

Epidemiology Unit

developmental research base for implementing an ongoing outcomes management approach in the ACT health system, and possibly Australia. Such an approach will depend mostly on sound epidemiological and economic evidence, clinical judgment and acceptance, and joint decision making at the clinical and administrative levels. As some proof of my success a number of clinicans in the ACT are starting to implement 'sister' studies to the Care Continuum Project. This compliment highlights the effect findings from the CCHOP could have on health outcomes evaluation and reform in Australia.

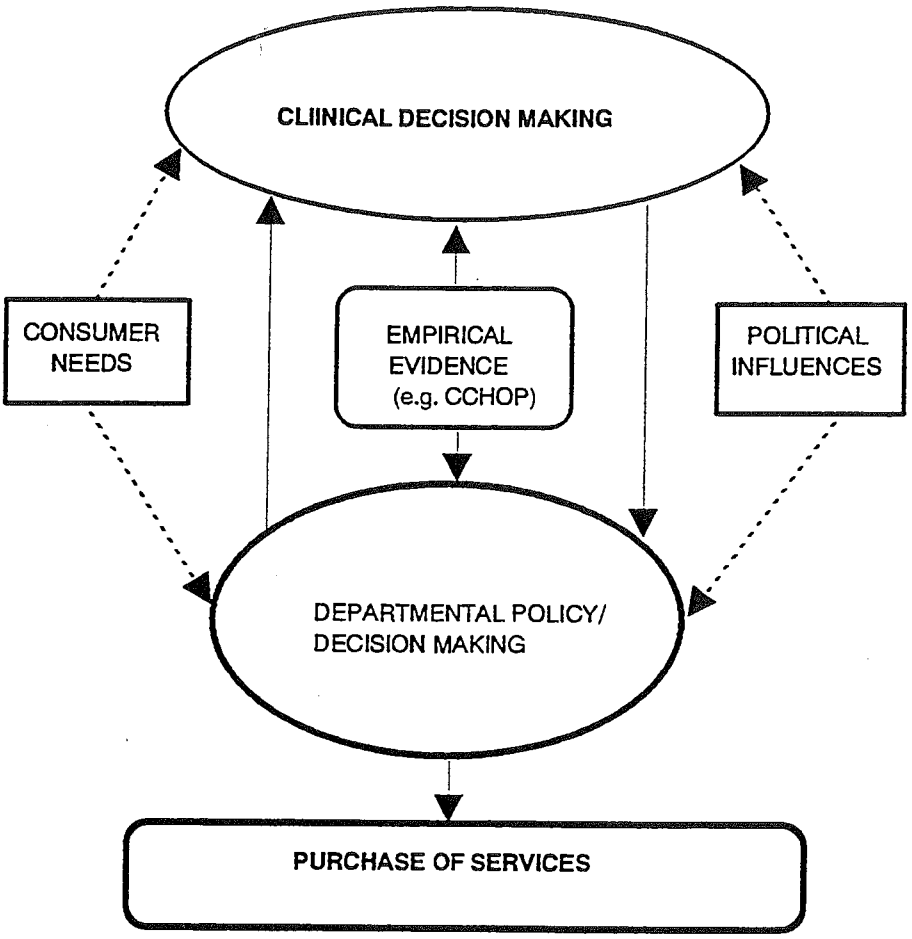
It is envisaged that once an ongoing process is put in place and evidence is accumulated the ACT should be in a strong position to implement evidence–based changes and evaluate their cost–effectiveness. In addition to classification systems, major issues still to be addressed include developing a methodology to minimise the data capturing burden on patients and service providers; determining who owns the data; and how decisions will be made using findings from the data.

One possible solution is to divide the ownership and decision–making processes. Basically, clinicans (includes medical, nursing and allied health), patients (clients) and epidemiologists should determine standardized practice based on epidemiological and economic information (obtained from the literature, Australian norms and ongoing data collections similar to CCHOP). Administrators then examine how best to fund the services and treatments nominated. This division places most of the ownership and decision making in relation to patient care with professionals and those receiving the care. Administrators are left the clear role of securing adequate funds and accommodation, determining what to fund in the public sector, and determining staff levels and overhead operations. There brief, however, will always be governed by the decisions made by clinicans and patients about the level of care required. Figure 1 summarizes this process in a graphical form.

An important addition to the funding would be a provision for clinical teams to evaluate new technologies, drug therapies, and techniques in conjunction with the Epidemiology Unit. This part would be a fixed amount of funding with patients randomly assigned to these new approaches. This aspect of patient care is critical for clinicans to obtain rigorous enough findings to improve practice and communicate improvements to other clinicans.

Like all systems, the option mentioned above is open to misuse. However, the strong focus on patients' needs should minimise this misuse. Furthermore, certain checks can be better put in place than currently exist, such as comparing patient profiles against population estimates, and where large discrepancies occur seek clarification.

Figure 1: Proposed decision-making process based on an outcomes management approach



PRELIMINARY RESULTS

This part of the report uses the first three months of data collected (n=2088) from the hospital interview (HI). At this stage, other data have not been processed, and therefore are not presented (see CCHOP progress report on page 23 for more detail).

Demographics

Of the 2088 patients examined 72 per cent of them were recruited from Woden Valley Hospital, 22 per cent from Calvary Public Hospital and 6 per cent from Calvary Private Hospital. Slightly more women were recruited (53%) than men (47%). Figure 2 shows the age distributions for males and females. There were no significant differences between males and females in their age distributions, with most patients being aged 45 to 49 years. There were, however, significant differences in the average age of patients between hospitals ($P < 0.005$), with Calvary Public Hospital tending to have younger patients ($X = 48$ yrs) than Woden Valley Hospital ($X = 51$ yrs) and Calvary Private Hospital ($X = 52$ yrs).

Figure 2: Age distribution for males and females, August 1995 (weighted)

Figure 3 shows that there were substantially more married patients than those who were single. In addition, there were significant differences in the age distributions between the marital statuses ($P < 0.0001$). Widowed patients tended to be the oldest ($X = 74$ yrs) and the never married the youngest ($X = 33$ yrs). Married and divorced patients were of a similar age ($X = 54$ yrs), while separated ($X = 45$ yrs) and those in a de facto union ($X = 36$ yrs) tended to be younger than those married. In relation to differences between hospitals, there was a slight significant tendency ($P = 0.05$) for Calvary Private Hospital to have less patients who were divorced or separated or in a de facto union than the other hospitals.

Figure 3: Distribution of marital status, August 1995 (weighted)

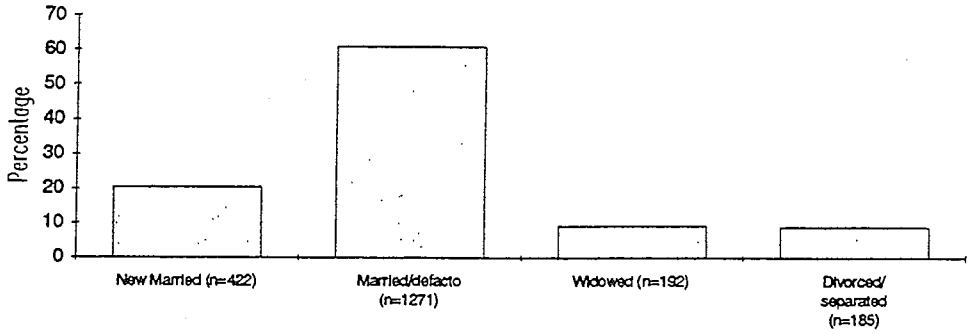


Figure 4 shows a 'J' shaped distribution for school levels attained among patients. This trend was moderately associated with age ($r = -0.39$): older patients tended to have achieved lower schooling levels than younger people. In addition, there were significant hospital differences in schooling levels, with Calvary Private Hospital tending to have patients who attained higher education levels and Woden Valley Hospital tending to have a greater proportion of those who attained lower levels.

Figure 4: Distribution of schooling levels, August 1995 (weighted)

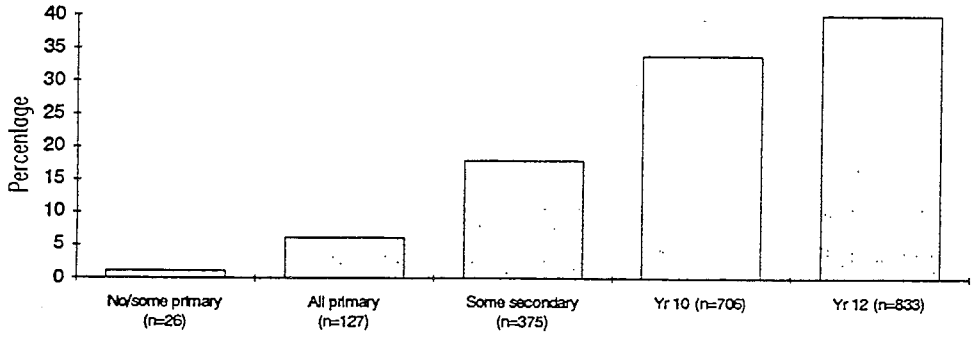


Figure 5 shows that the vast majority of patients were born in Australia. There was a significant difference between patients' ages and their country of birth ($P < 0.0001$): older patients tended to have been born in New Zealand/UK/Canada /USA ($X = 60$ yrs) or Europe ($X = 57$ yrs), while those born in Asia tended to be the youngest ($X = 45$ yrs). Australian born patients had an average age of 48 years. There were no significant differences between hospitals in patients' country of birth.

Figure 5: Distribution of country of birth, August 1995 (weighted)

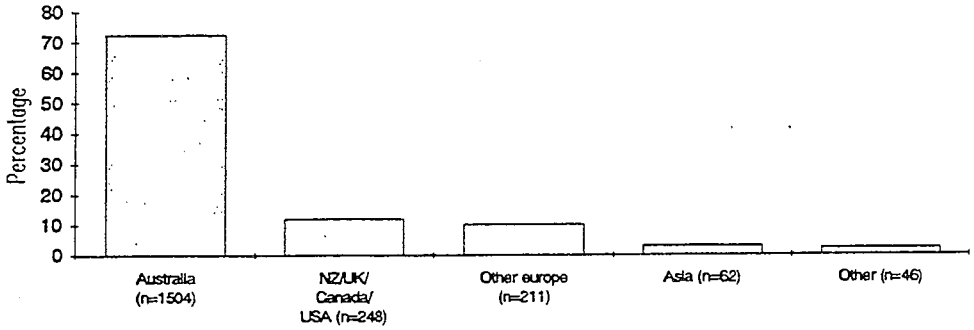


Figure 6 shows that most patients were not Social Security card holders. Among those who did hold such cards, a pension card was the most held, followed by a health benefits card, health care card and other card. As expected there were strong age trends, with patients 65 years and over more likely to have had a pension, health benefits or 'other' card. In contrast, relatively large proportions of health care card holders were under the age of 35 years. In relation to hospitals, a substantially greater proportion of Calvary Private Hospital patients were non-card holders (77%) compared to the other public hospitals (WVH – 64%; Calvary – 55%).

Figure 6: Distribution of Social Security Card Holders, August 1995 (weighted)

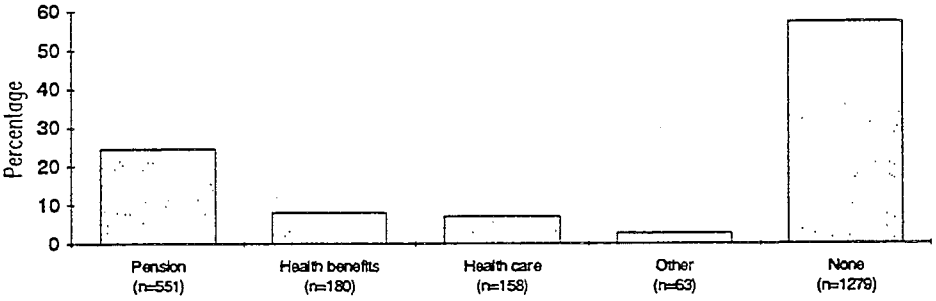


Figure 7 shows the distribution of types of government pensions or benefits received by patients. It can be seen that the majority of patients do not receive a pension or benefit. Of those who did, the age pension was the most received followed by a disability pension. Comparing hospitals, Calvary Private Hospital had the highest proportion who received no pension or benefit (79%), while Woden Valley and Calvary Public Hospitals had similar proportions not receiving a benefit (61% and 58%, respectively).

Figure 7: Distribution of pensions or benefits received, August 1995 (weighted)

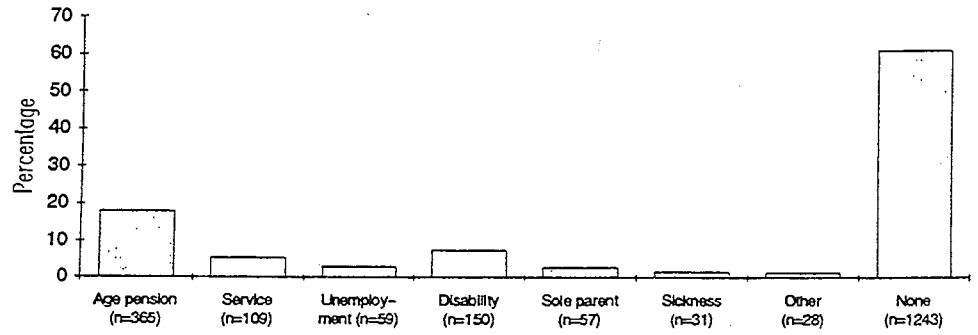
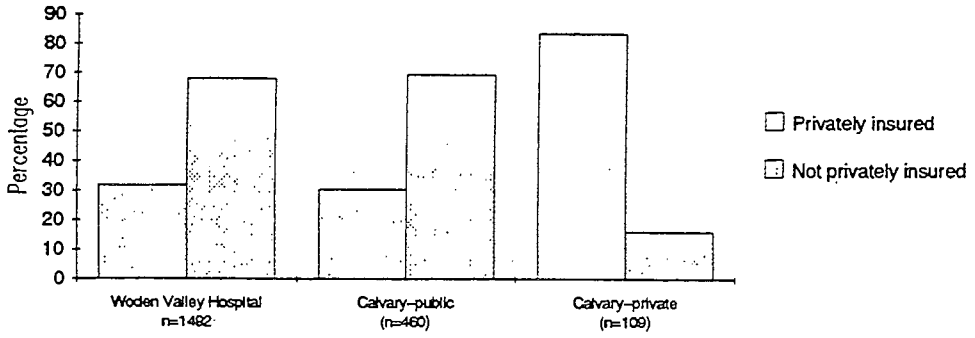


Figure 8 shows that Woden Valley hospital and Calvary Private hospital had similar proportions of patients who had private health insurance (31%). Note that having private health insurance does not necessarily mean using private insurance . It will be interesting when we compare those who have private health insurance to those using their insurance and what factors influence use. Also, interesting is the finding that 16 per cent of patients who used Calvary Private Hospital's facilities indicated that they had no private health insurance. This result suggests that either these non-insured patients were receiving compensation for their treatment costs from other sources or they were willing to pay the full price.

Figure 8: Distribution of private health insurance, August 1995 (weighted)



Patients who had private health insurance tended to be older (X = 52 yrs) than those without it (X = 50 yrs). On the other hand, there were no significant differences between privately insured and non-insured patients in the type of admission – elective versus emergency. There was, however, a significant difference in terms of reason for admission ($P < 0.05$): a greater proportion of patients who had no private health insurance were admitted to hospital for an operation (40%) than those who had private health insurance (32%).

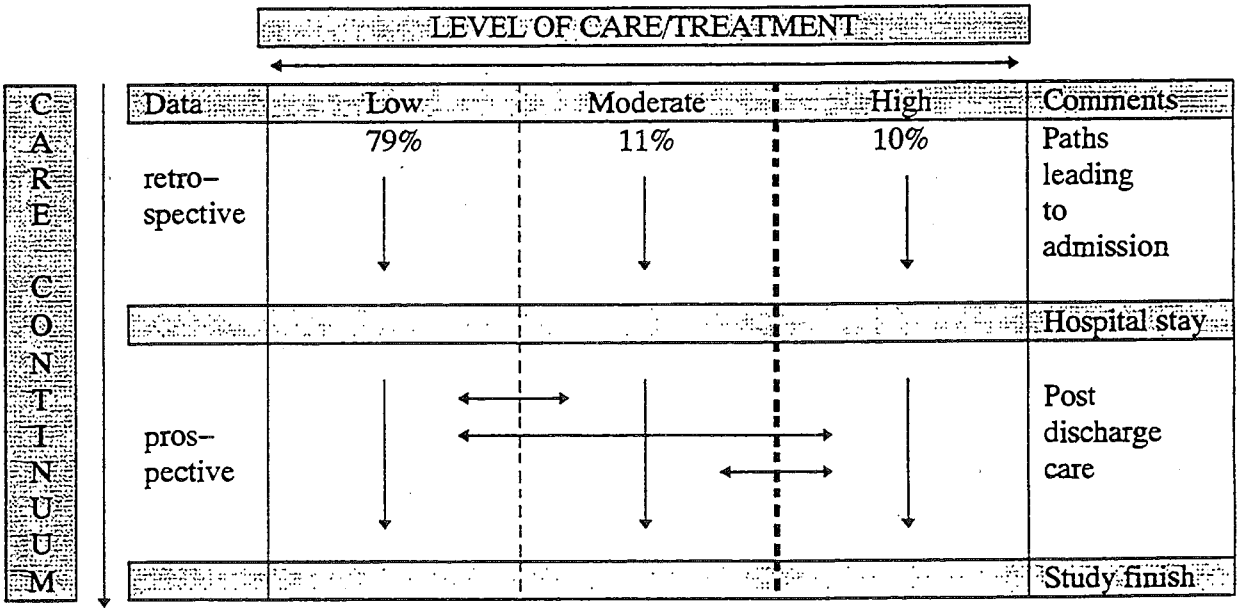
Paths Leading To Admission

Patients recruited into the sample are at various points in the care continuum. For example, a breast cancer patient may have been recruited during her first round of treatment, while another breast cancer patient may have been receiving her fourth round. Other patients may have been recruited at the diagnostic testing stage, or at the other extreme, close to death. This variation needs to be considered when developing service or health outcomes profiles.

Using the Hospital Interview (six months retrospective), hospital morbidity data (post June 1992) and HIC data (post December 1992), we will be able to categorize patients using a broad range of indicators. It is expected that not only will this information place patients in the care continuum at the time of their recruitment, but it will also provide valuable profiles on the courses that lead to admission for a broad range of health conditions.

The study was designed so that recruitment during a hospital stay acts as an anchoring point in the care and health continuums. The following diagram highlights the dynamics of the study design.

THE DYNAMICS OF CARE CONTINUUM RELATED TO THE DESIGN OF THE STUDY



At this stage, we are able to examine some of the formal care paths leading to admission. Based on retrospective Hospital Interview (HI) data, level of service use six months prior to admission was defined as those who had less than 10 visits to all identified services (low end); those who had 10 to 19 visits to a service (moderate); and those who had 20 or more visits to a service (high end), although this group was

further divided into those who had a high service use with only one type and those who had high service use with two or more types. The types of service providers making up these ratings included specialists, general practitioners, nurses, acupuncturists, audiologists, chiropodists/podiatrists, chiropractors, dietitians/nutritionists, naturopaths, occupational therapists, opticians/optometrists, osteopaths, physiotherapists, social workers and speech therapists. Furthermore, only visits related to the health condition patients were admitted to hospital for were considered.

By far, the most visited were specialists and general practitioners, with the vast majority of patients seeing at least one of them in the six months prior to admission and about 10 per cent seeing either one of them at least 10 times. The next most visited were physiotherapists with eight per cent of patients having at least one visit in the six months prior to admission. Psychologists were next with four per cent of patients visiting a psychologist at least once. Nurses, social workers and dietitians each saw three per cent of the patients, followed by chiropodists, chiropractors, acupuncturists and naturopaths who saw two per cent, followed by audiologists and occupational therapists who saw one per cent.

In relation to the seriousness of illness, high-end users (20+ visits) tended to have the most with serious illnesses ($P < 0.0001$), although this association was strongest for those using only one type of service such as a specialist or general practitioner 20 or more times. In terms of illness type and service use prior to admission, there were no significant differences between those with circulatory conditions and digestive disorders. On the other hand, there was a tendency for high-end users, especially for those with multiple types of service use, to have an illness associated with the endocrine and nervous systems and mental disorders. Cancer also tended to be more prevalent for high-end users.

There was a tendency for Calvary Public Hospital to have more low-end users (85%) than Woden Valley and Calvary Private Hospitals (77% and 74%, respectively). There were significant sex differences ($P < 0.005$), with males more likely to be low-end users prior to admission (81%) than females (76%). On the other hand, there were no significant age differences.

A significantly larger proportion of high-end users of health services were pension card holders (40%) than those described as moderate or low-end users (25%). Also, a substantially greater proportion of high-end users received a disability pension/benefit (20%) than moderate (10%) or low-end users (6%); while high-end multiple service users were also more likely to receive a sole parents pension (17%) than other users (about 3%). Following on, a greater proportion of high-end multiple users were separated (13%) and less likely to be married (41%) than other users (about 3% and 58%, respectively). In contrast, there were no significant differences in level of private of health insurance between those who had different levels of service use prior to admission.

Figure 9 shows that the reason patients were admitted to hospital varied significantly between level of service use before admission ($P < 0.0001$). A larger proportion of low-end users were admitted because of an injury (6%) than higher level users (about 1%). In addition, low-end and moderate users were more likely to have been admitted

for an operation (37% and 35%, respectively) than high–end users (about 19%). Also, moderate and high–end users of one service were more likely to have been admitted for a routine check–up (13% and 19%, respectively) than low– and high–end users of multiple services (4% and 2%, respectively). On the other hand, high–end multiple service users were more likely to have been admitted for rehabilitation (8%) than other users (about 2%). Furthermore, high–end service users, regardless of mix of services (18% and 26%, respectively), were most likely to have been admitted for supportive care (e.g. renal dialysis, chemotherapy) than lower level users.

Figure 9

Distribution of admission type by level of service use before admission, August 1995 (weighted)

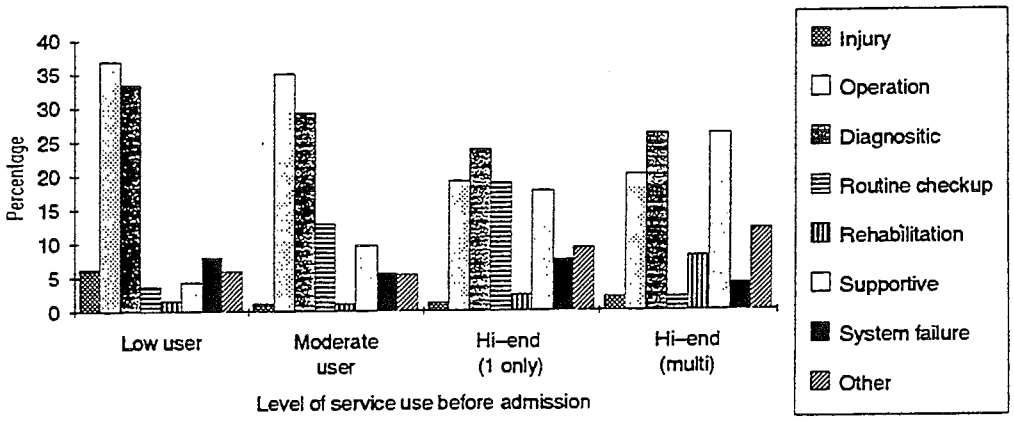
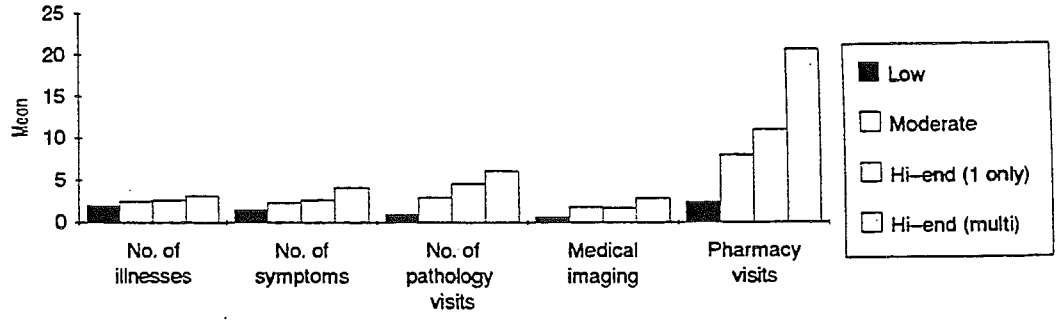


Figure 10 shows that the average numbers of illnesses, symptoms, diagnostic services and pharmacy visits increased with level of service provider use ($P < 0.0001$). Furthermore, high–end users of multiple services tend to have had the highest averages. Given that these profiles reflect use in relation to the current health condition of the patient, it is interesting and worth exploring as more data are linked the ordering patterns of diagnostic tests by providers for different classes of patients.

Figure 10: Average number of illnesses, symptoms, pathology visits, medical imaging and pharmacy visits by level of service use 6 months prior to admission, August 1995 (Weighted)



As an exercise leading to the analysis of the full set of data next year, the Table 2 shows the results of a logistic regression analysis examining factors associated with whether or not an admission was elective (68%) or an emergency (32%). A large range of factors were considered, including age, sex, country of birth, educational attainment, marital status, number of illnesses, the seriousness of the illness, number of symptoms, private health insurance status, pensioner or benefit status, level of service use prior to admission, admitting hospital and reason for admission.

Table 2: Forward stepwise logistic regression showing the factors significantly associated with admission type, elective versus emergency (n=1866)

Factors	B(S.E.)
Constant	−0.05 (.22)
At time of admission	
Hospital:	
Woden Valley	–
Calvary Public	0.18 (.15)
Calvary Private	−0.54 (.25)*
Reason for admission:	
Injury	–
Operation	−2.37 (.17)****
Diagnostic	−0.91 (.15)****
Routine	−2.46 (.36)****
Rehabilitation	0.97 (.45)*
Supportive care	−1.19 (.26)****
System failure	2.88 (.41)****
Other	0.49 (.33)
Prior to admission	
Physical illness:	
No report	–
Intermediate level	0.30 (.07)****
Number of symptoms (1 mnth prior)	0.27 (.04)****
Number of pathology visits (6 mnths prior)	−0.14 (.03)****
Number of medical imaging (6 mnths prior)	−0.16 (.06)***
Number of pharmacy visits (6 mnths prior)	−0.03 (.01)***
Marital status:	
Never Married	–
Married	−0.39 (.13)***
de facto union	0.04 (.30)
Widowed	0.12 (.20)
Divorced	−0.04 (.24)
Separated	0.03 (.37)

Model $\chi^2 = 840.5$; 19 d.f.; $P < 0.0001$

Relying on a forward stepwise procedure, the final model predicted 83 per cent of cases, with 94 per cent of elective admissions being identified and 58 per cent of emergency admissions. It was found that significant admission factors were the

hospital and reason for admission. For example, as expected patients admitted to Calvary Private Hospital were less likely to be emergency admissions than those found at Woden Valley or Calvary Public Hospitals. Similarly, patients admitted for an operation, diagnostic investigation, routine checkup and supportive care were more likely to have been an elective admission than those who were injured. Conversely, those most likely to be an emergency admission were those receiving rehabilitation or experiencing a system failure.

Significant factors relating to the paths leading to admission were the seriousness of the illness, number of symptoms in the month prior to admission and the number of pathological and medical imaging tests and pharmacy visits in the six months prior to admission. Also, marital status significantly differentiated between admission types. Patients who had intermediate level illness and those who had more symptoms were more likely an emergency admission. On the other hand, patients who used more pathological, medical imaging and pharmaceutical services were more likely to be an elective admission. Finally, patients who were married were more likely to be an elective admission than other patients.

Many of the results found in the above table were expected, and therefore support the validity of the data. The findings also highlight the complexity of the associations and colinearity between factors, requiring us to test hypothsized models of health care rather than simply let factors compete. As the data become more rich in the CCHOP, both in terms of data items and longitudinality, these types of models will be valuable for better understanding the dynamics of our health system.

The Medical Outcomes Study (MOS) SF–36 As An Outcome Measure For Hospital Patients

Tracking patients to define episodes of care for the purpose of solely bundling together the costs associated with particular DRGs is not the main aim of the CCHOP. Evidence from the United States of America suggests that reforms based on such a narrow economic focus will lead to cost shifting by hospitals to reduce their expenditure that is most likely not going to improve the quality of the service or the health outcomes of patients. In addition, a pure economic perspective is difficult for health professionals to understand and accept, making the reform process inefficient and resented. Consequently, it is important that clinically meaningful approaches are adopted, including the measurement of health outcomes.

It has been widely argued that a measure of patient–reported general health is important to clinical research and decision making because measures such as survival and readmission rates are relatively crude indicators.[1–4] For instance, only a small proportion of patients die soon after treatment, and therefore survival outcomes poorly differentiate treatment outcomes for the vast majority of patients. In contrast, the fine level of detail obtained from general health measures provides a more sensitive measure of patients' changing health status. The Medical Outcomes Study SF–36 has been used extensively in the western world as such a measure. It is made up of eight scales – physical functioning, role physical, bodily pain, general health, mental health, role emotional, social functioning and vitality.[5,6]

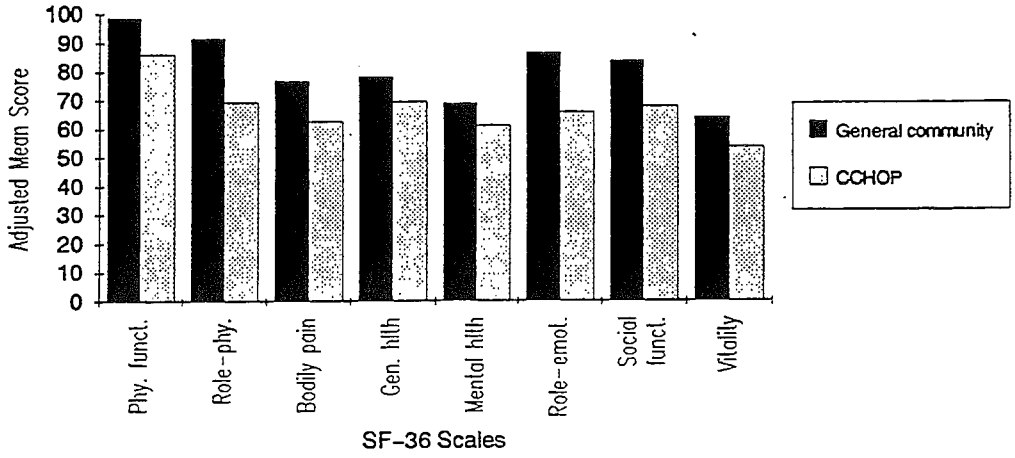
As a measure of health outcomes, the SF–36 has been used predominantly in the United States of America. In Australia, its use has been limited, mainly because this type of research is in its infancy. Currently, however, there are a number of studies collecting SF–36 data in Australia (refer to the Australian Health Outcomes Clearing House, Australian Institute of Health and Welfare); and over the next few years we should start to see a wave of publications using the SF–36 measure as an outcome of treatment.

Like most instruments measuring health, the SF–36 can be influenced by a variety of factors: some of which are clinical, while others are cultural or psycho–social in origin.[7] Understanding the breadth of these factors is important to the interpretation of findings when using the SF–36 as an outcome indicator of treatments. The main aim of this section is to test the validity and reliability of the SF–36 for a large and diverse sample of hospital patients. The emphasis is on correlates with the SF–36 to highlight clinical aspects of the measure rather test psychometric properties. This approach is a form of construct and predictive validity. It is expected that the eight scales of the SF–36 will be influenced by a variety of factors including socio–demographic indicators, the seriousness of the patient's health conditions, symptoms and service use. The results from these correlational models will provide some insights into the use of the SF–36 as a health outcome measure within clinical populations.

Figure 11 shows that patients from the CCHOP when compared to a sample from the general community have consistently lower adjusted average scores on the eight scales of the SF–36 (variables adjusted for include age, sex, country of birth and educational attainment). These differences are significant at the $p < 0.001$ level. On the other

hand, there were no significant age and sex interactions between the two samples. This finding suggests that the age and sex trends between hospital patients and people in the general community were similar.

Figure 11: Adjusted Mean SF-36 Scores for patients from the CCHOP sample and respondents from the general community, weighted



Among CCHOP patients, each of the SF-36 scales had high levels of data completeness, with the worse scale being physical functioning (95% complete across 10 items). In relation to sub-groups, the vast majority of scales had completeness rates in the high 90s. The exceptions were the physical functioning scale for patients aged 70 or more years (90%) and those who had seven or more health conditions (82%), and the mental health scale for patients born in a European country (91%).

Table 3 shows that the eight scales of the SF-36 have good internal consistency (Cronbah's Alpha). In addition, there was reasonable agreement over time within scales (test-retest reliability): the lowest intraclass correlations were found for role physical and general health (0.47 and 0.41, respectively). The low correlations for these two scales were offset by non-significant differences in mean scores (paired t-tests). These findings suggest that a large number of the scores for the role-physical and general health scales were similar if not the same over time. On the other hand, the mental health and vitality scales had good agreement over time but significantly different mean comparisons, indicating that where scores did not agree the scores were dramatically different. The other scales had non-significant paired t values.

Table 3 also shows that a number of the SF-36 scales had substantial 'floor' and 'ceiling' effects. For example, role-physical and role-emotional scales had 76 and 82 per cent respectively in the two extreme ends of the scales. In terms of shape, bodily pain, physical functioning and social functioning tended to have J-shaped distributions. General health, mental health and vitality were more normally distributed but negatively skewed. The role emotional and physical scales were bimodially distributed, with the extreme scores containing the peaks.

Looking at more specific groups, age influenced the SF–36 distributions: older patients tended to score lower than younger patients (see Table 4). Thus, older patients tended to have less negatively skewed distributions, although the shapes of the distributions tended to be similar between age groups. The only exception was physical functioning where a bimodial distribution emerged for patients aged 75 years or more. Patients admitted to the aged care unit (frail elderly) tended to score the lowest, with the distributions reversing in their shape when compared to the total CCHOP sample. Extreme floor effects were found for role emotional and role physical scales, highlighting the relatively crude measurement of these two scales.

Table 3: Distribution indicators and reliability coefficients from the CCHOP sample, weighted

Indicators	SF–36 Scale							
	PF	R–P	BP	GH	MH	R–E	SF	Vital.
Floor (%)	2.3	33.2	2.6	0.6	0.2	24.8	2.4	1.1
Ceiling (%)	27.4	42.8	33.4	5.5	5.9	57.4	36.7	3.3
Skewness	–0.7	–0.2	–0.4	–0.7	–1.0	–0.7	–0.7	–0.4
Mean	69.7	54.7	65.5	67.4	73.7	66.2	72.0	57.9
S.D.	31.7	44.5	31.2	23.9	19.9	42.9	29.2	25.2
No. of cases	1989	2048	2066	2042	2023	2024	2010	2016
Cronbah's α	0.9	0.9	0.9	0.8	0.8	0.9	0.9	0.8
$\rho^{(a)}$	0.7	0.5	0.8	0.4	0.8	0.7	0.8	0.7

PF – physical functioning; R–P – role physical; BP – bodily pain; GH – general health; MH – mental health; R–E – role emotional; SF – social functioning.
Floor – lowest score on scale (0); Ceiling – highest score on scale (100); ρ – intraclass correlation.
(a) Based on a sample of 24 patients receiving a cardiac catheter or vascular surgery. Average duration between completion of forms was three weeks.

Despite lower averages, patients who at the most obtained some secondary schooling and those born in Europe (other than U.K.) had similar shaped distributions to the total sample for most of the SF–36 scales. The only exception was the role–physical scale where zero scores dominated the distributions (findings not shown). On the other hand, Table 4 shows that the number of symptoms and service use influenced the SF–36 distributions, with more symptoms and higher service use associated with lower scores across all the scales. Furthermore, the distributions were mostly positively skewed rather than negatively skewed, and again extreme floor effects were found for the
role–physical and emotional scales. Figure 12 highlights selected distributions for the total sample and patients with five or more symptoms, showing the shape and spread of scores.

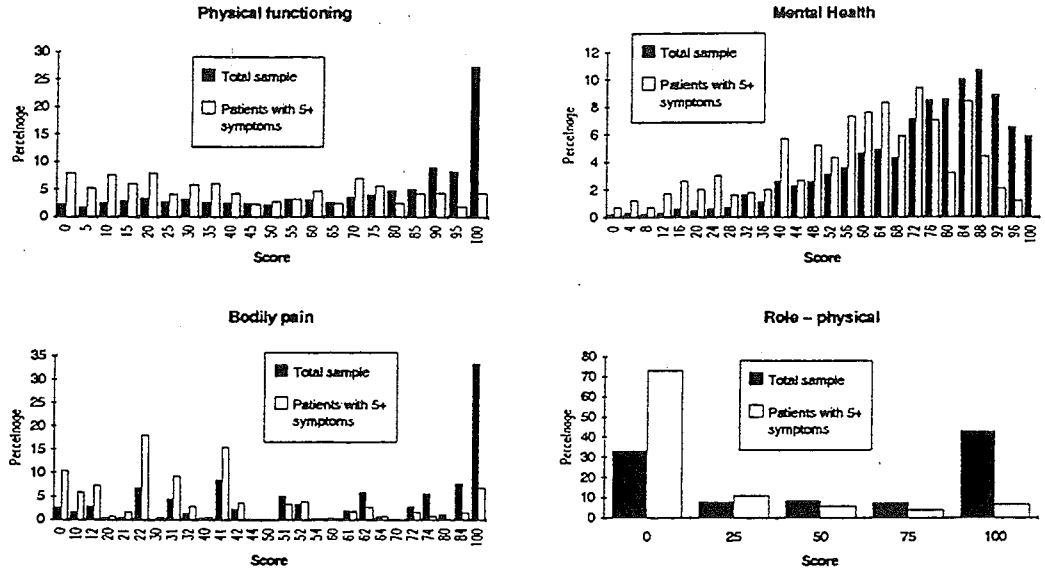
Psychiatric patients also had strongly positively skewed distributions across most of the scales, the exceptions being the physical functioning and bodily pain scales where the physical dimensions of health were best represented. In contrast, day surgery patients had similar SF–36 distributions to the total sample.

Table 4: Distribution indicators for a selection of sub-groups within the CCHOP sample, weighted

Indicators	SF-36 Scales							
	PF	R-P	BP	GH	MH	R-E	SF	Vital.
Aged 18-44yrs								
mean	78.9	62.5	65.4	68.5	70.4	68.4	71.2	58.6
floor	1.2%	26.7%	3.6%	1.2%	0.4%	21.6%	2.5%	1.1%
ceiling	41.8%	51.7%	32.4%	7.3%	6.7%	58.2%	34.6%	3.6%
skewness	-1.3	-0.5	-0.4	-0.8	-0.9	-0.8	-0.7	-0.4
Aged 75+yrs								
mean	47.4	37.8	65.2	64.8	80.6	58.7	72.1	57.4
floor	3.8%	55.3%	0.6%	0.7%	0.3%	32.9%	1.7%	0.7%
ceiling	3.1%	33.0%	33.3%	2.3%	5.4%	52.0%	34.0%	3.0%
skewness	0.2	0.5	-0.2	-0.7	-1.1	-0.3	-0.8	-0.3
ACU								
mean	33.8	11.5	61.6	47.7	75.7	23.1	45.2	42.4
floor	19.2%	80.8%	7.4%	7.4%	7.7%	65.4%	11.5%	3.7%
ceiling	7.7%	3.8%	44.4%	7.4%	3.8%	15.4%	15.4%	3.7%
skewness	0.6	2.5	-0.3	0.5	0.1	1.5	0.4	0.5
5+ symptoms								
mean	43.1	15.0	35.0	43.3	58.4	33.5	41.5	30.7
floor	8.0%	73.1%	10.4%	3.6%	0.7%	56.7%	9.2%	4.6%
ceiling	4.3%	6.6%	6.8%	0.5%	1.2%	25.0%	6.5%	0.5%
skewness	0.3	2.0	1.0	0.3	-0.6	0.7	0.5	0.5
Hi-end users								
mean	50.0	31.6	53.1	49.6	65.6	48.0	55.2	44.1
floor	4.9%	57.4%	6.5%	3.9%	0.6%	42.9%	6.4%	4.5%
ceiling	8.7%	19.9%	22.8%	1.9%	1.8%	40.0%	19.9%	0.3%
skewness	0.1	0.8	0.1	0.0	-0.8	0.1	-0.1	0.2
Day surgery								
mean	77.5	64.3	69.4	72.7	75.8	65.8	77.7	63.4
floor	0.9%	26.4%	0.9%	0.9%	0.9%	22.7%	0.9%	0.9%
ceiling	37.0%	57.3%	36.9%	6.5%	13.9%	55.5%	38.2%	4.6%
skewness	-1.3	-0.6	-0.4	-1.0	-0.7	-0.6	-1.0	-0.6
Psychiatry								
mean	76.3	38.4	58.7	49.3	39.1	20.4	30.6	33.9
floor	1.2%	44.1%	5.4%	2.2%	4.3%	65.9%	23.3%	6.7%
ceiling	27.4%	22.6%	29.0%	2.2%	4.3%	9.4%	5.6%	1.1%
skewness	-1.2	0.5	-0.1	0.1	0.3	1.5	0.9	0.7

PF - physical functioning; R-P - role physical; BP - bodily pain; GH - general health; MH - mental health; R-E - role emotional; SF - social functioning.
Floor - lowest score on scale (0); Ceiling - highest score on scale (100).
ACU - Aged Care Unit; Hi-end users - patients using a particular type of service at least 20 times over a six month period; Psychiatry - Psychiatric wards.

Figure 12: Distribution comparisons between patients with five or more symptoms and the total sample for selected SF–36 scles, weighted



It is hypothesized that the SF–36 contains two dimensions; a physical health factor and a mental health factor.[6,8] Table 5 shows that the eight SF–36 scales for the CCHOP sample are highly correlated with a single factor (the weakest correlation between scales involves physical functioning and mental health, r = 0.26). Forcing two factors yields physical and mental factors, but scales such as role physical and role emotional (r = 0.64) do not contribute solely to their hypothesized dimensions.

Table 5 – Rotated Principal Components Analysis showing the associations between SF–36 scales, weighted

SF–36 scales	Single factor		Hypothesized two factors		
		h^2	Physical	Mental	h^2
Physical funct.	0.71	0.51	0.83	0.16	0.71
Role–phy.	0.81	0.65	0.83	0.30	0.77
Bodily pain	0.70	0.49	0.71	0.27	0.58
General health	0.74	0.54	0.46	0.59	0.56
Mental health	0.67	0.45	0.05	0.92	0.85
Role –emot.	0.73	0.54	0.53	0.51	0.54
Social funct.	0.81	0.65	0.47	0.67	0.67
Vitality	0.83	0.70	0.46	0.73	0.74
Variance	0.57		0.57	0.11	

Looking at selected sub groups (findings not shown), there is considerable variation in the level of association between the scales and factors. These findings highlight the effect of socio–demographic and illness on people's perceptions of their health; and the close relationship between physical and mental health for ill people.

In relation to socio–demographic and clinical correlates, the results in Table 6 indicate that substantial amounts of variance were explained by the selected correlates for each of the SF–36 scales. Furthermore, these multivariate models show that each scale has a unique combination of explanatory variables, although scales representing similar dimensions (physical versus mental) have more in common than others. The correlates shown for the role physical and role emotional scales, however, should be treated with caution because there were significant violations of the Ordinary Least Squares (OLS) assumptions.

Physical functioning, bodily pain and social functioning clearly had two types of distribution: a dichotomy of those with and without limitations/pain, and a relatively normal distribution among those with limitations/pain. As a result, Table 6 shows the findings for those with limitations/pain. Logistic regressions were employed to examine correlates that differentiate between those with and without limitations/pain (see Table 7).

In relation to particular correlates, the seriousness of health conditions was important, as well as the type of condition. For instance, there was a strong agreement between the type of health condition and the dimension of the SF–36 scale being represented. Figure 13 further supports this finding: the figure shows adjusted average SF–36 scores for four health conditions (variables adjusted for include, age, sex, country of birth, educational attainment, number of co–morbidities and the seriousness of co–morbidities). The results suggest that patients who have at least one of the conditions examined scored significantly lower on the SF–36 scales than the general community. The only exception being mental health where only those who had depression scored substantially lower. Between conditions there was a significant tendency for patients diagnosed with depression to score lower on all of the scales except physical functioning; while patients who had a back problem tended to have the lowest bodily pain scores.

Within most of health conditions recorded in the study there were relatively large variations in SF–36 scores. For instance, patients who had depression and who were being treated in hospital for a physical condition had significantly better mental health than those currently being treated in hospital for depression. Similarly, patients who had cancer and who were admitted to the oncology ward had worse physical functioning than those who were ambulatory and receiving chemotherapy.

In relation to symptoms, the findings suggest that, regardless of the SF–36 scale, the more symptoms patients had the worse their health–related quality of life. There was, however, some variation between scales when examining particular symptoms. The SF–36 scales hypothesized to represent the physical dimension of health, in particular physical functioning and bodily pain, were not significantly associated with a number of symptoms (e.g. lack of appetite, vomiting and diarrhoea). On the other hand, the SF–36 scales hypothesized to represent mental health dimensions tended to be significantly influenced by most symptoms measured.

Table 6: Stepwise OLS regression models of the eight SF-36 scales showing multivariate associations (Beta coefficients and standard errors in brackets) with socio-demographic indicators, health conditions and service-use measures for hospital patients

Correlates[1]	Phy. function[3] n=1398	Role - phyical[4] n=1989	Bodily pain[2,3] n=1359	General health n=2015	Mental health n=1966	Role - emotion[4] n=1997	Social function[3] n=1253	Vitality n=1990
Age (5 yr grps)	-0.26 (.04)****	-0.31 (.05)****	–	–	0.20 (.02)****	–	–	–
Sex (female)	–	–	–	2.56 (.90)***	-2.19 (.76)***	–	–	-4.03 (.87)****
Birthplace (Australia):	^	^	^	^	^	^	^	^
NZ/Canada/UK/USA	-0.74 (2.1)	-0.82 (2.5)	–	3.87 (1.4)***	-2.07 (1.2)	-2.76 (2.7)	–	-2.78 (1.3)*
Europe	-0.64 (2.3)	-0.98 (2.7)	–	-3.18 (1.5)*	-5.00 (1.3)****	-2.50 (2.9)	–	-1.02 (1.5)
Asia	15.0 (5.1)***	10.1 (4.7)*	–	2.07 (2.6)	4.99 (2.2)*	17.5 (5.0)***	–	12.4 (2.5)****
Other	7.24 (5.2)	-0.44 (5.5)	–	2.56 (3.0)	5.84 (2.6)*	-0.90 (5.8)	–	5.82 (3.0)*
Educational attainment:								
(higher degree)	^	^	^	^	^	^	^	^
yr 12 or equival.	-7.39 (2.2)***	–	-3.83 (1.7)*	–	–	-4.52 (2.6)	–	–
yr 10 or equival.	-7.09 (2.3)***	–	-6.21 (1.9)***	–	–	-1.44 (2.8)	–	–
at most some second.	-12.3 (2.4)****	–	-2.81 (1.9)	–	–	-8.84 (2.9)***	–	–
Health conditions:								
minor - physical	5.81 (1.9)***	–	–	–	–	–	–	-3.32 (1.2)***
minor - mental	–	–	–	–	-23.1 (10.)*	–	-35.0 (15.)*	–
intermediate - phyical	–	–	-2.82 (1.3)*	–	–	–	–	–
intermediate - mental	–	–	–	-5.57 (1.8)***	-20.7 (1.5)****	-31.0 (3.4)****	-16.8 (2.1)****	-12.2 (1.8)****
serious - physical	–	-5.96 (1.8)***	–	-5.92 (.98)****	–	-4.35 (1.8)*	-3.77 (1.3)***	-2.41 (.97)**
serious -mental	–	–	–	–	–	–	-22.3 (7.6)***	–
Number of conditions	-1.77 (.47)***	-2.32 (.56)****	-0.99 (.38)**	-1.16 (.30)****	–	–	–	-0.73 (.32)*
Number of symptoms	-6.56 (.43)****	-12.4 (.52)****	-4.64 (.31)****	-5.51 (.28)****	-4.08 (.23)****	-8.81 (.53)****	-5.80 (.36)****	-7.53 (.28)****
Service use: (low, 0-9)	^	^	^	^	^	^	^	^
moderate (10-19)	-5.85 (2.1)***	-12.0 (2.6)****	-7.61 (1.8)****	-3.53 (1.4)**	-0.20 (1.2)	-6.94 (2.8)**	-3.91 (1.8)*	-2.87 (1.4)*
high - one (20+)	-7.90 (2.2)***	-9.36 (2.8)***	-2.40 (1.9)	-10.3 (1.6)****	-1.61 (1.3)	-6.70 (3.0)*	-5.35 (1.9)**	-3.90 (1.5)**
high - mult. (20+)	-12.3 (5.4)*	-11.8 (7.3)	-9.40 (4.6)*	-17.2 (4.0)****	-7.33 (3.4)*	-6.41 (7.9)	-9.63 (4.5)*	-10.6 (3.9)**
Constant	98.1 (3.0)****	103. (2.6)****	64.8 (1.7)****	86.6 (1.1)****	74.9 (1.2)****	92.0 (2.5)****	75.1 (1.2)****	78.7 (.93)****
R^2	0.27	0.37	0.23	0.35	0.30	0.24	0.29	0.43

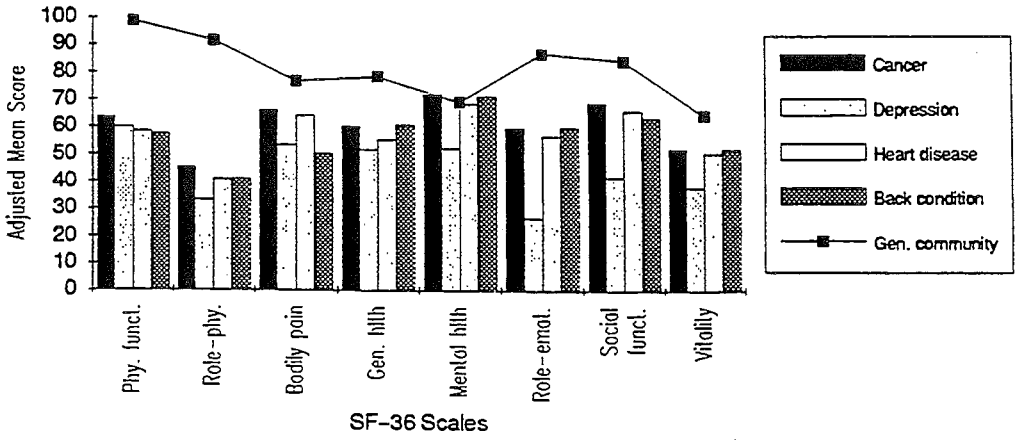
^ refers to the reference group * p < 0.05; ** p < 0.01; *** p < 0.005; **** p < 0.0001.

1. The analyses also included private health insurance status, aborinality and marital status but these indicators were not significant for all eight SF36 scales.
2. When looking at the association between number of symptoms and bodily pain, pain symptoms were excluded from the count.
3. Includes only patients who had some limitation or disability according to the scale. 4. Role-physical and role-emotional models dramatically violate OLS assumptions.

Table 7: Stepwise logistic regression models of the physical functioning, bodily pain and social functioning scales (Beta coefficients and standard errors in brackets), weighted.

Correlates[1]	Phy. function n=1914	Bodily pain n=1985	Social function. n=1930
Age (5 yr grps)	-0.05 (.004)****	0.01 (.003)**	-
Sex (female)	-0.16 (.06)**	-	-
Birthplace (Australia):	^	^	^
NZ/Canada/UK/USA	-	-	-0.05 (.16)
Europe	-	-	-0.51 (.18)***
Asia	-	-	0.34 (.28)
Other	-	-	0.44 (.29)
Educational attainment:			
(higher degree)	^	^	^
yr 12 or equival.	-	0.11 (.08)	-0.08 (.08)
yr 10 or equival.	-	0.21 (.09)*	0.31 (.10)***
at most some second.	-	-0.26 (.10)**	-0.02 (.10)
Health conditions:			
minor - physical	-	-	-
minor - mental	-	-	-
intermediate - physical	-	-0.17 (.06)***	-
intermediate - mental	-	0.25 (.11)*	-0.59 (.15)****
serious - physical	-	-	-
serious -mental	-	-	-
Number of conditions	-0.25 (.06)****	-0.19 (.04)****	-
Number of symptoms	-0,53 (.05)****	-0.33 (.04)****	-0.68 (.04)****
Service use: (low, 0-9)	^	^	^
moderate (10-19)	0.07 (.32)	-	0.30 (.31)
high - one (20+)	-031(.34)	-	0.13 (.31)
high - mult. (20+)	-0.48 (.78)*	-	-1.07 (.79)
Constant	1.79 (.34)****	-0.15 (.19)	-0.41 (.33)
χ^2 (model improvement)	558 (7 df)****	210 (8 df)****	508 (12 df)****

Figure 13: Adjusted Mean SF-36 Scores for selected patient groups from the CCHOP sample and respondents from the general community, weighted



In an analysis of the components making up the bodily pain scale it was found that pain symptoms related to both the particular condition being treated in hospital and other pain being experienced substantially explained the variance in scale ($R^2 = 0.44$). This finding highlights the non-specificity of the bodily pain scale, with scores representing pain for the whole of the body.

Finally, the significant associations shown in Tables 6 and 7 for socio-demographic and health-service indicators suggests that the SF-36 scales are influenced by more than clinical status. For example, over and above health conditions and symptoms, the greater use patients made of health services prior to admission the lower their SF-36 scores, especially scales representing physical dimensions. Thus, where patients are in the care continuum influences their health-related quality of life. Similarly, age, sex, country of birth and educational attainment effected patients' SF-36 scores, suggesting that cultural and societal factors also influence people's perceptions of their health.[7,9]

It is evident, therefore that the SF-36 is not simply a measure of disease seriousness. The SF-36 provides a general indicator of health related-quality of life rather than a measure of how 'life threatening' a condition is or whether or not a treatment was technically successful. Thus, more than one health outcome may be necessary to properly evaluate a treatment.

This complexity represents the difficulties faced in trying to evaluate treatments. Regardless whether it is a clinical trial or observational study, issues around co-morbidities, lifestyle factors, and the benefits or detriments of other treatments being received all influence results. Consequently, comprehensive and holistic approaches to health outcomes and treatment are needed.

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CCHOP PROGRESS REPORT: OPERATIONAL ISSUES

On the 17 May 1996 the study will have completed one full year of recruitment of patients. At this stage, we have 6392 patients recorded in the sample with 80 per cent choosing to participate in the survey component (see Table 8 for more detail). Of those participating, 85 per cent agreed to have their medicare data linked to other study data. Given the commitment we want from patients, these response rates are extremely good.

Table 8: The sample by wards, 18 May 1995 to 17 April 1996

Hospital	Ward	Description	Sampling fract.	Sample size (n)	Survey Part. Rate (%)
Woden Valley	10A	Plastics, Gen. sur., Oral, Eyes	1–in–2	450	79
	11B	Gastro., Gen. med.	1–in–2	231	73
	ACU	Aged Care Unit	1–in–2	64	73
	REH	Rehabilitation	1–in–2	22	73
	14B	Oncology ward	1–in–2	41	61
	5A	Vascular, Thoracic	1–in–2	198	86
	5B	Orthopaedics	1–in–2	394	76
	7A	Rheumatology, Cardio., Endocrin.	1–in–2	195	85
	7B	Urology, Gynae., Dental, ENT	1–in–2	543	78
	8A	Nephrology	1–in–2	104	74
	8B	Respiratory	1–in–2	262	71
	9B	Neurology	1–in–2	177	85
	CCU	Coronary Care Unit	1–in–2	376	73
	CLD	Cath. lab., Day ward	1–in–10	77	91
	DIA	Dialysis	1–in–3	23	74
	DSU	Day surgery	1–in–10	194	81
	GAS	Gastroenterology	1–in–10	163	80
	ICU	Intensive Care Unit	1–in–2	73	53
	MDC	Medical Day Care	1–in–10	26	81
	ONC	Oncology	1–in–5	203	76
	PLA	Minor theatre	1–in–10	73	77
	PSA	Psychiatry	1–in–2	91	46
	PSB	Psychiatry	1–in–2	96	53
Calvary Pub.	2S	Psychiatry	1–in–2	102	81
	4E	Surgical	1–in–2	487	87
	4W	Orthopaedics	1–in–2	389	88
	5E	Medical	1–in–2	220	88
	5W	Surgical	1–in–2	206	86
	CCU	Coronary Care Unit	1–in–2	29	83
	ICU	Intensive Care Unit	1–in–2	201	84
	DSU	Chemo., Day Surg.	1–in–1, 1–in–10	147	93
Calvary Pri.	6E	Medical	1–in–2	207	80
	6W	Surgical	1–in–2	336	83

The original estimate of 9,370 patients in the sample from the research proposal was based on 1992–93 data and did not consider some exclusions such as those mentally incapable of consenting to be in the study or those staying in hospital for longer than six weeks. Furthermore, it became evident through pilot work that a seven day a week selection was impractical with employees only able to work Monday to Friday. The establishment and costs of positions with more flexible work hours was beyond the study. Consequently, six day a week selections were conducted with days randomly selected between Friday and Sunday (selected patients interviewed between Monday and Friday). Six rather seven days in a week selection also contributed to a reduced sample size. A weight will be applied to the data to adjust for the six day a week selection.

At this stage, the withdrawal of participating patients from the study through patient choice is difficult to estimate. The main reasons for withdrawal seem to be patient poor health and good health. Often carers phone us and describe the patient's poor condition and inability to maintain the demands of the survey. As a method to maximise the compliance of participants, patients were given the option to drop the diary component: to date 227 patients have chosen to do this. On the other hand, patients who were relatively well also were more likely to drop out of the survey, with a number of them unable to see the relevance of the questions once they had 'recovered'.

Psychiatric patients were particularly difficult to recruit and maintain in the study, supporting my original expectations as outlined in the research proposal. ICU patients at Woden Valley Hospital were the only other group where recruitment was a problem. The main reasons were the relatively poor health of ICU patients; and the fact that most of them had to be recruited once they had left the ICU ward, making it difficult to capture them (22% non–contact rate). The biases associated with study recruitment and withdrawal will be examined when the survey data are compared to the total population of hospital patients, and where possible adjustments will be made by weighting the data.

Sample Selection Process

The sample is based on patients rather than admissions, with each patient within an admitting ward having an equal chance of selection over the recruitment period. Thus, patients admitted more than once have the same chance of selection as a patient admitted once. This approach provides a very rigorous sample and avoids many of the problems associated with a sample based on admissions. For example, a sample based on admissions over represents patients who have multiple admissions, and leads to difficulties when a patient is selected more than once.

Within Woden Valley and Calvary Hospitals computer programs were set up to interface with the medical records systems to produce lists of eligible patients by ward on a daily basis. These lists are used by the interviewers to select patients for the

sample. The programs exclude patients who are:

- under the age of 18 years;
- maternity admissions;
- transfers from Woden or Calvary Hospitals; and
- previously eligible for the study. This part is achieved by maintaining a separate file on eligible patients to the medical record system.

Once a list is produced, patients are then selected using either a sampling fraction of 1–in–2 or 1–in–10 or 1–in–5 or 1–in–3 depending on the ward (see Table 8). Different sampling factions are applied to ensure that the more rare conditions are adequately represented. After selection, patients are excluded if they are:

- mentally incapable of participating in the survey;
- die in hospital;
- staying too long in hospital (6 weeks or more); or
- overseas visitors.

Exclusions at this point require reselection. Over the course of the recruitment to date there have been 638 reselections.

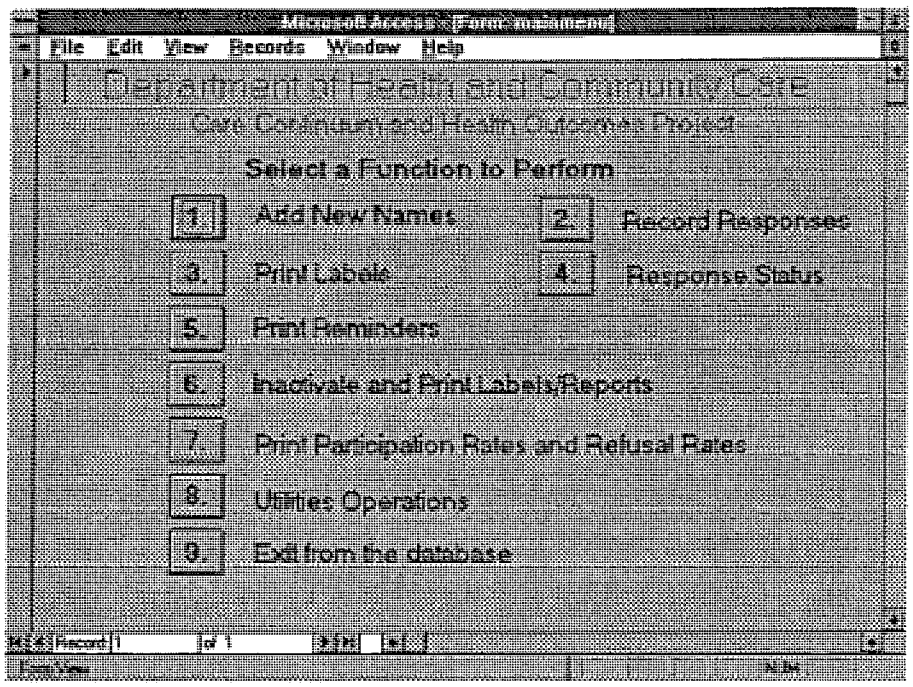
Applying a probability error α of 0.05 and a power $(1-\beta)$ of 0.90, results from pilot investigations suggest that groups of approximately 20 patients will be adequate to examine a broad range of health service and outcome comparisons between many diagnostic groups, procedures and population sub groups. A preliminary examination of the first three months of data indicates that most sample sub–groups are more than adequate in size to achieve sufficient power in the types of statistical analyses to be carried out. In relation to descriptive statistics, the large sampling fractions combined with the reasonably sized population indicates that the relative standard errors for most of the estimates will be small.

Records Management System (RMS)

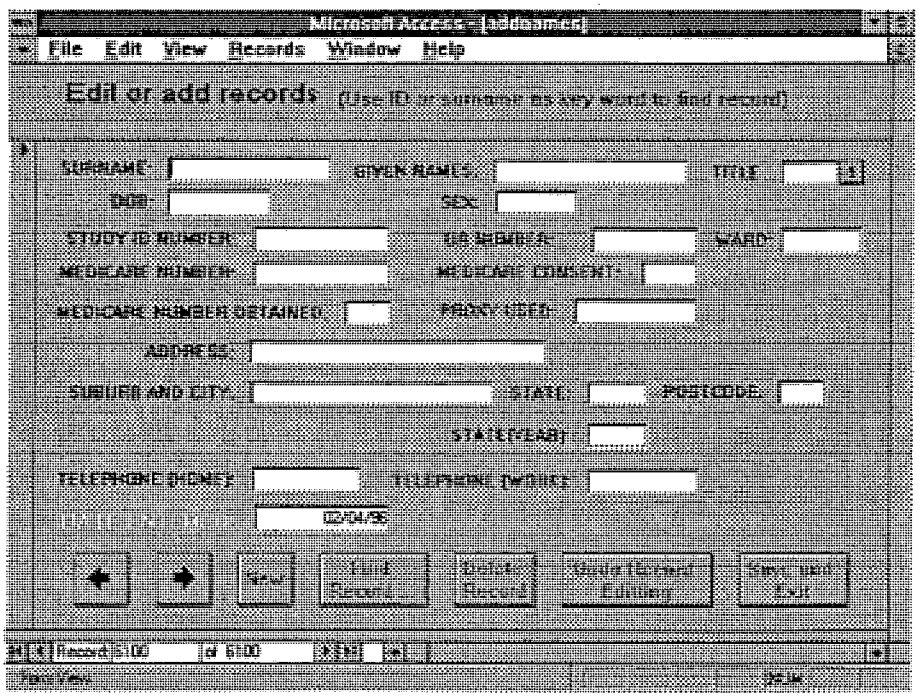
It was necessary to develop a computer system to manage the large volume of patients and their requirements over the study. An attempt to conduct the study without this support would have led to extremely large staff numbers and mistakes, making the study more inefficient. The RMS was written in Access Version 2. It contains the master patient index, and it is used to:

- record participant details and project status;
- generate reports and mailing labels for each of the four self completion questionnaires that are sent to participants at 1 week, 6 weeks, 3 months and 6 months post discharge;
- record responses to questionnaires returned;
- generate reminder lists when questionnaires have not been returned;
- produce statistics such as participation rates, refusal rates and no contact rates; and
- provide a base for the record linkage component of the project.

Below is a picture of the 'Main Menu' screen for the RMS: it provides access to the main functions of the database.

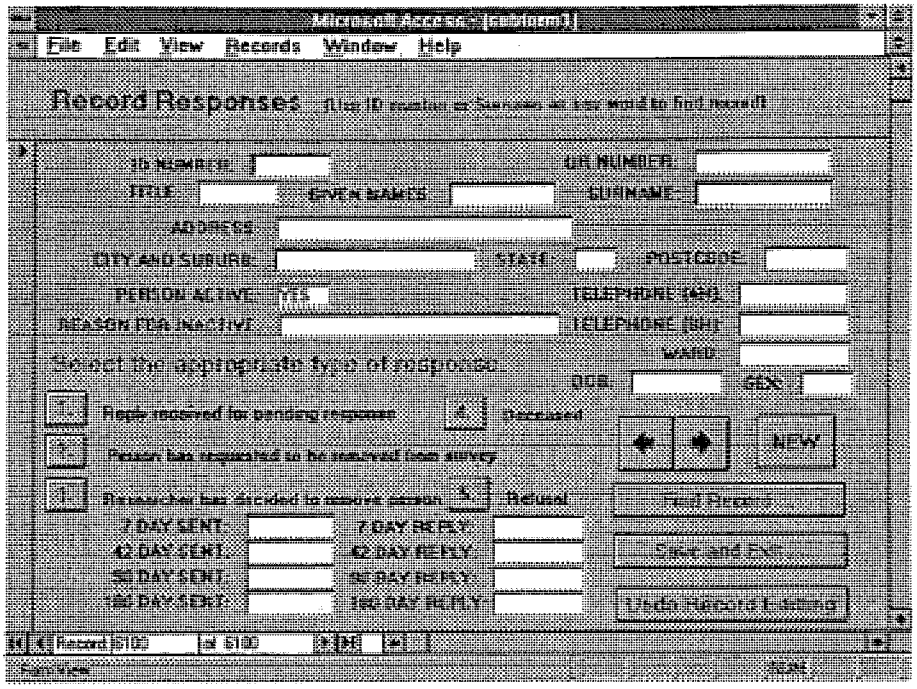


The 'Edit or Add Records' screen is used to enter participant details after they have been discharged from hospital.

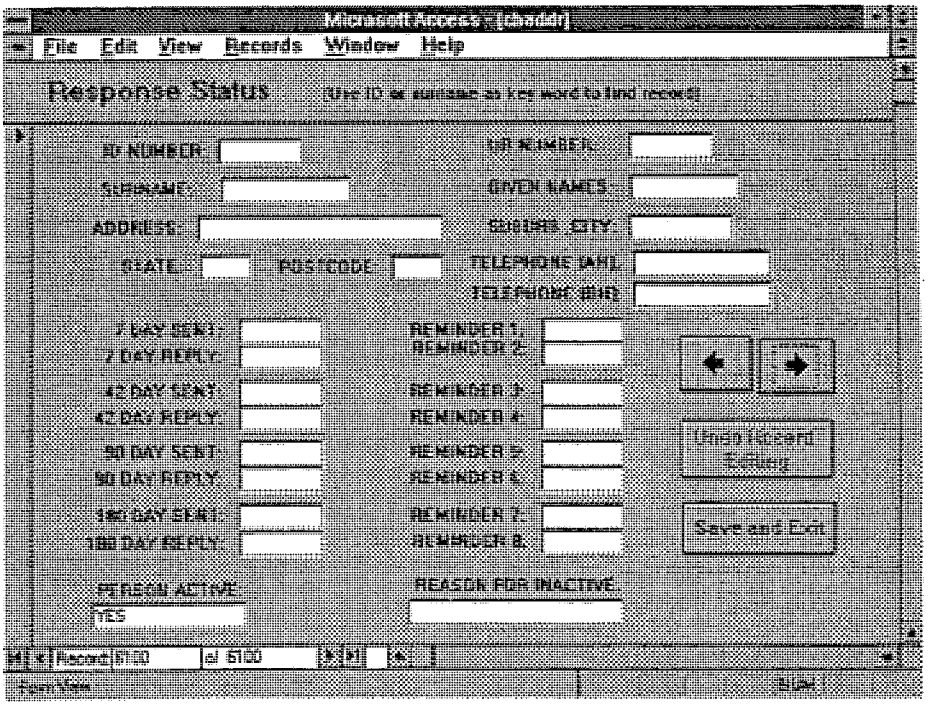


The 'Record Responses' screen is used to:

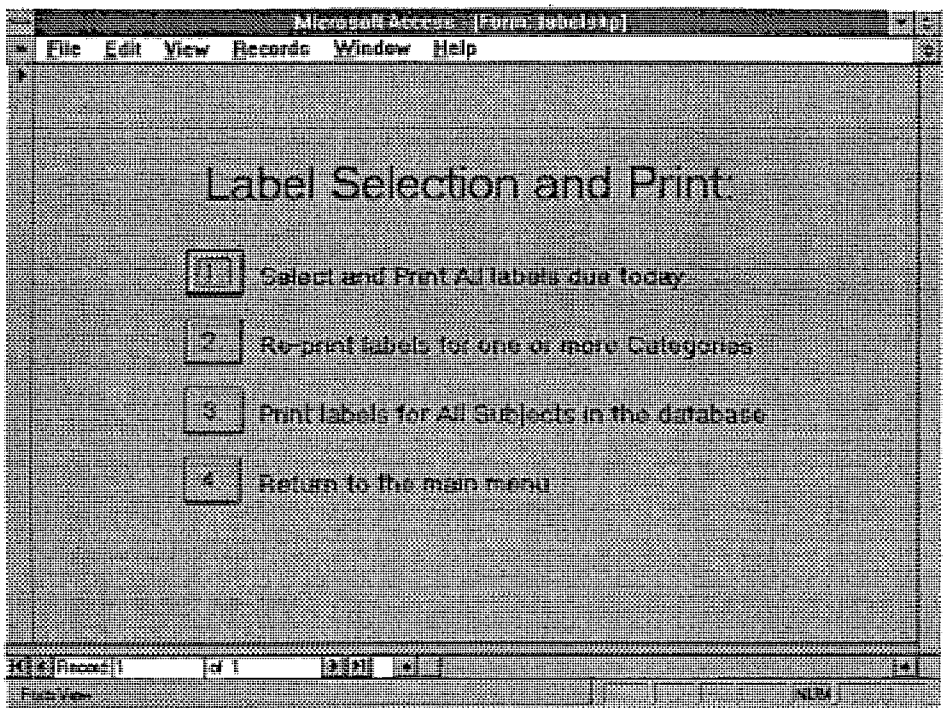
- record return date of questionnaires;
- enter details for refusal and no contact; and
- change project status for withdrawals, refusals and no contacts.



The 'Response Status' screen displays the participant's contact details, dates questionnaires returned, and the dates, if any, when reminders have been sent out. It is also used to obtain contact details for those questionnaires with missing information.



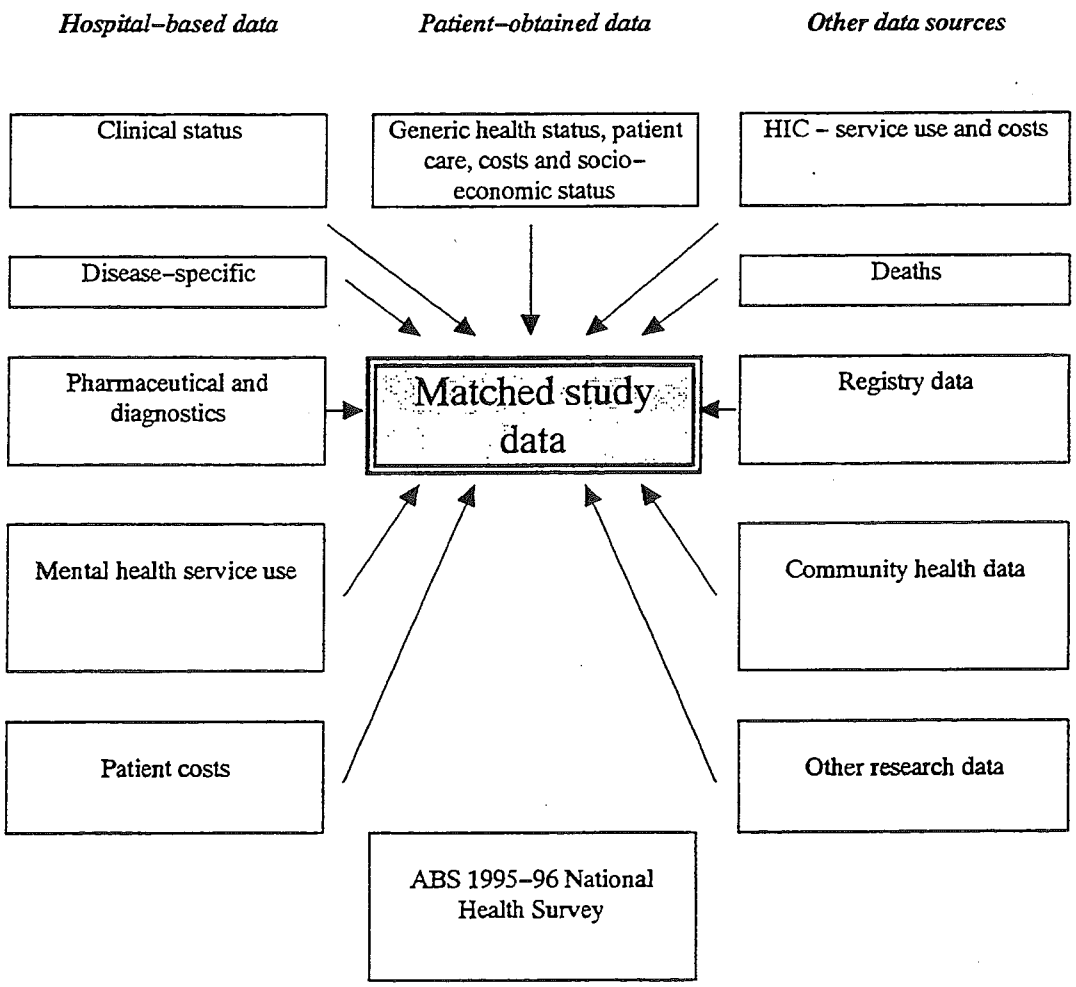
Item 1 in the 'Label Selection and Print' screen prints reports and mailing labels for questionnaires due to be sent out each day. The other items are self-explanatory.



Data Entry and Acquisition

In addition to the patient master records held in the RMS, the study has a broad range of other data sources (see Table 9). Note the Australian Bureau of Statistics' 1995-96 National Health Survey (NHS) data will not be linked to the study's sample. The acquisition of the NHS data, however, will provide comparisons with the CCHOP data on a number of health service use patterns, demographic profiles and health status measures, including the SF-36. Despite the CCHOP focussing on inpatients and their care continuum, these other comparisons with the general population will provide another beneficial dimension to the findings, as well as, identify differences between the populations. The NHS data includes about 4,000 ACT respondents and the data should be available near the end of 1996.

Table 9: DATA SOURCES OF THE STUDY



Patient–obtained data are mainly collected through the survey in the form of questionnaires and a personal health diary. To date the hospital interviews (HI) have been coded and data entered, although proper cleaning of the data is still underway. The follow–up questionnaires at one week (SC–1), six weeks (SC–2), three months (SC–3) and six months (SC–4) have been collected but have not been coded or data entered. The Personal Health diaries have been collected but again coding and data entry has not commenced. Table 10 summarises the status of the various instruments. The main hold up is people to do the task. Once the recruitment component of the study is finished there will be resources to start the coding and data entry of the SC questionnaires and diaries.

Table 10: Summary Status Report on Survey Instruments

Hospital Interview (HI)	
Status:	Coded and data entered
Collection:	Finishes 17 May 1996
Source:	Patients
Follow-up questionnaires (SC1-SC4)	
Status:	Not coded or data entered
Collection:	Finishes 30 November 1996
Source:	Patients
Personal Health Diaries (PHD)	
Status:	Not coded or processed
Collection:	Finishes 30 November 1996
Source:	Patients

Hospital-based data for inpatient separations have been extracted from Woden Valley and Calvary Hospitals but the process will need to be done several times due to delays in coding some patients' diagnoses and procedures. Programs are run that first assign hospital unit record numbers to patients in the sample; then programs are run to extract morbidity data. John James Memorial Hospital is yet to be formally approached about using the programs to extract data. Also, there may be a need to approach interstate hospitals.

Oupatient data, Emergency Department data, Diagnostic and Hospital Pharmacy data, Disease-Specific data, and Hospital Costing and Staffing data are yet to be extracted from the hospital systems.

Table 11: Summary Status Report on Hospital Data

Inpatient separations from Woden Valley, Calvary Public and Private, John James and interstate hospitals	
Status:	majority of programs written/100% coverage not yet obtained
Collection:	Ongoing
Source:	Medical records/IT
Oupatient occasions of service at Woden Valley and Calvary hospitals	
Status:	No progress
Collection	Ongoing
Source:	Mainly individual clinics
Emergency Departments at Woden Valley and Calvary Hospitals	
Status:	No progress
Collection:	Ongoing
Source:	Emergency Department

Table 11 continued

Diagnostics and pharmaceuticals at Woden Valley and Calvary Hospitals	
Status:	No progress
Collection:	Ongoing
Source:	Mainly individual areas
Disease–specific data	
Status:	Some progress
Collection:	Study period
Source:	Individual areas
Costing/staffing data	
Status:	Some progress
Collection:	Study period/some ongoing
Source:	Casemix units

Other data sources include the Community Health Division (e.g. community nursing and primary care, mammography screening); the ACT Cancer Registry; the ACT Deaths Registry and Australian Institute of Health and Welfare National Death Index; Health Insurance Commission (e.g. MBS and PBS collections); Nursing homes, Hostels and other agencies. Extraction of data has not yet commenced.

Table 12: Summary Status Report on Other Data Sources

Community Health Division, including community nursing, primary health care and alcohol and drug service	
Status:	No progress
Collection:	Study period
Source:	Individual areas
Other health and support agencies	
Status:	No progress
Collection:	Study period
Source:	Individual areas
HIC data for MBS and PBS	
Status:	Approval obtained
Collection:	1993 to 1996
Source:	HIC
ACT Cancer Registry	
Status:	No progress
Collection:	Ongoing
Source:	Population Health Division

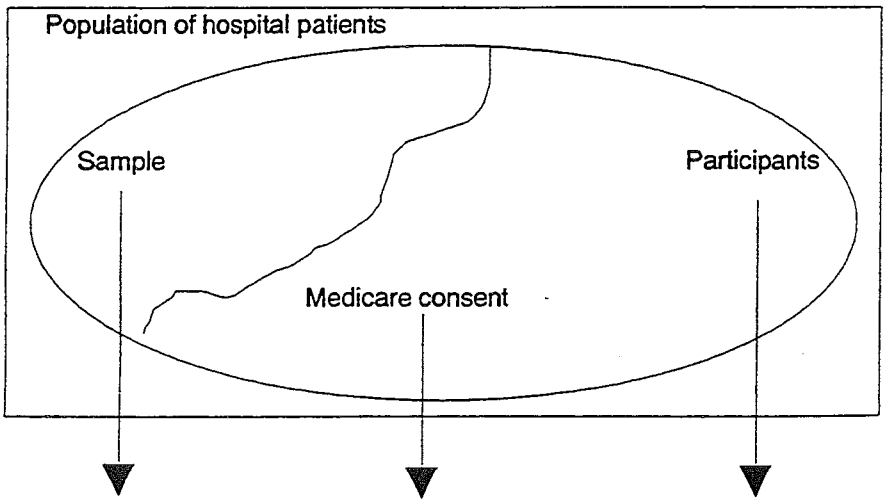
Table 12 continued

ACT Deaths Registry and National Death Index	
Status:	No progress/some deaths recorded from hospital data
Collection:	Ongoing
Source:	ACT Deaths Registry, AIHW

Most of the progress towards acquiring the non–survey data will occur in the last six months of the project when the team's time is less concentrated on the recruitment of patients.

Record Linkage

The diagram below illustrates that the CCHOP has a variety of levels at which data will be linked. For instance, the sample of hospital patients will have hospital morbidity data extracted and other ACT Health owned data linked (pending each hospital's approval). On the other hand, data requiring patient consent will only be linked for patients providing consent: level of consent can be in terms including or excluding Medicare data.



Data sources	Data sources	Data sources
• In–patient morbidity	• In–patient morbidity	• In–patient morbidity
• Hospital outpatients	• Hospital outpatients	• Hospital outpatients
• Emergency Dept.	• Emergency Dept.	• Emergency Dept.
• Hospital diagnostic and pharmacy	• Hospital diagnostic and pharmacy	• Hospital diagnostic and pharmacy
• Hospital disease–specific indicators	• Hospital disease–specific indicators	• Hospital disease–specific indicators
• Hospital costing/staff	• Hospital costing/staff	• Hospital costing/staff
• Community Division	• Community Division	• Community Division
	• Non–Govt. agencies	• Non–Govt. agencies
	• Cancer Registry	• Cancer Registry
• Deaths	• Deaths	• Deaths
	• HIC data	
	• Survey data	• Survey data

Identifiers used for data linkage are as follows:

- Study Identification
- Hospital Unit Record Number
- Medicare number
- Personal Details such as name, date of birth, sex, address

The type of identifier used will depend on the data, although once an individual is identified in a particular data set the study identification number will be attached to her/his data. For example, in-patient hospital morbidity data will be extracted according to the Unit Record Number. Once the morbidity data are extracted to the study identification number will be attached to those records.

Data Storage

Electronic Data will be stored in a series of files linked by the study identification number. Basically, the data will be stored in two dimensions (type by time):

- Data files containing different types of data, e.g. HI information and hospital morbidity data will be stored in separate files; and
- Data files containing the same type of data but in different time periods. For example, SC information at one week, six weeks, three months and six months will be stored in separate files.

At this point all personal identification information, such as name, address, hospital unit record number and medicare number will be removed from the data files.

In relation to data analysis, working files will be created that combine various types and time-based data to carry out investigations. Obviously, it would be extremely inefficient to combined all data files into one large file. In fact, I don't think there is a statistical package that could deal with such a large single database.

Paper-based data will be stored in a locked compactus in a locked room until the end of 1997. Then in 1998 it will be professionally archived for the statutory period, and finally destroyed.

Financial situation

The original budget of $462,400 proved to be inadequate to maintain a full year recruitment of patients. Consequently, supplementary funding was sought from the Commonwealth Department of Health and Family Services at $72,000. The funding was approved, and abled the project to meet its original research plan. The main reason for the over-run was an under estimation of the staff needed to conduct the follow up component of the study: I budgeted for two people and we needed five.

Lessons to be Learnt

Given the size of the project and its novelty, the biggest lesson was appreciating the amount of staff needed to maintain the follow-up component of the study, as well as the developmental work needed to start the project. For instance, it took one year to devise the instruments and tools for tracking patients and selecting the sample; and it takes a minimum of five staff to adequately run the central office tasks. These resource intense activities translated into dollars – dollars I did not budget for. Consequently, I had to seek additional funding. Thanks must go the Commonwealth Department of Health and Family Services for their understanding and willingness to quickly provide this funding.

An obvious lesson was the need to have staff who have different skills over the course of the project. For example, currently we need less skills in data capture and more in data manipulation and analysis. This changing mix means that there is a large amount of work needed in the management of the project and the need for a readily available pool of people with the diversity of skills required. This pool is extremely difficult to find and maintain. As evidence-based decision making in the health sector becomes more accepted, one solution would be to have a unit that contained the breadth of expertise and skills needed.

As we move more into the data linkage and manipulation aspects of the project, I expect that time and expertise are going to be major factors. For example, to simply link two HI data files took me a full days work. Also, I'm sure new lessons will be learnt as we enter the data analysis phase of the study.

In relation to design, the study may have been enhanced by employing the originally proposed variable finish points by 'recovery' status. For instance, at six weeks patients could have been assessed on their SF-36 scores as either 'recovered' or not. If they were 'recovered' then they could stop with the survey, and if not then continue. This approach would have made the survey more attractive to more patients. On the other hand, variable stop points based on 'recovery' status may cause bias in the study results. An analysis will be carried out to determine the extent of any bias based on 'recovery' status.

In terms of exclusion status, again the original proposal to exclude psychiatric patients may have been more favourable. Basically, psychiatric patients at Woden Valley Hospital performed poorly within the study design. A proper evaluation of patient group performances will be carried out and recommendations on variations in methodology will be put forward.

Associated Events Over The Year

In August 1995 a paper was presented at the Health Outcomes and Quality of Life Measurement Conference in Canberra. At Attachment 1 is a copy of the paper presented. Dr John Ware was the keynote speaker: he is a renowned expert in the area of health outcomes and health services research, and travelled from The Health Institute, New England Medical Centre, Boston , USA.

In November 1995 the Epidemiology Unit within the ACT Department of Health and Community Care co–sponsored a health outcomes workshop with Dr David Lansky from the Centre for Outcomes Research and Education, Sisters of Providence, Portland, Oregon. The workshop attempted to bring together a broad range of clinicans to discuss and work towards outcome measurement and decision making within their clinical areas.

During 1995 a 'sister' project emerged called the Care Continuum and Quality of Life Project. This study uses the CCHOP's methodology to examine palliative cancer patients at Woden Valley Hospital. Dr Paul Craft, Director, Medical Oncology is the Chief Investigator. A number of other proposed studies are currently being considered that utilise the CCHOP's design and data.

Next Steps

Over the next six months the project team will be conducting the following tasks:

1. Data acquisition, coding and cleaning
2. Rigorously evaluating study methodology
3. Rigorously evaluating measurement instruments, in particular the SF–36 and Personal Health Diary
4. Data linkage
5. Data storage
6. Data analysis programming
7. Analysis of data to meet the aims of the project
8. Production of the final report.

ATTACHMENT 1

The Care Continuum and Health Outcomes Project: a longitudinal study of ACT Hospital Inpatients

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ACT Department of Health and Community Care

Introduction

In May 1994 the Care Continuum and Health Outcomes Project (CCHOP) was funded by the Commonwealth Department of Human Services and Health under the Ambulatory Care Reform Program. The study focuses on the health, care and costs associated with a large sample of ACT hospital inpatients. The concept and design of the project were a result of my desire to see epidemiological-type findings play a major role in determining health services management.

The main aims of the study are to provide rigorous epidemiological findings on the health of hospital inpatients over a relatively long period; and examine the types and co-ordination of care they receive; and the socio-economic conditions they experience; and model the economic costs associated with their condition and outcomes. The richness of the findings then can be used to establish an outcomes management approach to health care delivery.

The study will achieve these aims by developing:

- profiles of inpatients and their ambulatory care utilisation (this care includes all care outside of the inpatient stay not just outpatient visits). Such profiles will provide valuable information about the paths leading to hospital admission, and the services patients use after discharge, including their informal personal care/support;
- profiles of health outcomes associated with particular interventions;
- profiles of derived costs incurred at each stage of the care continuum;
- health outcome models to help achieve better resource utilisation by adopting best practice in terms of health outcomes, care and costs;
- models of health outcome that identify high risk population groups;
- access and equity issues; and
- recommendations for improving data collection systems. For instance, the care continuum project will provide insights into the types of data needed to better monitor trends and evaluate changes to the health system.

Outcomes management

An outcomes management approach integrates numerous health services research tools into the practice of medicine and health care to help determine best practice at all levels of care and co-ordination of care. It focuses on more than just the hospital stay, with health status measures obtained over a large part of the illness episode playing a major role in the process. For example, you can ask questions about how much do patients who have different clinical conditions vary in their health status? How responsive are particular sub-populations to physical therapy? How much therapy is required to produce a measurable improvement in health status? At what point do additional therapy sessions fail to produce marginal improvements in functioning? And which sub-groups require more types of particular services? These sorts of questions then can be continually asked as new technologies and practices arise since an outcomes management approach is designed to meet the dynamic nature of the health system.

Drawing on overseas experiences, Dr Paul Ellwood, presenting the key note lecture at the Annual Meeting of the Massachusetts Medical Society in 1988, believes that physicians are convinced that the financial concerns of funding agencies and administrators are jeopardising the care of patients.[1] He claims a powerful management tool is needed to anticipate and evaluate the impact of health care on the patient's quality of life. And that such a tool will supply the missing ingredient in optimising patient care in a cost effective manner.

Ellwood believes that outcomes management is a technology of patient experience designed to provide such tool. It will help patients, funding agencies, administrators and health professionals to make rational health care choices based on better insights into the effect of their choices on the patient's life. The approach allows us to examine relationships between medical investigations and outcomes, as well as those between health outcomes and service use, providing an opportunity for each decision-maker to work with other decision-makers in making the best choices.

Ellwood prescribes the inclusion of general health status measures and long-term patient follow-up, challenging the traditional identity of the acute care hospital. For example, hospital staff tend to know little about a patient's previous condition and rarely receive information about post-discharge outcomes. Ellwood called upon health providers to tend to a patient's overall well-being by managing the use of health care resources over

the entire course of a patient's illness. From this viewpoint, it is believed that an economic approach, such as bundling together costs across the continuum of care, and profiles of health outcomes beneficial to clinical management will interact to produce an environment for positive change. Furthermore, this type of interaction may provide a good base to assess the future needs of patients by drawing upon casemix, socio-demographic indicators and health status measures to allocate resources.

There are three broad areas that outcomes management can effect:[2,3,4,5]

Clinical research – Outcomes management's closest relative is the clinical trial. It consists of the same steps: a rigorous and scientific protocol, measurements of results, data pooling, analysis, and dissemination. Unlike the clinical trial, however, this approach is a routine part of health care. Outcomes management lacks the purposeful randomization of a clinical trial, but it generates information about the results in a natural way, allowing standards and outcomes to be constantly subject to modification based on the results of analyses and feedback.

The types of investigations that can be carried out are limited only by data quality and coverage and the enthusiasm of the investigator. And since the late 1980s there has been a dramatic increase in the literature reporting findings using health status measures in the hospital and postdischarge settings.

Patient care – By using clinical and policy research and normative findings, clinicans can use the results to improve the patient's care and their communication with the patient. For example, identification of high risk groups may permit clinicans to direct supplemental services to individual patients (e.g. THR patients experience more difficult and delayed recoveries if they have inadequate social supports). In relation to communication, by using a common language between patient and practitioner patients feel reassured about their own recovery when they see how their progress correlates with the norm. It also allows clinicians to tell patients with confidence that a certain treatment is likely to produce specified results in a predicted time frame. It should be pointed out that data published from clinical trails often leaves practitioners unable to describe expected results for an individual with a particular combination of risk factors and symptoms.

Policy research – An outcomes management approach provides a mechanism for bringing together a broad range of decision-makers to determine best practice in terms of medical interventions, treatments, service use, costs and resource utilisation. With

the health of the patient as the focus rather than simple outputs, policies can be developed that deal with patient needs to achieve the optimal health outcome. Using clinical status, patient risk factor information, service use, costs and treatment outcomes, a predicted set of health care requirements can be identified for groups of patients. For example, you can predict the types and amount of services a person will need to achieve a certain health outcome given the disease, stage of disease, co-morbidities, demographic characteristics, informal support and socio-economic status of the patient. Thus, allowing funding to be focused on obtaining best practice and health outcomes rather than simply basing funding on counts of output. Once these models are developed it will be interesting to see the appropriateness of Diagnosis Related Groups (DRGs).

As already mentioned, an outcomes management approach is interactive and dynamic. As a result, as new technologies and practices emerge the management of the system can be readjusted to determine new standards. Also, as new policies are made and reforms implemented the effect of these changes can be evaluated in a comprehensive way. In sum, an outcomes management approach can bring order and predicability to our health care system in a more desired way. It will provide health professionals with the tools to achieve these goals – the improved health and quality of life of patients in a cost-effective process.

The initial challenges are to convince governments, executives and health professionals of the benefits, and then to develop standardized tools, measurement procedures and finally on-going data collections. The cultural, technical and organisational barriers to widespread utilisation of health status measurement in the hospital setting are numerous.[2] The only chance of success hinges on well designed research projects that provide clear evidence of the advantages in establishing an outcomes management approach to health care.

Over the last four years, the commonwealth, state and territory governments have recognised the need to move towards an outcomes focus. The national health policies 1991-92 and 1995, the 1994 Ambulatory Care Reform Program and most recently, the 'green paper' from the Council of Australian Governments Taskforce all have identified the need to base health care on health outcomes. Similarly, health professionals frustrated with simple accountancy management are demanding the health and care of patients be the main focus of funding decisions. Unfortunately, the lack of outcome data has prohibited comprehensive investigations, especially in terms of cost-effectiveness models. Consequently, much work, both in terms of long-term strategies and research need to be conducted before major shifts in practices and funding can occur.

The measurement of health status: methodological issues

The first issue is at the core of most barriers to the acceptance of health status measures in clinical populations. Who determines a patient's health status? Social scientists and other academic researchers would say that patient completed instruments provide a suitable approach.[6] Many clinicans, however, would say that data gathered from patients is too 'soft' a basis for drawing definitive clinical, research or policy conclusions. The common opinion is that physiologic data or clinican observations are inherently more accurate, reproducible, and 'hard'. In contrast, several studies suggest that items of medical history or questionnaire responses can be more reproducible than a clinican's examination or interpretations of imaging tests.[3] Furthermore, clinicans often underestimate or fail to recognise functional disabilities that are reported by their patients. They overstate functional impairment to a lesser extent.[7] In sum, many clinicans are probably unduly pessimistic about the reliability of questionnaire data and unduly optimistic about the salience of many physiologic measures.

The next issue concerns generic versus disease–specific patient completed measures. According to Patrick and Deyo (1989) generic health status measures are those that purport to be broadly applicable across types and severities of disease, across different medical treatments or health interventions, and across demographic and cultural subgroups.[6] On the other hand, disease–specific measures are those designed to assess specific diagnostic groups or patient populations, often with the goal of measuring responsiveness or 'clinically important' changes. The primary goal of studies using disease–specific measures is to assess within–subject change in health status over two or more points in time. The ability to detect small changes is important in determining statistical power of a trial or the necessary sample size to detect a difference between the experimental and control groups. In contrast, policy analysts involved in health services evaluation, resource allocation or population comparisons also may be interested in health status change, but primarily across different diagnostic groups and usually using large samples.

The type of instrument used depends to a large extent on the needs of the research being conducted, although Patrick and Deyo outline four models most commonly applied:

- separate generic and disease–specific measures within the one study. The major problem with this model is the concepts covered by the different instruments may substantially overlap;

- modified generic measures. This approach adds disease–specific items or modifies the focus of some items to be more specific to better capture the experiences of the population being studied.;

- generic measure with disease–specific supplementation. This model is similar to the first approach except that the condition–specific measure is constructed to have a different conceptual basis and minimal overlap with the generic measure; and

- batteries of specific measures refers to the collections of specific measures that are scored independently and reported a individual scores (generic instruments may be included, but this is uncommon).

Recently, a number of researchers have been using short generic measures, like the Medical Outcomes Study SF36, because they are easy to administer and perform as good as most of the disease–specific instruments in terms of validity, reliability and sensitivity to change in health status.[8]

Barriers to using health status measures

According to Deyo and Patrick (1989), the barriers include scepticism about the validity and importance of self–rated health; preferences for physiologic outcomes or death rates; unfamiliarity with questionnaire scores; a paucity of direct instrument comparison to aid in selection; and the costs of pilot testing, data collection and data manipulation.[3] In clinical trials, the uncertain responsiveness of questionnaire instruments to small but clinically important changes of particular concern. For patient concern, additional barriers are posed by the need for rapid processing data, the need for providing highly understandable results to clinicans, and clinicans' uncertainty about how to use the information. In policy research, there is often insufficient time for responding to decision makers' needs, and many have reservations about concepts such as quality–adjusted life years that arise from health status measurement.

The above barriers can be broken down by more research comparing clinical scales and traditional physiologic measures with health status indicators; and better education of health professionals about health status measurement techniques and analysis. As part of

this process, it must be also recognised by researchers and clinicans that health status measurement by its self will not provide answers. Well designed research studies are needed to advance our knowledge: studies which comprehensively examine the effects of interventions or evaluate the health outcomes of care delivery will provide the rigour to move this necessary work forward and consequently improve the quality of life of many patients.

The CCHOP's methodology

If one applies a conventional approach to examining the care continuum and health outcomes of patients then the state of knowledge would be unimpressive. The use of the existing 'administrative' data systems in health outcomes research leads to large uncertainties, both in terms of linking care to a specific condition and missing important aspects of care received and health outcomes achieved. Most of the problems mentioned, however, can be overcome by supplementing ongoing data collections with sample survey data that prospectively follows patients through questionnaires that ask about formal and informal care, and aspects of quality of life. The present study has designed such a cohort study: it attempts to link existing data collections with detailed survey data obtained from patients over a six month period of this illness episode (see Table 1).

Recruitment sites

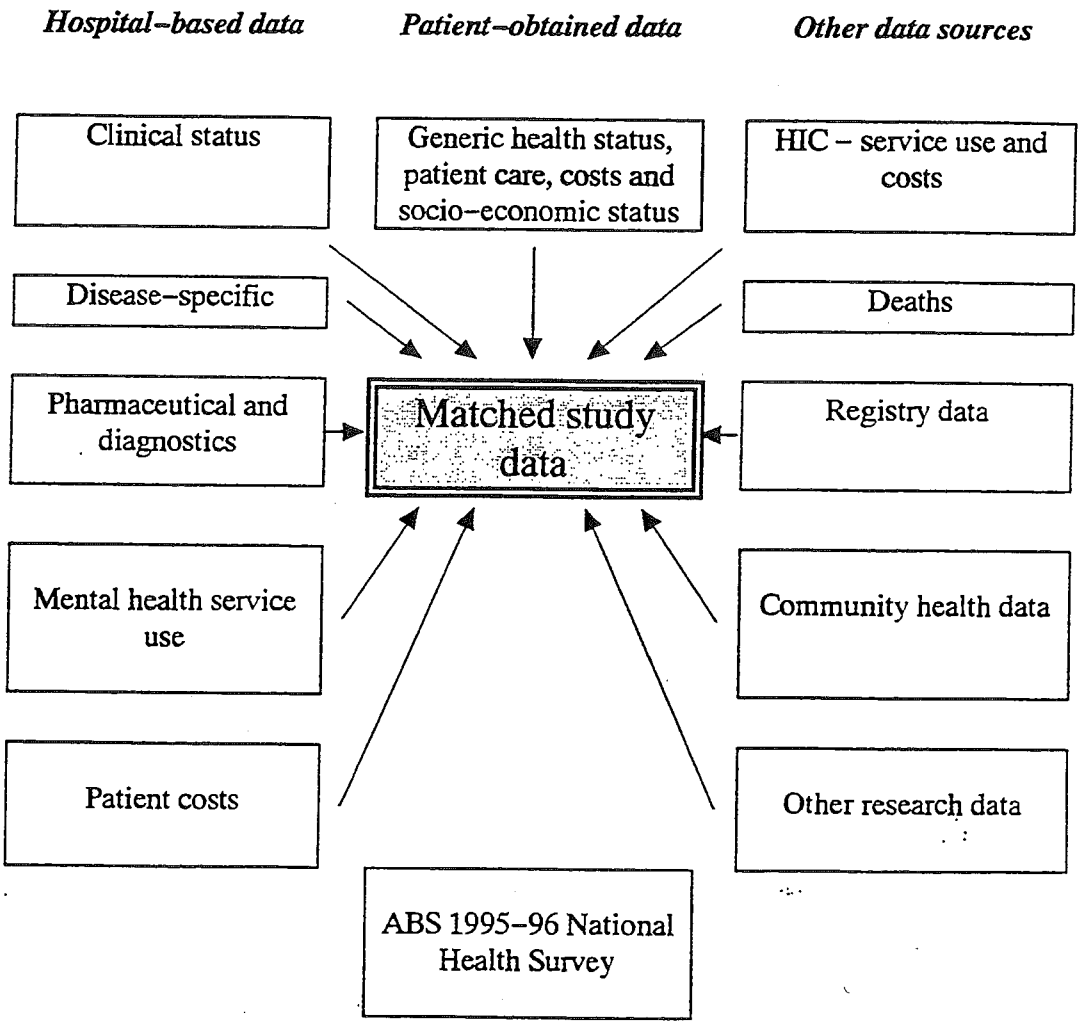
Three sites have been chosen – Calvary Public and Private Hospitals and Woden Valley Hospital. These sites represent about 70 per cent of hospital admissions in the ACT. The two public hospitals represent approximately 99 per cent of public hospital admissions (excludes Queen Elizabeth II), while Calvary Private Hospital represents about 16 per cent of private hospital admissions. The 84 per cent not covered in the private sector are admissions to John James Memorial Hospital (54%) and a number of registered day hospitals performing procedures such as endoscopies (30%).

Selection of the study population

The study is designed to examine ill people who need to use a hospital inpatient service. Generally, the findings will not represent those who have a particular disease within the ACT population. For instance, the study does not cover people who are admitted to John James Memorial Hospital or those who are living in a nursing home or those only using

other kinds of health services (such as outpatients). From this perspective, the study population is hospital specific, although it does well represent the total public hospital system.

TABLE 1: DATA SOURCES OF THE STUDY



Patients in ACT hospitals also include those residing outside the ACT, comprising on average about 20 per cent of admissions. The majority of these (approx. 92%) are usually resident in New South Wales, with ACT hospitals being the most proximate for the type of treatment they require. According to tables produced in a recent commonwealth publication, the distribution of separations within DRGs for ACT public hospitals is comprehensive and similar to the Australian average.[9]

The following characteristics associated with ACT's hospital inpatients will help the success of the present study.

- Relatively few ACT residents use hospital services outside the ACT (approx. 5%);
- The regional role of the ACT makes it possible to isolate and examine those that travel into the ACT to use its hospital services;
- The ACT hospital system has an extremely good coverage of the range of conditions treated in Australia;
- High levels of educational attainment within the community suggest that patients will be able to cope with the survey instruments; and
- The variety of household compositions and ethnic groups within the ACT will allow comparisons between a broad range of population subgroups within the study.

Limited resources and logistical concerns have caused the study to be restricted to a sample of about 10,000 patients. Consequently, an attempt to represent all conditions in the hospital system would lead to under-represented sub-samples for numerous diagnoses. The solution has been to exclude three groups from the study:

- obstetric patients – the fact that many pregnant women admitted to hospital are well, most of their care occurs before hospitalisation, parts of the survey questionnaire would not apply to a majority of them, and they represent such a large volume of admissions have lead to their exclusion;
- patients under the age of 18 years – the survey instruments, consent and other ethical concerns make their inclusion problematic; and
- chronically confused patients or patients who die before discharge.

Sample selection

The sample was based on patients rather than admissions because this approach is more rigorous and likely to yield a random sample. For example, over the study a patient may be admitted to hospital more than one time, and therefore, basing the sample on admissions would give some patients a greater chance of selection, and lead to difficulties when a person is selected more than once. Computer programs were written to obtain the appropriate lists of patients for daily selection.

The broad aims of the study require a relatively large sample to ensure that both descriptive and analytical analyses can be effectively carried out for various diagnoses, procedures and population sub groups. It is expected that the study population for May

1995 to May 1996 will be about 24,000 (excludes obstetric patients and patients under the age of 18 years). Using lists of patient names, a random sample of patients within the recruitment sites by wards will be selected. The sample is stratified as follows:

- day only at 1–in–10;
- renal dialysis patients at 1–in–3;
- cancer patients (including most outpatients) at 1–in–5; and
- others at 1–in–2.

In total, the chosen sample fractions will yield a sample of about 9,500 patients over the year long recruitment period. The sample, however, is 'self–weighting' within wards so that the actual distribution of patients will depend on the population at the time of recruitment. Table 2 provides a breakdown showing expected numbers for each recruitment site and for selected indicators. Based on pilot work and other studies, the response rate is expected to be high – at least 80 per cent. Over the six month follow–up probably another 10 per cent will be lost, leaving an estimated total response rate of about 70 per cent. Table 2 also shows expected numbers using a 70 per cent response rate for the cohort.

TABLE 2: THE ESTIMATED PATIENT NUMBERS (LOWER AND UPPER BOUNDS) EXPECTED IN THE CARE CONTINUUM AND HEALTH OUTCOMES PROJECT FOR SELECTED INDICATORS[1]

Selected indicators	Woden Valley Hospital	Calvary Hospital (Pub)	Calvary Hospital (Pri)	Total
Admission type				
elective	2084–2978	765–1092	541–773	3389–4843
urgent	2309–3298	816–1165	51–72	3175–4536
Usual area of residence				
ACT	3006–4294	1285–1836	481–688	4772–6818
other	1387–1982	295–421	110–158	1792–2560
Day only patients	797–1139	158–225	45–62	1000–1428
Age				
< 65 years	3014–4307	1061–1516	457–652	4533–6474
65+ years	1379–1969	519–742	135–193	2032–2904
Country of birth				
Australia	3236–4623	1115–1593	472–675	4832–6890
UK/NZ/USA/Can.	465–664	176–251	54–78	695–993
Europe	451–664	192–274	40–58	683–976
Asia	125–179	49–69	11–16	185–264
other	116–166	48–71	14–19	178–256

(continued)

Selected indicators	Woden Valley Hospital	Calvary Hospital (Pub)	Calvary Hospital (Pri)	Total
Marital status[2]				
married/defacto	2537–3624	899–1284	411–587	3847–5495
never married	851–1215	329–470	104–149	1284–1834
wid/div/sep	865–1236	348–498	76–109	1288–1841
Principal diagnosis				
Infectious/para. dis	59–84	23–33	–	82–117
Neoplasms[3]	578–825	114–164	62–89	754–1077
Endocrine & Immun.	76–108	26–37	–	102–146
Dis. of blood	38–54	9–13	–	47–67
Mental disorders[3]	189–270	85–121	–	274–391
Nervous system dis	229–327	68–97	40–57	337–481
Circulatory dis	750–1071	251–359	51–72	1051–1502
Respiratory dis	273–389	123–176	23–33	419–599
Digestive dis	498–712	248–354	126–180	872–1246
Genitourinary dis	350–500	139–198	70–100	559–798
Skin & subcut. tissue	67–95	21–30	–	88–125
Musculoskeletal dis	207–295	214–305	154–220	574–821
Symptoms & signs	226–323	100–143	13–19	339–485
Injury/poisoning	604–863	106–152	29–42	739–1056
Supplementary class.	238–340	47–67	21–30	306–437
Total	4393–6276	1580–2258	592–845	6565–9378

1. The range uses a response rate of 70% as the lower bound and an upper bound based on a sample of 1–in–2 patients (1–in–10 acute day only) from the 1992–93 study hospital population.
2. Data contained a large proportion of missing information.
3. These diagnoses are likely to be supplemented by supporting studies.

Applying a probability error α of 0.05 and a power $(1-\beta)$ of 0.90, results from pilot investigations suggest that groups of approximately 20 patients will be adequate to examine a broad range of health service and outcome comparisons between many diagnostic groups, procedures and population sub groups. An examination of the 1992–93 data indicates that most sample sub–groups are more than adequate in size to achieve sufficient power in the types of statistical analyses to be carried out. In relation to descriptive statistics, the large sampling fractions combined with the reasonably sized population indicates that the relative standard errors for most of the estimates will be small.

Table 3 shows participation rates for the first three months of the study. These rates include patients who entered into the study, those who refused and those who were 'non–contacts' (this group mostly comprises those who went home before the

interviewer could recruit them). Overall, about 13 per cent of selections were refusals and 7 per cent non-contacts. The ward with the lowest participation rate is the psychiatry ward at Woden Valley Hospital: this was expected due to the characteristics of the admissions.

TABLE 3: RECRUITMENT PARTICIPATION RATES AS AT 4TH AUGUST 1995

Hospital	No. selected(a)	No. recruited	Participation rate (%)(b)
Woden Valley	1211	956	79
Calvary (pub+priv)	598	524	88
Total	1809	1480	82

(a) Includes recruited patients, refusals and non-contacts.

(b) Excluding non-contacts the rates are 84%, 96%, 88%, respectively.

Follow-up of patients

Using a sophisticated computer program, participants in the study are followed up at numerous points.

Self-completion questionnaires at:

- 1 week post discharge
- 6 weeks
- 3 months
- 6 months

Personal health diaries (service use):

- ongoing over 6 months post discharge

All follow up is conducted in a central office: a records management system (RMS) maintains a record of each selected patient and determines over the course of the study the action needed to be taken on a daily basis. For example, who, when and which questionnaire needs to be sent to a participant; who needs a reminder and for which questionnaire; who has finished with the study and why; and what are the participation rates.

Patient–obtained data

Table 4 summarises the breadth of data collected from patients. The first is an interview questionnaire, administered at recruitment during the hospital stay. The questionnaire gathers details about co–morbidities, past treatments, the path leading to admission, quality of hospital stay, and health status, including a symptoms list, pain levels and the SF36. Also, demographic data collected at the time of admission by the hospital staff will be verified. Finally, an interviewer assessment of the patient's English language proficiency and health condition will be obtained.

TABLE 4: PATIENT–OBTAINED DATA INSTRUMENTS

Hospital interview	*Self–completion questionnaires*	*Personal health diary*
• demographics • paths leading to admission • symptoms list • pain • SF36	• family and work circumstances • SF36 • lifestyle indicators • symptoms list • pain • personal care • needs assessment	• visits/contacts • pharmacy (medications) • admissions (emergency departments, inpatient episodes, hostels and homes)

The follow–up survey instruments include a set of four self–completion mail–out questionnaires. The first questionnaire will be sent to patients one week after recruitment, the second at six weeks, the third at three months; and the fourth at six months. Each questionnaire contains items on socio–economic status, household composition, social activities, lifestyle factors, personal care and support, transport, symptoms, pain and the SF36.

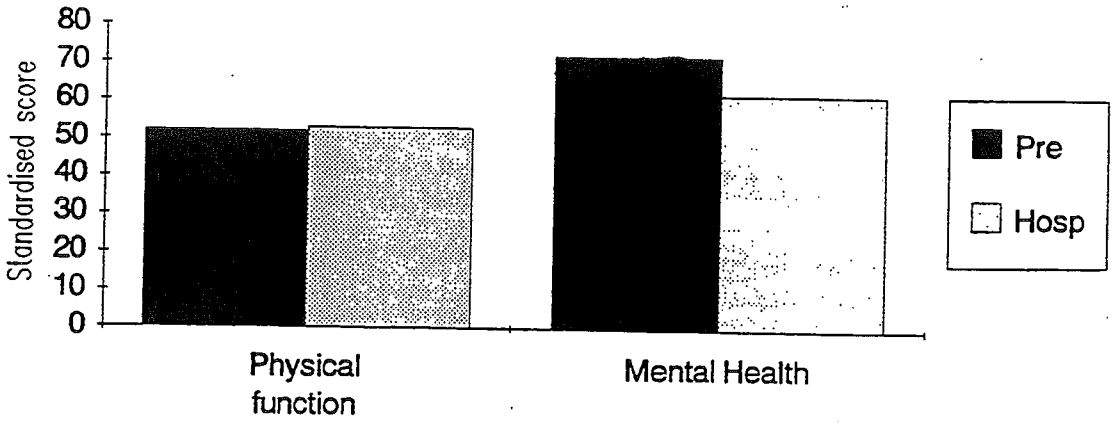
The personal health diary is maintained by the patient, although mostly filled out by health professionals. It prospectively gathers information about health services used after discharge from hospital for six months. The types of data items to be collected include information on the date of service, place of service, type of service, duration of the consultation, reason for the visit, treatment provided, MBS item number (where appropriate) and charging details. The types of service include medical, diagnostic, nursing, allied health, pharmacy services, complementary health services and community support.

The CCHOP approach to health status measurement

Health status is a crucial part of the study. Given the broad nature of the study's aims, it was important that a short generic measure of health status could be used that is reliable, valid, sensitive to change and responsive to interventions. After an extensive examination of instruments found in the literature, the SF36 was chosen because it had many of required qualities, and it is being used in the 1995 Australian Bureau of Statistics (ABS) National Health survey.

Despite retrospectively capturing services used and diseases experienced prior to admission, the health status of patients before they entered hospital was logistically beyond the study (patients are recruited during their hospital stay). A pilot was conducted, however, that examined the health status of vascular and cardiac patients about three or four weeks before their admission, during their stay in hospital and about one or two weeks after discharge. Using the SF36, the findings suggest that the overall effect of hospitalisation on health status is not significant, with average scores being similar between pre-admission and the hospital stay. This result is not surprising since patients were asked to assess their health over the last month and, when in hospital, over the last month excluding their current stay in hospital. Figure 1 shows, however, that most variation was between scores on the mental health scale (vitality also showed a similar trend), with scores in hospital being lower on average than prior to admission.[10]

Figure 1: Comparisons between pre and a retrospective examination of pre-hospitalization for physical functioning and mental health scores



In sum, the measurement of health status during the hospital stay produces a reasonable approximation of physical health prior to admission. Also, the hospital provides a standard environment and time to develop a starting point of comparison. This situation is particularly important because of the diversity of patients and their circumstances in the study. As an alternative baseline, age, sex and condition–specific norms will be obtained from the ABS National Health Survey (conducted over a similar period) so that the success of hospital treatments can be compared to population averages, as well as to changes over the follow–up period of the study.

In relation to change in health status, the results from the pilot work suggest that the SF36 was sensitive to predicted change, with bodily pain, general health, vitality and mental health showing significant changes pre and post hospitalisation. The generic measurement of health, however, limits conclusions because the 'exact' effect of the hospital intervention on health status can not be easily established. To improve this situation the SF36 was supplemented with illness–specific pain indicators and a symptoms list (note that the SF36 was administered as a whole). Also, due to 'floor' effects for the frail elderly, especially for physical functioning, an additional instrument was used that is more sensitive to the health problems of the elderly.

BENEFITS OF THE SF36

- Short and easy to administer
- Covers a broad range of health dimensions
- Valid and reliable
- Relatively sensitive to change in health status

CAUTIONS

- Mental health dimensions are sensitive to current circumstances
- SF36 is most useful when compared to some 'norm' since critical cut–offs are not yet established
- The distribution for many of the dimensions can be extremely skewed
- The generic nature of the SF36 limits the conclusions of health outcomes from interventions (e.g. responsiveness)

Conclusions

The research design follows Ellwood's outcomes management model, satisfying both economic and clinical/epidemiological aspects by bringing together a broad range of health service research tools. The design reinforces that:

- health outcomes research is much more than administering an instrument like the SF36;
- it can bring order and predictability to our health care system; and
- it should be a catalyst for bringing together a broad range of groups related to the care of patients.

Hopefully, this project will provide the ACT with an opportunity to be at the forefront of developing a health outcomes model that improves care and the quality of life of patients in a cost–effective way. The approval and support of health–care workers, however, is paramount to the success of the study. Consequently, efforts have been made to include them in the development of the research project, and steps will be taken to seek their input on recommendations arising from the research, including the development of health service research tools for future standard collections.

The next step

After the completion of the data collection, working parties will be established to develop outcome management models. It is anticipated that health professionals, administrators, health economists and epidemiologists will be the main participants. These models then will be offered for national consideration in the process towards standard measurement tools and reform of the health care system.

REPORTING OF FINDINGS

All findings will be presented to the following committees for discussion before release:

1. the Medical Staff Committee comprising chairs from the various specialty divisions;
2. Hospital Management Committees at Woden Valley and Calvary Hospitals;
3. ACT Department's of Health Corporate Executive; and
4. Commonwealth Department of Human Services and Health.

TIMETABLE

- Pilot work (Jun–Dec 1994)
- Main consultation (Feb–March 1995)
- Interviewer training (March–April 1995)
- Trial collection (April 1995)
- Study proper (May 1995–November 1996)
- Preliminary results (Feb 1996)
- Final first report (Feb 1997)

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