

Hospital outcomes management: The Care Continuum and Health Outcomes Project

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Abstract

The Care Continuum and Health Outcomes Project is part of a national initiative to build an outcomes management approach in health care. This paper examines the baseline performance of the study: In 1995–96, 7154 Australian Capital Territory hospital inpatients were selected to take part in a five-wave survey over six months. In addition to the survey, the project involved the unit record linkage of routine data collections. A total of 5668 people (79%) agreed to participate in the survey, with 85% of these people agreeing to release their Medicare data. There were significant variations in participation rates between hospitals and wards. Factors contributing to these variations included patient socioeconomic status, disease type and illness severity. In conclusion, the success in establishing the project indicates that it is possible to conduct a broad scientific study within the health system, and that there are strong implications that ongoing scientific evaluations can be embedded within routine clinical practice.

Introduction

The Care Continuum and Health Outcomes Project collected data from a large number of hospital patients in Australian Capital Territory (ACT) public and private hospitals and followed them over six months. It was part of a national

endeavour organised by the Commonwealth Department of Health and Family Services to explore the relationship between hospital inpatient episodes and ambulatory care. The project was designed to model outcome processes, with the study goals including (Shadbolt 1995):

- developing profiles on health-related quality of life, informal care, formal service use and financial costs over the care continuum for hospital inpatients
- comparing the outcomes of various patient and population groups
- helping clinicians and administrators improve their decision-making to achieve more cost-effective treatment by using these data
- testing different methodologies of data collection, specific variables and classification systems.

There is an absence of a well-defined literature on treatment and patient outcomes, especially covering the period from hospital admission to post-hospital care. This situation reflects, in part, a clinical focus on traditional randomised clinical trials, and administrators' concentration on 'throughput' indicators such as diagnosis related groups. Ellwood (1988) proposed the development of an 'outcomes management system' to integrate numerous health services research tools into the practice of medicine. The system is centred on the illness of a patient rather than an episode of care. Developing this notion further, Wilson and Cleary (1995) suggested that a major end-point is the health-related quality of life of a patient. Shadbolt and colleagues (in press) proposed a set of measures to maximise the influence of health outcomes research findings on clinical practice and government policy: these were incorporated into the Care Continuum and Health Outcomes Project. In the long term, however, the process of measurement needs to fit within a theoretical framework which merges science and clinical practice. Such a framework requires a dynamic process which focuses on improving clinical practice and the health outcomes of patients rather than comparing different treatments as in randomised clinical trials. The Care Continuum and Health Outcomes Project provides an opportunity to explore scientific and practical issues in developing such a theoretical framework.

An *outcomes management system* requires long-term patient follow-up on factors beyond routine inpatient data. It also requires a major change in Australia to current research approaches, information infrastructures, staff skills and evidence-based knowledge (Shadbolt 1996; Shadbolt, Zonta & Tran, in press). The cultural, technical and organisational barriers to widespread utilisation of such a system in the hospital and community settings are numerous. Administrators and health professionals have to be convinced of the benefits, and standardised tools have to be developed, along with measurement procedures and ongoing

data collections. Successful development will hinge upon well-designed research projects that provide clear evidence of the advantages in establishing an outcomes management approach to health care.

After three years of survey work, the Care Continuum and Health Outcomes Project is at a stage where the study design, baseline participation rates and sample representativeness can be presented. A paper has been published validating the satisfactory performance of the Medical Outcomes Study's SF-36, using the first three months of baseline data (Shadbolt, McCallum & Singh 1997). The current paper details the methods and processes of the study. The explanation of methods is of practical importance to those considering hospital research.

Methodology

The Care Continuum and Health Outcomes Project is a large community study containing both retrospective and prospective data collections. Recruitment into the study was anchored around a hospital inpatient episode. It has a record linkage component, as well as a prospective patient survey containing five waves, covering patient experience, clinical and service-use dimensions. This multifaceted design allows observation of trends in patient experiences and investigation of the outcomes of various interventions.

The population

The study was designed to represent ill people who need to use a hospital inpatient service at some point in their care continuum. It includes ACT and non-ACT residents. ACT hospitals comprise, on average, about 20% of non-ACT admissions, approximately 92% of whom are usually people living in New South Wales. In terms of casemix, the findings from a recent Commonwealth publication suggested that the distribution of separations within diagnosis related groups for ACT public hospitals was similar to the Australian average (Commonwealth Department of Human Services and Health 1994). The major areas where the ACT hospital system did not provide inpatient treatment were cardio-thoracic surgery, and liver, heart and heart/lung transplants.

The sample

The study's sample was selected over one full year, from May 1995 to May 1996, in three of the four major hospitals in the ACT – The Canberra Hospital (formerly Woden Valley Hospital), Calvary (Public) Hospital and Calvary (Private) Hospital. John James Memorial Hospital was not selected because of

issues associated with resourcing a fourth site. A full-year period was chosen to avoid bias from seasonal variation, and to obtain a reasonable sample size, especially for some of the less common conditions treated. Furthermore, the sample is based on patients rather than admissions, with each patient having an equal chance of selection over the recruitment period. Thus a patient admitted more than once has the same chance of selection as a patient admitted once. This approach provides a rigorous sample of patients and avoids many of the problems associated with a sample based on admissions.

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 were used by trained interviewers to select patients for the sample. The programs excluded patients who were:

- under 18 years of age
- maternity admissions
- transfers from The Canberra or Calvary Hospitals
- previously eligible people.

A small group of day-only patients at the Calvary Private Hospital also were not included because patient records prior to hospitalisation were unavailable to the study. Logistically, it was not possible for the interviewers to cover admissions on every day of the week. As a result, a random selection of patients admitted on Friday, Saturday and Sunday was employed. Also, many of the wards dealing with day-only patients did not have these patients on the medical records system at recruitment time. A manual system was therefore set up to identify many of the eligible day-only patients. The exclusion process was done by hand.

Sampling fractions of 1-in-2, 1-in-10, 1-in-5 or 1-in-3 were used to select patients. Different sampling fractions were employed to ensure that the less common conditions were adequately represented, and that sample sizes would be large enough to carry out subgroup analyses. The actual fractions were calculated using 1992–93 ACT hospital morbidity data (Shadbolt 1995).

After selection, patients were further excluded if they were:

- mentally incapable of participating in the survey
- persons who died in hospital during the recruitment episode
- persons who stayed too long in hospital at recruitment (expected six weeks or more), or
- overseas visitors.

These exclusions were then reselected from the lists. Over the course of the recruitment there were 855 reselections.

Data sources

Figure 1 shows the range of data currently linked for each participant by a unique study identification number.

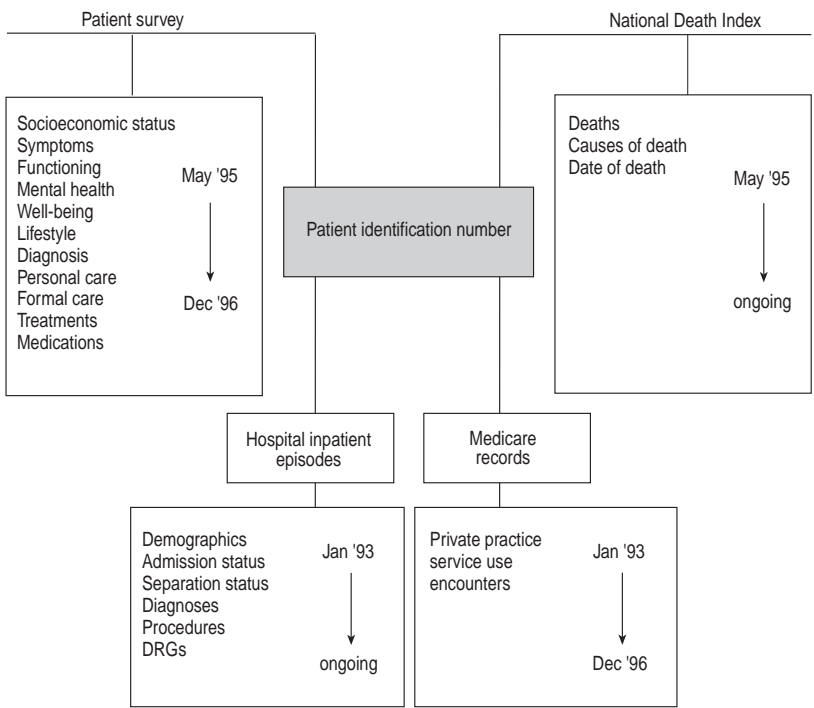


Figure 1: Data linked in the study

Patient survey data were collected in survey questionnaires and a personal health diary. The questionnaires were administered at the hospital interview, and by mail at one week post-discharge, six weeks post-discharge, three months post-discharge and six months post-discharge. Patients were tracked through the hospital until an appropriate time became available for interview. This time was negotiated between nursing staff, the patient and interviewer. Once participants were discharged, they were sent a follow-up questionnaire. Those who did not return their questionnaire by a given date were telephoned or sent a reminder letter with another questionnaire. Participants who failed to respond at one week were moved onto the six-week mail-out. No response to the six-week questionnaire resulted in the person being classified as 'inactive'. Similarly, people who did not respond to the three-month or six-month questionnaires were

classified as 'inactive'. At the end of the survey period all 'inactive' participants were sent a shorter health status questionnaire.

The questionnaires cover many aspects of a person's life, including symptoms (Osoba et al. 1994), functioning, mental health and general health perceptions from the SF-36 (McCallum 1995), lifestyle, personal care, treatments, medications (prescribed and non-prescribed) and socioeconomic circumstances. Where possible, the questions were modelled on the Australian Bureau of Statistics 1995 National Health Survey or other Australian Bureau of Statistics instruments, and were repeated over the series. Participants completed personal health diaries for the corresponding six-month period post-discharge. People were given two diaries – one at interview and a new diary at six weeks post-discharge. The return of diaries was tied to the return of questionnaires. The diary collected information in four sections – visits/contacts, programs, medications, and admissions to institutional care. Each section gathered detailed data on the service, including the date, type, reason, result/medication dispensed, duration/length of stay, where service provided, source of referral/script, whether or not the condition being seen was related to the condition associated with their recruitment into the study, and who completed the entry.

Hospital-recorded data were extracted from a number of sources. Hospital inpatient data covered the recruitment episode, including demographics, admission and separation details, ICD-9-CM diagnoses and procedures, and diagnosis related groups. Similar data were also extracted for each patient retrospectively, prospectively, and between hospitals to obtain a comprehensive set of data on inpatient activity, diagnoses and treatments from January 1993.

Currently, work is under way to collect data on study participants from outpatients, emergency departments, diagnostic services and hospital pharmacies. Information is being sorted on the date, type of service, and result of contact/medication dispensed. Similarly, work is being undertaken to obtain more clinical detail on particular groups of patients (for example, those diagnosed with cancer) from the medical record. In addition, hospital costing and staffing data are being extracted.

Medical Benefits Schedule (Medicare) data have been obtained from the Health Insurance Commission for individual participants. The information collected includes the date of the service, type of health service used (Medicare item number), where the service was provided, and the cost. The period covered by the data is from January 1993 to December 1996.

The National Death Index was used to identify people who had died in the sample, and to link causes of death, place of death and date of death.

Data sources potentially to be extracted and linked include community care services within the ACT Government's health portfolio (for example, community nursing, primary care and mammography screening); the ACT Cancer Registry; and nursing homes, hostels and other support agencies.

Statistical methods

The findings presented here provide a picture of the study's performance and characteristics of patients in the sample and survey. Mann-Whitney *U* and Kolmogorov-Smirnov tests were used to compare the sample to non-sample within stratum (day-only/overnight) by demographic and clinical indicators to examine sample selection bias. Similarly, survey participants and non-participants were compared to identify the significance of non-response bias. All analyses were carried out using *SPSS*® Version 6.1 (SPSS Inc. 1994).

Results

A total of 7154 patients were selected for the sample between 18 May 1995 and 17 May 1996. Of those selected, 5668 people consented to take part in the survey component of the project, yielding a 79% participation rate. Among those not participating, 948 refused (13%) and 533 were not able to be contacted (7%). For the Health Insurance Commission Medicare records, 4845 people consented to have their Medicare data extracted and linked (85% of survey participants or 68% of the sample). Generally, there was good consistency between survey participation rates in wards, although Calvary Public and Private Hospitals tended to have consistently higher rates than The Canberra Hospital. Contributing factors were the higher socioeconomic status and less serious nature of the health conditions people presented with at the Calvary Hospitals compared to The Canberra Hospital. The nephrology ward (69%), intensive care unit (54%) and the psychiatric wards (40% and 56%) at The Canberra Hospital yielded the lowest rates. Thus the expectation that psychiatric patients would be difficult to recruit and maintain in the study was supported.

Representativeness

Tables 1 and 2 show that both the sample and survey participants closely resemble the population in terms of demographic characteristics and disease profiles, although there were significant differences. A larger proportion of Australian-born were found for the sample than for the population; while a greater percentage of the hospital population than the sample were resident in central Canberra.

Table 1: A comparison between the population, sample and survey participants showing means or percentages for demographic indicators, 1995–96

Indicator	Hospital population (n = 22 713)	Sample ¹ (n = 6999)	Survey participant ¹ (n = 5541)
Age			
Mean years (S.D.)	49.7 (18.9)	49.9 (18.5)	49.3 (18.3)
Sex			
Female	52.5	52.3	52.0
Aboriginal status			
Aboriginal/Torres Strait Islander	0.5	0.5	0.4 ³
Birthplace			
Australia	73.6	74.9 ²	76.1 ³
UK/USA/NZ/Canada	10.2	9.9	10.3
Europe	10.2	9.3	8.5
Asia	3.3	2.8	2.6
Other	2.8	3.1	2.4
Marital status			
Married/de facto union	45.0	45.7	46.2
Never married	20.7	21.0	20.4
Widowed	7.8	7.8	7.4
Divorced	21.9	21.1	22.0
Separated	2.3	2.1	2.2
Usual residence			
Central Canberra	18.8	17.2 ²	16.7
Belconnen	22.8	22.3	23.4
Woden Valley	8.4	8.4	8.1
Weston Creek	5.9	6.5	6.6
Tuggeranong	16.5	17.7	18.1
Other ACT	2.9	3.4	3.4
NSW	23.0	23.3	22.8
Other interstate	1.7	1.2	0.9

continued

Table 1: A comparison between the population, sample and survey participants showing means or percentages for demographic indicators, 1995–96 *continued*

Indicator	Hospital population (n = 22 713)	Sample ¹ (n = 6999)	Survey participant ¹ (n = 5541)
Hospital			
The Canberra	65.9	70.0 ²	67.5 ³
Calvary Public	27.4	24.6	26.9
Calvary Private	6.7	5.5	5.6
Patient status			
Private patient	18.0	17.4	18.0

Notes:

1. Sample and survey participants are weighted for the sampling design. Both groups exclude outpatient recruits from medical oncology.
2. A significant difference was found between the sample and non-sample, $p < 0.05$.
3. A significant difference was found between survey participants and non-participants, $p < 0.05$.

The high rates of recruitment into the survey provided similar distributions between the survey participants and the sample (see Tables 1 and 2 and Figures 2 and 3). There are some significant differences, however, between participants and non-participants. Survey respondents tended to have been Australian-born or diagnosed with a digestive disorder; while non-participants tended to be more likely to be born in Europe or Asia, an Aboriginal, recruited at The Canberra Hospital, or diagnosed with a mental disorder. Participants who consented to have their Medicare data extracted and joined with their survey data ($n = 4845$) were similar to survey respondents in that significant differences found between Medicare consenting patients and those not consenting were similar to those differences found between survey participants and non-participants. These differences were expected since patients who had a mental disorder, those who had poor English language proficiency or those who had a lower socioeconomic status were expected to be the hardest to recruit into the study.

Table 2: A comparison between the population, sample and survey participants showing the percentage distribution of principal diagnoses, 1995–96¹

ICD-9	Principal diagnosis category ²	Hospital population (n = 22 713)	Sample (n = 6999)	Survey participants (n = 5541)
1-	Infectious and parasitic diseases	1.2	1.2	1.2
140-	Neoplasms	9.3	8.9	8.4
240-	Endocrine, nutritional and metabolic diseases, and immunity disorders	1.3	1.5	1.5
280-	Diseases of the blood and blood-forming organs	1.0	1.3	1.4
290-	Mental disorders	3.6	3.3	2.5
320-	Diseases of the nervous system and sense organs	4.4	4.2	4.1
390-	Diseases of the circulatory system	13.2	13.8	14.1
420-	Diseases of the respiratory system	4.8	4.6	4.4
520-	Diseases of the digestive system	19.2	20.3	21.3
580-	Diseases of the genito-urinary system	8.9	8.8	9.3
630-	Complication of pregnancy, childbirth and puerperium	2.1	1.2	1.0
680-	Diseases of the skin and subcutaneous tissue	2.4	2.5	2.4
710-	Diseases of the musculoskeletal system and connective tissue	7.7	7.3	7.4
740-	Congenital anomalies	0.3	0.3	0.2
780-	Symptoms, signs and ill-defined conditions	5.5	5.6	5.6
800-	Injuries and poisoning	9.9	10.2	9.8
V	Supplementary classification	5.2	5.1	5.3
	Average number of diagnoses (S.D.)	2.0 (1.2)	2.0 (1.2)	2.0 (1.2)

Notes:

1. Sample and survey participants are weighted for the sampling design. Both groups exclude outpatient recruits from medical oncology.
2. Survey participants and non-participants are significantly different, $z = -2.67$, $p < 0.01$. The differences between the sample and non-sample are not significant, $p > 0.05$.

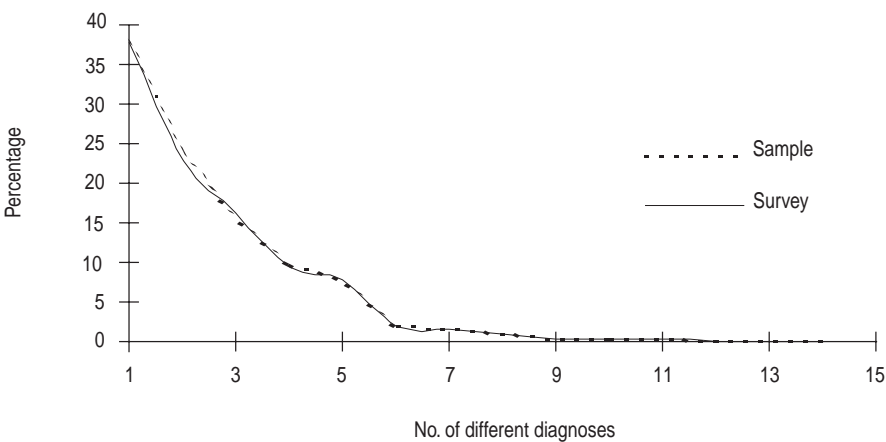
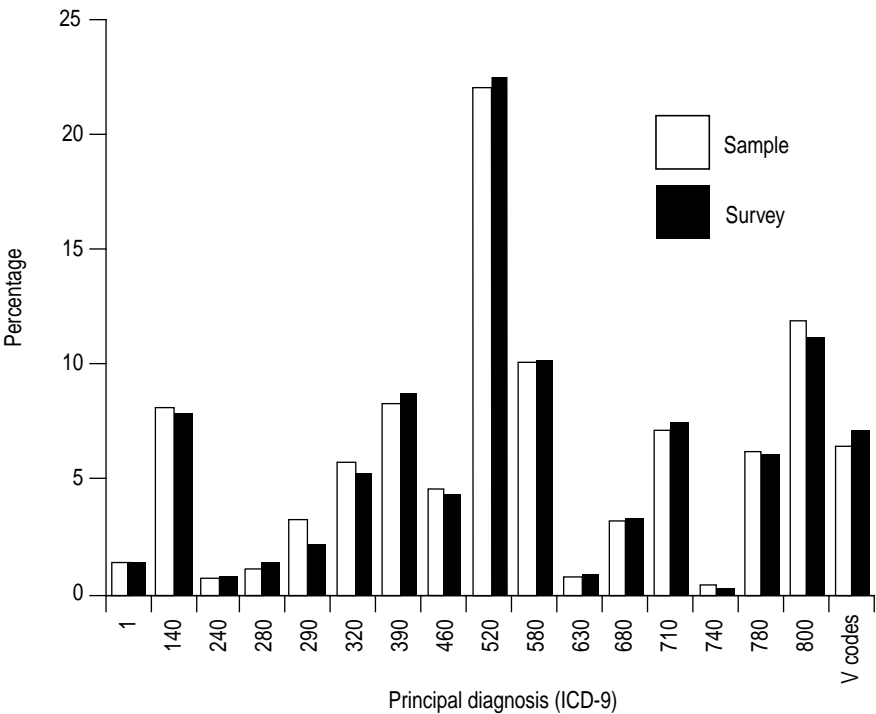
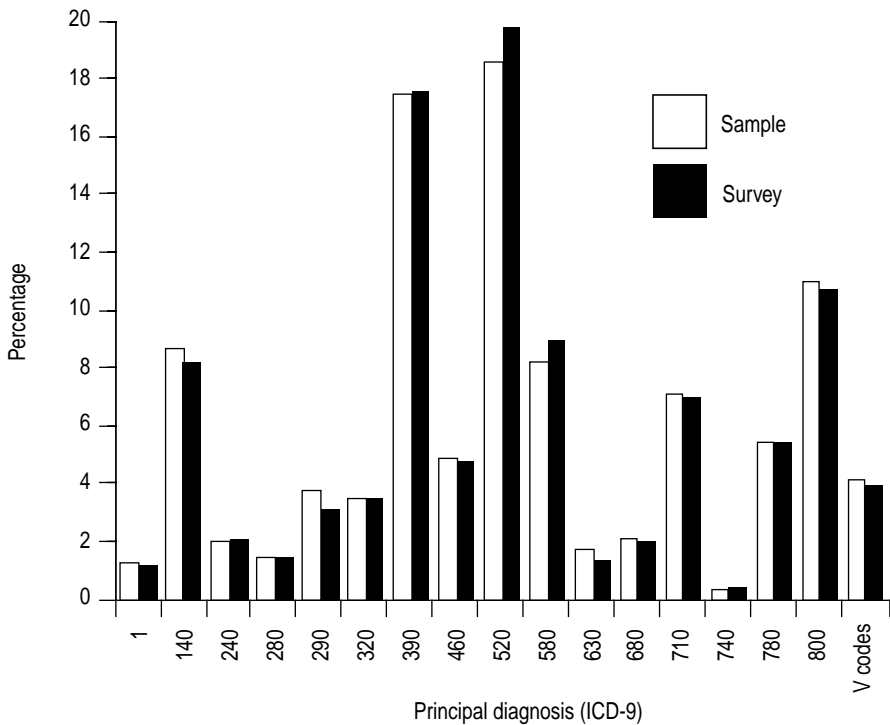


Figure 2: Percentage distribution of the number of different hospital diagnoses recorded over a one-year period for the sample and survey participants



a. Patients who had one diagnosis type over one year (sample n = 2371; survey n = 1884)



b. Patients who had two or more diagnoses over one year (sample n = 4628; survey n = 3657)

1. Refer to Table 2 for descriptions of each ICD-9 group listed above.

Figure 3: Percentage distribution of principal diagnoses¹ at the time of recruitment for patients who had one diagnosis (a) and those who had two or more (b) different diagnoses over a year, by the sample and survey participants

Trends

People 18 years or older utilising hospital inpatient services in the ACT are more likely to be middle-aged; are more likely to be women; and more likely to be admitted to The Canberra Hospital (Table 1). Furthermore, a large proportion of them reside in New South Wales, and were not married or in a de facto relationship. The most common group of conditions treated in ACT hospital inpatient services were conditions of the digestive system, followed by diseases of the circulatory system, and injury and poisonings (Table 2). Similarly, procedures on the digestive system were the most common, followed by musculoskeletal procedures.

Table 3: Percentage distribution of different co-diagnoses over one year for each principal diagnosis at recruitment, survey (n = 3657)¹

Co-diagnosis ²	Principal diagnosis at recruitment																
	1-	140-	240-	280-	290-	320-	390-	460-	520-	580-	630-	680-	710-	740-	780-	800-	V
1-	4.7	2.3	6.0	3.0	3.5	2.5	1.8	8.9	12.0	6.7	1.6	15.4	4.2	0.0	6.0	5.6	1.7
140-	4.7	15.6	1.1	8.3	0.0	2.5	2.5	3.3	3.6	8.0	0.8	10.4	2.0	0.0	4.6	2.7	16.8
240-	13.4	4.2	15.9	5.9	10.0	10.7	16.2	10.0	4.7	6.4	0.8	9.0	6.6	3.2	7.4	6.2	6.2
280-	3.9	3.0	1.5	3.0	1.0	2.5	1.9	1.7	2.0	0.5	0.8	1.0	0.9	3.2	0.7	2.2	1.1
290-	3.9	0.6	3.7	0.0	25.4	6.8	1.3	4.6	2.7	0.8	3.3	2.5	1.9	0.0	4.9	8.2	1.5
320-	4.7	1.7	7.1	1.5	6.0	11.7	3.0	3.5	2.0	2.2	0.0	2.5	4.5	3.2	3.3	5.3	4.2
390-	9.4	14.9	13.8	24.6	10.4	18.9	29.8	17.5	14.6	10.1	0.8	13.4	19.7	16.1	21.8	13.5	10.2
460-	7.9	4.2	6.0	4.5	3.0	4.6	6.3	18.1	3.6	3.3	0.0	1.0	5.6	9.7	8.8	5.2	2.7
520-	8.7	10.4	6.7	26.7	6.5	7.1	6.2	8.1	22.9	7.3	2.5	7.0	4.5	3.2	13.3	6.4	8.1
580-	9.4	9.1	5.4	1.8	3.5	5.7	4.1	3.1	5.6	19.7	6.6	4.0	4.9	3.2	7.4	4.2	6.8
630-	0.8	0.8	0.7	0.0	2.5	0.4	0.1	0.2	0.8	4.6	18.0	0.5	0.5	16.1	0.7	0.4	6.2
680-	3.9	7.1	3.4	0.0	1.0	0.7	1.7	0.4	1.2	1.8	0.0	6.0	2.3	3.2	0.2	3.6	1.0
710-	4.7	2.6	3.7	3.6	4.0	3.9	2.6	3.3	3.2	2.5	4.1	6.0	13.2	6.5	2.5	9.9	2.8
740-	0.0	0.3	0.4	2.1	0.0	1.4	1.2	1.3	0.6	0.4	0.0	0.5	0.8	3.2	0.4	0.6	0.2
780-	9.4	2.5	7.7	2.4	6.0	6.0	5.8	4.6	4.7	6.4	4.9	2.5	3.5	3.2	6.7	4.9	3.1
800-	2.4	7.1	5.4	1.2	11.9	6.0	4.0	3.3	3.9	3.9	3.3	12.4	14.0	3.2	3.2	14.0	9.4
V	7.9	13.5	11.4	11.6	5.5	8.5	11.5	8.3	12.0	15.4	52.5	6.0	10.9	22.6	8.4	7.0	17.9
Total	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100

Notes:

1. Refer to Table 2 for descriptions of each ICD-9 group listed above.
2. Co-diagnoses represent hospital diagnoses recorded over one year prior to and including the recruitment period. For the purposes of this table, co-diagnoses that fall in the same group (for example, ICD-9 780 to 799.9) are counted only once, thus providing a distribution of the occurrence of different diagnoses.

The vast majority of people had only one hospital diagnosis over a year, although they may have been hospitalised with that diagnosis more than once (Figure 2). Figures 3a and 3b compare the distributions of principal diagnoses at recruitment for people who had only one diagnosis with those who had two or more. The distributions between the two groups are substantially different ($\chi^2 = 197$; d.f. = 16; $p < 0.0001$): for example, a larger proportion of people who had two or more diagnoses (17%) than those who had only one (8%) were diagnosed with a disease of the circulatory system. In contrast, a significantly larger proportion of people diagnosed with a disease of the digestive system had one diagnosis (22%) compared to those who had multiple diagnoses (18%).

Looking at the relationship between the principal diagnosis at recruitment and co-diagnoses over a year, there are a large variety of relationships between conditions, although diseases of the circulatory system are a major co-morbid condition for the majority of principal diagnosis groups (Table 3). Similarly, most principal diagnoses have a high proportion of their same diagnostic group as a co-diagnosis. Exceptions include infectious and parasitic diseases, diseases of the blood and blood-forming organs, and congenital anomalies. The groups of diseases least likely to be a co-morbid condition included diseases of the blood and blood-forming organs, complications of pregnancy, childbirth and puerperium, diseases of the skin and subcutaneous tissue, and congenital anomalies. There are relatively small proportions of people within these disease groups.

Mental disorders and neoplasms also had a strong tendency for no co-morbidity. Given the distress often reported by cancer patients, this finding possibly reflects the reluctance to classify people with a mental disorder while suffering a life-threatening condition.

Discussion

The comprehensive data and large sample in the Care Continuum and Health Outcomes Project will provide an excellent base for exploring outcomes management in practice. Like other significant databases, that of the Care Continuum and Health Outcomes Project was initiated by the bipartisan relationship between the Commonwealth and State/Territory Governments. This relationship is vital for the continued shift towards an improved national health information system that goes beyond process issues to include outcomes measurement for both disease and patient experience. Furthermore, databases like that of the Care Continuum and Health Outcomes Project provide an opportunity to make advances in health services research: not only in measurement, but also in developing theoretical approaches. From this

perspective, it is envisaged that findings from the Care Continuum and Health Outcomes Project will help add another dimension to evidence-based medicine which focuses on local clinical practice evaluation. Such a focus is a crucial step towards marrying the literature, national guidelines, local treatment protocols and the health outcomes of patients. To this end, the ACT Department of Health and Community Care is reorienting itself to adopt an outcomes management approach in which evidence-based decision-making will be central in policy, planning and purchasing of services (ACT Department of Health and Community Care 1996). Its aim is to achieve an ongoing scientific evaluation of the health outcomes of local clinical practice, where assessments are part of everyday patient care.

In relation to specific process performance, the baseline participation rates of the Care Continuum and Health Outcomes Project are relatively high and at least comparable to those obtained in similar studies (Harris, Weinberger & Tierney 1997; Kendall, Lipskie & MacEachern 1997; Rasanen et al. 1997). The variation in hospital response rates can be explained by the higher proportion of patients at The Canberra Hospital compared to the Calvary Hospitals who were very ill or who had low socioeconomic status, especially those with no fixed address (Shadbolt 1996). These factors particularly influenced the participation rates within the psychiatric wards at The Canberra Hospital (40% and 56%). As well, the intensive care units allowed some patients to be discharged directly home from the ward. Given that interviewing people in intensive care units was not preferred, a large percentage of those not participating resulted from the interviewer being unable to capture them before discharge. Efforts were made to contact these people by phone, without great success, possibly because many had temporarily left home to convalesce.

As shown in Figure 1, there are a wide variety of poorly utilised data available on patients, including administrative, patient and clinical sources, which were included in the Care Continuum and Health Outcomes Project. Such a comprehensive set of information provides an opportunity to explore many aspects of a disease and its effect on people's lives. Record linkage was a major procedure needed to create the study's database. Despite having many personal identifiers, the linking of records is a time-consuming task that requires extremely 'clean' data to maximise the benefits of linking. The rate of 85% of people who participated in the survey and who provided consent for their Medicare records to be extracted is similar to the rate found in the first Medicare Record Linkage Study (McCallum, Lonergan & Raymond 1994). The reluctance of some people to release their Medicare data reflects the sensitive nature people place on their health information and reinforces the need for multiple level consents to maximise participation in the main part of the study.

Issues around medication use and valid consent were extremely important, especially for day-only patients, a rapidly growing proportion of admissions. Day-only patients were approached either before medication was administered or once they had left the hospital. By far the most successful recruitment approach was to capture patients while they were in hospital. Longer stay patients were logistically more easy to recruit. There were some instances, however, where people's judgements were affected by medication. Despite consultation with nursing staff about the alertness of patients, a number of people only became fully aware of their participation in the study after leaving hospital. The main prompts were the letter of introduction, brochure about the study and the diary they had in their possession. All participants had the opportunity to withdraw from the study at any time, or have the study explained to them more than once.

Two groups of patients, the frail elderly and psychiatric patients, yielded relatively high reselection rates due to poor mental capabilities to deal with the community follow-up. In addition to a weight for the sampling framework, a non-response weight has been developed to improve the representation of the population. The factors used in the weight are country of birth, Aboriginality, principal diagnosis and hospital. Few previous studies have designs that allow a detailed investigation of sample selection and non-response. The rigour of the recruitment process here suggests that there is a high probability that most similar studies have significant non-response biases that are not detected by simply comparing age and sex distributions with the corresponding population. A key factor in the Care Continuum and Health Outcomes Project's success was the development of 'in-house' computer software to identify eligible people and register selected ones: this software is now being used in other studies (Shadbolt 1996). The software tracked patients through the study, and provided prompts and output for relevant action. The computerisation of records dramatically improved the accuracy and efficiency of the tasks, as well as reducing the costs and labour.

The complexity of co-morbidities among hospital inpatients shown in the Care Continuum and Health Outcomes Project profiles highlights the challenge faced by hospital and community services. Despite a willingness to focus on the 'total person', the treatment process and associated infrastructure encourage condition-specific care. Even coding systems are more single-condition focused than recording a complete disease history. The ageing of the population will increase the importance of dealing with co-morbid conditions and improving recording and treatment systems to deal with this reality.

In conclusion, the qualities found in the Care Continuum and Health Outcomes Project data set allow it to be used to explore many different questions. The project's broad aims give a general indication of the areas in which the data can

be utilised. Many of the more specific questions, however, will be secondary to the collection of data. For example, results from analyses have started to answer questions arising about the service use and quality of life of people defined as benefiting from coordinated care: cancer patients; people receiving a pension from the Department of Veterans' Affairs; and people requiring rehabilitation or recovering from a major fracture. Analyses are under way examining the effect of socioeconomic status on health resource use, an economic model of cardiovascular disease, and a classification system of palliative care in the hospital setting. In terms of continuing the momentum towards an outcomes management system, the next step with the Care Continuum and Health Outcomes Project is to develop profiles of treatment and quality of life for patient groups within clinical areas of the ACT hospital system. These profiles will be used to make estimates of current outcomes from clinical practice. From these estimates and traditional sources of medical evidence, expectations will be considered by clinicians about the amount of improvement that can be gained by modifying practice. Efforts will then be made to formally test these expectations using ongoing information systems as they are established.

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