



University of  
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Allied Health Evidence

ICAE

*A member of the Sansom Institute*

# Independent Community Living after Discharge from Hospital



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## Chapter One

This report outlines a longitudinal study which followed a group of elderly patients, and their carers, for six months following the patients' discharge from the acute hospital setting. To set the scene, each chapter commences with a vignette about one of the participants in our study.

**February 2000.** Mr Smith is 86 years old and lives alone in a five bedroom house. He describes himself as a 'happy bachelor' who retired in the mid 1980's from the farm due to cardiac problems. He was the youngest boy of a family of five, and he set aside his own vocational aspirations to care for his mother when she became ill. After she died, he cared for his father and worked the farm. He decided to stay on the farm as all of his older brothers and sisters were established in other careers. After he retired, he bought a house in town to be closer to the hospital, library and the church. His driver's license was not renewed two years ago, and now he uses the bus to get around. He does all his chores himself and he works two days a week voluntarily at the local charity organisation. He has numerous visitors to his home. He has a strong faith and is closely associated with the activities run by his church. He has two walking sticks, one by the front door and one by the back door. He uses them when he goes outside as 'it doesn't take much to tip me over'.

### 1.1 Introduction

We undertook this project to explore issues raised during our recently completed project, which had been funded by the South Australian Health Commission (now Department of Health Services, SA) through the Primary Health Care Initiatives scheme (Grimmer et al 1999). From the findings of this project, we drew attention to the many issues faced by recently ill elderly people on their return to the community after an episode of hospitalisation. We found that these individuals may not be adequately supported in their attempts to maintain independent living in the community, and that this may result in unnecessary and unplanned use of expensive hospital and residential care beds, as well as reactive (rather than proactive) use of community health and support services. The short time frame of that study precluded investigation of elderly people's ability to cope longer term after illness. Thus we undertook this current study, which was jointly funded by the Strategic Policy and Planning Division of SA Department of Human Services, and SA Office for the Ageing.

In this study, our overall aim was to describe and analyse strategies and community supports used in the short and long term by elderly patients and their carers following discharge from the acute

hospital setting. The focus was to identify strategies and services that were most useful, flexible, sensitive to change, which could be implemented in a timely and cost effective manner, and which would empower patients and their carers to make decisions that supported independent and successful return to the community after hospitalisation.

This report provides

- ◆ A critical and systematic appraisal of the higher levels of the research literature regarding discharge planning and community supports for recently ill, elderly people, in order to establish the framework for areas requiring further research
- ◆ Key themes identified from pre-project interviews with key stakeholders (prominent systems personnel in Government and non-Government organisations, and representative service providers), which attempt to describe the structure and variability of local aged care systems
- ◆ Responses by patients [this word better reflects the role these people saw themselves taking than the word "consumer"] and carers to the PREPARED instrument, administered immediately post discharge. We developed this instrument to evaluate the perceived quality of planning for discharge by community consumers (Grimmer and Moss 2001). These responses are compared with those reported from our previous project (Grimmer et al 1999).
- ◆ Description of changes in an index of health –related quality of life of patients and carers over the six months post discharge, using the SF36 instrument for initial post discharge assessment, and the SF12 instrument for subsequent assessments
- ◆ Description of the key themes derived from the monthly interviews with patients and carers, and comparisons between key themes across the study period. The report also provides 20 of the most illustrative case histories obtained in this study, as a way of highlighting the impact of the key themes within individual experiences.
- ◆ Commentary and discussion on issues arising from the project findings, including:
  - ◆ Differences in key themes between rural and city participants
  - ◆ Changes in key themes over time
  - ◆ Differences in insights and opinions between patients and carers
  - ◆ Use of, access to, and satisfaction with community health services

- ◆ The models of care currently operating in the participating hospitals and communities, and how these addressed patient and carer needs
- ◆ Identification of patient and carer needs, and whether these could be addressed within current systems
- ◆ Housing issues
- ◆ Issues of the hospital / community interface
- ◆ The influence of the introduction of the 'user pays' initiative in community services
- ◆ Continuing education in transition planning for hospital and community service providers
- ◆ Ways of making information available to patients and carers
- ◆ Recommendations on practical strategies that can be implemented in hospitals and communities to address participant needs and expectations

Where feasible, differences in responses between rural and metropolitan patients, patients with and without carers, and patients with different conditions have been investigated.

## **1.2 Background**

Discharge planning has been defined as the systematic identification and organisation of services and supports to assist recently ill people to safely transfer from hospital to the community (Armitage and Kavanagh 1996). The overarching purpose of discharge planning appears to be to link care provided during the hospital stay with care required to effect recuperation in the community (Townsend 1988). There is debate however, about the appropriate terms to describe these activities, with support for use of the words 'transition planning', to encompass the concept of appropriate transition from one type of care to another within the continuum of community living. For many elderly people, intermittent hospital admission is part of a continuum of independent community living (Byles 2000, Penning 1995). The provision of appropriate and timely community- and hospital-based services may be required to optimise opportunities to retain independence in the community (Armitage and Kavanagh 1996). Independence is believed to contribute to quality of life (McCallum 1996). Keeping elderly people in their own homes for as long as possible would also appear to be an imperative driven by rising hospital costs, shorter hospital stays, and limited access to residential care places (hostel and nursing home) (Wang, Mitchell, Smith and Leeder 1999b).

It has been suggested that quality planning to assist leaving the hospital setting and re-entering the community can reduce unplanned readmission to hospital, by identifying and dealing with potential problems, which could compromise downstream health and/ or community safety. This was highlighted by Williams (1988), who found that a formal assessment of patients within the hospital setting prior to discharge and provision of care following discharge significantly reduced return to hospital with foreseeable / preventable problems. However, while a reduction in length of hospital stay may decrease in-patient costs, it may well be offset by increased costs in the community by requiring additional community health services (Zook 1980, Anderson 1984, 1985). Little research has been undertaken to evaluate total costs associated with an admission to hospital, or the influence of discharge planning on these costs. Definitional issues generally accurate calculation of these costs, such as diagnosis, length of an episode (including hospitalisation and community care associated with the diagnosis), and good health outcomes. Moreover, direct, indirect and opportunity costs incurred by patients and their carers (including neighbours and family) have been poorly estimated and are not usually the subject of illness cost calculations. In particular, McCance et al (1997) describes difficulties with defining 'caring', this view being supported by varying perspectives and reports in the literature. Our review of the literature indicates the lack of information provided to carers about how to cope with caring for a recently ill elderly person at home.

The emphasis placed on discharge planning varies from country to country. For example, in the United States of America, discharge planning is mandatory for hospitals participating in the Medicare and Medicaid programs. In the United Kingdom, health authorities have been directed by the Department of Health to draw up written plans for the discharge procedure. In Australia, whilst there is concerted support at both state and national levels for health care settings to have discharge planning policies, there are no agreed performance standards and no formal benchmarking activities to support quality discharge planning activities.

In order for transition from hospital to community to be successful, community services should complement within-hospital services. There is little information in the literature about which services are commonly utilised by the elderly once they are discharged from the hospital, or which service produce the most valuable outcomes. Furthermore, the cost-efficiencies of services utilised by elderly patients post hospital discharge is poorly evaluated. In our earlier work, we highlighted the need for discharge planning to be timely, efficient, responsive to need and based on good communication between key stakeholders (Hedges et al 1999a,b). Difficulties in consistently achieving these quality processes is constrained by a range of issues, including a range of funding

sources for hospital and community services, variable staff training, complements and commitment, and lack of standard evaluation tools to determine need and to measure outcomes. We also identified the lack of a standard mechanism for feeding back information to hospital staff from the community consumers of discharge planning.

A substantial number of community services available to the elderly have been identified as important in their maintenance of independent community living status (Wang et al 1999a,b, Lusky 1986, Penning 1995). These include assistance with health-related issues such as hygiene, medications, dressings and rehabilitation activities, assistance with home activities such as meals, shopping, house cleaning and gardening, and assistance with maintaining community involvement, such as transport and membership of support networks. While there has been a recognition of the need to expand and enhance community based support services (Wang et al 1999a,b, Mooney and Scotton 1998), the supports required to successfully maintain elderly people at home require a far greater understanding than is currently available (Sims et al 2000). Also required is a better understanding of elderly people's strategies to manage in their home environment, particularly addressing the nexus between their needs for, and use of, formal community health services and their access to informal care provided by family and friends. While advances have been made in attempting to quantify social supports in the elderly (Goodger et al 1999, Hanson, Isacsson, Janzon and Lindell 1989, Penning 1995, Wang et al 1999b), there is still a paucity of information on what keeps an ill elderly person living independently in the community. A study by Baume et al (1993) in western Sydney found that home care services were seen by the elderly as most important in maintaining their level of functioning in the community, as were, to a lesser extent, hospitality services such as Meals on Wheels. However the study identified unmet needs for community services from the perspective of patients and their carers, referrers and service providers, reflecting issues of access, availability and equity. Similar findings were reported by Steinberg et al (1996), who used in-depth capture of information from a small patient sample over several months post hospitalisation.

Our precursor project (Cost Efficient Discharge Planning: Satisfaction for All) (Grimmer et al 1999) highlighted the lack of consumer feedback to hospital staff on the quality and outcomes of discharge planning activities. It also demonstrated the opportunity for mismatched perceptions, between health care providers (within the hospital system and in the community) and patient and their carers, on what constitutes quality in discharge planning, and on valuation of aspects of planning for discharge. A key outcome of that research project was the development of a new evaluation instrument (entitled PREPARED) (Grimmer and Moss 2001). Its purpose was to provide feedback to



hospital staff from community informants, and thus complete the Total Quality Management cycle. This instrument currently consists of four separate yet congruent questionnaires, for patients, their primary carer, their general practitioner (administered if the patient is discharged home), and for the nursing home administrator only (if the patient is discharged to a nursing home). Further development of this instrument is planned for community health care providers, such as Domiciliary Care workers. For those patients who are discharged home, both the patient and carer questionnaires are sent to the patient's home address one week post discharge. If the patient provides written permission on their returned questionnaire, the general practitioner version of the questionnaire is then sent to the nominated medical practitioner. Where the patient is discharged to a nursing home, only the nursing home administrator is surveyed, on the presumption that the patient is too ill or infirm to respond. During this current project, PREPARED was modified and re-validated against patient and carer comments from interviews. This enabled the process and outcome domains in PREPARED to be validated against unstructured interview data immediately post discharge, as well as evaluation of the sensitivity of PREPARED in predicting poor longer term outcome as related to poor discharge planning.

The responses to PREPARED from our earlier project (Grimmer et al 1999) identified a range of areas for improvement in discharge planning by hospital staff. They also indicated that, for patients and carers, coping successfully with returning to community living after discharge from hospital was related to a complex set of societal, educational and behavioral constructs, the importance of which was rarely recognised in the acute hospital environment. Thus, this current research project was undertaken to explore the issues associated with coping post discharge in the community, in order to better inform community and hospital efforts to support patients in transition from hospital to community.

### ***1.2.1 Recommendations from the Previous Project***

From our earlier project (Grimmer et al 1999), we made recommendations regarding improvements in the structures and processes of planning for discharge. These recommendations are outlined below. This current project specifically addresses issues relating to Recommendations 1, 3, 6 and 7. The full set of recommendations can be found in the project report (Grimmer et al 1999)

- 1. The concepts of discharge planning and its related activities need to be clearly defined with respect to elements that are valued by hospital staff, patients and their carers, and community service providers.*

2. Best Practice discharge planning models need to be built into service agreements for hospitals.
3. *Only those discharge planning activities that are outcome focused and based on stakeholder evidence should be promoted as Best Practice, and provided with appropriate resources.*
4. *In order to ensure consistent Best Practice, routine monitoring systems are required that seek information on satisfaction with processes and outcomes of hospitalisation, from patients, carers and community health service providers, and to collect information on real costs associated with all discharge-focused activities.*
5. *Routine monthly hospital statistics should be augmented to incorporate discharge planning information, e.g. feedback from stakeholders which could be monitored as the percentage of discharges reaching an agreed standard of performance.*
6. *The marginal gain in outcome from discharge planning should be related to the marginal cost.*
7. *The concept of a more transparent interface between hospital and community could be pursued in a tangible sense.*
8. *Tangible incentives need to be developed for hospital staff to improve the quality of their discharge planning activities.*
9. *Revised and targeted discharge planning standards should be considered for formal adoption by accrediting organisations.*

### **1.3 Issues integral to the planning and execution of this study**

Discharge planning has been defined as the systematic identification and organisation of

Between finishing the Cost Efficient Discharge Planning project and commencing this current project, we grappled with a range of issues that appeared to significantly impact on discharge planning practices. These issues ranged from the systems supporting planning for discharge from hospital to individual moral and ethical responsibility for ensuring patient safety when leaving the hospital. The key issues which we propose as relating to developing a better understanding of discharge planning quality issues are outlined in the following sections. We attempted to consider these issues within the framework of the study findings. However, we recognised that it was unlikely that we could appropriately address and provide answers to these questions, given the complexity of the health,

family and community systems within which elderly people operate. Nevertheless, by flagging the key issues of concern, and by providing some insights into their impact on elderly ill people who are coming to terms with the ramifications of illness in the community, we hoped to provide food for thought for those who will carry this work forward.

### **1.3.1. Incentive for change**

The issues underpinning poor quality discharge are widely recognised, as are the problems associated with improving the quality of discharge planning processes and outcomes. The literature reports on a plethora of site- or condition-specific initiatives to improve the quality of planning for discharge, but as identified in our earlier literature review (Hedges et al 1999a undertaken in the 1999 project), most discharge planning initiatives are short term (in terms of available personnel and funding) and are poorly evaluated (if at all). While the issues associated with poor quality discharge seem able to be clearly articulated at a number of levels within the health care system, very little seems to have been done to support targeted, long term and sustainable change. Why is this so? It would seem that the overarching driver is the lack of incentive for change. The outcomes of better planning and organisation for discharge are relatively intangible and difficult to measure in cost or benefit terms. For patient and carers, these are generally better patient health and confidence to remain at home, reduced burden on carers, and reduced unplanned usage of the health system, while for health providers (hospital and community) they mostly relate to increased job satisfaction and reduced stress.

At a systems level, the extent of funding and infrastructure required to support meaningful change to discharge planning practices is not clear. Potential variability in interpretation and implementation of existing policies at an administrative level, and the time delay in developing and implementing new policies preclude speedy actions regarding improvements to transition from hospital to home. At a hospital level, funding constraints appear to be leading to contraction to core business (i.e. immediate acute care). Hence new or revised initiatives regarding supporting improvements in the quality of preparation for transition from hospital to community would seem to be low priority. Among community service providers, funding constraints and changes to funding sources have also meant refocussing on, and redefining, core business, as well as introducing a 'user pays' philosophy and rationalising services to those perceived to be most needy. The potential for mismatched expectations at policy and health provider levels has been identified in much of the research literature. Evaluation of, and supports for, quality discharge planning activities would seem to be an area where mismatch in expectations could readily occur. Moreover, from the patient and carer perspective, disempowerment within the hospital system, short lengths of stay and having to

deal with dramatic changes in health status and lifestyle seem to be sometimes insurmountable problems. It also seems that the service menus of community health care providers often do not address the most pressing of patient and carer needs post discharge. Services currently provided to assist in the transition from hospital to home also do not appear to address the long term time frame that is often necessary for patients' and carers' adaptation to changed circumstances.

### ***1.3.2. What is required to make a difference in health service administration and delivery?***

Our challenge has been to take a research and reporting approach that would make a difference to discharge planning quality at policy and service provision levels. This has meant consideration of the generalisability of the findings, particularly given the current plethora of site- and condition-specific research literature on discharge planning activities that were patently not able to be widely applied, and which had not addressed the identification of generic problems and solutions. Thus, our approach was firmly anchored at patient and carer level, with a view of identifying opportunities to make life easier for aged care users of health services. This meant identifying and synthesising experiences of patients and carers post discharge, in order to identify the services that they valued, and how these services had impacted on their ability to cope in the community post discharge. A key approach taken in this project has been to continually feedback findings to patients and health care providers, in order to ensure that observations had been appropriately interpreted. Iteratively during the project, we also discussed the interim findings with health service providers in hospital and in the community, in order to gain a better understanding as to whether patient and carer needs could be addressed within the current health service structure, and whether mismatched expectations could ever be identified and considered.

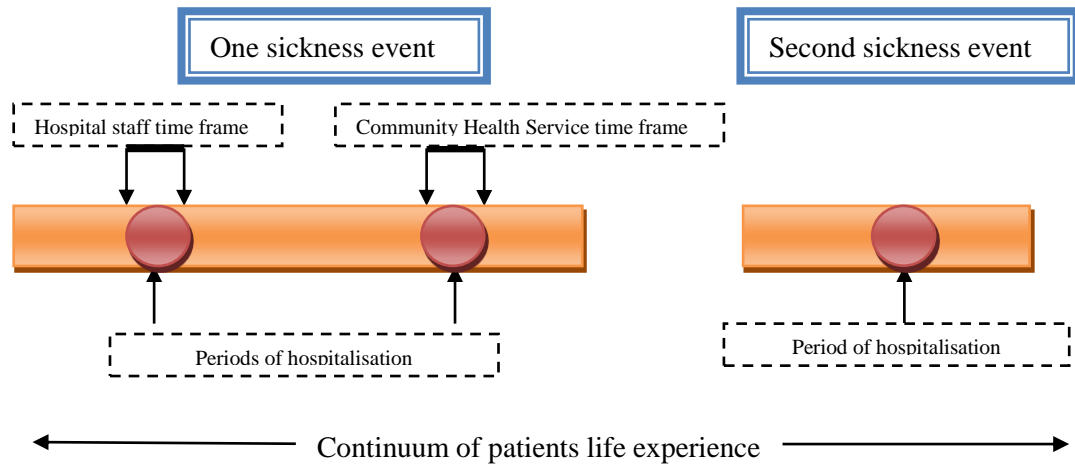
We also recognised the nexus between this research project and policy development: that in order to make the project data meaningful for policy makers, we needed to do more than demonstrate existence of problems that policymakers already knew about or suspected. We needed to point towards practical, achievable, sustainable and affordable solutions. Thus we were clear that this research project needed to synthesise information from a range of sources into practical outcomes that could be considered from systems and service delivery levels, within current funding constraints.

While seeking solutions, the value of existing models of discharge planning needed to be considered. As we identified in our earlier project (Grimmer et al 1999), there are a range of models in place in hospitals and the community, which are believed to support quality transition from hospital to community. These models range from ward-specific discharge planning meetings, to liaison officers

within hospitals, to dedicated discharge planners who bridge the hospital / community interface, to care coordinators / case managers in coordinated care programs within the community. There has been little evaluation of the costs and effectiveness of any of these models, although anecdotal evidence would suggest that their success is as dependent on personalities, as on the management structure, supporting resources or system. Issues that needed to be addressed from patient and carer perspective were whether these discharge planning models reduced fragmentation in service delivery, and whether they empowered the patient and carer for managing in the community after discharge.

### ***1.3.3. Where does discharge planning from the acute hospital sit within the continuum of care?***

The various participants in discharge planning differ in the time frame of their evaluation perspective. The period of patient hospital admission appears to represent the total 'experience' for hospital staff. They know something of what went on before admission to hospital, but usually hear little, if anything, from the patient after discharge. However, for the patient and carer, the hospital admission is but an episode within the continuum of their life. For community health service providers, the perspective appears to be more long-term than for hospital staff, in that they associate the patient with the home environment. However, the community health provider's time perspective on quality discharge planning is still shorter than that of the patient or carer, who have to live with their health problems on a daily basis. Thus, particularly for a person with emerging chronic and complex health problems, acute hospital admissions and their associated community care interactions before and after admission, are episodic. Conceptually, this is outlined in Figure 1.1.



**Figure 1.1** Conceptualisation of hospital admissions within the continuity of patient experience

#### 1.3.4. What does this research project need to produce in order to drive change?

We sought in this project to better understand the constructs of quality planning for discharge that would support long term health quality for patients and carers. We attempted to match findings from the research literature with issues which concerned all stakeholders and participants in discharge planning / transition from hospital to home by posing a range of questions. We sought to integrate answers to these questions into practical strategies that would support improvements in discharge planning quality at relevant levels in the health system.

##### 1.3.4.1 Systems

1. What are the similarities and differences in site-specific health care systems?
2. Which aspects of these systems support quality transition from hospital to community? For instance:
  - ◆ Hospital size, referral base and the role of general practitioners within the hospital
  - ◆ The focus on aged care within the available hospital and community services
  - ◆ Type of services offered in hospital and community
  - ◆ Personnel overlap between hospital and community
  - ◆ **Existence of step-down units and other mechanisms of moving from hospital to community**

- ◆ Mechanism of communication between hospital and community service providers (email, telephone, fax etc)
3. How could the system have been improved for individual patients and carers?

#### **1.3.4.2 Service use**

1. What is the mix of services used by aged patients and their carers that seems to provide the best health outcomes, and the most confidence about managing well in the community?
2. As a corollary to this question, how much service, and what type, is required by recently discharged patients and carers to maintain themselves?
  - ◆ Out of acute hospital admissions, if living independently in the community?
  - ◆ Out of nursing home/ residential care admission if living independently in the community?
3. How flexible are services?
4. By what mechanisms do patients and carers, and health service providers, find out about these services?
5. Why are some service types chosen over others?
6. How much effort is required to obtain these services?
7. How many different services and persons are usually involved with patients, and what is the mechanism of their communication?
8. What services did patients want to access but were unable to because of systems issues (closure of books etc)
9. Could some services have been substituted for others with a better outcome?
10. What services have community and hospital health service providers, patients and carers valued the most?
11. What services have they valued the least?

### **1.3.4.3 Providers of services: their perspectives**

In any one health care system, there appear to be many community-based service providers. Providers can be variably funded from non-government as well as government (federal, state, local) budgets, which are frequently subject to change. The community health providers involved in this study included nursing homes, private general medical practitioners, Royal District Nursing Service, Domiciliary Care, CareLink, Coordinated Care programs such as Care 21, GP Home link, Support Link, Options programs, migrant and young disabled programs, pharmacy education projects and Aged Care Assessment Teams. This project aimed to understand from the patient and carer perspective what these services offered in the way of service provision, liaison and support, as well as the ease of contacting and contracting with these services regarding appropriate service provision to suit individual patient and carer needs. Costs (direct and indirect) of accessing these services were also sought.

### **1.3.4.4 Patients and carers: being seen as people**

1. How much information is required so that health service providers view the patient and carer as whole people, with histories, futures, experiences and needs?
2. How can the carer also be seen as an individual, not an extension of the patient?
3. What has been carer's experience when acting as an advocate for the patient, or themselves?
4. What was, and is, the patient and carer involvement in the wider community?
5. What is the balance of responsibility and roles within the family unit?
6. What are the opportunities and benefits of being involved with caring for a patient?
7. Do patients on their own, or patients with carers, have better health outcomes?

### **1.3.4.5 Societal and home supports**

1. What is it about the home environment that supports or hinders successful return to community living following hospitalisation?
2. What is it about the urban environment that supports or hinders successful community living, e.g.

- ◆ transport difficulties



- ◆ unavailability of after hours services
  - ◆ safety within the community
3. What do elderly people think about their environment if they have been living in their own home all their lives?
  4. Do they want to move to other accommodation, and why?
  5. How useful are home inspections by health service providers to identify potential risks in the environment, and how useful are home modifications in supporting successful community living?

#### **1.3.4.6 Systems aspects specific to patients and carers**

1. What are the best measures by which health service providers judge the state of wellness of patients and carers? (i.e. what measures do hospital staff, or community services apply to know whether a patient and carer will cope or not, post discharge?)
2. What is patient and carer ability to navigate the system (seeking out information on services, making contacts etc)?
3. What worked and what did not, addressing the possible mismatch between telling someone and educating them, or the notion that the message sent is not the message received?
4. How do they learn to navigate the system?
  - ◆ For instance, how important to patients and carers is ease of reaching service providers, and knowing whom to talk to?
5. What is perceived by patient and carer as integrated services?
6. What unmet needs do patients and carers have?
  - ◆ How could services have been adapted to meet these needs?
7. How reliable and valid is patient and carer ability to self assess?
8. How reliable and valid is their perception of their ability to self manage?

9. What are patients/ carers expectations immediately after discharge, and how are these modified over time?
10. Do patients/ carers understand and estimate the true costs of providing services?
11. Do they believe that the taxpayer is getting value for money from services?
12. How much knowledge should carers be expected to have, and how much support needs to be provided for them in order to adapt to change?
  - ◆ e.g. the ability to adapt to changed menus (in the case of a newly diagnosed diabetic patient) or the ability to cope with changed sleep or activity patterns)
13. Do carers and patients understand and use respite services?

#### **1.3.4.7 Economic issues**

1. What priority should be placed on what patients need, within current systems?
2. How flexible should and can community health and hospital services be?
3. Why do people value one service over another (meeting perceived or actual need?)
4. Can health care provided to older people be seen as an investment in the life of that person?
  - ◆ This addresses an application of the law of diminishing marginal returns: What is the level of nursing dependency beyond which the costs of home care outweigh the costs of retirement home, and whose responsibility is it to recognise this point?
5. What is the place of the concept of mutual obligation (or reciprocal obligation), when supporting aged ill people in the community?
  - ◆ This has affinities with a community development approach to service provision, where communities are stakeholders in the delivery of appropriate, flexible and cost-efficient services. It also addresses what service recipients can learn to do to help themselves and others.

#### *1.4 Outcomes of this study*

We proposed a number of outcomes from this research.

- ◆ Outlining the health needs of, and the continuum of health care provided for, elderly patients living independently in the community
- ◆ Identification of the strategies employed by patients and their carers in successfully returning to, and maintaining independent community living status post discharge from hospital
- ◆ Identification of the types of community supports required by patients and their carers when successfully returning to, and maintaining independent community living status post discharge from hospital. This investigation will outline issues of equity, availability and access to requisite services
- ◆ Description of the roles and responsibilities of community health and support services in providing appropriate, timely and requisite services to recently ill elderly patients and their carers
- ◆ Determination of patient and carer satisfaction with community health and support services, both in the short term (immediately post discharge) and longer term
- ◆ Identification of the minimum and optimum community health and support service requirements of the recently ill elderly, and their carers with respect to successful return to independent community living
- ◆ Examination of differences in rural and metropolitan settings
- ◆ Suggestions for components of policy statements that support appropriate, timely and responsive community services for recently ill elderly patients and their carers.
- ◆ Description of the level of funding, and appropriate funding sources and mechanisms that address appropriate, timely and responsive community services that maintain elderly ill people in independent community living.

## Chapter Two

This chapter outlines how the overall study was conducted.

**March 2000.** Mr Smith left hospital without chest pain. He was feeling generally well, although a bit tired. He promised to wear his pendant alarm all the time, and gave his sister-in-law a spare key to his house. In hospital, he had begun new medication for his heart and was confident that he knew what he was doing with both his new tablets and the ones he was continuing on.. Immediately after returning home he went back to his old routine of going shopping every Friday and going to church every Sunday. The only change that he made to his lifestyle was cutting down his voluntary work to one day a week. In his first few weeks home, friends dropped by with cooked meals. He also found benefit in afternoon sleeps, which he had not taken before. He visited his GP regularly once a week at his rooms.

### 2.1 Method

#### 2.1.1 Aim

The aim of this study was to describe and analyse strategies and community supports used in the short and long term by elderly patients and their carers following discharge from the acute hospital setting.

#### 2.1.2 Definitions

We applied the following definitions:

1. *Successful independent community living is the ability of the elderly to feel safe and to participate in the activities they wish, while living in their own homes or other non-institutional living environments.*
2. Community supports encompass
  - ◆ Formal health service use, such as general practitioner, allied health services, district nursing, domiciliary care etc
  - ◆ Formal support service use, such as meals on wheels, home help
  - ◆ Access to, and use of community networks, such as church groups, recreational facilities and community groups

3. Health and support services may be provided in an acute or rehabilitation hospital setting (either inpatient or outpatient), or by services based in the hospital yet delivered in the community, or by services based and delivered in the community.

### **2.1.3 Inclusion criteria**

Our selection criteria for recruiting patients into the study were developed from our previous research and our preliminary interview findings (outlined in Chapter 4). We sought the type of patient who was believed by many to be poorly serviced within the aged care system. We were particularly interested to study people who were on the 'cusp of chronicity'. By this we mean people presently coming to terms with a chronically changed health state which has called into question their ability to live independently in the community, and who therefore may not yet have learnt how to navigate the aged care system to obtain required community services. As the study progressed, it became clear that their needs were unrecognised in the structures that had been established to support individuals with chronic conditions (such as disease-specific support groups). We initially described our eligible patient sample as being:

- ◆ 65 years or older
- ◆ male or female
- ◆ with or without a carer
- ◆ about to be discharged from medical wards of acute hospitals with any condition whose health implications would become more severe and/ or chronic
- ◆ had consumed more than the average length of stay (LOS)
- ◆ had had one to two previous admissions only for the condition, but who is expected to become worse
- ◆ more than six weeks since last readmission
- ◆ lives within 20 kms of the hospital
- ◆ met ward nurses' perception of being positioned on the 'cusp of chronicity'
- ◆ comorbidities eligible (depression, anxiety)

However, during the early recruitment period it became apparent that the age limit of 65 years was too stringent, as many potential subjects has passed the chronicity cusp and their medical problems were well established (as was their usage of services). Consequently the age limit was lowered to 60 years, producing a concomitant increase in ease of recruitment of suitable and consenting subjects.

#### **2.1.4 Ethics approval**

Ethics approval was obtained from both sponsor universities (South Australia and Adelaide) and each of the participating hospitals (North West Area Health Service (encompassing Lyell McEwin Hospital and Health Service), Whyalla, Port Augusta and Port Pirie). Ethics approvals letters, information sheets and consent forms are provided in Appendix 1.

#### ***There were specific ethical implications of this project.***

Given the potential respondent burden of participating in this project, all participants were asked to confirm their permission to participate at each monthly contact, as well as having provided their initial written permission to participate in the study. Furthermore, those subjects who agreed to take part in a videotaped exit interview provided written permission that the taped data could be used for research purposes. Where photographs or videotape were taken of participants, written permission was again obtained to reproduce this information in the reporting process. Prior to commencing the study, subjects were given a schedule of contacts that they could expect throughout the period of the study, to ensure that they were fully aware of their contributions to the study prior to agreeing to participate. Subjects were advised at each contact that they could withdraw at any time throughout the study without penalty, and without compromising access to future medical care.

Patients' and carers' names were required on all their data throughout the study, so that the repeated information could be linked by subject. The names and contact details of participants were held on a master list in the research office during the period of the study, and then the list was destroyed. For analysis purposes no names are reported, although in photographs and videos consenting participants are identified by their given name, at their request. The information sheet and consent form used in the study spelt out the confidentiality constraints.

We recognised a potential ethical dilemma involving the project officer (Julie Falco) who worked on secondment on this project, alternating weekly with her usual job undertaking discharge liaison at the Lyell McEwin Hospital. This potentially placed her in a difficult situation, where she may have needed to cross the boundaries of the two jobs. This potential ethical dilemma was addressed on a

case-by-case basis, where Julie perceived unmet needs, or situations which could potentially have been resolved by referral to services. In the five instances where this occurred, we all discussed her concerns, and in every case it was agreed to suggest to the patient (or carer) to contact their general practitioner, or local care coordinator (if one was in place) for assistance. Thus, the project officer did not offer any direct assistance or advice to subjects enrolled in the study.

## **2.5 Subjects**

### **2.5.1 Primary subjects: patients**

Patients who met the inclusion criteria and who were admitted to the medical and/ or surgical wards of the participating hospitals between the months of February and July 2000 were invited to participate in the study. Invitation to participate was ultimately the responsibility of the Director of Nursing in each site, indicating the commitment of the hospital to the patient's welfare. This strategy has been reported by Stevenson et al (1997) and Czarn et al (1992) and was employed by us with success in the precursor study (Grimmer et al 1999).

The first 50 patients from the metropolitan and the first 25 patients in the three rural locations who were eligible for the study, and who agreed to participate, were enrolled, whilst still in hospital, or immediately post discharge. These people consented in writing to be surveyed each month over the next six months by questionnaire and telephone interview. A convenience sample of consenting subjects (N = 20) also agreed to be visited at home, so that personal interviews could be conducted and the home environment assessed. A further convenience sample of this subgroup consented in writing to participate in video interviews for research purposes and to enhance the summarised findings of the study.

### **2.5.2 Primary subjects: Carers**

Carers of patients who had agreed to be in the study independently completed consent forms and participated independently from patients in completing questionnaires and personal interviews.

### **2.5.3 Secondary subjects: Hospital staff and community health providers**

Hospital staff and community health providers in all four sites participated in informal interviews prior to the commencement of the study, and in focus groups and discussion groups throughout the study to assist the researchers in interpreting findings from patients and carers. No material which could tend to identify either patient or carer was revealed during these sessions.

## **2.6 Outcome measures**

We collected quantitative and qualitative data to allow exploration of the full story of patients and carers, and to place these in perspective within the aged care health system. The main outcome focus in this study was qualitative, being patients' and carers' experiences up to six months post discharge. This was measured by the presence of the patient and carer in their own home, and qualitative information on their perceptions of the success of this arrangement, obtained by repeated semi-structured interviews. Other measures used were PREPARED (Grimmer and Moss 2001) which provided information on patient and carer perception of the quality of their discharge planning one week post discharge, the SF-36 / SF-12 which measured health-related quality of life for patient and carer (Ware and Sherbourne 1992) and the Barthel Index (Steinberg et al 1996).

## **2.7 Data collection from primary subjects**

### **2.7.1 Demographic data**

*On enrolment of consenting patients into the study, information was collected from them on:*

1. Age
2. Gender
3. Presence and identity of carer (spouse, child etc)
4. Carer demographics were then collected, similar to those obtained from the patient
5. Number of children and how close they lived to the patient
6. Pets and their care
7. Private health extras cover (that would support use of private community services)
8. Health history
9. Employment history
10. Housing tenure
11. Distance lived from hospital
12. Transport availability and ease



### 2.7.2 Collection of outcome measure data

In the week following discharge from hospital, subjects and their carer (if present) completed the relevant version of the PREPARED<sup>1</sup> questionnaire to quantify their perceptions of the quality of preparation for discharge. At this time they also completed the one week (acute) version of the SF-36 Quality of Life Survey and the Barthel Index, these instruments both being validated methods of providing baseline quantification of health, functional and/or emotional status. At the end of the first month post discharge from hospital, and each month for the next five months, patients (and their carers where applicable) completed the one week (acute) version of the SF-12 Quality of Life Survey.

All patients and their carers were personally and individually interviewed by the project officer (JF) each month for six months, mostly by telephone. At each interview, participants were asked for specific consent for that interview, and all telephone interviews were audiotaped with the participant's consent. Personal visits to patients' homes (in the subset as described previously) provided practical evidence of their ability to cope (such as home cleanliness and safety state of their garden, food supplies etc). The interviews were unstructured and ranged over the following issues. *(NB For some participants these issues were not relevant at all, and for others, issues were relevant one month but not the next. Therefore this list outlines a general overview of the content of interviews only).*

1. How much service, and what type, is required by recently discharged patients and carers to maintain themselves in the community?

- ◆ Out of an acute hospital
- ◆ Out of nursing/ residential care
- ◆ How did you find out about this service?

---

<sup>1</sup> P rescriptions

R eady to re-enter community

E ducation

P lacement

A ssurance of safety

R ealistic expectations

E mpowerment

D irected to appropriate service

- ◆ Why did you choose it?
- ◆ How many different services and persons are on your case?
- 2. How much information do we need to see patient/ carer as whole person?
  - ◆ What has been carer's experience when trying to act as advocate for patient?
- 3. How much effort is required to obtain these services?
- 4. What was and is their involvement in the wider community?
  - ◆ Responsibility and role
  - ◆ Extent of benefit of being involved
- 5. What is it about the home environment that supports / hinders? (for instance, design of house, support services already in place etc)
- 6. What is it about the urban environment that supports / hinders? (for instance transport difficulties, availability of after-hours services etc)
- 7. What service did patients want to access but were unable to because of systems issues? (closure of local services etc)
- 8. What do elderly people think about their environment if they have been living in their house for many years?
  - ◆ Do they want to shift, and why?
  - ◆ Home inspection by health professionals to assess risks in the environment
- 9. Patient as a whole person
- 10. Carer as an individual, not an extension of the patient
  - ◆ What has been carers' experience when attempting to advocate for the patient?
- 11. Aspects of patients and carers
  - ◆ Wellness

- ◆ How they learned about services and how to obtain them
- ◆ What costs this incurred
- ◆ Ease of reaching people
- ◆ Knowing whom to talk to
- ◆ What is perceived by patient and carer as integrated services?
- ◆ What services have you valued the most?
- ◆ What services have you valued the least?
- ◆ How could the system have been made better for you?
- ◆ Service substitution
- ◆ What unmet needs do you have?
- ◆ Ability to self assess
- ◆ Ability to self manage

## 12. System design issues

- ◆ Service flexibility

Where permitted, videotaped exit interviews were also conducted with participants. In the two main sites (Lyell McEwin Health Service, Whyalla Hospital and Health Service) all participants (patients and carers) were invited to participate in exit focus groups, conducted by the principal researchers and the project officer (JF), at which study findings were fed back and discussed with participants. The study plan is outlined in Figure 2.1.

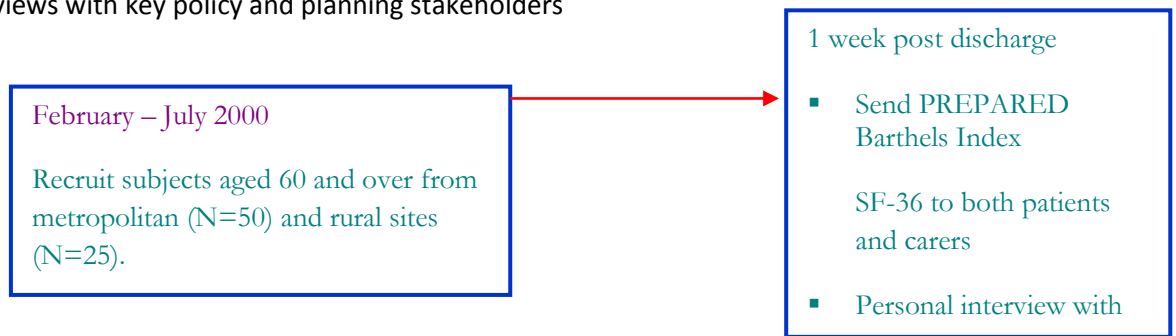
### **2.7.3 Site-specific personnel**

Our simultaneous sample recruitment in four different sites succeeded because we employed site-specific personnel to assist us with identifying patients for inclusion in the study, and in organising consent from them, and their carers. In each site, we identified and funded individuals who worked on the medical / geriatric wards, and thus could scan the admissions lists regularly, and who also had good 'people' skills, enabling them to explain the study, and to ensure that consenting participants

were fully aware of the imposts of the study. Without the assistance of these individuals, we would not have had the resources to complete subject recruitment within the study time period.

Preliminary project activities

- ◆ Systematic review of the literature
- ◆ Interviews with key policy and planning stakeholders



**1 month post discharge**

- Send out questionnaires to all subjects
- Personal interview with chosen subset
- Telephone interview all other subjects

**2 months post discharge**

- Send out questionnaires to all subjects
- Phone interview all subjects

**3 months post discharge**

- Send out questionnaires to all subjects
- Personal interview with chosen subset
- Telephone interview all other subjects

**4 months post discharge**

- Send out questionnaires to all subjects
- Phone interview all subjects

October – May 2001

Data analysis

**5 months post discharge**

- Send out questionnaires to all subjects
- Personal interview with chosen subset
- Telephone interview all other subjects

**6 months post discharge**

- Send out questionnaires to all subjects
- Exit interviews for all subjects
- Exit focus groups where appropriate

**Figure 2.1.** Project plan and time frame

## 2.8 Planning prior to undertaking the study

1. Systematic review of the research literature on discharge planning, community services and coping strategies by the elderly, including registration of a COCHRANE protocol.
  - ◆ The findings of this review are reported in Chapter 3.
2. Interviews with key policy and planning stakeholders.
  - ◆ Commencing in November 1999, we conducted interviews with key stakeholders in aged care service policy, organisation and delivery, in an attempt to obtain a better understand of aged care as a system. Each interview was extensive (taking 1-2 hours) and provided helpful insights into the conceptual basis of aged care services, as well as detailed information on service delivery issues. The types of issues discussed in interviews included:
    - ◆ strategies and supports used by elderly sick people
    - ◆ confirmation of our understanding of current arrangements for discharge planning and effective return to home and community
    - ◆ "mapping" of the coverage of current discharge planning and community service programs
    - ◆ projects currently (or about to be) funded in this area
    - ◆ *the main information needs of health service planners when addressing the continuum of care (from acute care settings to independent living in the community), especially with regard to handling multi-system disease*
    - ◆ *the imperatives of policy makers and service providers regarding care of the elderly*
    - ◆ *overlaps and gaps in services, and opportunities for cost shifting.*
    - ◆ *the current situation in elderly care funding, and aspects of the departmental budget cycle which will influence this*
    - ◆ *forward estimates for health service provision for the elderly into the next decade*
    - ◆ *identification of successful and unsuccessful health service interventions for the elderly, and the basis for these decisions*

- ◆ *the types of information, analysis and reporting that will influence thinking, how this can be made available on a routine basis, and how it would be used*
- ◆ *anticipating how the insights we will gain in our research project will flow into implementation, so that we can provide useful information at the end of the research project.*

Interviewees comprised:

Adam Longshaw (Mutual Community)	Nigel Fidgeon, Chris McCoy (Ashford Hospital)
Alan Crockett (FMC)	Paul Smith (DHS)
Ann Nosworthy (Northern Div. General Practice)	Peter Stewart (Lyell McEwin Hospital Outpatients)
Everard Altus, Jennie Commane (Northern Domiciliary Care)	Tina Koch (RDNS) David Wilkinson (SACRRH)
George Beltchev (DHS)	Marg Nihill (CEO), Jim McMenemie (Director of Nursing), Bruce Edwards (Community Health Services) (Whyalla Hospital and Health Services)
Ian Yates, Karen Richardson and the policy team (COTA)	
Jane Fletcher (Dept Housing)	Michael Cousins, SADI (General Practice Divisions)
Jeff Feibig and Jane Mussared (OFTA)	
Jill Whitehorn (DHS)	Pat Toomer (Whyalla Council)
Julianne Cheek and Alison Ballantyne (Centre for Research into Nursing and Health Care, Uni SA)	Roger Kirchner (CEO), Marilyn Preditis (Director of Nursing), Miriam Hunter (Health Promotion), Tracy Jarred (Admissions/Referrals Officer), Jill Lewis (Database manager), Trish Feluci (CNC Medical Ward)(Port Pirie Hospital)
Julie Patterson and Wendy Dolejs (Care 21) Director of Yalambi Nursing, Nursing Home, Whyalla	

General medical practitioners, Northern Justin Beilby (Division of General Practice,  
Division, Adelaide Uni Adelaide)

General medical practitioner, Port Pirie

Using a consolidation and ‘snowballing’ approach, as recommended in the qualitative research literature (for instance Rice and Ezzy 1999), we planned to continue conducting interviews until no new information was forthcoming. Even at the time of writing this final report, such a saturation point has yet to be reached, illustrating the sheer complexity of the conceptual and operational bases of systems supporting elderly, ill patients in the community and how this information is held in fragments amongst many stakeholders. Further evidence of the complexity of the aged care system is found in the systems maps for the participating sites provided in Chapter 4 of this report.

## **2.9 Further validation of the PREPARED instrument**

We attempted to further validated our PREPARED instrument (Grimmer and Moss 2001) during this study by comparison of the qualitative information obtained from participant interviews with their responses to the PREPARED instrument.

1. The validity of the domains in PREPARED was confirmed by comparison with key themes raised in interviews conducted immediately after discharge. Synthesis of pre- and post discharge interview data was initially employed to identify the elements in the PREPARED questionnaire (and hence the key domains), and thus this study provided an opportunity to retrace the developmental steps for PREPARED, to ensure that it addressed all key issues.
2. The responses to PREPARED (which were made within one week of discharge) were compared with events that occurred later after discharge, allowing us to determine the usefulness of the PREPARED in predicting patient concerns down the track.

## **2.10 Data analysis**

This study used a combination of qualitative and quantitative methods. Triangulation of the available data (interview responses, service use and satisfaction with that use and health, functional and emotional status) was undertaken where possible, to enhance the validity of the study findings and to explore the complex nature of participants' responses.

Key themes from interviews were identified in a three step process.



1. The audiotape of each interview was replayed by the project officer until all issues mentioned were identified.
  - ◆ For clarification, the participant was reminded of the issues from their previous interview at each subsequent interview.
2. One of the principal researchers (KG) independently evaluated a selection of the taped interviews to establish the reliability of the project officer in identifying the key issues.
3. These two individuals then synthesized the key themes from each months' interviews into a summary list of overall key themes. Cogent comments illustrating these key themes were identified verbatim from the monthly interviews.

The data were stratified by rural or metropolitan location, carer presence and main diagnostic groups. A range of statistical analyses was employed, including basic descriptive statistics, analysis of variance techniques, logistic regression and time series analysis.

The data from representative and illustrative patients/ carers is presented as case studies, enabling illustration of key themes, and grounding of concepts uncovered in this study in the context of patient and carer experiences.

## Chapter Three: Systematic review of the research literature

This chapter presents a systematic review of the research literature on discharge planning, and services provided to the elderly and their carers to facilitate successful return to community living.

**April 2000:** Mr Smith has been home from hospital for a month and is still using his walking sticks outside. Last week he had a fall. He was carrying a bundle of sticks to his rubbish bin when he lost his balance and fell against the fence. He was not using his walking stick at the time. He wasn't hurt, although he had a headache 'due to being upset over the fall'. 'I managed to get my fingers in the groove of the fence and after a long time managed to get myself standing. I called out to a man walking past but he didn't hear me. I didn't push my alarm because I wanted to try to get myself up'. He went to bed after the fall to sleep off the headache. A few days later he had been outside pruning some vines when someone called out to him over the gate. It was an ambulance crew. He had activated the alarm accidentally, and was embarrassed by this and worried that he would do it again. 'I got up from that fall by myself, and I'll be OK until the next one (laughs)'. He has no problems with his medications but the cold affects his angina. He has made one significant change to his routine since coming home – he doesn't go to church every Sunday like he used to, but instead people from the congregation visit him three times a week. He is very happy with this arrangement.

### 3.1 Method for the systematic review

The aim of this review was to assess the evidence of effectiveness of initiatives related to planning patient discharge from hospital to the community.

#### 3.1.1 Criteria for review

Preferred studies for this review were initially identified as prospective studies (randomised (RCT), quasi-randomised/controlled clinical trials (CCT) or non-randomised clinical trials (NRCT). Meta-analyses of RCTs and other high quality studies were included. However, after a preliminary search, it became clear that the number of studies of the preferred type in the literature was limited. Hence publications with other study designs, such as critical reviews and literature reviews were also included. Appendix 2 provides a complete list of the studies and their design type identified in the systematic search of the literature.

Computerised bibliographic databases were searched without any year restrictions for medical, chiropractic, osteopathic, physiotherapy and other allied health literature. These databases had to be accessible from either the University of South Australia library, or the libraries of Adelaide

University or Flinders University. In addition four teaching hospital libraries, namely those of the Royal Adelaide Hospital, The Queen Elizabeth Hospital, Flinders Medical Centre, and the Women's and Children's Hospital were also accessed. Non-English studies were excluded.

Databases searched were:

- ◆ Ageline
- ◆ AMED
- ◆ Australasian Medical Index
- ◆ Austhealth
- ◆ Cinahl
- ◆ Cochrane Controlled Trials Register
- ◆ Current Contents
- ◆ Expanded Academic ASAP
- ◆ IDEAL – International Digital Electronic Access Library
- ◆ Medline
- ◆ MD consult
- ◆ PubMed
- ◆ SPORT Discus
- ◆ Uncover
- ◆ Science Direct

In order to identify the maximum number of articles, no time frame was set. To reduce the likelihood of missing out on information published but not necessarily included in the databases searched, manual searching of the reference lists of all retrieved articles was undertaken to identify additional relevant citations. Manual searches were also performed on selected clinical journals, and on recognised texts. In certain databases, including the Cochrane database, subject headings (MeSH) as well as key words were used.

### **3.1.2 Participants**

The review includes trials of elderly (60 years and older) individuals of either gender living in the community. Evaluations of obstetric and paediatric home care schemes were excluded from the review.

### **3.1.3 Interventions**

Included in this review were services providing long term care; services provided in in-patient or outpatient settings or after discharge from hospital; self-care by the patient in their home, for example the self-administration of an intravenous infusion; hospital-at-home schemes including: community based hospital-at-home, hospital based hospital-at-home, hospice-at-home, early discharge hospital-at-home, and admission avoidance hospital-at-home.

### **3.1.4 Outcome measures**

- ◆ Mortality
- ◆ Clinical complications
- ◆ Re-admissions
- ◆ Cost: to the patient and family, to the general medical practitioner, to the hospital and to society.
- ◆ Days of hospital stay avoided
- ◆ Discharge destination from home care
- ◆ General and disease-specific health status
- ◆ Functional status
- ◆ Psychological well-being
- ◆ Patient satisfaction
- ◆ Carer satisfaction
- ◆ Carer burden
- ◆ Staff views (including general medical practitioners' satisfaction)

### **3.1.5 Key words used to search the databases (all words used in combination)**

- ◆ Elder\*, age\*, old\*, mature\*, senior\*, frail\*, weak\*, delicate\*, feeble\*, poor health
  
  - ◆ hospital near home, home care services, and early discharge
  
  - ◆ systematic review\*; systematic overview\*; meta-analy\*, meta analy\*; review; random\*; singl\*, double\*, tripl\*, trebl\* +blind\*, mask\*;
- crossover; clinical trial; controlled study; clin\* trial\*; control\* trial\*, control\* study\*; comparison; comparati\*, evaluati\*, volunteer\*.
- ◆ Carers, caring personnel, care\*, nursing\*, attention\*, custody\*, charge\*, control\*, protection\*, guardianship\*, attention\*, nurture\*, supervision\*, tending\*

- ◆ Agencies\*, help\*, action\*, institution\*, group\*, society\*, organisation\*, bureau\*

*Example of search strategy in Cinahl*

1. Elder\*, age\*, old\*, mature\*, senior\*, frail\*, weak\*, delicate\*, feeble\*, poor health
2. Carers, caring personnel, care\*, nursing\*, attention\*, custody\*, charge\*, control\*, protection\*, guardianship\*, attention\*, nurture\*, supervision\*, tending\*
3. 1 and 2
4. Agencies\*, help\*, action\*, institution\*, group\*, society\*, organisation\*, bureau\*
5. hospital near home, home care services, and early discharge
6. 4 and 5
7. 3 and 6
8. systematic review\*; systematic overview\*; meta-analy\*, meta analy\*; review; random\*; singl\*, double\*, tripl\*, trebl\* +blind\*, mask\*;
9. crossover; clinical trial; controlled study; clin\* trial\*; control\* trial\*, control\* study\*; comparison; comparati\*, evaluati\*, volunteer\*.
10. 8 and 9
11. 7 and 10

To reduce the potential for publication bias, searching was also undertaken at all three university libraries in South Australia for unpublished data, for example research degree theses and their references lists were checked for new references. Content experts were also contacted to assist in identifying other literature not identified by the search.

The other source of literature was the Internet. All the search engines available from the University of South Australia library were used, namely AltaVista, Infoseek, Net Search, HotBot, Lycos, Euroseek, Deja News, Anzwers, Excite, WebCrawler, Northern Light, LookSmart, Yahoo!, Metacrawler, Savvy Search, Dogpile, Inference Find and Web Wombat.

In ideal circumstances, systematic reviews would be undertaken by two or more blinded reviewers, thereby reducing the chance of bias in applying the quality rating systems, and providing evidence of

agreement between reviewers on the quality of the articles. Blinding the reviewer should minimise the possibility of his/her bias in regard to the year of publishing, the author, and the country and journal of publishing. However due to time restraints, one reviewer only was employed, and he was not blinded to the study authors or journal of publication.

**3.1.6 Searching the databases**

The following terms in Table 3.1 were used in each database in the same order. Each term was given a number and the separate or combinations of terms were used in the search. These strategies are referenced against the article list provided in Appendix 2, and also the number of 'hits' reported in the Results section.

**Table 3.1** Search strategies

Number	Terms used in search
1.	◆ Elder*, age*, old*, mature*, senoir*, frail*, weak*, delicate*, feeble*, poor health
2.	◆ home care services
3.	◆ early discharge
4.	◆ hospital near home
5.	◆ systematic review*; systematic overview*; meta-analy*, meta analy*; review; random*; singl*, double*, tripl*, trebl* +blind*, mask*; crossover; clinical trial; controlled study; clin* trial*; control* trial*, control* study*; comparison;
6.	◆ care*
7.	◆ nursing*
8.	◆ attention*, custody*, charge*, control*, protection*, guardianship*, attention*, nurture*, supervision*, tending*
9.	◆ Carers

10.	◆ Caring personnel
11.	◆ Agencies*, help*, action*, institution*, group*, society*, organisation*, bureau* comparati*, evaluati*, volunteer*.
12.	◆ Post discharger at home
13.	◆ Caring at home
14.	◆ Coping of carers
15.	◆ Carers

## 3.2 Review Methods

### 3.2.1 Study Selection

The titles and abstracts of articles identified from the computer searches were reviewed for relevance to the topic. The selected studies were sought through the catalogues of the available libraries. Studies not located in any of these seven libraries within Adelaide were excluded. No additional information was sought from study authors due to time and financial constraints.

### 3.2.2 Studies classified according to a hierarchy of evidence

The study types collected in this review were classified according to the hierarchy of evidence, based on the system devised by Lloyd-Smith (1997), outlined in Table 3.2.

**Table 3.2.** Hierarchy of Evidence

1. Meta-analysis of randomised controlled trials
2. One randomised controlled trial
3. One well-designed, non-randomised controlled study
4. Meta-analysis of all clinical trial
5. Well-designed – quasi-experimental study
6. Professional standards (procedures/guidelines if based on strong research performance)
7. Non-experimental descriptive studies – comparative/case studies

8. Respectable opinion/review papers by an expert authority
9. Professionally accepted practice (text book recommendations not supported by reference studies)
10. Personal or anecdotal experience

### **3.2.3 Application of quality scoring systems**

During the review process, two scales were used to evaluate studies.

These were the PEDro Scale to evaluate RCT, CCT and CTs, and a modified scale containing elements of the Oxman (1994) and Crombie (1996) scales to review critical reviews and systematic reviews. This scale is currently used in the Cochrane Collaboration for scoring literature reviews and systematic reviews.

#### **3.2.3.1 The PEDro scale**

This scale was chosen to evaluate all clinical trials (randomised and non-randomised) because it is simple, efficient and is used widely in Australia by allied health professionals. Moreover, the project officer is an accredited PEDro reviewer, having undergone a standard training program. The PEDro scale is an 11-point scale with yes/ no responses that account for various quality aspects of an RCT. Criteria 2-9 relate to the internal validity of the paper, while criteria 10-11 provide information about statistical analysis. Criterion 1 relates to the external validity of the trial. For each fulfilled criterion, one mark is given, and the scores are summed to provide a total. Two significant drawbacks of the PEDro scale are the failure to acknowledge reliability and validity considerations for intervention and outcome measures, and the lack of consideration of the effect of sample size on study quality. Both these issues are integral to evaluation of the overall quality of the study.

#### **3.2.3.2 The systematic review scale**

The modified scale to review systematic reviews (combination of Crombie and Oxman scales) contains 10 points under three main headings covering important aspects of a literature or systematic review. Each main heading has 2-5 subheadings. For each criterion met, a mark was given, and a total mark was calculated for each paper reviewed.

The scale is detailed in its evaluation of literature quality, but at the same time it is subjective. For example, unlike PEDro, this scale does not seek Yes or No answers. It is left to the interpretation of the reviewer to decide whether criteria have been fulfilled. Another drawback of the scale is that



each criterion has few guidelines for application by reviewers, and those guidelines are subjective. This leads to questions about the reliability of the review process. Nevertheless, at this stage the combined scale is the most efficient one for scoring literature reviews and systematic reviews.

### 3.3 Results

The results of searching each database (i.e. the number of 'hits') is outlined in Table 3.2a in alphabetical order of the databases. The column numbers relate to the search terms, as outlined in the Methods Section. The results of search strategies used in specific databases (such as the COCHRANE Collaboration) are outlined in the following subsections of Table 3.3. The numbers on the top line of Table 3.3 relate to the search strategies described in Table 3.1.

Table 3.3a **Search strategy results for library data bases**

Databases	1	2	3	4	5	6	7	8	9	10	1 1	1 2	1 3	14	15
Ageline	51	30	6 7	5 8	65	43	88	43	98	43	7 6	5 4	2 1	43	21
AMED	488	26	3	5	3	3	31	165	50	59	9	0	0	14	5
Cinahl	160	13	1	4	11	89	474	663	17	15	3	0	0	87	177
	5	4	3	6	3				6	5	0				
Medline	132	51	3	3	55	19	895	453	36	43	7	0	0	16	304
	07							6	6					3	
Pubmed	60	4	1	4	0	30	122	153	75	49	1	0	0	20	119
				1		2	7	55	1		5			5	5
Sports discuss	172	0	0	2	8	1	14	50	10	0	0	0	0	4	12
Current contents	576	29	2	2	15	9	548	211	20	18	0	0	0	80	127
	1							9	3						

Table 3.3b Search strategy results for Cochrane database

Terms used	Type of studies found	Number of studies found
Aged care and early discharge	Complete reviews	17
	Protocols	22
	Abstracts of quality assessed systematic review	9
	References	500
Services utilised at home	Complete reviews	4
	Protocols	3
	Abstracts of quality assessed systematic review	1
	References	3

Table 3.3c Search strategy results for Science Direct

Terms used	Number of studies found
Home care	0
Early discharge	0
Service at home	130 (all medical)
Carers	150 (all medical)

Table 3.3d Search strategy results for MD Consult

Terms used	Number of studies found
Home care	0
Early discharge	0
Service at home	60 (all medical)
Carers	89 (all medical)

Table 3.3e Search strategy results for Expanded Academic

*When all the single terms were used, no separate study was identified. So combination of terms were tried to identify new articles. All other combinations of terms did not identify any studies which could be used for this review.*

Terms used for the search	Number of articles found
Home care and early discharge	71 (all medical)
Service at home	0
Carers	1
Management at home	0
Coping at home	0
Managing at home	25

**Internet searching** in all available search engines did not yield any articles which could be used for this review.

The studies that were ranked in the top three levels of the hierarchy of evidence (N=30) are listed in Table 3.4. These studies were subsequently included in this systematic review.

**Table 3.4a** Systematic reviews of randomised controlled studies

- ◆ Parkes and Shepperd (2000)
  - ◆ Thompson and Thompson (1998)
  - ◆ Langhorne (1999)
  - ◆ Gillespie et al (1997)
- } In total four (4)

**Table 3.4b** Randomised controlled trials

- ◆ Evans (1993)
  - ◆ Hendricksen (1990)
  - ◆ Kennedy (1987)
  - ◆ Moher (1992)
  - ◆ Naylor (1994)
  - ◆ Naughton (1994)
  - ◆ Parfrey (1994)
  - ◆ Weinberger (1996)
  - ◆ McWilliams et al (1999)
  - ◆ Corr (1995)
- } In total ten (10) studies

**Table 3.4c** Clinical trials

- ◆ Chang (1999)
  - ◆ LoGiudice et al (1997)
  - ◆ Edwards and Jones (1998)
- }

- ◆ Ellul et al (1998)
- ◆ Walsh and Connelly (1996)
- ◆ Yohannes et al (1998)
- ◆ McCool and Schneider (1999)
- ◆ Wellwood et al (1995)
- ◆ Homer and Gilleard (1994)
- ◆ McCance et al (1997)
- ◆ McLoughlin et al (1996)
- ◆ Stewart et al (1997)
- ◆ Roberts et al (1999)
- ◆ Fulton Picot et al (1999)
- ◆ Brown and Mulley (1997)
- ◆ Saad et al (1995)

In total sixteen (16) studies

### **3.3.1 Quality of studies**

These studies were reviewed using the relevant scales as outlined in Section 3.2. The quality scores are listed by study in Table 3.5.

**Table 3.5a.** Systematic reviews

Study	Criterion										Total
	1	2	3	4	5	6	7	8	9	10	
Parkes and Shepperd	1	1	0	1	1	1	1	1	1	1	9
Thompson and Thompson	1	1	0	1	1	1	0	1	1	1	8
Langhorne	1	1	0	1	1	1	1	1	1	1	9
Gillespie et al	1	1	0	1	1	1	0	1	1	1	8

**Table 3.5b.** Randomised control trials

Study	Criterion											Total
	1	2	3	4	5	6	7	8	9	10	11	
Evans	0	1	1	0	0	0	1	1	0	1	1	6
Hendriksen	1	1	1	1	0	0	1	1	0	1	1	8
Kennedy	1	1	1	1	0	0	0	0	0	1	1	6
Moher	1	1	1	1	0	0	1	1	0	1	1	8
Naughton	1	1	1	1	1	0	1	1	0	1	1	9
Naylor	1	1	1	0	0	0	0	1	0	1	1	6
Parfrey	0	1	1	1	0	0	0	1	0	1	1	6
Weinberger	1	1	1	1	0	0	1	1	1	1	1	9
McWilliams et al	1	1	1	1	0	0	0	1	0	1	1	8
Corr	1	1	1	1	0	0	0	1	0	1	1	8

Table 3.5c. Clinical trials (using PEDro scale)

Study	Criterion											Total
	1	2	3	4	5	6	7	8	9	10	11	
Chang	0	0	0	0	0	0	0	1	0	0	1	2
LoGiudice et al	1	0	0	0	0	0	0	1	0	1	1	4
Edwards and Jones	1	0	0	0	0	0	0	1	0	1	1	4
Ellul et al	1	0	0	0	0	0	0	1	0	0	1	2
Walsh and Connelly	1	0	0	0	0	0	0	1	0	1	0	2
Yohannes et al	1	0	0	0	0	0	0	1	0	1	0	2
McCool and Schneider	1	0	0	0	0	0	0	1	0	1	0	2
Wellwood et al	1	0	0	0	0	0	0	1	0	0	0	2
Homer and Gilleard	1	0	0	0	0	0	0	1	0	0	0	2
McCance et al	1	0	0	0	0	0	0	1	0	1	1	4
McLoughlin et al	1	0	0	0	0	0	0	1	0	0	0	2
Stewart et al	1	0	0	0	0	0	0	1	0	1	1	4
Roberts et al	1	0	0	0	0	0	0	1	0	1	1	4
Fulton Picot et al	1	0	0	0	0	0	0	0	0	0	0	2
Brown and Mulley	1	0	0	0	0	0	0	1	0	1	1	4
Saad et al	1	0	0	0	0	0	0	1	0	1	1	4

### 3.3.2 Analysis of scores

#### 3.3.2.1 Criterion quality

The quality scores for the studies varied. An analysis of these scores was undertaken in order to determine in which criterion studies were deficient. Table 3.6 lists the percentage of studies which met each criterion.

**Table 3.6a.** Systematic reviews (N=4)

Criterion	Percentage
1	100%
2	100%
3	0%
4	100%
5	100%
6	100%
7	50%
8	100%
9	100%
10	100%



**Table 3.6b.** Randomised controlled trials (N=10)

Criterion	Percentage
1	75%
2	100%
3	100%
4	75%
5	12.5%
6	0%
7	62.5%
8	87.5%
9	12.5%
10	100%
11	100%

**Table 3.6c. Clinical Trials (N=16)**

Criterion	Percentage
1	66%
2	0%
3	0%
4	0%
5	0%
6	0%
7	0%
8	100%
9	0%
10	66%
11	100%

### 3.3.2.2 Average scores of articles

The average score (and standard deviation) per research design type was:

Systematic review      8.5 (SD 0.5) out of 10

RCT                      7.25 (SD 1.2) out of 11

Clinical trial              3.33 (SD 3.2) out of 11

The quality of the clinical trials was considerably less than that of the RCTs, with scores mostly constrained by absence of blinding and concealed allocation.

### 3.4 Discussion

The aim of this review was to assess the evidence of effectiveness of initiatives related to planning patient discharge from hospital to the community. This discussion deals with those studies which

our critical appraisal found were of sufficiently high quality (research rigour) to provide believable evidence.

Overall, the findings of the publications included in this review were mixed, and provide equivocal evidence regarding the effectiveness of discharge planning initiatives, and community support services for elderly people post discharge. The lack of clear direction in the evidence may be explained by different study design types, varying sample sizes, different study populations, different and variable descriptions of discharge planning / community support interventions and different methods of implementation of these interventions. The ways in which outcomes were measured, and their time frame of measurement also varied, and therefore there was no consistent framework that we could use for evaluation of effectiveness.

The evidence for the efficacy of the process of planning patient transition from hospital to community prior to discharge is equivocal. Moher et al (1992), Parfrey et al (1994) and Corr (1995) found some evidence to suggest that discharge planning may reduce the length of stay in a hospital thereby expediting their return to home care. However, they also indicated that the timing of any discharge planning intervention which depends on organising other services, will be constrained by how quickly these services can commence delivering care. Furthermore, the context in which these services are delivered will depend on the organisation and orientation of primary care services in each of the countries where the studies were conducted. Thus the generalisability of study findings is minimal.

Kennedy et al (1987), Corr (1995), Evans and Hendricks (1993), McWilliams et al (1999) and Naylor et al (1994) provide good evidence to suggest that consistent discharge planning and subsequent organised utilisation of community services reduces readmission and/or the days spent in hospital due to readmission in the short term. These studies particularly indicated that the patients with chronic medical conditions who managed their problems at home with the aid of services/carer had greater independence, better perceived ability to manage their own health and better quality of life.

The evidence divides on the long term influence of home services in preventing readmission and maintaining quality of life. Kennedy et al (1987), Evans and Hendricks (1993) and Naylor et al (1994) report an increase in the rates of readmission in the long term indicating a decreasing ability to cope or inability to sustain the care by the carers/services, whilst McWilliams et al (1999) at one-year review found that there was a decrease in the use of self care agency. Moher et al (1992) and Weinberger et al (1996) echoed similar comments in their studies, which noted that patients who

were involved with some form of discharge planning presented with increased levels of satisfaction of care in the short and long term.

Kennedy et al (1987), Hendriksen et al (1990), Evans and Hendricks (1993) and Naughton et al (1994) discuss the importance of the presence of carer or a family member at home when patients are discharged from hospital care to home care. The extent to which these carers were actually involved with the every day care of these patients was not explored in detail in any study. There was also considerable variability in the reporting of the specific involvement of the carer in the process of home care. Brown and Mulley (1997), Homer and Gilleard (1994), Wellwood et al (1995), McCance et al (1997), Fulton Picot et al (1999), Roberts et al (1999), Saad et al (1995) and Chang (1999) report on numerous instances of the role of carers and the identify the lack of proper training and education and the lack of consultation leading to increased stress and injury for carers of these elderly patients. Another finding from these studies was the lack of support and services available in the community for carers of elderly patients leading to breakdown of caring at home and the end result being a reduction in quality of life of both carers and patients.

The timing of home care and the level of education available to the patients also varied extensively in the literature searched for this report. Parfrey et al (1994) noted that this process started on day one while Weinberger et al (1996) noted that this had not been undertaken until three days prior to discharge. The services available for patients to utilise within the community to extend their stay at home were also variably reported and described, making it difficult to determine which mix of services, at which frequency, provided the best outcomes for patients and carers (Yohannes et al 1998, Edwards and Jones 1998, McCool and Schneider 1999).

A further problem identified from this review was the variability and lack of description of the extent of communication between hospitals and community. While most authors supported the notion that in order for patients conduct their lives independently post discharge from hospital, communication between hospital, community, patient and their carers need to be constant and effective, none of the publications addressed this issue in practical terms. This may explain the mostly poor patient and carer outcomes, especially in the long term.

### **3.5 Conclusion**

This review provided some evidence of benefits of utilisation of services provided at home for elderly, recently ill people, as a package of discharge planning from the acute hospital setting. However, variability in study designs, study settings, patient groups, descriptors of home services and discharge planning activities suggest caution should be taken in adopting the findings of any one

study. Furthermore there is equivocal evidence in the long term that discharge planning activities that provide home care services produce consistently good outcomes for elderly ill people and their carers. There are few quality studies that have examined the effect on carers, or the costs of hospital versus community based care in the short or long term.

Our review indicates that before more research is undertaken to test the effectiveness of activities of discharge planning/ transition from hospital to community, further descriptive research is required to:

- ◆ better understand and describe systems within which discharge planning occurs (for instance timeliness, responsiveness of related services etc)
- ◆ standardise descriptions and components of discharge planning initiatives
- ◆ standardise descriptions of community care initiatives
- ◆ more carefully identify the role of the carer
- ◆ determine sensitive and responsive measures of outcome in the short and long term

Thus, this critical review of the higher levels of the research literature confirmed the importance and relevance of our research project.

## Chapter Four: What we learnt from interviewing key stakeholders

This chapter reports on the second aspect of the preliminary project planning, which involved interviewing the key stakeholders. These interviews provided an abundance of insights into a systems framework against which to analyse the patient and carer case histories.

**June 2000:** Mr Smith has got into a routine again. He feels that he is coping 90%. He is still doing all of his own gardening. 'Next job I have is to spray all the fruit trees'. He has had no more falls and is 'trying to be as careful as I can'. He is still anxious that he may accidentally set off the alarm again. When he has been gardening he rests on the bed periodically. 'It's the only way I can do it'.

### 4.1 Stakeholder interviewees and their recruitment

Our stakeholder interviewees came from a wide range of health funding, service delivery and research activities. They also reflected a variety of service provision models. We had a 100% response rate to our invitation to participate in the interview, and all invitees were keen to talk to us in detail. Each stakeholder we interviewed appeared to believe that he/ she had specific insights into aspects of health service delivery for recently ill, elderly people. There was common recognition of the need for our research and agreement that *'things could be handled better than they currently are'* (direct quotation from interview notes). In one way or another, each of our interviewees was concerned that, when aged people attempted to remain living independently in the community after illness, this frequently led to a poor outcome, as well as incurring significant medical and social costs. In total, thirty-seven interviews were conducted with key stakeholders.

The health authorities and service delivery models represented in our stakeholder interviews are outlined in Table 4.1.

**Table 4.1** Where our stakeholder interviewees came from

Health authorities represented	Service delivery models / organisations represented
<p>Government</p> <ul style="list-style-type: none"> <li>◆ Commonwealth</li> <li>◆ State</li> <li>◆ Human Services</li> <li>◆ Health and housing</li> <li>◆ City and country health</li> <li>◆ Different country health regions</li> <li>◆ Local</li> </ul>	<p>Public hospitals</p> <ul style="list-style-type: none"> <li>◆ discharge planners</li> <li>◆ nurses</li> <li>◆ Management</li> <li>◆ allied health service providers</li> </ul> <p>Community health service providers</p> <p>Community support service providers</p> <p>Policy makers</p>
<p>Non-government</p> <ul style="list-style-type: none"> <li>◆ churches</li> <li>◆ non-government organisations (NGO)</li> </ul>	<p>Coordinated care models</p> <p>Private enterprises operating within the hospital system</p> <p>Divisions of general medical practice</p>
<p>Private</p> <ul style="list-style-type: none"> <li>◆ health insurers</li> <li>◆ hospitals</li> <li>◆ service providers (eg GPs)</li> </ul>	<p>Residential aged care facilities</p> <p>Day care aged care facilities</p> <p>Academia</p> <p>Advocacy groups</p>

## 4.2 Key general aspects of our stakeholder interviews

A number of key areas were identified by our interviewees as being of concern in maintaining the aged, ill person as an independent member of the community, especially after an episode of

hospitalisation. We cannot emphasise too strongly that none of these comments was a criticism of any particular individual person or persons, but rather they recognised the shortcomings of the present state to which the overall system had evolved over many years. We came away from this set of interviews feeling quite subdued about the sheer complexity of this system, yet heartened by the goodwill of the individuals attempting to do their best for patients and carers under difficult circumstances.

1. The consumer role

- ◆ the need for aged people to recognise their own problems and to assist in identifying their own solutions
- ◆ recognition that the system cannot provide all supports, and that the aged person needs to contribute to their own care in some way
- ◆ the tension between elderly people resisting yet in reality, requiring, supports
- ◆ the interaction effects between loneliness, decreased health status, pride, lack of insight into health needs, and desire for continuing independence.

2. Gaps and duplications in current services

- ◆ Difficulties in mapping services within any system, given service fragmentation and mostly short-term funding sources for discharge planning and community transition options

3. The frustration that solutions from previous research may well be sitting on library shelves (reflecting the grey literature), but too few people have access to them, or time to access them and make sense of their findings

4. The key role of researchers in service evaluation and refining (*for instance we were told on several occasions how valuable our findings would be to the next round of coordinated care trials*)

5. Difficulties prioritising and/ or individualising services within the menu-driven model

- ◆ Frustration related to recognition of individual needs when unable to meet them within the current environment

6. Shifting ground in training and employing hospital and community service providers

- ◆ debate regarding the role of expensive health professionals versus more generic, cheaper options such as personal care attendants
  - ◆ short term funding models constrain workforce planning, particularly in country areas where health professionals need to be provided with a career path that may not be possible if funding for a position or a specific initiative is only provided for (say) 12 months
7. The issue of risk determination
- ◆ Who decides that a patient and/ or carer is at risk of a poor health outcome?
  - ◆ What tools should be employed to assist such decisions?
  - ◆ What is the relative weighting of risk (i.e. physical / mental / social risk)?
  - ◆ What constitutes high risk?
  - ◆ What costs are associated with failing to manage high risk cases appropriately?
8. Talking to, and integrating activities between, other government services (Commonwealth, state and local), at all levels within the system (policy, management, health service provision, patient)
9. Integrating health needs with the needs of patients growing older in their own homes
- ◆ Making houses user-friendly, and more readily adaptable for walking aids, bathroom appliances, low maintenance gardens etc
  - ◆ Integrating housing needs for young and older dwellers
  - ◆ Making housing, transport and recreational facilities flexible so that they can adapt to changing needs

Many of our interviewees referred to their own experiences with ill, aged people - often their own family. Without exception, they all demonstrated a strong commitment to making things better for this client group. *En masse*, they recognised the problems of supporting long term, recently ill, aged people in independent living environments in the community, and there were a number of generic solutions proposed for the identified problems in the system.

However, individually, most of our interviewees were not in a position to address the identified problems with solutions. This appeared to be because of difficulty in implementing systems change.



For instance, quality discharge planning and community service organisation potentially crossed organisational boundaries, therefore requiring power sharing with another agency. This would involve issues such as keeping all players in the loop (and hence a recognition of who the players were and how to contact them), the legal issues of responsibility and decision-making, the need to recognise cost shifting and accountability for costs, and issues of reporting back. These are the very issues that we had recognised in our earlier project to be operating within the acute hospital system, frequently constraining the quality of planning for discharge.

### **4.3 Reflections on our proposed research**

#### **4.3.1 Research questions and our subject group of interest**

All interviewees commended our general research question, the need for our research, and our subject group of interest. Whether to include Aboriginal patients in our sample was discussed in a number of interviews, and it was decided (with assent from the interviewees) that we needed to learn more first about the systems and supports for the continuum of community experiences in living with a chronic illness in general before we would be equipped to tackle the culturally-sensitive issues around Aboriginal patient discharge and community living.

Our proposed inclusion and exclusion criteria for our patient group were discussed widely in the interviews, and were subsequently refined and approved. Our later decision to lower the age of entry into the study to 60 years was presented to, and discussed with, a reconvened group of representative interviewees prior to decision implementation. It was clear that, while the interviewees had working knowledge of the general area of aged, ill patient discharge, no one individual had a grasp of all the issues. They were unsure of which conditions to target, which people were more likely than others to do badly, what the age range of pre-chronicity was, which people used community services most with what outcome, and which strategies were in place for which patient type. This project will improve knowledge of these issues at decision-making levels.

#### **4.3.2 Research questions**

One of our original research questions related to the experiences and decisions underpinning elderly ill people's strategies to remain at home rather than move to residential aged accommodation. We sought to tease this issue out with interviewees in order to refine our measures. They confirmed our impression of a paucity of research into the context of health and social deterioration of elderly people, the lack of information on valuation on health and support services with respect to maintenance of independence, and the lack of evaluation of policy initiatives which targeted at-risk

elderly people who were potentially residents in aged care facilities but who were currently still making do at home.

We were also interested in where and how aged persons obtain their information on community services. There appeared to be no clear approach to ensuring empowerment of aged ill people with respect to deciding on their own service use, or on organising it themselves. It became apparent that there was no one central coordinator whose responsibility extended for more than a short period of time. The liaison / discharge planning services in the hospital focused on the short term, (immediate transfer from hospital to home). Unless patients were already 'on the books', community services generally did not provide services until at least several days (as a minimum) after discharge. The general practitioner was not aware of all service provision options, nor in many instances was he/ she able to organise them for the patient. Some of the initiatives that were described to us involved service brokers, whose role was to identify and organise services once contacted by the patient (or an advocate). However their role was not to identify the patients who needed the service, and so slippage was possible where the patient and/ or his/ her contacts did not know of service availability.

We were interested in mapping health services in each of the locations that we surveyed. We sought guidance during our interviews on how services and systems developed, and what the drivers of such development were. Our interviewees commonly described and identified the 'topsy-like' proliferation of services, with new services being created to address perceived gaps in existing ones, and where short-term funding opportunities were seized in order to implement services to address perceived needs, but without being able to address the sustainability or appropriateness of the service in the context of the overall health system. They were able to identify service duplication between different levels of Government, and that there were few mechanisms within and between Government levels and agencies to exchange information on service development, description and evaluation. To deal with the increasing complexity of services and systems, additional tiers of service providers and administrators have been established, in order to direct health service providers and patients to appropriate services or resources. This has created an environment of 'need to know' and 'being in the know' for most users of health systems (patients, carers, health service providers) where it seems almost as difficult for health professionals to negotiate the system as it does for patients and carers. Our interviewees had quite a lot to say about the tension between central control and local responsiveness, where a central system needed to be flexible enough to ensure that services could work appropriately at local community and local patient levels.

#### **4.3.3 Evaluation of service success**

We were interested in how to evaluate during our project whether a service was making a difference to patients' and carers' lives after discharge. While our interviewees were keen to assist us with identifying appropriate measures of outcome, there seemed to be few measures that would provide us with sensitive information on changes to lifestyle or tips on successfully making do that could be used in a generic sense in our research. Moreover, in a quality improvement sense, there seemed to be few ways in which we could evaluate service delivery from the sense of marginal costs and marginal gains (what small changes could be put in place to make the service better) without asking patients directly on an individual by individual basis. This validated our decision for undertake repeated one-to-one interviews with patients and carers in our study.

#### **4.4 The contexts of our research**

##### **4.4.1 Current initiatives**

We identified the existence of a plethora of current initiatives to deal with issues associated with aged, recently ill people. Many had been developed to fill niche markets. Our interviewees admitted to difficulty in keeping up with all current initiatives, and like the continued emergence of new key themes with each new interview, new current initiatives also emerged with regularity. Many of these initiatives were linked to local need, specific funding sources or opportunities, and there appeared to be little formal evaluation of the impact of initiatives on health outcomes or costs. Even in rural areas, there appeared to be incomplete knowledge of local initiatives and how they operated. Synthesising the interview findings, reasons for lack of complete knowledge on current initiatives related to:

- ◆ compartmentalisation (for instance medical versus social)
- ◆ hospital versus community funding and service availability / resource issues
- ◆ community agency versus community agency (within and across communities) - relating to funding and service availability / resource issues

Many of the current initiatives seemed likely to run into difficulties in achieving their objectives at an affordable cost because:

- ◆ The system had neither all the virtues of a market economy nor all the virtues of a command economy
- ◆ Monopolistic power bases had emerged, as not all the players were equal

- ◆ Information about service availability was of itself not a valued commodity
- ◆ It appeared difficult for any player to 'get on top of' the system and to fully understand how initiatives worked within their system

#### **4.4.2 Systems maps**

In attempts to understand the services and initiatives that were operating in each of our research sites, we developed systems maps for each site. These maps were accurate (to our best knowledge) as of January 2001. However, given the rapidity with which change could occur in the aged care health system, these maps may not longer fully represent the system in any site. These maps are provided in Appendix 3.

#### **4.4.3 The multidisciplinary team**

We uncovered considerable inter-and intra-professional disquiet regarding roles, responsibilities, team membership and workload in the provision of supports for elderly people living independently in the community. In many instances, rhetoric did not match reality. General medical practitioners consistently reported playing the key role in patient care, but they also identified the need to limit the amount and type of service to fit into a standard appointment schedule. To do this they focused on one problem at a time, and they dealt with mainly physical problems, because to delve into emotional or social problems, or to coordinate services required more time. They reported often not knowing what community-based services were available for their patient and had few general networks for finding out. It seemed as difficult for general practitioners to navigate the system as it did for patients. We identified the lack of an accepted standard approach (i.e. one that was supported by the GP Divisions) regarding service organisation to ensure that:

- ◆ Discharge information from hospitals was read in a timely manner by general medical practitioners
- ◆ GP appointments with recently discharged patients were automatically coordinated with their hospital discharge
- ◆ Vital information on medications and test results was transferred in a timely manner between hospital and community.

Particularly of concern were elderly folk taking multiple medications, and/ or substitution of one drug for another whilst patients were in hospital. In many instances this occurred without the GP being informed. General practitioners also admitted to sometimes resorting to the 'easy' option of

providing medication instead of non-prescription management for problems such as anxiety and depression, because of the difficulty of dealing appropriately with these problems in a non-medication framework within a general practice model.

Issues with communication and role differences were identified for other players in the multidisciplinary team, such as the district nursing service and allied health services. Commonly mentioned issues were the constraints imposed by the 'user pays' system with respect to equipment provision, workforce shortages necessitating restriction of available services, frustration of only being able to offer limited services in the face of obvious need, and similarly to general medical practitioners, the difficulty of navigating the system in order to find alternative services or service providers, or to act as advocates for the patient. Frustrations were identified where general medical practitioners were provided with funding for case conferencing (the new extended MBS item number) and yet other members of the multidisciplinary panel were required to attend without financial recompense. This was particularly an issue for private nursing and allied health providers, or those whose service delivery model was of a private enterprise approach operating within the public sector.

#### ***4.4.4 The difficult role of discharge planners / liaison officers***

The discharge planner / liaison officer role was highlighted as potentially problematic. Schon's (1971) theory of organisational change highlights the dynamic conservatism of social systems in actively resisting pressure to adapt. Should they eventually change, they do so by the minimum response capable of neutralising the intrusion. It appeared from our interview data that liaison officers were that 'minimum' response. They often carried large burdens in order that the system be seen to be supporting quality initiatives. By passing responsibility for discharge planning on to liaison officers / discharge planners, ward and community staff were 'unloaded' of responsibility. Discharge planning quality ceased being central to other staff's work focus. Liaison officers needed to be special people with good communication skills and compassion, possessing an understanding of aged care issues and an interest in older people, come into the job with strong support networks (established on their own initiative) and be prepared to take career risks. They had to understand their system from within and outside the hospital, and be able to keep on top of change (in service types, funding models and constraints, and in the incumbents in positions). We were told on a number of occasions how effectiveness in the position was personality dependent. Given that the funding support for many of the current liaison positions was restricted, this added a further reason as to why the system was unlikely to change. For quality discharge planning to continue to be recognised as integral to successful transition from hospital to home, it seems important that the

person, and the position be protected, by longer term initiatives, and a more positive valuation of the role and effort associated with it.

#### **4.4.5 City versus country**

Contrary to our expectations, we were told that it was not common for a patient to be admitted to a city hospital directly from the country, or returned home to the country directly from the city hospital. The country hospital generally admitted the patient prior to transfer to the city hospital, or patients were discharged between hospitals (i.e. city to country).

Country general practitioners had admitting rights to their local hospital. Whilst this should have been expected to reduce some of the discharge problems that appeared to occur in the city (as the general medical practitioner was in effect discharging to him/herself), problems were still reported when other doctors were on call, or when locums were working. Having the general medical practitioner discharge the patient from hospital to community also did not seem to eradicate the divergence of opinion between medical versus social or nursing readiness for discharge, where the time allowed by the GP when visiting the hospital did not encompass discussions with appropriate nursing or allied health staff in the hospital or in the community.

In the country, nursing and allied health staff often had to be generalists to cover all wards and patient types. Hospital and community staff had to be interchangeable, working across sites when there were staff shortages, or on a roster basis. This presumed that policies and procedures in all sites were transparent and understood by all, although this did not seem to always be the case.

#### **4.4.6 Making a difference**

##### **4.4.6.1 Advocacy**

Who should provide advocacy for aged people trying to manage in the community and what should they do? Our definition was that an advocate identified someone's needs and ensured that they were met on an ongoing basis, in instances where patients could not do this for themselves. The current system seems to be more associated with 'brokering' or 'doling out' services on a short-term basis, with an acceptance that not all needs of all people can be met, and on the understanding that services can only be provided for a short period of time. The feeling amongst our non-medical interviewees was that the general practitioner was the best advocate for the patient, as he/ she saw the patient on an ongoing basis, and was in the best position to identify needs and find ways in which these needs could be met.

However, the general practitioners interviewed for this study indicated that:

- ◆ They could only deal with one or two problems at most at each consultation because of the current fee structures
- ◆ They were not sure that they were the best people to identify all needs, particularly where needs were more related to surviving at home (environmentally, physically and emotionally) or social supports
- ◆ They did not fully appreciate all the issues faced by elderly, ill patients living at home
- ◆ They had few solutions for patients regarding resource information on support services
- ◆ It took time for them to organise support services for patients where networks were already in place - time which they were reluctant to commit, and therefore this was often undertaken by the practice nurse or receptionist.

#### **4.4.6.2 Needs**

Many of the people we interviewed recognised that current services were not meeting the needs of aged ill people in the community, particularly via the variable menus of available community services. We were interested in why this issue had not been sorted out at administrative levels, given the widespread acknowledgment of the existence of problems. In light of the responses to our questions, we wondered whether it was because the common perception was that in order to deal with individual patient needs, systems needed to be developed to ensure that all people got a 'fair' deal. The notion that individual service providers could work without a 'system' by using their professional judgement and be monitored using agreed performance indicators, seemed not to have been not considered by many of the people we interviewed. If our conjecture is correct, then implementable findings from our study will need to provide practical solutions, at small cost, which did not involve the construction of new systems.

The issues of defining, identifying and meeting patient needs are complex and consumed much time in our interviews. Legal liability seemed to be the most potent force behind recognition and consideration of patient needs. Perceived patient needs are often ranked by health professionals, with those needs which relate to safety and legal responsibility being the ones most commonly addressed (for instance, it is unlikely that anyone has ever been sued for not organising the washing of a patient's windows, but there might be legal ramifications if services were not organised for a patient who was unable to prepare meals). Our interviewees indicated that communication

problems between health professionals, or between health professionals and patients, were the most common underlying reason for litigation.

Those interviewees working in aged care flagged the possibility that our research may not be generalisable into the next generation of elderly ill people. Our target group (those patients currently aged over 60 years who had recently been discharged from hospital with a disease that is becoming chronic) were identified as potentially being different from the next generation of similarly challenged patients. Our target group, because of their experiences through world war, severe economic depression, and variable access to education were not perceived to expect too much of any system or any person. They were perceived to be independent and to accept that they have to make adjustments to their life and lifestyle, as they had done throughout their life time. The next group of elderly, reflecting the baby boomer generation, potentially will have different expectations and different abilities to cope with life changes, and thus the systems that are in place for our target group, and our recommendations about making these systems work better, may not be so relevant in 10 years time.

#### **4.4.6.3 Adjusting to disability**

In years past, before there were such tight constraints on hospital length of stay, it was a common perception amongst our interviewees that convalescence occurred in hospital, after the end of the acute illness. During this time, people were given the time and professional support to come to terms with changed abilities and lifestyles, and to put their own systems and solutions in place before they ventured into independence in the community. Thus the individual bore only some of the responsibility for transition from one health state to another. With decreasing lengths of hospital stay, convalescence now occurs in the community, often in the patient's own home. The patient and their family now appear to bear the bulk of the responsibility for transition from one health state to another, using a mere few community supports. This raises the issue of whose responsibility it is to prepare and assist patients and their families in their transition from being well to being disabled, adapting to functional capacities that have often diminished for ever. In the first few months post discharge from hospital with a condition that would become chronic, the perception was that individuals may be too debilitated to be concerned with such matters as house cleanliness or gardening. The perception amongst our interviewees was that their main concerns were for their health and safety. As time went on, and their health stabilised, they were then perceived to be in a position to organise their own household management for themselves.

## **4.5 Summary**



We cannot emphasise too strongly that none of these comments was a criticism of any particular individual person or persons, but rather they recognised the shortcomings of the present state to which the overall system had evolved over many years. We came away from this set of interviews feeling overwhelmed about the sheer complexity of this system, yet heartened by the goodwill of the individuals attempting to do their best for patients and carers under difficult circumstances.

Our interviews with key policy-makers, service organisers, educators and clinicians recognised the shortcomings of the present state to which the overall system had evolved over many years. Because of the sheer complexity of this system, there was a wide variability in knowledge - of the system itself and of elderly, recently ill, people's needs - coupled with acute concerns 'to do it better'.

The interviews confirmed the need for careful study of aged, recently ill people's experiences in navigating the system, in order to provide tangible examples for decision-makers of 'real life' situations which could be used as building blocks for better structures/services/approaches to organising transition from hospital to home, when health status was dramatically altered.