An exploration of the reasons for frequent readmissions in patients with chronic disease

Activation from Frequent Flying to Self-Management

Susan Edwina Kirby

A thesis presented in fulfillment of the requirements for the degree of Doctor of Philosophy.
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- Kirby, S, Dennis, S, Jayasinghe, U. and Harris, M. “Frequent emergency attenders: is there a better way?” Australian Health Review, 2011, 35(4) 462-467

http://dx.doi.org/10.1071/AH11067.

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<tr>
<td>Sarah Dennis</td>
<td>10%</td>
<td>Support, checking and discussion of analysis</td>
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<td>Upali Jayasinghe</td>
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Declaration by co-authors

The undersigned hereby certify that:

1. They meet the criteria for authorship in that they have participated in the conception, execution, or interpretation, of at least part of the publication in their field of expertise;
2. They take public responsibility for their part of the publication, except for the responsible author who accepts overall responsibility for the publication;
3. There are no other authors of the publication according to these criteria;
4. Potential conflicts of interest have been disclosed to the head of the responsible academic unit; and
5. The original data are stored at the following location and will be held for at least five years from the date indicated below:
In the case of the papers entitled:

- Kirby, SE, Dennis, SM, Bazeley, P and Harris. MF, “What distinguishes clinicians who better support patients for chronic disease self-management?” Australian Journal of Primary Health -http://dx.doi.org/10.1071/PY11029, Submitted: 8 March 2011 Accepted: 23 August 2011. Published online: 2 December 2011 and


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<td>Support, checking and discussion of analysis</td>
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<td>Pat Bazeley</td>
<td>5%</td>
<td>Qualitative analysis support and assistance with interpretation</td>
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<td>Mark Harris</td>
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4. Potential conflicts of interest have been disclosed to the head of the responsible academic unit; and
5. The original data are stored at the following location and will be held for at least five years from the date indicated below:

Location

CPHCE staff file on password protected server

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<td>Mark Harris</td>
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DEDICATION

To Jack

Let me not to the marriage of true minds
Admit impediments. Love is not love
Which alters when it alteration finds,
Or bends with the remover to remove:
O no! it is an ever-fixed mark
That looks on tempests and is never shaken;
It is the star to every wandering bark,
Whose worth's unknown, although his height be taken.
Love's not Time's fool, though rosy lips and cheeks
Within his bending sickle's compass come:
Love alters not with his brief hours and weeks,
But bears it out even to the edge of doom.
If this be error and upon me proved,
I never writ, nor no man ever loved.

William Shakespeare
(1564 - 1616)
This study could not have been done without the cooperation of the patients and clinicians at Shellharbour Hospital. I thank the patients for talking to me so openly about living with chronic conditions and giving me a window into their lives. Their generosity still amazes me. The clinicians gave me their thoughts and feelings about chronic disease management unstintingly. They are very busy and I acknowledge my debt to them.

My supervisor Sarah Dennis has been a tower of strength during this work. Sarah has all the attributes of a good supervisor - patience, wisdom, experience and humour. I have learnt a great deal from her. I also thank my co-supervisor Mark Harris for his cogent and insightful comments which were there when I needed them. I thank my co-authors, Upali Jayasinghe and Pat Bazeley and acknowledge the contribution they have made to this work. I have enjoyed working with them.

There are many friends who have supported me faithfully through this journey, especially since Jack’s death. I thank them all. Julie Bail, Ruth Campbell, Jo and Alex Wodak, Sandra Alexander, Nick Herd and Anna Whelan have been there to lift my spirits. Emeritus Professor Robert Bartels showed me how to transform the data files for analysis. Without his help the regression models could not have been constructed. It has been a treat to share the ups and downs of the PhD journey with my colleagues at CPHCE, Julie McDonald, Barbara Booth, Rachel Laws and Anna Williams and Sunny Chang. Special thanks to Sarah Ford for her brilliant formatting. My family - children, Harry and Sam, and my grandchildren, provided much needed encouragement.

Finally, of course, without Jack’s support and love I wouldn’t have started.
## LIST OF ACRONYMS

<table>
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<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>ACSCs</td>
<td>Ambulatory care sensitive conditions</td>
</tr>
<tr>
<td>CDSM</td>
<td>Chronic disease self-management</td>
</tr>
<tr>
<td>CHFS</td>
<td>Chronic heart failure service</td>
</tr>
<tr>
<td>COPD</td>
<td>Chronic obstructive pulmonary disease</td>
</tr>
<tr>
<td>ED</td>
<td>Emergency department</td>
</tr>
<tr>
<td>EDIS</td>
<td>Emergency department information system</td>
</tr>
<tr>
<td>FA</td>
<td>Frequent attender (4 or more times a year)</td>
</tr>
<tr>
<td>FRP</td>
<td>Frequently readmitted patient (3 or more times a year)</td>
</tr>
<tr>
<td>GP</td>
<td>General (medical practitioner)</td>
</tr>
<tr>
<td>ROC</td>
<td>Respiratory outpatient clinic</td>
</tr>
<tr>
<td>SMP</td>
<td>Self-managing patient</td>
</tr>
<tr>
<td>URVP</td>
<td>Unplanned returned visit patient (return to ED within 28 days of the first presentation for the same condition)</td>
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Repeat hospitalisations by frequently readmitted patients (FRPs) are costly and might be avoidable. Many frequent readmissions are due to acute exacerbations of chronic disease treatable outside hospital. FRPs were defined as patients who were admitted three or more times in a year. The aim of this research was to explore the reasons behind frequent readmissions in patients with chronic disease.

The study at a regional hospital in NSW, involved analysis of emergency department data to distinguish patient factors associated with three types of frequent hospital users: FRPs, frequent attenders (FAs) with four or more presentations in a year and patients who have an unplanned return visit to hospital within 28 days for the same condition (URVPs). Differences in attitudes to and beliefs about chronic disease self-management were explored by analysing interview data from FRPs compared with data from self-managing patients (SMPs), who had all been FRPs but had adopted self-management. A sample of clinicians treating patients with chronic disease in hospital, general practice and self-management services was interviewed to determine differences in attitudes to and beliefs about self-management.

FRPs, FAs and URVPs shared some characteristics, but were discrete groups. The findings confirmed that patients with chronic disease contributed to the FRPs group and provided a basis of developing solutions to frequent use. The qualitative findings indicated that patients adopted self-management in response to encouragement by a proactive clinician. Activation involved acceptance; responding emotionally and changing identity, which was not described by FRPs. Hospital clinicians and general practitioners thought that some patients were resistant to self-management, were less familiar with self-management services and saw their role as being restricted to referral to services. Clinicians involved in self-management had the skills to be proactive and believed that all patients could be activated to self-manage.
The findings provide insights into interactions between patients and clinicians leading to patient activation. The implications are that self-management activation in patients presenting to hospital can be increased by improving clinician skills in and understanding of the process of patient activation in self-management. This may help to reduce further reliance on presentation to hospital.
Overview
This chapter describes how the study was conceived, detailing the influence of the researcher’s background and the rationale for the theoretical framework. The chapter is divided into the following sections:

• The influence of the researcher’s background
• Theoretical underpinnings
• Formulating the research questions
• Methodology
• Summary
Influence of Researcher Background

From the late 1980s to 2006, I worked in the public health system in the Australian Capital Territory and NSW as a senior manager of a community health services and as a hospital manager. During this time, "frequent flyers" were the subject of much discussion at senior management meetings. The term “frequent flyer” was clearly used in an ironic and derogatory way. The attitude prevalent in the public health system was that FRPs were a nuisance and the goal was to discharge them back home as soon as possible. In many cases, the discharge process did not address the patient’s underlying problem thereby making their return to hospital more likely.

In my role as a hospital manager, I examined patient files and found that although FRPs had nominated GPs, there was no evidence on the files as to whether they had been to see their GP after discharge. The medical records showed that some of them had been seen by allied health professionals to address the complex problems associated with chronic diseases, that they were taking many medications and had multiple co-morbidities. It was clear they were high needs patients and difficult to manage, but it was not clear whether this was due to patient, service or access factors.

Because of my hospital management experience, I commenced this study with the assumption that FRPs were less resilient and less able to cope than SMPs. The hospital clinicians seemed to share this view. My change of heart came after talking to clinicians directly involved in chronic disease self-management services who were convinced that it is possible to support all patients to self-manage over time. This encouraged me to reflect more deeply on what FRPs told me about their lives with chronic disease and on how their descriptions differed from those of SMPs.
The Theoretical Underpinnings

The starting point for the study was my idea that FRPs were a distinct subgroup of patients who had personal characteristics that made them resistant to self-management and led them to keep coming back to hospital. The goal was to identify the patient characteristics associated with frequent readmissions.

The frameworks put forward by Crotty [1] and Carter and Little [2] formed the basis for the theoretical underpinning of the study. Crotty’s hierarchy provides a way of navigating from epistemology, theoretical perspective, methodology and methods to achieve overall congruence.

The components specified in Crotty’s hierarchy are:

- Methods – techniques or procedures to collect and analyse data.
- Methodologies – the plan behind the choice of methods.
- Theoretical perspective – the philosophical stance providing the context for the research.
- Epistemology – the theory of knowledge which encompasses the theoretical perspective and the methodology.

The work of Carter and Little provided a way of demonstrating the reasoning behind the choice of methods and the link through methodology to epistemology. Creswell’s [3] examples of the five traditions demonstrated how the different approaches to qualitative research influence research design and research questions. Morse and Richards [4] discuss the two fundamental principles of qualitative research which inform research inquiry: methodological **purposiveness** and **congruence**.

That is, for qualitative research to make sense, it must establish how the research questions lead the researcher to particular data sources and analysis strategies. Drawing on Crotty’s [1] hierarchy, the links between the epistemology and methods are set out in the **Table 1**.
Table 1. Hierarchy of the study methods.

<table>
<thead>
<tr>
<th>Epistemology</th>
<th>Theoretical perspective</th>
<th>Methodology</th>
<th>Methods</th>
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<tbody>
<tr>
<td>Constructionism</td>
<td>Interpretivism</td>
<td>Phenomenology</td>
<td>Patient and clinician interviews Patient and clinician details Psychological patient scales Emergency department data on patient arrival, clinical, demographics and usage</td>
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Because the study was about a group of FRPs in situ, (i.e. in hospital) ethnography seemed an appropriate methodology. The study group of FRPs and their clinicians was the culture under investigation. The methods of observation, analysis of patient and clinician data, were consistent with an ethnographic methodology. The guiding principle in ethnographic studies is that, even though the setting may be familiar to the researcher, it should be treated as anthropologically strange. The research aims to document the culture – the perspectives and practices – of the people in these settings by getting inside the way the study group sees the world. To do this effectively, the researcher must try to put aside preconceived ideas about the group and the setting, or at least to recognise his or her biases and try to nullify their impact. I tried to identify and put aside the preconceptions derived from my previous role as a manager of both hospitals and community health services.

Ethnography is used extensively in health research because it allows for the perspective of the culture under study to be gained through immersion in the field. Morse [5, 6] provides a vivid account of her research into what constitutes the giving of comfort by nurses. In Morse’s study the field data consisted of detailed accounts of what nurses said about how they gave comfort to their patients. Anspach and Mizrachi [7] describe how the ethical issues of ethnography in medical sociological research provide a useful practical guide to the pitfalls of clinical research. The quote
below illustrates the dilemma which faces the researcher analysing data from a field in which he or she had been involved. The researcher also needs to preserve the confidentiality of interviewees in reporting the findings.

While in the field, ethnographers are forced to choose between sociology and their obligations to host members, as they decide whether to disclose their actual research agendas, whether to ask tough questions or to reveal their concerns, and whether to give advice. The tension persists when field workers leave the field to write, forcing them to choose between competing interpretations and to decide what to reveal or conceal in the interests of confidentiality. Through these moral choices about what to ask, record or present to the reader, ethnographers shape the academic field even as it shapes them.

The work of Agar et al [8] reports work on heroin addiction illustrating how ethnography is essential to understanding the context of heroin use. It was the methodology of ethnography that enabled Borgois [9] to graphically describe life on the streets with heroin addicts. Simmons [10] used ethnography to examine the interactions between different health professionals. Savage’s thoughtful review of ethnography in health care [11] suggests that ethnographic techniques can shed new light on interactions within the context of the complex health care system. These studies were directly relevant to this thesis and suggested that the approach was appropriate. The ethnographic tradition also enabled the rich field data to be incorporated into the analysis and interpretation.

However, as the study progressed to the qualitative analysis of the patient and clinician interview data, it became clear that what was important was the patient’s or the clinician’s lived experience of chronic disease. The focus of the study became the lived experience of the patients rather than the group situation. Developing from Husserl’s philosophy, phenomenological psychology is concerned with an individual’s personal perception or account of an object or event as opposed to an attempt to produce an objective statement of the object or event itself [1]. Symbolic interactionism argues
that the meanings individuals ascribe to events should be of central concern to the social scientist, and also that those meanings are only obtained through a process of interpretation. It also considers that meanings occur (and are made sense of) in, and as a result of, social interactions.

This study used phenomenology, constructing and interpreting the lived experience of patients with chronic disease and their clinicians treating them in the hospital the emergency department, the wards and the chronic disease self-management and GP services.

The choice of phenomenology was justified by other reports in the literature of research into patient health issues. For example, Osborn and Smith [12, 13] studied patients with low back pain using interpretative phenomenological analysis to understand the patients' personal experience of their situation and their health. In addition, Wyer et al [14] used interpretative phenomenology to determine the factors affecting the patient's decision to attend a cardiac rehabilitation program. In these studies, the researchers drew on existing theories of behaviour to guide their research. Smith [15] recently reviewed the contribution of interpretative phenomenological studies and found that the "biggest specific area of research is the illness experience". This is in contrast to adopting a grounded approach which would allow for the development of a theory from the data. However, in the phenomenological approach it is necessary for the researcher to put aside preconceptions about what might influence patient behaviour to achieve a deeper level of understanding.

As the epistemology that underpins this study is one in which the meanings of the patients' and clinicians' attitudes and beliefs are constructed from the interview data, allowing meaning to be subjectively constructed from the data collected. This constructionist epistemology can be contrasted with a positivist epistemology, in which truth or meaning, how we know things, is uncovered and conceived of as existing without consciousness or experience. Constructionism has been described as:
“the view [that] all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context”[1].

The epistemology of constructionism also enables the untrammelled relationship between the researcher and the participants, the patients and clinicians.

Kvale [16] used two powerful metaphors to illustrate the difference between positivist and constructionist research: the miner who looks for ore to uncover the precious metals hidden within (positivism) and the traveller who travels around the world talking to people and interacting with them so that he can tell a story about them when he gets back home (constructionism). The original supposition was that people were frequent flyers because of specific personality traits which made them choose not to take up chronic disease self-management. The assumption was that their attitudes and beliefs made them resistant to chronic disease self-management. However, after talking to FRPs and clinicians and observing them in the context of the hospital, a different view of their attitudes and beliefs was constructed. Like the traveller in the analogy above, as the work progressed the story was constructed to fit what the FRPs and clinicians reported about living with chronic disease and taking up chronic disease self-management. The construction and interpretation of the reasons for frequent readmissions was influenced by my managerial background, but the patient and clinician stories were constructed and interpreted to give them new meaning. This study therefore can be seen as a constructionist approach.

This study also adopts the theoretical perspective of symbolic interpretivism. Symbolic interpretivism [1] has been described as the theoretical perspective which deals with how human beings exist in their world with language, communication, interrelationships and community. A researcher adopting symbolic interpretivism observes the attitudes and values of a community by putting himself or herself in the place of those being observed. In this research, the community is the hospital and the groups of interest are the patients and clinicians. The theoretical perspective
that provides the best fit with the research study is interpretivism because it is the view that the lived experience can be understood by studying what people think about, their feelings, and the meanings that are important to them. Under the interpretivism model, all knowledge is a matter of interpretation.

**Formulating the Research Questions**

This study was about a group of people who were frequently readmitted to hospital, often known as “frequent flyers” and referred to in this thesis as frequently readmitted patients (FRPs). There is some debate about the number of admissions in a year which constitutes “frequent”. The definition of three or more adopted in this study is in line with that proposed by Condelius [17]. Most hospitals report FRPs. The problem of FRPs is important because of the increasing demand for hospital beds and the escalating costs of delivering health services, particularly inpatient services. Hospital managers facing increasing throughputs are under pressure to clear beds to meet the demand of admissions from the emergency department. Evidence to support the safe diversion of a group of patients away from hospital services is a high priority. Moreover, the problem has now entered the public debate and hospital diversion is part of Commonwealth Government policy [18] and the Serious Chronic Care Program in NSW [19].

Knowledge of the patient characteristics associated with frequent readmission could be used to inform the design of interventions to prevent frequent readmissions where clinically appropriate. There is some evidence that chronic disease patients returning to hospital to manage the symptoms of their chronic disease because they believe their condition warrants hospital service [20-22]. Chronic obstructive pulmonary disease is the most common chronic disease implicated in frequent returns to hospital [23-27]. At this stage, there is little evidence about the proportion of chronic disease patients who present to hospital contrary to clinical advice [28].
Defining the study group

In preliminary discussions at the hospital when the study was being scoped, emergency department clinicians reported that a high proportion of FRPs had chronic diseases. This opinion was in line with published reports [29-32]. The Chronic Care Model, developed by Wagner and his team [33] describes system-wide aspects of caring for people with chronic disease. Chronic disease self-management, one component of the Chronic Care Model, is defined as the process by which people manage the symptoms of their disease, medications as well as other aspects of daily living. Under the Chronic Care Model, the major aim is to transform patients into active partners working with a proactive team of health professionals to manage their disease. There is strong evidence of the efficacy of chronic disease self-management [34] in improving health outcomes and decreasing hospitalisations due to chronic disease. Possible reasons for frequent readmissions include clinical need, patient perceived need, lack of access to alternative treatment services and preferences for services, such as GP services or chronic disease self-management services. It is likely that both patient and service related factors contribute to the reasons for frequent readmissions.

In addition to FRPs, two other frequent user groups identified in the literature were included for investigation: frequent attenders (FAs), who presented frequently to emergency, were discharged from emergency without the need for admission and patients who have an unplanned return visit within 28 days of discharge from emergency department (URVPs). The degree of overlap between the frequent user groups FRPs, FAs and URVPs was not investigated in this study. The number of unplanned return visits is a key performance indicator in NSW hospitals for monthly reporting to the Health Ministry because there is the possible association between URVPs and quality of care [35]. The research questions were developed to distinguish between the three groups of frequent users. This was considered an approach which would yield information directly applicable to the hospitals wishing to develop strategies to prevent emergency department overcrowding and avoidable admissions.
There is a second group of FRPs identified in discussions with emergency department clinicians at
the hospital with mental health and/or drug and alcohol problems. This opinion is in line with
published reports [32, 35]. Clinicians placed a high priority on developing solutions to divert this
group of patients away from the emergency department because of the violence related issues.
They also indicated that it would be difficult, and possibly unsafe, to interview them in hospital
without a clinician being present – not a practical option in this study. On that basis, mental health
and drug and alcohol patients were excluded from the study.

Data sources

The types of data accessed for analysis in this study were:

- De-identified patient data from the Emergency Department Information System (EDIS) were
  quantitatively analysed to derive patient factors which contributed to frequent usage.
- FRP, SMP and clinician interview data were qualitatively analysed to generate information
  on attitudes and beliefs relating to chronic disease self-management and service usage.
- Medical record data from FRPs and SMPs to ascertain admission history and co-morbidities.
- Additional patient data collected at interview from FRPs and SMPs from three short
  validated scales: the four question attachment style scale [36]; the three question sense of
  coherence scale [37] and the one-question self-rated health scale [38].

The ethical considerations in relation to consent to interviewing FRPs seemed at first to present
problems as these patients were sick, some of them very sick in hospital. Ethics committee approval
was contingent on the clinician’s agreement that it was safe to interview the patient and on the
initial approach to the patient being made by a known clinician.

The first two patients interviewed reported that they were happy to talk about their condition face-
to-face, but that they would not be confident about completing and returning a questionnaire
mailed to them at home. On this basis the option of using validated questionnaires and/or scales for
collecting more detailed patient information on the reason for frequent hospital use was ruled out. Instead, patients were interviewed and asked to consent to allowing access to their medical records for details on co-morbidities and clinical and admission history. It should be noted that the original plan to collect FRP data by questionnaire would have yielded very different results from interview data, because those patients likely to respond to a questionnaire would have been a different subgroup who felt more confident about responding to questionnaires. The findings would have reflected this bias.

Other questions about possible data sources arose in the early stages of thinking about the study. For instance, there is evidence from a study in Ireland that frequent hospital users are also frequent primary care users [39]. Linking patient hospital data with general practice data would have provided a comprehensive picture of patient service usage. However, the difficulty of data linking proved to be an insurmountable barrier to this line of research.

In line with the processes detailed by Punch [40], the research questions were developed by establishing the purpose of the study, then thinking about the detailed questions which would answer the questions. The process was iterative because a fit between questions and method was essential, rather than deciding on the first methods. The link between the questions and the method was predicated on the data available for analysis. In the end, the final iteration of the research questions was based on practical, ethical and feasibility considerations.

The key issues which lead to the research questions were: emergency department overcrowding, preventable presentations and admissions, and the patient and service factors leading to frequent hospital use. The aim of the research was to explore the reasons behind frequent hospital use by patients with chronic disease.
Research questions

The research questions were:

1. Can frequent hospital users be distinguished from the rest of the patient population on the basis of patient related factors in Emergency Department Information System data?
2. Are FRPs, FAs and URVPs distinct patient groups?
3. Are the attitudes and beliefs of FRPs about living with and managing chronic disease different from those of SMPs?
4. What do FRPs and SMPs report about adopting chronic disease self-management?
5. What do clinicians think are the reasons for frequent readmissions in chronic disease patients and chronic disease self-management uptake?
6. Do clinician skills and attitudes influence frequent readmissions and chronic disease self-management uptake?

The table below details the sections of the Discussion where the research questions are discussed.

Table 2. Summary of Discussion of Research Questions

<table>
<thead>
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<th>Research Question</th>
<th>Discussion Section, Page and Paragraph</th>
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<tr>
<td>1. Can frequent hospital users be distinguished from the rest of the patient population on the basis of patient related factors in Emergency Department Information System data?</td>
<td>Discussion pages 138-141: frequent hospital users can be distinguished from the rest of the patient population on the basis of patient related factors in the Emergency Department Information System data base.</td>
</tr>
<tr>
<td>2. Are FRPs, FAs and URVPs distinct patient groups?</td>
<td>Discussion pages 138-141: FRPS, FAs and URVPs are three distinct patient groups.</td>
</tr>
<tr>
<td>3. Are the attitudes and beliefs of FRPs about living with and managing chronic disease different from those of SMPs?</td>
<td>Discussion pages 141-145: there are clear differences between FRPs and SMPs attitudes and responses to chronic disease.</td>
</tr>
<tr>
<td>4. What do FRPs and SMPs report about adopting chronic disease self-management?</td>
<td>Discussion Pages 141-145: SMPS have an open relationship with their clinician(s); accept and own their condition; have an emotional response to their chronic disease; change their identity and take up self management. FRPs do not go through this process.</td>
</tr>
<tr>
<td>5. What do clinicians think are the reasons for frequent readmissions in chronic disease patients and chronic disease self-management uptake?</td>
<td>Discussion pages 145-148: hospital clinicians and GPs differ in their views on the reasons for readmissions in chronic disease patients.</td>
</tr>
<tr>
<td>6. Do clinician skills and attitudes influence frequent readmissions and chronic disease self-management uptake?</td>
<td>Discussion pages 145-148: chronic disease self-management clinicians have well developed skills in activating and supporting patients to self-manage.</td>
</tr>
</tbody>
</table>
Questions one and two were addressed by analysing the de-identified emergency department data from the Emergency Department Information System related to the patient characteristics. Analysis of emergency department data had the advantage of a large patient sample, thereby conferring increased precision in determining the influence of patient factors. The disadvantage is that the data items are designed to provide service information to health services, not to answer the research questions. In addition, emergency department diagnosis data can be inaccurate because diagnostic test details may not be available at the time of data entry. Lack of test results is particularly problematic in patients with co-morbidities.

Building a profile of FRPs, FAs and URVPs is a useful tool in the development of possible solutions to the issue of frequent hospital use. However, a profile of patient characteristics does not provide the complete picture of why people frequently use hospital services. The quantitative research findings were supplemented by qualitative research methods. Qualitative methods allowed for the direct collection of data from patients and clinicians to provide information on the “how” and “why” questions which provide information on the reasons underlying frequent hospital use. There are different ways in which the supplementary information could have been collected: by quantitative analysis of patient and clinician questionnaire data or by qualitative analysis of patient and clinician interview data. Questionnaires have the advantage of being able to reach a large sample so that the data can be subjected to precise quantitative analysis. A disadvantage is that pre-prepared questionnaires restrict flexibility in data collection without allowing for the subject’s views to emerge. In addition, the fact that FRPs had expressed reluctance about responding to a mailed questionnaire strongly influenced the decision to opt for interviews as a method of data collection to supplement the findings of the quantitative analysis of emergency department data. Interviews had the advantage of collecting more detailed and less constrained information on patient and clinician beliefs and attitudes influencing service choice and usage.
Interview data
Analysis of patient interview data enabled a comparison of the attitudes and beliefs between FRPs and SMPs. Patient interviews centred on living with chronic disease(s), service choice and access to services. Patient interview data answered questions three and four. Analysis of clinician interviews focused on what the clinicians thought and felt about FRPs, chronic disease self-management, patient service choices and access to services and the advice they gave to patients about returning to hospital. Clinician interview data addressed questions five and six.
**Summary**

In this chapter the influence of the researcher’s background as a health service manager on the research highlighted the preconceptions that the researcher brought to the study and how they changed during the course of the study. In this way, the possible bias of the researcher’s perspective was identified. The theoretical underpinnings of the study were discussed and justified to show the logical fit between the theoretical approach and the methods adopted. In particular, the translation from epistemology, through the theoretical perspective and the methodology to justify the methods adopted was detailed and discussed to demonstrate congruency. The processes by which the research questions were developed were identified in the context of the problem of frequent readmissions establishing the fit between the research questions and the data sources used in the study. The development of the definitions of the study group and the data sources were traced to ensure that the methods were consistent with the data sources. This chapter aimed to justify the underlying approach of the study.
The purpose of this chapter is to review the literature relating to the study and to determine the place of the study in the published research. The review is divided into the two fields of research which underpin the thesis: the factors associated with frequent hospital use and the factors influencing chronic disease self-management uptake. The chapter is structured to reflect the publications that are part of this thesis which fall into the two fields of research. The publications covering quantitative analysis of the factors associated with frequent hospital use are:


- Kirby, SE, Dennis, SM, Jayasinghe, UW, and Harris MF, Frequent emergency attenders: is there a better way? Australian Health Review, 2011Received 9 August 2010, accepted 16 February 2011, published online 14 October 2011.


The papers dealing with qualitative analysis of the factors influencing chronic disease self-management uptake are:


The chapter is divided into the following sections:

- Framework for conceptualising frequent hospital use
- Frequent attenders (FAs)
- Frequently readmitted patients (FRPs)
- Unplanned return visit patients (URVPs)
- The Chronic Care Model
- Chronic disease self-management – models, theories and factors relating to uptake.
- Summary

Each of the publications included in this thesis contains reviews of the literature relating to the focus of the individual papers. The purpose of this chapter is to provide an overview of the literature so that the contribution of the whole study can be seen. The journals accessed for the literature search are shown in Appendix A.
Framework for conceptualising frequent hospital use

Andersen's model of health service utilisation [41] provides a framework for thinking about the influences on patient service usage. The model, shown schematically in Figure 1 demonstrates that a range of factors influence service use.

Figure 1. Andersen's Model of Health Service Utilisation [41].

Health care system factors in the environment include factors such as availability of services, eligibility for services, fees and co-payments and health insurance. Other factors in the external environment include factors such as air pollution (of particular relevance in respiratory conditions), transport to health services, income and education levels. The model incorporates person/patient related factors which can be predisposing or enabling and involve need. Examples of predisposing factors are genetic susceptibility to disease and disadvantage. Enabling factors include awareness of risk factors, ability to understand health information and willingness to attend services. Need relates to clinical need for the service and need perceived by the patient (which may be different from clinical need). Health behaviours include personal health practices, such as taking medications, regular exercise, good nutrition habits, appropriate alcohol consumption, quitting smoking and weight loss. Health behaviours involve patient motivation and choice as well as knowledge and...
understanding. The model indicates that there are feedback loops between the environmental, personal, health behaviour and outcome factors.

The importance of the model is that it highlights the broad range of influences on patient health behaviour and service usage. The model predicts that patient behaviour and service usage are influenced not simply by patient related factors, but also other factors outside the direct control of the patient. In thinking about frequent hospital use therefore all these factors need to be taken into account. It might not be possible to directly examine the full range of factors, but the model provides a way of speculating on the influences on frequent service use, in this case, frequent hospital use. For example, working from the theoretical model, a patient with a need for services for chronic disease or minor health problems, may access hospital services rather than community services because of lack of access to or low availability of community non-hospital services. The underlying cause of frequent hospital usage may therefore be poor access or availability of services, lack of transport, low income or low education level. It can also be postulated that frequent hospital usage is related to lack of knowledge by the patient of community services or by a patient having more confidence in hospital services compared to community services. It might be related to patient lack of motivation to take up chronic disease self-management. Finally, frequent hospital use might be a direct consequence of clinical need.

In a recent comprehensive literature review, Nelson et al [42] pointed out that despite 30 years of research the reasons for frequent emergency department use are still not clear. They found that high emergency department users:

“often have high and complex health needs, engage extensively with other health services and have poor long-term health outcomes. The issue of multiple presentations to the ED is complex and ongoing because of the morbidity of the people concerned, the preference of patients to attend, the purpose of the ED and preparation and role of the personnel and the difficulties with continuity of care. The provision of care for people who present on multiple
occasions can be improved within the ED and health services generally through a better understanding of presentations."

This review highlights the complexity of the factors which influence that use and raises the important factor of patient preference in frequent emergency department use. The authors’ approach was to integrate the research findings on frequent emergency department usage in the context of the patient journey from the time of the decision to go to emergency department. The review identifies the gap in what is known about the reasons for frequent emergency department use from the patient’s perspective.

A recent retrospective study of emergency data in Melbourne, Australia [43] showed that the increase in presentation rates over the last 10 years was beyond that expected from demographic changes. The authors contended that existing models of emergency and primary care were failing to meet community needs at times of acute illness. It could be argued that the problem of meeting the increasing demand for services has reached a crisis point.

The descriptions of frequent emergency users include judgmental and colourful terms. As well as “inappropriate” re-attenders, patients are labelled with a range of usually derogatory names like “frequent flyers” [44-46], “boomerangs” [47], “bounce backs” [47] and even “recidivists” [23]. The terms used to describe frequent use may reflect negative attitudes of clinicians and service managers concerned about the increasing numbers of presentations. As many frequent emergency attenders are disadvantaged and vulnerable, the use of labels that imply deliberate overuse seems unfair [20]. Re-attendance might simply reflect need and/or lack of access to general practice services [21, 46] and other primary health care and social support services. It is impossible to ignore the influence of access to alternative services on frequent hospital use.

In summary, Andersen’s model provides a framework which helps to organise the thinking about the influences on frequent emergency department service use. These influences might be related to
patient factors, service availability and access and other health system and environment/community influences.

FREQUENT ATTENDERS (FAs)

Factors which influence frequent attendances at emergency department

Literature from around the developed world indicates that repeat attenders of inner city hospital emergency department services are predominately males from a disadvantaged background and of minority ethnic origin [39] (Ireland), present with psychiatric and alcohol problems [22] (UK), and overdose, minor injuries, alcohol intoxication and seizures, and a high proportion are single and homeless [48] (UK), [24, 49, 50] (USA). The feeder populations for inner metropolitan hospitals would be expected to have a relatively high proportion of homeless or disadvantaged people attracted to inner city locations because of public housing and cheaper accommodation. Hong et al [29] in the USA found that frequent attendances were associated with low socioeconomic status rather than race or ethnicity.

Factors other than access might involve patient perceptions, such as perceptions about the urgency of their condition and the perception that diagnostic tests would be required. Results from an Australian study supported the notion that emergency attenders thought they needed urgent care and diagnostic tests [28]. Swedish studies showed that frequent attenders had difficult lives and believed they needed urgent care [30], had a higher mortality, higher use of primary care, were sicker and more vulnerable [11] and had a lower quality of social network [12]. Lucas and Sandford [51] in the USA found that frequent attenders had access to other sources of primary care and that they used the emergency department for complaints they believed serious and those requiring immediate attention. The same authors also found that frequent attenders often had chronic complaints and were more likely to be admitted. Contradictory findings from the USA reported by Zuckerman et al [52] and Hunt et al [53] indicated that frequent attenders did not appear to use the emergency department as a substitute for primary care but were a less healthy population who needed and used more care overall. From these studies, access to primary care appears to be
important in frequent attendance. Chan and Ovens in Ontario, Canada [8] found three quarters of the patients who visited emergency departments 12 or more times a year also visited a family physician six or more times a year and that these patients received 73% of their primary care from their main family physicians. The link between access to primary care services and frequent emergency department use is by no means clear, and further work is needed before the relationship is fully clarified.

Reports in the literature confirm that older people tend to use emergency departments more frequently, possibly reflecting the incidence of chronic disease in the older age groups. Aminzadeh and Dalzeil [25], reviewing the literature on the reasons for high emergency department usage rates, reported that older people had more urgent conditions, longer stays in emergency, more admissions or repeat emergency department visits, and adverse health outcomes after discharge. Moreover, they reported that risk factors contributing to negative outcomes were age, functional impairment, recent hospitalisation or emergency department use, living alone, and lack of social support. However, results of studies of geriatric screening and discharge planning designed to improve outcomes in older emergency patients have proved inconclusive. Aminzadeh and Dalzeil expressed the view that current disease-oriented and episodic models of emergency care did not meet all the needs of frail older patients and that consideration should be given to the impact of co-morbidities. This line of reasoning is in accord with the Chronic Care Model [33] discussed in more detail later in this literature review.

The overlap of primary care and emergency department services has been the subject of debate in Australia because of emergency department overcrowding. The position of the Australasian College of Emergency Medicine [54] is that general practice and emergency patients differ markedly on the following:

- Reason for encounter.
- Diagnosis.
• Complexity (investigations, procedures and referral needs).

• Severity (admission rate of 35% compared to <1% in general practice).

On this basis, the College does not concur with the view that patients with less urgent conditions, that is, Triage categories of 4 and 5, are “inappropriate” presentations to emergency [55]. Instead it contends that these patients are often referred by general practitioners to the emergency department and that the presentations were appropriate. Dent et al [56], in an Australian study, reported that FAs were not suitable for general practice services because patients in the lower Triage categories often have illnesses that prove to be fatal. In a recent review in the USA, De Lia and Cantor [50] enumerated the causes of emergency overcrowding as bottlenecks across the system, from lack of beds leading to patient “boarding” in emergency and poor management of patient flows, lack of clinical staff, and the growing burden of mental health patients. They contended, like the Australasian College of Emergency Medicine, that non-urgent emergency use and Medicaid and uninsured patients did not account for emergency overcrowding. They also reported, as did Masso et al in Australia [28], a mismatch between patient and clinician perceptions of urgency.

Evidence from Italy, Taiwan and Australia [28, 57-59] indicates that that a proportion of the non-urgent use of emergency department services can be attributed to chronic disease patients self-assessing their condition as requiring emergency treatment. These findings are relevant to the study which is the subject of this thesis because FRPs could be self-assessing their condition as requiring hospital services. Another reason cited in the literature for non-urgent emergency department use is that patients felt that they would be unable to get an appointment with their GP (USA) [50, 60].

In summary, the reasons for frequent attendances at emergency department are often not related to patient need. These factors include such as ethnicity, disadvantage, patient preference and patient expectations. The range of factors was predicted by Andersen’s model of health service utilisation.
**Interventions to reduce frequent attenders**

The interventions employed to address the frequent attender problem are many and diverse. In an Australian study in Queensland, Hegney *et al* [61] reported evidence for the effectiveness of specialist community nurses undertaking risk screening in reducing re-presentations of older people. In NSW, the focus has been on fast tracking and streaming patients within emergency, with a range of strategies such as Emergency Medical Units which concentrate on medical stabilisation of older patients, multidisciplinary aged care assessment teams which address medical, mobility and social issues [62], and hospital-in-the-home options which include geriatric assessments [63]. These strategies have shown some success in moving older patients with chronic disease out of emergency department more quickly. O’Connell [62] suggested that by improving uptake of chronic disease self-management services, the number of FAs would be decreased. However, the suggestion was based on preliminary evaluation of services rather than randomised control trials. In NSW the Connecting Care Program for Severe Chronic Disease Management [64] has been introduced which aims to address the issue of long waiting times for chronic disease self-management services and offers care coordination.

**FREQUENTLY READMITTED PATIENTS (FRPs)**

**Factors which influence frequent readmissions**

Most of the literature concentrates on readmissions from the viewpoint of clinical parameters in a single chronic disease. Many of the studies describe the success of clinical interventions designed to reduce readmissions. Findings from literature referring to a single disease entity are included here because the factors or issues identified as important may be applicable to readmissions in chronic disease generally.

As with FAs, the problem of FRPs was also related to a range of access and system factors. Muecke [65] in a review of Australian data from NSW and Victoria reported that frequent hospitalisations for Ambulatory Care Sensitive conditions, which might be amenable to treatment outside hospitals, were associated with complications of diabetes, remoteness, and disadvantage.
A 2002 review of studies in Europe and the USA [66] found that countries with shorter hospital stays had higher readmission rates. The authors postulated that differences in factors such as managed care penetration, after-care by GPs, or home care made the differences in length of stay and readmission rates. The problem of early discharge as a contributing factor in readmission was reported by Dobrzanska and Newell [67] in older people. These findings identify system issues as influencing frequent hospitalisations.

Both severity of illness and age have been found to be a contributing factors in repeated hospitalisations. Severity of illness is a need factor. Because older people tend to have chronic illness, age can also be seen as a need factor. Early research by Burns and Nichols [68] in 1991 indicated that chronically ill patients who were severely ill at index admission, with several hospitalisations in the preceding year were at high risk of readmission. There is strong evidence for the proposition that older people [17, 69] with more severe illness, more co-morbidities, less social support, needing help with activities of daily living [70], lower quality of life [70], disadvantaged [71] and [29], and longer length of hospital stay at the index admission are more likely to be readmitted [72]. The burden of the older chronic disease patients on the health care system is great, with frequent readmissions in the 65-year plus group making up around one third of all admissions and having frequent contacts in outpatient care [17]. The association between readmissions and poorer social support has been found by a number of studies [73] and [74].

Other demographic factors apart from illness severity and age contribute to repeated hospitalisations. Quality of life was found to be a strong predictor of readmissions in chronic heart failure patients [75].

Smith et al [76] found that the risk of readmission was increased in patients with more admissions and emergency visits in the prior 6 months, lower mental health function, a diagnosis of chronic obstructive pulmonary disease, and increased satisfaction with access to emergency care assessed on the index admission. Patient satisfaction with access to emergency [76] was found to be a predictive factor in readmissions. There is no information in the published literature comparing
frequent readmissions between different chronic diseases, such as chronic obstructive pulmonary disease, diabetes and chronic heart failure.

The application of the findings of factors associated with readmission has been demonstrated in various reports of risk assessment tools and algorithms. However, the value of these in predicting readmissions has been questioned by some researchers. Roland et al [77] pointed out that there was no information from matched control studies to identify suitable interventions to prevent readmissions in high risk patients. Howell et al [78] in an Australian study reported that an algorithm developed to identify patients at risk of readmission was moderately successful. In their study the factors found to be associated with readmission were age, co-morbidities, economic disadvantage and the number of previous admissions. Other tools, the Identification of Seniors at Risk (ISAR), in a multicentre study in the US [79], and Silver Code [80], in Italy, for assessing risk of readmission, especially in older patients, have been used with success. On the basis that co-morbidity and prior admissions predicted readmissions, Moloney, Bennett and Silke [81] suggested further exploration of interventions to identify and prevent patients at high risk for hospital readmission. A checklist developed for preventing readmissions in veterans' hospitals in the USA, reported by Oddone et al [82], indicated that patient-related factors accounted for about 20% of readmissions and clinician and hospital system factors 40% each. In a recent Australian study, Longman et al [83] argued that there has been little work on hospital admission as an outcome measure and that the current evidence is insufficient to propose any specific intervention to reduce avoidable admissions. In NSW the Connecting Care Program for patients with severe chronic disease [84] has been introduced to identify patients who are readmitted and to develop solutions to reduce hospital readmissions where possible. Longman et al also contended that more qualitative research is needed to evaluate the effectiveness of interventions to reduce readmissions.

All hospitals would benefit from being able to assess risk of readmissions in their patient population to develop appropriate solutions. In general, reports in the literature indicate that frequent readmissions are associated with a range of access and system factors as well as patient factors such
as severity of illness, age, quality of life, level of co-morbidity, social support, more serious illness and ethnicity/disadvantage. Many chronic diseases are associated with frequent readmissions, including chronic heart failure, diabetes, chronic obstructive pulmonary disease, stroke and asthma.

**Interventions for frequently readmitted patients**

Vest *et al* [85], in a 2010 review of interventions to prevent readmissions, warned that definitional variations and methodological differences limit translation of research findings into guidance for health organizations. Likewise, in a 2001 review of readmissions, Hasan [86] contended that the reasons for readmissions were still poorly understood, pointing to the need for clearer definitions and further research using agreed methodologies.

The interventions which have been reported to reduce readmissions are listed below.

- Geriatric assessment and multidisciplinary intervention after an emergency visit, reported by Caplan *et al* in Australia [87].

- Individualized exercise program and long-term telephone follow-up in Australia; this reduced emergency use and improved quality of life of older adults at risk of hospital readmission [88].

- Intermediate care at a community hospital which decreased readmissions for the same disease to a general hospital [89].

- A six-month, multidisciplinary approach to chronic heart failure management which improved clinical outcomes at a similar cost in recently hospitalized high-risk patients (Kasper *et al* [90])

- Multidisciplinary community-based intervention in chronic heart failure patients in Singapore which reduced hospitalisations [91] and team-based interventions in heart failure patients [92].

- Telehealth interventions in chronic disease patients [93].
• Clinical review of the decision for discharge, and improving clinical care and enhancing patient knowledge of the early warning signs for relapse in the public hospital system in Hong Kong [94].

• Interventions such as patient education and the development of asthma plans in asthma patients [34, 95].

• Patient-focused care, which included an education component to promote greater self-management adherence and delivered a continuum of care through the acute and community health sectors for chronic heart failure patients in Australia (Bird et al [96]).

The relative benefits and proof for efficacy of discharge programs and intervention models have been the subject of some debate. Kee and Borchers [97] argued that more research on these interventions is needed to test efficacy. Roland et al [77] pointed to the need for randomized controlled trials to determine the effectiveness of interventions designed to prevent readmissions, because high patient mortality cast doubt on preliminary intervention findings. Steeman et al found that discharge planning intervention did not significantly alter readmission rates in geriatric patients [98].

Several interventions have been effective in reducing readmissions. Caution in the comparison and interpretation of results across hospitals must be applied, however, because of the range of settings, patient conditions, models of care and providers. The strategies need to be tailored to the patient population and the access and system features in the hospital. The focus has been on comprehensive assessment of the needs of older patients as this group forms the bulk of potentially preventable readmissions.
UNPLANNED RETURN VISIT PATIENTS (URVPs)

Factors which influence unplanned return visits
Because unplanned return visits to hospital are generally acknowledged as indicators of possible treatment failures, there has been considerable interest in preventing them [99]. Heggestad and Lilleeng [100] stressed that the time between the reference visit and the unplanned return was of the utmost importance in comparing the reasons for unplanned return visits between hospitals. The longer the time, the greater the number of patients returning as unplanned return visits. Individual hospitals stand to benefit from analysis of their unplanned return visits to determine the solutions to the problem.

The literature on unplanned return visits shows that they are associated with medical errors [32], older age [101], chronic disease [31, 102], chronic mental illness [35], low acuity conditions [103] including follow-up care [32] and poor physical and mental health [101], painful conditions [23], lack of health information and advice [32], income below the poverty line [27] and discharge to nursing home with dementia and chronic obstructive pulmonary disease [104]. One study in the USA reported that age was not associated with unplanned return visits [23]. An Australian study reported that unplanned return visits were more likely to occur in late winter and early spring and on Fridays [102].

Interventions for reducing unplanned return visits
As with frequent attendances and frequent readmissions, many of the solutions are related to access and the range of alternative services available. Australian studies by Montalto et al [105, 106] reported a reasonable success rate in reducing unplanned return visits using hospital-in-the-home interventions. Cardin et al [107] in the USA found that increasing physician coverage, designating physician coordinators and streamlining diagnostics reduced unplanned return visits. In another study in the USA, Jencks et al [108] reported that one fifth of presentations were unplanned return visits. For half the patients who were re-hospitalised within 30 days after a medical discharge there was no visit to a physician's office, and three quarters of patients who were re-hospitalized within 30
days after a surgical discharge were re-hospitalized for a medical condition. They concluded that
return visits were costly and preventable. Stronger patient advice about follow-up visits in the
community after discharge might reduce the rate of unplanned return visits. It is possible that access
to community medical care is the problem.

Table 3 summarises the literature on frequent hospital users. The summary of findings from the
literature shows the conflicting results, particularly in demographic factors. It also shows the
similarities and differences in the factors reported. It is important to note that there is little evidence
in the literature on access and attitudinal factors across all frequent user categories.
<table>
<thead>
<tr>
<th>Frequent user type</th>
<th>Demographic</th>
<th>Clinical</th>
<th>Access</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Frequent attender</strong></td>
<td>Male (9); minority ethnic (9); single male (36); homeless (36); low socio-economic (40); older age (46); living alone (46); poorer social networks (12, 46); more vulnerable (11);</td>
<td>Psychiatric (35); alcohol (35, 36); overdose (36); seizures (36); higher mortality (42); sicker (11); chronic complaints (43, 41, 50-52); less healthy (44, 45); longer emergency stays (46); more admissions (46); poorer outcomes on discharge (46); functional impairment (46); recent hospitalisation (46)</td>
<td>Frequent access to other primary care (43, 8); other primary care not used (44, 45); unable to access GP (39, 53)</td>
<td>Belief that condition required urgent treatment (41, 42, 43); belief diagnostic tests required (42); higher use of primary care (11);</td>
</tr>
<tr>
<td><strong>Frequent re-admissions</strong></td>
<td>Remoteness (58); disadvantage (58); old age (1, 62); less social support (63, 66, 67); lower quality of life (63, 68); disadvantaged (29, 64, 70)</td>
<td>Ambulatory Care Sensitive conditions (58); diabetes (58); shorter hospital stays (59); early discharge in older patients (60); longer hospital stays (65); severely ill (1, 61, 62); several hospitalisations in previous year (61, 69, 70); co-morbidities (63, 70, 71, 72); lower activities of daily living (63); frequent outpatient use (1); lower mental health function (69); chronic obstructive pulmonary disease (69)</td>
<td></td>
<td>Increased satisfaction with access to emergency department services (69)</td>
</tr>
<tr>
<td><strong>Unplanned return visits patients</strong></td>
<td>Older age (95); income below poverty line (100); not associated with old age (32)</td>
<td>chronic disease (98, 95); chronic mental disease (98, 95); low acuity conditions (99); follow-up care (94); painful conditions (32); discharge to nursing home (101); chronic obstructive pulmonary disease (101)</td>
<td>Late Winter and early Spring and Fridays (96)</td>
<td>Medical errors (94); lack of health information and advice (94)</td>
</tr>
</tbody>
</table>
In summary, there is less evidence about the factors influencing unplanned return visits than about frequent readmissions and frequent attendances. Individual hospitals would benefit from identifying the characteristics of frequent users so that solutions applicable to their hospital can be devised. The solutions are likely to depend on a range of environmental, access, clinical and patient factors. There is a paucity of literature reporting studies of frequent users from the patient’s perspective to supplement the quantitative studies which produce profiles of patients at high risk of frequent emergency use. Qualitative research will contribute to unravelling the reasons for frequent use, particularly patient preferences and access issues.

**Chronic disease self-management**

Chronic disease self-management is important in a study on patients who use emergency department services frequently because the literature has shown that one of the reasons for frequent use is chronic disease [29, 30, 58, 75, 109]. The starting point for understanding chronic disease self-management is the Chronic Care Model put forward by Wagner and associates [33]. The Chronic Care Model describes the relationships between the factors which come into play for people living with chronic disease. Like Andersen’s model of health service utilisation, the Chronic Care Model incorporates health system and community factors which influence chronic care. The expanded Chronic Care Model is presented schematically in Figure 2.
Both Andersen’s model of health service utilisation [41, 111] and Wagner’s Chronic Care Model [33, 112, 113] incorporate a whole-of-system approach, encompassing patient- and clinician-related factors, factors related to access and external factors in the community. The difference between the two models germane to this study is in the specification of “productive interactions and relationships” depicted in the lower segment of the Chronic Care Model. These relationships are important in achieving population health, functional and clinical outcomes. The qualitative component of this study concentrated on these relationships between chronic disease patients and clinicians and on the activation for uptake of self-management. Chronic disease self-management is a component of the Chronic Care Model in which the productive interactions and relationships assume a crucial role.
The Australian National Health Disease Strategy, Chronic Disease Strategy [18] defined self-management as “the active participation by people in their own healthcare” and identified the elements incorporated in self-management as the following:

- Health promotion and risk reduction;
- Informed decision making;
- Following care plans;
- Medication management and
- Working with health care providers to attain the best possible care and to effectively negotiate the often complex health system.

This definition involves the patient in a series of complicated actions which require help and support from clinicians. For self-management to be successful, patients need to maintain motivation throughout the course of their chronic disease. It involves all levels of health care, but in particular, it requires both the patient and the clinician to take action – as depicted in productive interactions and relationships in the expanded Chronic Care Model (lower segment) which involve “informed and activated patients” and “prepared and proactive practice teams”. Wagner et al [113] described the relationship between patients and health professional teams in the following way:

“Interactions are more likely to be productive if patients are active, informed participants in their care. Patients must have the information, skills, and confidence to make best use of their involvement with their practice team. On the other side of the interaction, practice teams must have the necessary expertise, relevant patient information, time, and resources to act, rather than just react, to ensure effective clinical and behavioral management.”

There is evidence from Lorig’s work that chronic disease self-management programs result in improvements in such health outcomes as self-rated health, disability, social and role activities limitations, energy/fatigue, distress with health state and clinical/physiological signs [34] and [114]. However, evidence for sustained improvements for periods of over six months after the chronic
disease self-management intervention is lacking [114]. Norris and associates [115, 116] reported in a systematic review of patient education in type 2 diabetes that the impact of the intervention decreases within one to three months. The research focus to date has been on patients living with a single chronic disease, consequently, there is little evidence for the efficacy of chronic disease self-management programs for patients living with multiple chronic diseases [117].

It has been estimated that chronic disease self-management programs lead to a small but significant decrease in the average number of days in hospital in the prior six months and a trend towards fewer outpatient and emergency visits [118]. This report of decreased emergency department visits has direct bearing on the research which is the subject of this thesis.

Achieving the active participation of patients has proved difficult [18, 119] as most people offered chronic disease self-management programs do not take them up, women being the most frequent adopters, and drop-out rates are high. Improvements in chronic disease self-management uptake rates require an understanding of the factors that enhance and reduce uptake and why some people choose to self-manage when others do not. It has been acknowledged [113, 116, 120] that a shift in focus from teaching patients about their disease and its treatment to working on improving their confidence and skills in managing and living with their chronic disease is needed in improvements in chronic disease self-management, as pointed out in the quote from Wagner et al [113] on page 33.

Patient activation involves patients being able to self-manage and to achieve positive functional and clinical outcomes, such as reduced emergency department visits and readmissions. Hibbard et al [121] define activated patients as those individuals who believe they have an important role in their own health and health care and have the knowledge, skills, confidence, and emotional commitment to perform this role. Hibbard’s team developed the Patient Activation Measure as a tool for measuring the level of patient activation [122] for self-management. A study undertaken in Queensland, Australia, on hospital admissions and activation for self-management in people with diabetes [123] showed that patient activation, as measured by the Patient Activation Measure, was
directly linked to hospital utilisation as patients with a high activation score were less likely to present to hospital after controlling for disease severity and co-morbid depression.

In summary, the expanded Chronic Care Model shows the relationship between external factors, such as resources and policies operating in the community, and health system factors, and their influence on chronic disease self-management. The model emphasises the role of the relationships between activated patients and clinicians and provides the basis for the qualitative part of this study. There is evidence that chronic disease self-management programs are effective in achieving functional and clinical outcomes, including reduction of emergency department visits, for some chronic diseases. Furthermore, there is evidence that more highly activated patients are less likely to use hospital services for chronic disease self-management.

**Patient Attitudes and Beliefs in Activation for Chronic Disease Self-Management**

The process by which patients react to living with a chronic disease and the part this reaction plays in the uptake of chronic disease self-management is still unclear. However, patient attitudes and beliefs shape their reaction to chronic disease and determine the behaviours they adopt in living with their chronic disease. The review of Becker and Maiman [124] in 1975 identified that the emphasis of previous research was directed at investigating factors responsible for poor patient compliance with recommended health behaviours, with the focus on easily measured characteristics of the patient, treatment regimen, or illness. Their review indicated that patient compliance with recommended health behaviours also depended on patient social and psychological variables:

> *certain health beliefs (especially personal estimates of vulnerability to, and seriousness of, the disease, and faith in the efficacy of care) health related motivations, perceptions of psychological and other costs of the recommended action, various aspects of the doctor/patient relationship, and social influence are the most productive dimensions for present intervention and further exploration.*
Thus, how chronic disease is perceived by patients play a part in the action and the health seeking behaviours they adopt. Patients who perceive the threat imposed by their illness, have knowledge of and respond to symptoms are more likely choose health seeking behaviours, such as chronic disease self-management. Perceived threat, knowledge of and responding to symptoms can be seen as factors which motivate people to adopt self-management and reduce presentations to hospital.

Aizen proposed that patients who believed that a change in health behaviour is effective [125] were more likely to adopt the health behaviour. Patients who have the belief that self-management will help them in living with their chronic disease will therefore be more likely to be amenable to self-management. Thus, to take up chronic disease self-management, patients need to know about their disease, to take it seriously and understand the threat, and to believe the health behaviour will help them.

**Self Efficacy**

Self-efficacy is a concept which is critical in understanding patient chronic disease self-management. Bandura, in his work on self-efficacy, showed that people who had confidence in their own ability to act [126] were more likely to adopt healthy behaviours. Patients might have an understanding of the threat of their disease, knowledge of the disease and the belief that self-management will help them to live with their chronic disease but might lack the confidence that they can carry out the components of self-management. Patients with the confidence in their ability to self-manage are more likely to adopt self-management.

**Self Regulation**

Leventhal’s model of self regulation introduced the concept of constant self-appraisal of progress in managing thoughts and feelings about chronic diseases as influencing chronic disease self-management [127]. Life with chronic disease is constantly changing as events unfold and new symptoms emerge. Using Leventhal’s self-regulation theory, patients need to be able to keep monitoring their response to their disease including their strategies to deal with the disease, their medications, their behaviours and their thoughts and feelings to maintain self-management.
Agency and Identity

Bury [128] invoked sociological concepts of agency and identity when presenting the argument that individuals with chronic conditions are agents who are not simply defined by the context of their lives but take an active role, making choices in their future. The concept of agency or making a choice about future actions and behaviours fits with the notion of activated patients. Patients with stronger agency, or more activated patients, are those who are more able to self-manage their chronic disease. Work by Charmaz [129] on self-worth for those with chronic disease and by Corbin and Strauss [130] on the meaning of illness have added substantially to our understanding of living with chronic illness, by identifying the importance of personal agency and pointing also to the role of identity. Charmaz demonstrated that living with chronic illness disrupts a person's biography, with a consequent change in self-identity. Chronic disease patients undergo a process of changing their identity from a well person to become a person living with a chronic disease. Sociological models tell us that people's ability to act, their agency, and how they define themselves, their identity, are important in how they live with and manage their chronic disease management.

Linking the psychological and sociological issues helps to understand the factors leading to self-management. Self-efficacy and agency are strongly implicated in the adoption of self-management. People need self-efficacy, a belief that they can self-manage, and agency, the capacity to act independently and make choices to self-manage. Chronic disease patients also need to be able to deal with their thoughts and feelings throughout the course of their disease.

A recent Australian study on the motivational factors influencing chronic disease patients to take up chronic disease self-management [131] indicated that internal factors include desire to optimise health, independence and wellness and to avoid loss of function. This study also identified external drivers for chronic disease self-management uptake as being positive interactions with family, carers and health professionals. Understanding the motivation behind chronic disease self-management uptake is necessary to improve uptake.
Other Patient related factors
In addition to the patient related factors which were highlighted by the psychological and sociological approaches outlined above, there are other patient related factors which might be implicated in whether patients take up self-management. These factors are derived from measuring how people understand their world and relate to other people. Sense of coherence, a conceptual approach which incorporates the three factors of comprehensibility, manageability and meaningfulness, measures how individuals cope with stressors on the health/illness spectrum [132]. A weak sense of coherence is associated with higher morbidity and a higher long-term sickness rate. Evidence from general practice studies indicates that people with a strong sense of coherence are more likely to adopt healthy lifestyle choices [133]. In another study in general practice, Bergh et al [134] reported that sense of coherence was weaker among frequent general practice attenders. Patients who self-manage, therefore, would be expected to have a stronger sense of coherence than FRPs. Attachment style may also be relevant to chronic disease self-management because there is evidence that people with a more secure attachment style are able to better self-manage chronic diseases like diabetes [135-137] and pain [138]. There is evidence that self-rated health is a reasonable indication of a person’s clinical health [38, 139]. The correlation between self-rated health and clinical status could shed light on patient attitudes and beliefs about chronic disease.

The Chronic Care Model specifies that patient related factors must be seen in the context of the patient’s family and community [140]. Experience from work with the Aboriginal community in the Eyre Peninsular in South Australia [141] indicate that:

“regardless of the health care provider involved, support for the person with chronic disease requires the adoption of a respectful, collaborative and client-centred approach that utilises a range of motivational, communication and support skills.”

Moreover, those patients in Aboriginal communities who took responsibility for dealing with problems of family members were less likely to be able to engage in self-management because of
the complexity of their lives. Successful chronic disease self-management programs therefore need to incorporate these wider approaches to include family and community.

Although there is evidence for drawing up a patient profile for those patients who are more likely to self-manage and, therefore, less likely to over-utilise hospital services for chronic disease, there is still little known about how to encourage patients to become activated self-manage and to self-manage. Patient attitudes and beliefs are influenced by people close to patients, such as family, carers, friends and clinicians. The influence of clinicians on chronic disease self-management uptake is therefore worthy of study.

**Clinician factors important in Activation for Chronic Disease Self-Management**

There is evidence that structured self-management and behavioural change programs improve outcomes in a range of chronic diseases and that interventions are effective by class, one-on-one counselling, or computer program modalities (Wagner *et al* [33]). The literature on the Chronic Care model points to the ability of clinicians to identify and respond to the individual needs and priorities of patients as critical to the success of chronic disease self-management, as is helping patients to become more active participants in their care [33].

The implementation of chronic disease self-management across Australia was the focus of a supplement of the Medical Journal of Australia in 2008 [142] and provided valuable information of avenues for further studies in Australia. Glasgow *et al* [143], in the same supplement, pointed out that the input of both educators and psychologists would be helpful in developing chronic disease self-management programs which encouraged and supported patient autonomy.

In their 2001 paper on translating evidence into action, Wagner *et al* [113] identified key elements of chronic disease self-management:
We assume that every chronically ill person has a primary care practice team that organizes and coordinates their care. Whether led by a generalist physician, a nurse practitioner, or a medical subspecialist, this team tries to optimize patient outcomes through a series of interactions during which they (1) elicit and review data concerning patients’ perspectives and other critical information about the course and management of the condition(s); (2) help patients to set goals and solve problems for improved self-management; (3) apply clinical and behavioral interventions that prevent complications and optimize disease control and patient well-being; and (4) ensure continuous follow-up.

Patients often experience difficulty in navigating their way to the right service through a complex system of options and barriers. Linkages between services in primary health care and between hospital services and primary health care are therefore important in the success of chronic disease self-management, particularly for disadvantaged patients who experience more difficulty in accessing services [144, 145]. Linkages are depicted schematically in the Chronic Care Model in the community, health system and outcomes components. Williams et al [146] identified that a major problem in the area of chronic disease self-management is the lack of effective linkages between chronic disease self-management services and the primary health care sector. Indeed, GPs are often unaware of the other services being accessed by their patients. Most patients are not able to take responsibility for the oversight of communication between clinicians caring for people with chronic disease. Effective communication is imperative if chronic disease self-management is to succeed.

Self-management, in addition to addressing the patient’s condition and treatment, must fit with the lifestyle and social circumstances of the patient, their family and carer(s) and take account of the health care they are receiving [144]. It is not surprising that the patient’s lifestyle, social circumstances and health care are often overlooked, particularly in the hospital environment, where
the focus is on clinical treatment. Chronic disease self-management support as requiring a set of clinician skills which include

“providing information about the medical condition and treatment, giving broader education to build health literacy, developing the skills the person needs to monitor and manage their condition and providing support and encouragement” [144].

In successful chronic disease self-management programs, the clinician activates the patient to have the confidence to self-manage [147]. This emphasis is a central feature of the chronic disease self-management program in the USA [148] and Expert Patient Program in the UK [149]. Although patient activation is of critical importance in chronic disease self-management, the corresponding investment in developing the clinician skills necessary for activation to occur has not been made. The literature on the impact of clinician attitudes on chronic disease self-management uptake indicate that health professionals’ attitudes and understanding about how patients respond to living with chronic disease play an important part in whether patients self-manage [150-152]. Deficits in training and support for health professionals have been identified as barriers in the UK [153, 154], as have lack of skills in dealing with judgmental attitudes about patients who do not self-manage. Weeks et al [155] indicated that some health professionals were slow to embrace chronic disease self-management and to develop care plans. Guiciardi et al [156] found that health professionals needed to promote on-going patient use of chronic disease self-management services for the most effective results. Most of the work has been carried out in general practice rather than in the hospital system. The underlying paradigm of the health professionals involved in these studies was the medical model, and this was identified in the UK as a major barrier to moving to a patient-centred approach [153, 157-159]. Rogers et al [160] found that physicians in the UK tended to equate chronic disease self-management with compliance with medical instructions, and the way in which outpatients’ clinics were organized. Clinicians indicated that another barrier was their insufficient knowledge about chronic disease self-management services [154].
There is evidence in the literature that the clinician skills necessary for patient activation relate to moving away from the didactic role of patient education towards a role which encourages and supports patients to take charge of their own health and health care.

The literature highlights factors which play a part in the lack of chronic disease self-management uptake by chronic disease patients which include:

- Patient attitudes, beliefs, knowledge and understanding of chronic disease and chronic disease self-management.
- Access, particularly access to primary care and GP services.
- Clinicians' knowledge of and skills in
  - chronic disease self-management services,
  - the ability to identify and respond to the individual needs and priorities of patients, and
  - the ability to help patients to become more active participants in their care.
- Clinician role.
- Dominant paradigm of clinicians.

Although no previous reports comparing FRPs with SMPs appear in the literature, Longman et al [83] highlight the importance of studies of frequent and avoidable hospital users:

“There has been less research on the antecedents of frequent and/or avoidable admission from the perspectives of patients or those offering community based care and support for these patients.”
Summary

The review of the literature on frequent hospital use indicated that there are a range of patient clinical and personal factors and access factors which influence frequent hospital use. However, the studies have focussed on listing factors associated with frequent use. Consequently, there has been little exploration of the reasons for frequent use. The information on patient factors has been used with limited success in building patient profiles for individual hospitals to prevent frequent use where possible. The literature on chronic disease self-management shows that although there is strong evidence that patient activation by proactive clinicians and self-efficacy are important in chronic disease self-management, there are still gaps in our understanding of the reasons behind lack of chronic disease self-management uptake. The review of the literature yielded no published reports comparing FRPs with SMPs. This study exploring the reasons behind frequent readmissions was designed to fill the gap.
Overview of the chapter
The purpose of this chapter is to detail the methods employed in the studies and to link the research questions to the data collected, study phases and the publications. The chapter shows how the overall study was constructed and performed.

The chapter is divided into the following sections:

- Study environment
- Quantitative methods
  - Population
  - Sample
  - Data collection
  - Analysis
- Qualitative methods
- Integration of methods
- Summary
The study environment

The study was based at a 150-bed publicly funded regional hospital in an urban coastal area in south eastern NSW, Australia. The hospital website[161] describes the hospital’s role as:

“[Name] Hospital provides acute care, emergency, specialist surgical, medical and mental health services as well as a satellite dialysis unit. The hospital provides a lead role in the provision of family midwifery services together with gynaecological, breast, laparoscopic and ophthalmic services for the southern Illawarra.”

The service environment is a relatively low socio-economic [162] population with a paucity of general practitioners [163] and poor public transport services [164]. The feeder population is around 100,000 people. However, as there is a major referral hospital within 20 minutes drive, there are a considerable number of patient transfers between the hospitals depending on the bed availability and the patient’s condition.

Quantitative methods

The quantitative methods described here are also detailed in each of the three quantitative publications:

- Kirby, SE, Dennis, SM, Jayasinghe, UW, and Harris, MF. Frequent emergency attenders: is there a better way? Australian Health Review, 2011, 35(4) 462-467 and
- Kirby, SE, Dennis, SM, Jayasinghe, UW, and Harris, MF. Unplanned return visits to emergency in a regional hospital accepted Australian Health Review, August 2012.
The research questions (as developed in the chapter "Conceiving the study") to be answered by quantitative analysis were:

- Can frequent hospital users be distinguished from the rest of the patient population on the basis of patient related factors in Emergency Department Information System data?
- Are there distinct patient characteristics of FRPs, FAs and URVPs that can be identified from the Emergency Department Information System data?

**Population**
The study population for the quantitative component was the population of patients presenting to the emergency department at the hospital in one year.

**Sample**
The sample was the de-identified patient data for one year, 2008.

**Data Collection**
De-identified presentation data from the Emergency Department Information System were made available as Microsoft Office Excel files. About 20,000 patients presented to the emergency department each year. The data containing information on every presentation to the hospital emergency department for the year 2008 was extracted from the data files. The information consisted of personal demographic, service utilisation and clinical information linked to the unique patient identifier number. Patients who presented more than once in the year were able to be identified from the patient identifier number.

**Analysis**

**Independent Variables**
The original variables from the Emergency Department Information System data were: patient identifier number, age, gender, date and time of arrival, country of birth, International Classification of Diagnoses (ICD) 9 diagnosis, level of urgency based on the five categories of the Australian Triage Classification [50], type of visit and mode of separation (treated in emergency or admitted). Type of
visit is a local code referring to the type of emergency presentation: normal, planned return and unplanned return within 28 days of the original presentation. Each patient presentation was accorded one primary ICD 9 diagnosis based on the major reason for the presentation. Date and time of arrival variables were converted into hour, day and season of arrival. Preliminary univariate analysis, using non-parametric tests, was performed on the frequencies of presentations for the variables for which there were different or potentially different, values for each presentation: hour, day and season of arrival; urgency (derived from Triage category); unplanned return visit and diagnosis.

Presenting patients judged to have conditions warranting admissions may be either admitted to the study hospital or to another hospital in the network if the bed supply is inadequate. All admissions, including those for which patients were placed in a bed in another hospital, were included in the sample. The number of admissions variable was obtained by separating the presentations for patients admitted, converting to the row-for-each-patient format and merging the admissions variable in the main file.

**Primary outcome variables**

The data files were transformed so that the variables related to the patient, rather than the presentation. The primary outcome variable was a binary variable, with the two variables set at patients with less than three admissions in the year and patients with three or more admissions in the year. The cut-off point of three admissions was set as denoting “frequent” readmissions. The primary outcome variable for the frequent attenders study was set at a cut-off point of patients with four or more presentations in the year. For the unplanned return visits study, the primary binary outcome variable was patients with unplanned return visits and patients with no unplanned return visits.
Univariate Analysis
Files were converted for univariate and multivariate analysis using SPSS software (Version18; SPSS, Chicago, Illinois, USA). Two-sided P values of less than 0.05 were considered statistically significant. Univariate analysis was performed with the variables which were constant for each presentation (age, gender and country of birth). The purpose of the univariate analysis was to determine the most commonly occurring variables for the multivariate logistic regression on the patient data. An additional univariate analysis was performed on the data collected from FRPs and SMPs on their responses to short validated scales to measure attachment style [135-138], sense of coherence [132-134] and self-rated health [38, 139].

Multivariate Analysis - Regression models and manipulation of predictor variables
Two logistic regression models for multivariate analysis were constructed using the binary dependent variable. The independent variables were transformed by counting the number of occurrences in the nested variables for each patient and dividing by the total number of presentations for that patient resulting in a variable consisting of the proportion of occurrences. As the values in the proportion variables ranged from zero to one, they were treated as continuous covariates. The independent diagnosis variables included the proportion of the most common ICD 9 diagnosis codes for presentations resulting in frequent readmissions: neurosis, chronic heart failure, chronic obstructive pulmonary disease, dyspnoeas and chest pain. A second logistic regression model was created to determine the impact of diagnoses as in Ambulatory Care Sensitive conditions, which are deemed suitable for non-hospital services. Ambulatory Care Sensitive Conditions are defined as those for which hospitalisation is considered potentially avoidable through preventive care and early disease management, usually delivered in an ambulatory setting, such as primary health care (for example by general practitioners or community health centres). Under the Ambulatory Care Sensitive classification scheme [165] conditions are divided into the categories of vaccine preventable, acute or rapid onset and chronic. For the second logistic regression model, the independent continuous proportion- of-diagnoses variables based on the Ambulatory Care Sensitive
groupings: rapid onset conditions and chronic conditions [40] were substituted for the continuous ICD 9 diagnoses proportion variables in the first model. Logistic regression was considered the best option for analysis of the possible predictor variables because the dependent variable demonstrated Poisson distribution, with the variance higher than the mean, rendering linear regression models inappropriate [51,52]. However, there has been debate in the literature about the impact of intra-patient variability in emergency department presentations on the choice of statistical analysis. This has led to questioning of the appropriateness of logistic regression and the proposition that negative binomial regression should be used [53, 54]. The results of the logistic regression were therefore checked against those of negative binomial regression. A backward elimination approach was adopted in the interest of achieving a parsimonious model [55, 56]. The categorical variables, male gender and born in Australia both met the criterion of a minimum of ten cases in each category.

Similar methods were used for distinguishing FAs from the rest of the patient population with the same predictor variables and the primary outcome variable as a binary variable of the number of presentations set with a cut-off point at four or more presentations denoting frequent attendances. For URVPs, the categorical outcome variable was whether the presentation was an unplanned return visit within 28 days or not.

The quantitative studies provided information on the patient related factors associated with frequent hospital use distinguishing three different patient groups: FRPs, FAs and URVPs. There are examples in the published literature of how this information can be used by hospitals to identify patients likely to be frequent users and to develop strategies to prevent them where possible. The value of the quantitative analysis was that it confirmed that FRPs were likely to be older patients with chronic disease and that they were different from FAs and URVPs.
Qualitative methods

The publications dealing with the qualitative analysis of interview data are:

- Kirby, SE, Dennis, SM, Bazeley, P and Harris, MF. What distinguishes clinicians who better support patients for chronic disease self-management? *Australian Journal of Primary Health* -http://dx.doi.org/10.1071/PY11029, Submitted: 8 March 2011 Accepted: 23 August 2011 Published online: 2 December 2011 and


The first publication focussed on the perspective of the clinician to determine the clinician related factors which influence patients to take up chronic disease self-management. The second explored the perspective of the patient to determine the differences between FRPs and SMPs.

The 6 research questions addressed by the qualitative analysis (as developed in the chapter “Conceiving the study”) were:

- Are the attitudes and beliefs of FRPs about living with and managing chronic disease different from those of SMPs?
- What do FRPs and SMPs report about adopting chronic disease self-management?
- What do clinicians think are the reasons for frequent readmissions in chronic disease patients?
- Do different clinicians have different views on the reasons for frequent readmissions?
- What do clinicians report about the reasons for chronic disease self-management uptake?
- Do clinician skills and attitudes influence frequent readmissions and chronic disease self-management uptake?
Population
The population under examination was drawn from the hospital and associated services. It consisted of chronic disease patients frequently readmitted to the hospital (FRPs), self-managing patients (SMPs) who had previously been FRPs and hospital and community based clinicians treating patients with chronic disease.

Sample
The sample was recruited from the following groups:

- FRPs in hospital (N=16) in emergency department (N=3) or wards (N=13).
- Clinicians who provided care to FRPs in hospital (N=13), in chronic disease self-management services (N=3) and GPs (N=2).
- SMPs (N=17) either in the respiratory out-patients clinic (N=9) or at the chronic heart failure service (N=8).

Both clinician and patient samples were purposive or deliberately chosen. Clinicians treating FRPs and SMPs made up the clinician sample. The patient sample for interviews was comprised of patients identified as FRPs or as SMPs by clinicians. The identification of FRPs for recruitment into the FRP sample was undertaken by hospital clinicians, by the Nurse Unit Manager of the emergency department for patients recruited in emergency or by the Nurse Unit Manager in the ward for patients recruited in the ward. The patient’s five year admission history was later verified by checking the patient’s medical record. SMPs were recruited either from the Respiratory Outpatient service or the Chronic Heart Failure service. Self-management status was confirmed by the Respiratory Physician for respiratory patients or the Coordinator of the Chronic Heart Failure Service for heart failure patients. As with the FRP sample, five year admission history was checked by referring to the patient’s medical record.
Data Collection and Analysis

Data was collected by interview. Clinician interview questions focussed on the clinician's skills and attitudes in relation to people with chronic disease, the patient–clinician relationship and chronic disease self-management. Patient interview questions focussed on the patient–clinician relationship and referral to chronic disease self-management services. Care was taken to avoid derogatory labels about frequent service use and a judgmental stance about patient choice of management approach.

The interview data recorded electronically were analysed as they were collected [16]. Coding using NVivo 9 (QSR International) built on the interview questions, but was then reflexive and interactive, enabling continuous modification of the analysis to accommodate new data and new insights about those data. As the analysis progressed, in line with interpretative phenomenology, querying processes ensured deeper analysis and interpretation and best fit to the data.

Interviews with both clinicians and patients were semi-structured to give the participants ample opportunity to present their views and not just respond to questioning. In the first instance coding was uncomplicated and descriptive. The next round of analysis went deeper into the data to interpret clinician and patient attitudes, to identify links between attitudes to the reasons for frequent hospital use and failure to take up chronic disease self-management. The third level of analysis focussed on the research questions. Issues of trustworthiness in analysis were addressed through regular discussions with supervisors and co-authors to check the consistency of data interpretation and application of the theoretical models. Findings were also discussed with chronic disease self-management and hospital clinicians and self-managing patients to check for accuracy of interpretation. Saturation was deemed to be reached at a point where no new insights and interpretations were able to be gleaned.
Integration

This was a multi-methods approach employing two types of analyses of data.

- Quantitative - predetermined data collection methods:
  - De-identified aggregated patient data from the Emergency Department Information System.
  - Validated short scales data on attachment style, sense of coherence and self rated health and patient personal details.

- Qualitative:
  - Interpretative phenomenological analysis of semi-structured patient and clinician interview data.

The study was multi-methods rather than mixed methods because the synthesis of the data occurred at the completion of the study rather than throughout the study.

The study phases are depicted in Figure 3 showing the sequence of the different components, or phases, of the study and demonstrating when the findings were interpreted to develop the conclusions.
The first phase consisted of analysis of the Emergency Department Information System data on patient characteristics of FRPs, FAs and URVPs compared to the rest of the patient population.

Phase Two of the study was comprised of semi-structured interviews with patients and their clinicians. The semi-structured interviews were designed to elucidate the attitudes, behaviours and beliefs of participants and were focussed on chronic disease and its impact on patients’ lives. The interview questions were used as a prompt to elicit participants' views, rather than as a strict protocol. FRPs were compared to SMPs. The identification of the two groups of patients was a crucial part of the research design because it was important to ensure minimal overlap between the groups to highlight the differences observed. FRPs were identified by hospital clinicians who knew the patient and their clinical history. The categorization of FRP was later confirmed by checking frequency of admissions in the patient’s medical record. SMPs were identified as self-managing by their clinicians and their clinical diagnosis and co-morbidities data collected from the medical record. Clinicians were interviewed about their attitudes towards FRPs, SMPs and chronic disease management. The other component in Phase Two was the quantitative analysis of the personal
details on patients and clinicians. Both components were of equal priority. The final phase involved integration and synthesis of the results of analysis from the first two phases.
Summary

The purpose of the methods chapter was to describe the methods, demonstrate their appropriateness and to show how the different components were related to each other to form a coherent and integrated work.
The purpose of this chapter is to present the results as a whole in relation to the research questions and to determine the contribution of the work. This chapter presents the results as they appear in the four published papers and remaining paper under review:


Patient related factors in frequent readmissions: the influence of condition, access to services and patient choice
Sue E Kirby*, Salim M Dennis, Upali W Jayasinghe, Mark F Lumby

Abstract
Background: People use emergency departments services for a wide variety of health complaints, many of which could be handled outside hospitals. Many frequent readmissions are due to problems with chronic disease and are preventable. We postulated that patient related factors such as the type of condition, demographic factors, access to alternative services outside hospital and patient preference for hospital or non-hospital services would influence readmissions for chronic disease. The study aimed to explore the link between frequent readmissions in chronic disease and these patient related factors.

Methods: A retrospective analysis was performed on emergency department data collected from a regional hospital in NSW Australia in 2001. Frequently readmitted patients were defined as those with three or more admissions in a year. Clinical, service usage and demographic patient characteristics were examined for their influence on readmissions using multivariate analysis.

Results: The emergency department received about 20,000 presentations a year involving some 16,000 patients. Most patients (80%) presented only once. In 2001 one hundred and forty-four patients were readmitted three or more times in a year. About 30% of all presentations resulted in an admission. Frequently readmitted patients were more likely to be older, have a longer clinical classification, present with an unplanned reason, and have a diagnosis of chronic, obstructive pulmonary disease, dyspnoea or chronic heart failure. The chronic ambulatory care sensitive conditions were strongly associated with frequent readmissions. Frequent readmissions were unrelated to gender, time, day or season of presentation or country of birth.

Conclusions: Multivariate analysis of routinely collected hospital data identified that the factors associated with frequent readmissions include the type of condition, urgency, unplanned reason and age. Interventions to improve patient uptake of chronic disease management clinics and improving the availability of alternative non-hospital services should reduce the readmission rate in chronic disease patients.

Background
Emergency departments aim to provide treatment for more urgent and serious conditions. In Australia, the role of emergency departments has been specified as "prevention, diagnosis and management of acute and urgent aspects of illness and injury affecting patients of all age groups with a full spectrum of undifferentiated physical and behavioral disorders"[1]. However, many people who access emergency departments have complex social needs as well as a clinical condition requiring treatment [2-4]. Emergency departments across the world are reporting serious overcrowding resulting in lengthy waits which impact the quality of care and patient outcomes [5-7]. Investigation of patient profiles and the reasons behind the choice of emergency department services by frequent attenders and frequently readmitted patients is vital to guide the development of policy and design of interventions to address more appropriate patient management strategies and to prevent overcrowding [8].

Overcrowding of emergency departments has spawned a plethora of research on frequent emergency
department users. Byrne et al. [2] reported that frequent emergency department users were more likely to be males from low socioeconomic backgrounds with severe psychosocial problems who have a high morbidity and mortality. There have been similar findings from researchers in the UK [9-12], Canada [12,13], Sweden [14-16], USA [17-25], Italy [26], Taiwan [27,28] and Australia [29,30].

Frequent readmissions, however, have received less research attention. The Patients At Risk of Readmission (PARR) tool, used extensively in the UK for identification of patients at risk of readmission, [31,35] indicates that age, sex, ethnicity, number of previous admissions, and clinical condition are associated with readmissions. Howell et al. [33] in a 2009 study in Australia identified age, co-morbidities, economic disadvantage, number of previous admissions as risk factors for frequent readmissions through a statistical algorithm derived from repeated data. The Australian model was only moderately successful because of the relatively high number of false negatives.

Anderson's model of health service utilisation [34-36] provides a theoretical framework for thinking about why patients are frequently readmitted. This model posits that health service utilisation is dependent on a range of factors such as the environment, population characteristics and health behaviours resulting in outcomes such as perceived health status, evaluated health status and consumer satisfaction. The environment includes available services and access issues. Population characteristics include demographic details, age, gender, cultural background, needs and resources. Health behaviours are influenced by personal attitudes and beliefs. Identifying the clinical, service utilisation details and demographic patient characteristics available from hospital data can identify risk factors for frequent readmissions and thereby help to develop strategies to divert these patients away from hospitals where clinically possible. The direct application of this model to emergency department utilisation summarised by Padgett et al. [37,38], who suggests that only about 15% of emergency visits in the USA are for life-threatening reasons and that poor mental health, anxiety about health combined, with symptoms and injury influence people to decide to use the emergency department.

How important is access to primary care in readmissions? Hospitalisations for ambulatory care sensitive (ACS) conditions is used an outcome indicator for access to primary care [39]. It is acknowledged that treatment of ACS conditions outside hospitals, including chronic disease, reduces hospitalisations [40]. It would be expected that ACS conditions would contribute to frequent readmissions in areas with limited access to primary care services.

The problem that a small number of emergency department users account for a disproportionate use of scarce resources has been reported since the 1940s [41,42] and continues to plague the health system [43]. An Australian survey of emergency departments indicated that patients awaiting admission are a major contributing factor in emergency department overcrowding [44]. Two Australian States, NSW and Victoria, report diversion of chronic disease patients to chronic disease management services, including those provided by primary care, can reduce readmission rates [25,45].

We know little about the reasons behind the choice of emergency department services over other alternative medical services in the community. However, studies in NSW Australia have reported that patients came to the emergency department because they thought their condition warranted urgent services, with access to a doctor and tests or x-rays done in the same place but there was a mismatch between the views of clinicians and patients [46,47]. In a qualitative study performed in the USA [48], patients reported that they were unable to obtain an appointment with a primary care provider; were referred by the staff to be evaluated in the emergency department and it took less of their time to be seen in the emergency department than it did to contact their primary care provider, only to then be told to go to the emergency department.

Fulde and Duffy [3] argued that patients who present frequently to emergency departments are a vulnerable and marginalized group perceived as not looking after themselves. Padgett et al. [38] suggest that the emergency department is the least appropriate setting for treating multiple co-morbidities. These authors also reported that people who feel powerless and isolated tend to be high emergency department users.

Hong et al. [49] suggest that we need a radical paradigm shift to legitimise the role of emergency departments to include primary care services for those people on the lower end of the socioeconomic scale who tend not to have a primary care provider in the community. The contrary opinion would be to restrict the role of emergency departments and to increase the availability of alternative primary care services to thereby reduce emergency department overcrowding.

This research analysed emergency department data routinely collected by hospitals in the state of NSW, Australia, to identify patient related factors associated with three or more admissions a year and with admission for ACS conditions. The analysis was designed to answer questions about the impact on frequent readmissions of three sets of variables: demographic, clinical and arrival times and dates. The answers provide a basis for exploring the reasons underlying frequent readmissions. The research sets the scene for further
examination of the reasons why people with chronic conditions are repeatedly admitted to hospital rather than seeking chronic disease management services.

**Methods**

**Study design and site**

In this study, we analysed 2006 data from the Emergency Department Information System collected at a regional hospital. The University of Wollongong/South Eastern Sydney Illawarra Health Service Medical Human Research Ethics Committee approved the research study (approval HE07/271). All patient data were de-identified. The study was carried out in a one-hundred and fifty bed regional hospital in south eastern Australia which is part of a network with a major teaching and referral hospital. The hospital, funded by the State and Commonwealth Government, is located in a coastal regional urban area with a feeder population of around 100,000.

**Data Analysis**

All statistical analyses were performed using SPSS statistical software (Version 18, SPSS, Chicago, Illinois, USA). Two-sided P values of less than 0.05 were considered statistically significant.

**Predictor variables**

The original variables were: patient identifier number, age, gender, date and time of arrival, country of birth, ICD 9 diagnosis, level of urgency based on the Australian Triage Classification [50], type of visit and mode of separation (treated in emergency or admitted). Type of visit is a local code referring to the type of emergency presentation: normal, planned return and unplanned return within 28 days of the original presentation. Each patient presentation was accorded one primary ICD 9 diagnosis based on the major reason for the presentation. Date and time of arrival variables were converted into hour, day and season of arrival.

The data was analysed either from the perspective of presentations in row-for-each-presentation format or from the perspective of patients in a row-for-each-patient format with nested data for each patient. The primary research question was to uncover the patient characteristics associated with frequent readmissions required the row-for-each-patient format. However, preliminary univariate analysis was performed on the row-for-each-presentation format on the variables for which there were different or potentially different, values for each presentation: hour, day and season of arrival, urgency, unplanned return visit and diagnosis. Univariate analysis was also performed with the variables which were constant for each presentation (age, gender and country of birth).

**Primary outcome variable**

The primary outcome variable was a binary variable of the number of admissions set with a cut off point at three or more admissions denoting frequent readmissions. Presenting patients judged to have conditions warranting admissions may be either admitted to the study hospital or to another hospital in the network if the bed supply is inadequate. All admissions, including those for which patients were placed in a bed in another hospital, were included in the sample. The number of admissions variable was obtained by separating the presentations for patients admitted, converting to the row-for-each-patient format and merging the admissions variable into the main file.

**Regression models and manipulation of predictor variables**

Two logistic regression models for multivariate analysis were constructed with the binary dependent variable. The independent variables were transformed by counting the number of occurrences in the nested variables for each patient and dividing by the total number of presentations for that patient resulting in a variable of the proportion of occurrences and used in the multivariate analysis. As the values in the proportion variables ranged from zero to one, they were treated as continuous covariates. The independent diagnosis variables included the proportion of the most common ICD 9 diagnosis codes for presentations resulting in frequent readmissions: neurosis, chronic heart failure, chronic obstructive pulmonary disease (COPD), dyspepsia and chest pain.

In the second logistic regression model was created to determine the impact of diagnoses which are deemed suitable for non-hospital services. Ambulatory care sensitive conditions are defined as those which hospitalisation is considered potentially avoidable through preventive care and early disease management, usually delivered in an ambulatory setting, such as primary health care (for example by general practitioners or community health centres). For the second logistic regression model, the independent continuous proportion-of-diagnostics variables based on the ACS grouping: rapid onset conditions and chronic conditions [40] were substituted for the continuous ICD 9 diagnoses proportion variables in the first model.

Logistic regression was considered the best option for analysis of the possible predictor variables because the dependent variable demonstrated Poisson distribution, with the variance higher than the mean, rendering linear regression models inappropriate [51,52]. However, there has been debate in the literature about the impact of intra-patient variability in emergency department presentations on the choice of statistical analysis. This has
led to questioning of the appropriateness of logistic regression and the proposition that negative binomial regression should be used [53,54]. The results of the logistic regression were therefore checked against those of negative binomial regression. A backward elimination approach was adopted in the interest of achieving a parsimonious model [55,56]. The categorical variables, male gender and born in Australia both met the criterion of a minimum of ten cases in each category.

Results

There were 21,956 presentations in 2008, of which 29% were admitted. Results of the univariate analysis on patient data in Table 1 indicate that there were significant differences between the general patient population and the frequent readmissions group in age, country of birth and gender. Table 2, presentation data, comparing the frequencies of the independent proportion variables in the general presenting population and presentations resulting in frequent readmissions, shows there were significant differences in all of the five most common diagnosis codes amongst frequently readmitted presentations and the "other" diagnoses, in urgent presentations, unplanned return visits and the chronic and "other" ambulatory care sensitive variables.

Of the seasonal variables, only in summer was there a significant difference between the two groups. There were no differences observed in time or day of arrival.

Direct logistic regression uncovered the impact of the independent variables on frequent readmissions. Both models were initially set up with the independent variables gender, age, country of birth, and the proportion variables unplanned return visit, urgency, season, weekend after hours and the diagnosis. Subsequently, stepwise backward elimination of the variable with the highest $p$ value was performed to establish the most parsimonious model for the independent variables. The first model including the "proportion" variables for the five most common ICD 9 diagnosis was statistically significant with a $\chi^2$ value of 278.3 (7 degrees of freedom, $N = 15806, p < 0.01$) indicating the model was able to distinguish between frequently readmitted and patients not frequently readmitted based on the definition of frequent admissions as three or more. As a whole, the ICD 9 diagnosis model explained up to 17.1% (R$^2$ Nagelkerke value) of the variance [57,58] in the dependent variable. As Table 3 reveals, seven of the independent variables, age, proportion of unplanned return visits, urgency, diagnoses of necrosis, chronic heart failure, COPD and dyspepsia, made a statistically significant ($p < 0.05$) positive contribution to the model.

In the second model, a similar logistic regression analysis was performed substituting three variables of the proportion of preventable, rapid onset and chronic ACS conditions for the diagnosis variables in the first model. The other independent variables were similar to those used for model one. Overall, the ACS model was statistically significant with a $\chi^2$ value of 192.8 (4 degrees of freedom, $N = 15806, p < 0.01$) indicating that the model could distinguish between frequently readmitted patients and non-frequently readmitted patients. As a whole, the ACS model explained up to 12.3% (Nagelkerke R$^2$ value [57]) of the variance of the dependent variable. In model two, four of the independent variables age, proportion of unplanned return visits, urgency and proportion of ACS chronic conditions made a statistically significant ($p < 0.05$) positive contribution to the model (see Table 4).

The results of negative binomial regression models confirmed the logistic regression models.

Discussion

The majority of presentations to the emergency department were by patients who had a single presentation in the year. The patients under investigation in this study were the one hundred and forty four frequently readmitted patients who had three or more admissions in a year. The univariate analysis showed significant differences in all the independent variables except the seasons of autumn, winter and spring and time and day of arrival. However, the multivariate analysis identified age, chronic conditions of necrosis, COPD, dyspepsia and chronic heart failure, ACS chronic conditions, urgency and unplanned return visit as being associated with frequent readmissions. The study highlights the advantage of the multivariate analysis using the patient rather than presentation perspective to separate factors important in frequent readmissions.

Using the framework of Andersen's model of health service utilization, the results can be considered in terms of patient demographics, clinical significance,

<table>
<thead>
<tr>
<th>Table 1 Univariate analysis of patient characteristics comparing the general patient population with frequently readmitted patients 2008</th>
<th>All patients (n = 15,806)</th>
<th>Patients admitted &gt;= 3 times (n = 144) 1% of all patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>52%</td>
<td>48% p &lt; 0.001</td>
</tr>
<tr>
<td>Mean age (SD, range)</td>
<td>39 (16), 11-109</td>
<td>66 (21), 24-915 p &lt; 0.001</td>
</tr>
<tr>
<td>Born outside Australia</td>
<td>18%</td>
<td>37% p &lt; 0.001</td>
</tr>
</tbody>
</table>

"On second thought"
Table 2 Univariate analysis independent variables in the general presenting population compared to presentations resulting in frequent readmissions 2008

<table>
<thead>
<tr>
<th>Variable group</th>
<th>Variable</th>
<th>General presenting population N = 21915</th>
<th>Presentations resulting in frequent readmissions N = 327</th>
</tr>
</thead>
<tbody>
<tr>
<td>ICD9 diagnostic code²</td>
<td>Dyspepsia (ICD 78600)</td>
<td>2.2%</td>
<td>13.9% (p &lt; 0.01)²</td>
</tr>
<tr>
<td></td>
<td>Neurotic disorder (ICD 3079)</td>
<td>3.4%</td>
<td>16.0% (p &lt; 0.01)</td>
</tr>
<tr>
<td></td>
<td>Chest pain (ICD 78650)</td>
<td>4.4%</td>
<td>9.7% (p &lt; 0.01)</td>
</tr>
<tr>
<td></td>
<td>Chronic obstructive pulmonary disease (ICD 496)</td>
<td>0.7%</td>
<td>7.6% (p &lt; 0.01)</td>
</tr>
<tr>
<td></td>
<td>Congestive heart failure (ICD 428)</td>
<td>0.3%</td>
<td>2.0% (p &lt; 0.01)</td>
</tr>
<tr>
<td></td>
<td>All other ICD codes</td>
<td>60.0%</td>
<td>54.2% (p &lt; 0.01)</td>
</tr>
<tr>
<td>Triage category</td>
<td>Urgent (Triage 1 &amp; 2)</td>
<td>5.9%</td>
<td>8.8% (p &lt; 0.01)</td>
</tr>
<tr>
<td>Visit type</td>
<td>Unplanned return visit</td>
<td>4.7%</td>
<td>6.6% (p &lt; 0.01)</td>
</tr>
<tr>
<td>Season of arrival</td>
<td>Autumn</td>
<td>26.9%</td>
<td>35.4% (p &lt; 0.01)</td>
</tr>
<tr>
<td></td>
<td>Winter</td>
<td>24.3%</td>
<td>26.0% (p &lt; 0.01)</td>
</tr>
<tr>
<td></td>
<td>Spring</td>
<td>20.9%</td>
<td>24.6% (p &lt; 0.01)</td>
</tr>
<tr>
<td></td>
<td>Summer</td>
<td>25.0%</td>
<td>12.3% (p &lt; 0.01)</td>
</tr>
<tr>
<td>Day of arrival</td>
<td>Weekend</td>
<td>31.7%</td>
<td>28.3% (p &lt; 0.01)</td>
</tr>
<tr>
<td>Time of arrival</td>
<td>After hours</td>
<td>40.9%</td>
<td>44.9% (p &lt; 0.01)</td>
</tr>
<tr>
<td>Ambulatory Care Susceptible Conditions³</td>
<td>ACS chronic</td>
<td>1.3%</td>
<td>4.3% (p &lt; 0.01)</td>
</tr>
<tr>
<td></td>
<td>ACS other</td>
<td>94.0%</td>
<td>95.7% (p &lt; 0.01)</td>
</tr>
</tbody>
</table>

¹Three were ICD9 other ICD 9 codes with at least one presentation.
²Chi square results.
³ACS susceptible was excluded because there was only one presentation in the general presenting population and none in the presentations resulting in frequent readmissions group.

The finding that age significantly influenced frequent readmission is in line with other studies [31-33]. These studies also reported that other demographic factors, sex and ethnicity, are associated with readmissions. However, there was no discernible sex difference, nor was there a difference between Australian born and those born outside Australia, in our study.

The type of condition is important in readmissions. Our model looked specifically at the most common conditions in presentations by patients admitted to a hospital bed. The diagnoses of neurosis, COPD, dyspepsia and chronic heart failure, all serious conditions, were associated with frequent readmissions. Chest pain in our model was not associated with frequent readmissions. Although the regression models did not include a variable for severity of illness per se, other variables point to severity. The triage level specifically indicates urgency and more urgent conditions are generally more severe.

Unplanned return visits within 28 days of the previous visit for the same condition are reported by all public.

Table 3 Odds ratio and confidence limits for the variables having a significant impact on frequent readmissions in model one five most common ICD 9 diagnoses, results from logistic regression backwards elimination

<table>
<thead>
<tr>
<th>Variable</th>
<th>P value</th>
<th>Odds ratio</th>
<th>95% Confidence Interval for odds ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>0.003</td>
<td>1.046</td>
<td>1.046 - 1.064</td>
</tr>
<tr>
<td>Proportion of urgent (Triage categories 1 and 2)</td>
<td>0.003</td>
<td>11.931</td>
<td>10.792 - 13.150</td>
</tr>
<tr>
<td>Proportion of neurosis (ICD 78600)</td>
<td>0.003</td>
<td>13.070</td>
<td>9.402 - 18.276</td>
</tr>
<tr>
<td>Proportion of congestive heart failure (ICD 78649)</td>
<td>0.003</td>
<td>4.500</td>
<td>3.577 - 5.694</td>
</tr>
<tr>
<td>Proportion of chronic obstructive pulmonary disease (ICD 496)</td>
<td>0.003</td>
<td>9.863</td>
<td>7.413 - 13.203</td>
</tr>
<tr>
<td>Proportion of unplanned return visits within 28 days of previous visit</td>
<td>0.003</td>
<td>12.383</td>
<td>9.487 - 16.203</td>
</tr>
<tr>
<td>Constant</td>
<td>0.000</td>
<td>1.000</td>
<td>1.000 - 1.000</td>
</tr>
<tr>
<td>Variable</td>
<td>P value</td>
<td>Odds ratio</td>
<td>95% Confidence Interval for odds ratio</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>---------</td>
<td>------------</td>
<td>--------------------------------------</td>
</tr>
<tr>
<td>Age (years)</td>
<td>0.207</td>
<td>1.042</td>
<td>1.024 - 1.062</td>
</tr>
<tr>
<td>Proportion urgent admission</td>
<td>0.001</td>
<td>2.321</td>
<td>1.907 - 3.125</td>
</tr>
<tr>
<td>Percentage unplanned return/24h</td>
<td>0.001</td>
<td>13.613</td>
<td>5.414 - 35.940</td>
</tr>
<tr>
<td>Percentage ACS Chronic conditions</td>
<td>0.002</td>
<td>2.371</td>
<td>1.519 - 3.695</td>
</tr>
<tr>
<td>Constants</td>
<td>0.002</td>
<td>3.091</td>
<td></td>
</tr>
</tbody>
</table>

The finding that frequent readmissions are associated with diagnoses of COPD, depression and chronic heart failure is consistent with the notion that patients experiencing the symptoms associated with these conditions are more likely to believe their condition is serious enough for them to choose hospital care rather than primary care outside the hospital setting.

Seasonal variations in readmissions might have been expected because of the differences in temperature influencing the incidence of respiratory exacerbations. The fact that there were no seasonal variations is difficult to explain.

Patients with ACS chronic conditions were significantly more likely to be frequent readmissions. This finding could mean that access to primary care services for preventable conditions (immunisation and nutritional interventions) and rapid onset ACS conditions is adequate and access to chronic disease management services is not. Alternatively, the findings could indicate that patients are choosing hospital services over primary care services for chronic disease management.

Frequent readmissions for neutropenia might be associated with reduced access to community based mental health services in the area. Another interpretation of this finding is that patients are voting with their feet expressing a preference for hospital services over community care.

Does poor access to other services contribute to frequent readmissions? Time and day of arrival had no significant impact on frequent readmissions. It might be expected that the more frequent emergency department users would opt for after hours or weekend visits when other community based services are less available. Our findings tend to negate any notion that access to after hours and weekend services is an issue. However, the finding that ACS chronic conditions were associated with frequent readmissions suggests there are access issues at play. Although alternative general or specialist medical and chronic disease management services exists, there may be access difficulties other than the time of availability of services. Access factors such as, availability, accessibility, accommodation, affordability and acceptability, need to be further explored before we have a definitive answer on the impact on frequent readmissions. In particular, transport, location of community based services and waiting times would act as barriers to access.

In our analysis, age and type of illness influenced readmissions. The impact of access issues on frequent readmissions was less clear. The other factors which could influence readmissions are related to patient preferences for the type of services, for example, general and specialist medical and chronic disease management services. If the uptake of these alternative services were to be increased, readmissions rates would be reduced. Further research to explore patient choice of services would be of benefit to the problem of frequent readmissions.

On the basis of the findings presented in this study, the question of whether readmissions are preventable was not directly answered, but the evidence from other studies shows that hospitalisation of chronic disease patients can be reduced by a range of targeted interventions to improve chronic disease management [45]. Logistic regression models were developed to identify the characteristics associated with frequent readmissions. The reliability of the predicting factors identified is determined by the robustness of the models. Although the overall fit of the model was significant, the Nagelkerke R² values of less than 20% were relatively low. However, other studies of patient utilisation and clinical data have quoted similarly low Nagelkerke R² values in logistic regression models [61,62].
This study is limited by the fact that it involves data pertaining to one hospital only. Although the results may not be generalizable to all hospitals, they are relevant to similar sized hospitals in non-metropolitan urban areas. Comparison with other hospitals with a similar role would lend weight to these findings. Another limitation is the purpose of the data collection. The data forms part of the Emergency Department Information System collected by all NSW hospitals. The accuracy of the recording of primary diagnosis in the data base is complicated by the fact that many of the older patients have multiple comorbidities and the reason for their presentation may not be apparent until test results are available. It was not possible to make any estimation of socioeconomic status from the data available. However, the area which the hospital services, although it contains some affluent pockets, is generally a low socioeconomic area [63]. As this study examines emergency department data only there is an inherent selection bias. We did not examine the use of other primary care services by people who did not access emergency department services. An expanded study to include the patterns of emergency department and community based primary care, particularly general practitioner services, is needed to develop population-based solutions to emergency department overcrowding. Another possible limitation is the failure of logistic regression analysis to take into account the intra-patient variability [51-54]. To address this issue we have compared the results of logistic and negative binomial regression models and found similar results. The relatively wide confidence intervals for some of the variables reflect the precision of the estimates. The study is also limited by the lack of a specific measurement of severity of illness.

Conclusions

This study of routinely collected hospital data identified the factors associated with frequent readmissions with the aim of exploring the reasons behind readmissions. Strategies to identify and improve access to alternative non-emergency department services for neurosis, COPD, depression and chronic heart failure patients, including chronic disease self management and care coordination services, would reduce readmissions. An early warning system for the unplanned return visit patients would allow for special strategies to be put in place to address the needs of these patients. Possible community-based services access barriers such as transport, location of community-based services and waiting times should be explored and addressed. This study has opened up the possibility that a patient’s preference for hospital over non-hospital services might influence readmissions and warrants further investigation.

Acknowledgements

None are acknowledged.

Authors’ contributions

MB, JCH and MH planned the research study, MMJ and MNH conducted the PCO work, ES conducted the initial analysis, all authors reviewed and approved the final manuscript.

Competing interests

The authors declare that they have no competing interests.

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References

Frequent emergency attenders: is there a better way?

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Abstract

Background. Understanding the reasons for frequent re-attendances will assist in developing solutions to hospital overcrowding. This study aimed to identify the factors associated with frequent re-attendances in a regional hospital thereby highlighting possible solutions to the problem.

Methods. A retrospective analysis was performed on emergency department data from 2008. Frequent re-attenders were defined as those with four or more presentations in a year. Clinical, service usage and demographic patient characteristics were examined for their influence on re-presentations using multivariate analysis.

Results. A total of 3% of the total patients presenting to emergency re-attended four or more times in the year. Frequent re-attenders were older, presented with an unexplained return visit and had a diagnosis of neurotic, chronic obstructive pulmonary disease (COPD), convulsions, dyspepsia or repeat prescriptions, follow-up examinations or dressings and were less likely to present in the summer. Frequent re-attendances were unrelated to any time of presentation or country of birth.

Conclusions. Diversion of patients with minor conditions to alternative services; referral of COPD patients to follow-up respiratory services and patients with neurosis to community mental health services would reduce emergency utilisation. Improving access to and resourcing of alternative non-hospital services should be investigated to reduce emergency overcrowding.

What is known about the topic? Frequent re-attendances at emergency contribute to emergency overcrowding and are a problem worldwide. Generally, frequent re-attendances have been associated with disadvantage. Identifying patient factors that predict re-attendances will assist in developing strategies to prevent their occurrence. The reasons for re-attendances may vary depending on access to other services and the role of the hospital.

What does this paper add? This paper adds to the field by demonstrating how routinely collected hospital data can be used to determine patient characteristics important in frequent re-attendances. The factors associated with frequently re-attending patients include older age, type of condition, unplanned return visit and season.

What are the implications for practitioners? This paper has implications for both administrators and clinicians. The diversion of attending patients with neurosis, COPD, dyspepsia or repeat prescriptions, follow-up examinations or dressings and returns to alternative affordable and accessible services would reduce overcrowding in the emergency department.

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that we need to understand from patients, their families and caregivers about their preferences for different types of services. Campbell et al. found that reutilization rates and costs are higher for minor conditions in emergency departments, providing another reason to support structuring emergency departments for minor and urgent conditions and managing minor conditions more appropriately elsewhere.

Under Anderson’s health service utilisation model, the way in which people use health services, depends on the availability of services and individual patient factors, including patient preferences and health-seeking behaviours. Are frequent emergency re-attendees using emergency departments because they prefer the services or because they have access to less appropriate, and maybe more appropriate services? Pendancy’s framework specifically factors of availability, accessibility, accommodation, affordability and acceptability. In considering possible access barriers the frameworks help to pinpoint the way in which access influences utilisation.

The aim of this study was to identify patient characteristics associated with frequent attendances in order to suggest improvements to prevent their occurrence.

Methods
We carried out a retrospective analysis of 2005 data from the emergency department collected at a 150 bed regional hospital in north-eastern Australia. All patient data were de-identified. The data were collated by the Data and Confidential Care Team of the hospital and a feeder population of 100,000.

The primary binary outcome variable was the number of presentations within a cut-off point at an emergency department in a patient’s lifetime. The primary independent variable was gender, age, sex, date and time of arrival, urgency of birth, ICD-9 diagnosis, level of injury and mode of separation. Each presentation was recorded as primary ICD-9 diagnosis. Data on time and arrival variables were converted into hour, day and season of arrival.

The data were analysed from the perspective of presentations in the four-section format or from the perspective of patients in a row-for-each-patient format with nested data for each patient. The primary research question to uncover the patient characteristics associated with frequent re-presentations required the row-for-each-patient format. Preliminary univariate analysis was performed on the row-for-each-presentation format on the variables for which there were differences, or potentially different. Values for each presentation time, date and season of arrival, urgency, unplanned return visit and diagnosis. Univariate analysis was also performed with the variables that were constant for each presentation (age, sex and country of birth).

A logistic regression model was constructed with the independent variables transformed by counting the number of occurrences in the nested variables for each patient and dividing by the total number of presentations for that patient resulting in a variable of the proportion of occurrences. As the values in the proportion variables ranged from 0 to 1, they were treated as continuous covariates. The diagnosis variables included the proportion of the most common ICD-9 diagnosis codes for presentations resulting in frequent attendances determined by univariate analysis.

Logistic regression was considered appropriate as the dependent variable was binary categorical. A backward elimination approach was adopted in the interest of achieving a parsimonious model. The categorical variables, male and female, were included in the model. The dependent variables were men and women, compared with males in the total presentations in Table 3. Frequent re-attendances were significantly more likely to be for repeat prescriptions, non-urgent conditions, follow-up appointments, diagnoses, repeat prescriptions, follow-up appointments and COPD. Frequent re-attendances were significantly more likely to be for less urgent conditions and unplanned return visits. There were seasonal differences. Frequent re-attendances were more likely to occur in winter and spring. Frequent re-attendances were more likely during the week than during the weekend.

Three logistic regression models demonstrated the effect of the independent variables on frequent presentations (Table 3). The model was statistically significant with a Chi-square value of 72.56 (p < 0.001) and distinguished between frequently presenting patients and other patients. The model explained a (0.15.9%) (Nagelkerke 0.31) of the variance in the dependent variable. Ten of the independent variables were significantly associated with frequent presentations: age, the diagnosis of hypertension, COPD, cardiovascular conditions, repeat prescriptions, follow-up visits and diagnoses, unplanned return visit and summer presentations. Patients presenting as unplanned return visit was the strongest predictor of four or more attendances in the year. Those patients were over 50 times more likely to be attending medicine.

Table 1: Univariate analysis of the independent variables comparing the two patient groups: the total patient population and the frequent attenders with four or more presentations in 2005

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Total patient population</th>
<th>Frequent attenders with four or more presentations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 15,406</td>
<td>n = 1222</td>
</tr>
<tr>
<td>Male</td>
<td>52.6%</td>
<td>55.5% (NS)</td>
</tr>
<tr>
<td>Mean age</td>
<td>(26.6, 1-106)</td>
<td>(26.6, 0-98)</td>
</tr>
<tr>
<td>Australian born</td>
<td>83.9%</td>
<td>78.5% (NS)</td>
</tr>
</tbody>
</table>

NS = Chi-square tests; NS = Nonsignificant.
Table 2. Univariate analysis of the independent variables comparing characteristics of the total presentations with presentations of frequent attenders (four or more presentations in the year) for 2008

<table>
<thead>
<tr>
<th>Variable group</th>
<th>Variable</th>
<th>Total presentations (n=21,950)</th>
<th>Four or more presentations (n=1,260)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most common ICD-9 diagnostic codes**</td>
<td>Repeat prescriptions (V581)</td>
<td>2.3%</td>
<td>14.3% (P&lt;0.001)</td>
</tr>
<tr>
<td></td>
<td>Neurotic disorder (3079)</td>
<td>3.3%</td>
<td>6.5% (P&lt;0.001)</td>
</tr>
<tr>
<td></td>
<td>Chest pain (789.9)</td>
<td>4.6%</td>
<td>2.2%</td>
</tr>
<tr>
<td></td>
<td>Alcoholic symptoms (789.9)</td>
<td>5.4%</td>
<td>4.5%</td>
</tr>
<tr>
<td></td>
<td>Follow up examination (V579)</td>
<td>1.7%</td>
<td>4.0% (P&lt;0.001)</td>
</tr>
<tr>
<td></td>
<td>Dyspepsia (531.69)</td>
<td>2.3%</td>
<td>3.8% (P&lt;0.001)</td>
</tr>
<tr>
<td></td>
<td>Dressings and sutures (V63)</td>
<td>0.7%</td>
<td>2.9% (P&lt;0.001)</td>
</tr>
<tr>
<td></td>
<td>Urinary tract infection (J990)</td>
<td>1.3%</td>
<td>1.5%</td>
</tr>
<tr>
<td></td>
<td>Back pain (724.5)</td>
<td>1.3%</td>
<td>1.5%</td>
</tr>
<tr>
<td></td>
<td>Conditions (783)</td>
<td>0.8%</td>
<td>1.4% (P&lt;0.05)</td>
</tr>
<tr>
<td></td>
<td>Chronic obstructive pulmonary disease (490)</td>
<td>0.7%</td>
<td>1.3% (P&lt;0.05)</td>
</tr>
<tr>
<td></td>
<td>Persistent vomiting (5362)</td>
<td>1.2%</td>
<td>1.3%</td>
</tr>
<tr>
<td></td>
<td>Cellulitis leg (5425)</td>
<td>0.7%</td>
<td>1.3% (P&lt;0.01)</td>
</tr>
<tr>
<td></td>
<td>All other ICD codes</td>
<td>79.6%</td>
<td>59.5%</td>
</tr>
<tr>
<td>Triage category</td>
<td>Urgent (Triage 1 &amp; 2)</td>
<td>5.9%</td>
<td>5.3% (P&lt;0.01)</td>
</tr>
<tr>
<td>Visit type</td>
<td>Unplanned return visit</td>
<td>4.2%</td>
<td>10.5% (P&lt;0.001)</td>
</tr>
<tr>
<td>Source of arrival</td>
<td>Accident</td>
<td>24.9</td>
<td>17.9% (P&lt;0.01)</td>
</tr>
<tr>
<td></td>
<td>Water</td>
<td>24.3</td>
<td>26.0% (P&lt;0.01)</td>
</tr>
<tr>
<td></td>
<td>Sprig</td>
<td>25.0</td>
<td>31.3% (P&lt;0.001)</td>
</tr>
<tr>
<td></td>
<td>Summer</td>
<td>25.6</td>
<td>20.6% (P&lt;0.01)</td>
</tr>
<tr>
<td></td>
<td>Weekend</td>
<td>31.2%</td>
<td>27.7% (P&lt;0.001)</td>
</tr>
<tr>
<td>Arrival time</td>
<td>After hours</td>
<td>49.0%</td>
<td>51.1%</td>
</tr>
<tr>
<td></td>
<td>ACS (Antidote Care Sensitive) rapid onset</td>
<td>3.9%</td>
<td>4.0%</td>
</tr>
<tr>
<td></td>
<td>ACS (chronic)</td>
<td>1.3%</td>
<td>1.5%</td>
</tr>
<tr>
<td></td>
<td>ACS (other)</td>
<td>94.0%</td>
<td>94.0%</td>
</tr>
</tbody>
</table>

**A subset were ICD-9 codes with at least one presentation.

Table 3. Multivariate analysis of the effect of independent variables, including ICD-9 codes, on patients with frequent attendances of up to three and four or more presentations in 2008 by logistic regression

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Odds ratio</th>
<th>95% confidence interval</th>
<th>Lower</th>
<th>Upper</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age years</td>
<td>1.000</td>
<td>0.000</td>
<td>1.000</td>
<td>1.000</td>
</tr>
<tr>
<td></td>
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</tbody>
</table>

Discussion

The purpose of this study was to ascertain the characteristics of people who frequently re-attend at the emergency department to assist in the development of strategies to prevent their reattendance. Our finding that older people were more likely to be frequent re-attendees is in line with other work and supports the notion that older people, by virtue of their age, are more likely to have developing conditions requiring treatment. Whether the conditions require hospital services raises question of the role of emergency departments.

In contrast to other work reporting more men than women are frequent re-attendees, we found no sex difference in this study. Other studies reported that ethnic non-Caucasian patients are more likely to be frequent re-attendees whereas we found no significant difference between Australian born and non-Australian born patients after adjustment for confounding factors.

Unplanned return visits for the same condition within 28 days was the strongest predictor of frequent re-attendance. Patients could return to the emergency department because they had
difficulty accessing primary care services or because the original problem required extra emergency treatment.

The feeder population for this hospital has a low socioeconomic status and the area is underserviced by public transport (Shellharbour, IMR, see http://www.imr.org.au/index.php page 922, accessed 6 October 2011). People with a lower disposable income are less able to afford transport. The minor conditions associated with frequent re-attendance such as repeat prescriptions, follow-up examinations and dressings and sutures indicate either a patient preference for emergency department services or lack of access to alternative services. There is an undersupply of general practice services in the area with a significantly lower number of medical professional services than the national average.69.70 The dearth of public transport to support access to community-based services makes the use of emergency department services a desirable option.

Statistical significance is all very well but what are the clinical ramifications of these findings? COPD can be managed in the community, particularly in combination with support from chronic disease self-management services.69.70 Diversion of COPD patients to chronic disease self-management services, therefore, should prevent some re-attendances. However, diversion assumes that alternative services are resourced to cope with demand. One factor that would influence re-attendance (or acute exacerbations of COPD) is the frightening nature of the condition. It is sensible to assume that the patient's or carer's anxiety would influence them to return to emergency rather than seek regular care and advice. In addition, access to chronic disease services for COPD patients is often hampered by long waiting times, which act as a disincentive to patients. Another factor is the lack of ongoing support for self-management in the community. Possible solutions to address this issue would be to introduce supported referrals in which patients are assisted to take appointments to pulmonary rehabilitation services and to have access to telephone advice after the completion of the pulmonary rehabilitation course. Increased general practitioner (GP) involvement in supporting chronic illness with management would also be of assistance. Affordable transport options to alternative services should be part of the supported referral system.

Many of the conditions appearing in the top 10 conditions in frequent attenders are amenable to GP care. The availability of GP services is obviously a key issue. In addition, for all conditions, the lack of accessible outpatients care services is a problem. The introduction of adequately funded services operating outside GP business hours to reduce pressure on the emergency department.

There is some debate about the appropriateness of treating the so-called ambulatory care sensitive conditions in general practice. The Report of the Chief Health Officer in NSW states that the acute conditions, such as cellulitis, convulsions and epilepsy may not be preventable, but that hospitalisation can be avoided through timely primary care. The report also states that although chronic conditions, including asthma, hypertension, congestive heart failure and chronic obstructive pulmonary disease can be prevented through behaviour modification and lifestyle change, they can also be managed effectively through primary care, thereby preventing deterioration and hospitalisation.

The finding that patients with neurological re-attend the emergency department can be explained by the undersupply of alternative community-based mental health services in the area. Clinicians at the study hospital report that lack of alternative mental health services is a major problem that contributes to emergency overcrowding (S. Lepley, pen. comm.).

The finding that presentations from frequent re-attenders were less likely to present during summer can be linked to warmer temperatures with fewer respiratory conditions.

What are the implications of these findings? Issen and co-authors maintain that many emergency department patients with minor complaints are referred by general practitioners69 and that a GP per day today provides care to a community cost-effective way to meet their needs: Fast tracking of services for prescriptions, dressings and sutures and follow-up examinations in the emergency department by nurse practitioners, for example, would address part of the problem of overcrowding by frequent re-attenders, but would require additional resources in emergency. Other possible solutions include outpatient clinics either within the hospital campus or in an accessible location outside the hospital, possibly in GP clinics. Adequate resourcing of the additional services would obviously be necessary. As medical supervision would be required, the provision of the additional medically qualified personnel seems to be achievable.

A range of strategies has been trialled in NSW and early results indicate that hospitalisations and presentations may be reduced.6 The strategies include increased GP involvement in strategies focused on early identification and helping patients to manage at home, fast tracking, emergency and chronic disease self-management services in the community.

The strength of the work is the recognition model to identify characteristic conditions with frequent emergency re-attendances. A possible limitation is the robustness of the model. Although the overall fit of the model was significant, the Nagelkerke R² values of less than 10% were low. However, other studies of patient utilisation and clinical data have reported similarly low R² values. A reasonable magnitude of association and claimed good predictive efficacy. The 95% confidence limits for the odds ratios were fairly wide for some of the variables weakening the model somewhat. On balance, it is valid to claim that the model is effective in predicting the frequency of those variables on frequent attendances. Although the overall fit of the model was significant, the Nagelkerke R² values of less than 10% were low. However, other studies of patient utilisation and clinical data have reported similarly low R² values. A reasonable magnitude of association and claimed good predictive efficacy. The 95% confidence limits for the odds ratios were fairly wide for some of the variables weakening the model somewhat. On balance, it is valid to claim that the model is effective in predicting the frequency of those variables on frequent attendances. Although the overall fit of the model was significant, the Nagelkerke R² values of less than 10% were low. However, other studies of patient utilisation and clinical data have reported similarly low R² values. A reasonable magnitude of association and claimed good predictive efficacy. The 95% confidence limits for the odds ratios were fairly wide for some of the variables weakening the model somewhat. On balance, it is valid to claim that the model is effective in predicting the frequency of those variables on frequent attendances.
alternative services options are worthy of consideration. Possible solutions include supported referral of COPD patients to chronic disease self-management services, improved access to mental health services in the community and accessible acute care services for minor conditions such as follow-up examinations, sutures and dressing and repeat prescriptions outside the emergency department.

Competing interests
The authors declare that no conflict of interest exists.

Acknowledgements
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References
Unplanned return visits to emergency in a regional hospital.

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Keywords: emergency medical services; patient care management; disease management; health services accessibility.
What is known about the topic? Patients who present as unplanned return visits are older and have a range of chronic and acute conditions. Some unplanned return visits occur because of limited access to other non-hospital service.

What does this paper add? This paper adds to the field by providing information from a regional hospital in NSW, Australia, on the patient characteristics associated with unplanned returns. It provides a basis for differentiating between other groups of frequent emergency department patients. However, the reasons behind the unplanned return visits rate need to be more fully investigated.

What are the implications for practitioners? The findings have implications for policy makers, administrators and clinicians. This study identified the characteristics of patients who returned to hospital within a month of their first visit.
Abstract

Objective

The aim of this study was to determine the patient characteristics associated with unplanned return visits, using routinely collected hospital data, to assist in developing strategies to reduce their occurrence.

Methods

Emergency department data from a regional hospital were analysed using univariate and multivariate methods to determine the influence of clinical, service usage and demographic patient characteristics on unplanned return visits.

Results

Around 80% of the 16,000 patients attending emergency presented on only one occasion in a year. Some 5% of patients presented with an unplanned return visit. Older patients, those with minor and low urgency conditions and with non-psychotic mental health conditions, those presenting during winter and after hours were significantly more likely to present as unplanned return visits.

Conclusion

Although patient characteristics associated with unplanned return visits have been identified, the reasons the underpinning unplanned return visit rate, such as patient service preference and attitudes need to be more fully investigated.
Background

Researchers have proposed unplanned return visits (URVs) to hospital for the same condition within 28 days of the index admission as an indicator of quality of care [1, 2]. Collection and analysis of URV data is therefore of interest to hospitals. There is debate about whether URVs represent possible treatment failure [3]. URVs may be associated with poor access to alternative services.

Although quality of care and access to alternative services are hospital-specific, inter-hospital comparisons of URVs, however, give a valuable perspective to interpret the results and develop possible solutions. McLean and colleagues [3] in a study in an Australian regional hospital reported that the conditions responsible for returns to hospital were chronic conditions such as heart failure and chronic obstructive pulmonary disease (COPD), acute conditions such as complications of procedures, pneumonia, angina and acute bronchiolitis. Marcantonio et al. [4] in the USA reported patient factors associated with unplanned readmission within 30 days included: age 80 years or older, comorbidities, depression and lack of documented patient or family education. The latter finding suggests that patients might be encouraged to stay away from hospital if they are given information about other services and or about managing their disease. Foran et al. [5] in a study at a rural Canadian hospital, reported that return visits within 72 hours were for low acuity conditions, the most common of which was abdominal pain. These authors contended that “bounce-back” patients might return because of poor access to primary care services and possibly because they were provided with inadequate information about self care. On the other hand, it is reasonable to suggest that reoccurrence of abdominal pain should be regarded as serious and therefore treatment in hospital is the safest option. Unscheduled returns within 72 hours were associated with medical errors in prognosis, treatment, follow up
care, and information, and with dyspnoea and advanced age as reported by Nunez et al [6] in a hospital in the Canary Islands. It was their contention that longer observation times in emergency would lead to a reduction in unplanned returns for serious conditions. Kind et al showed that stroke patients were more likely to "bounce back" with return visits within 30 days [7]. However, as the chances of further transient ischaemic accidents would be high in this group of patients, return to hospital is the safest option. Unplanned return visit ("recidivism") rates were reported in a US hospital to be higher in emergency observation unit patients with painful conditions, although characteristics such as age, sex, or initial length of stay were similar to patients who do not return [8]. The finding that age was not a factor in this study might be due to the restricted sample from the observation unit patients. Jencks et al found that re-hospitalisations among Medicare beneficiaries in the US are prevalent, costly and modifiable [9]. Cardin and others reported on emergency department interventions such as increased physician coverage, physician coordinators, and fast tracking diagnostics and admission procedures without resulting in increased return visits to the ED or hospital readmission [10]. Although some URVs may be avoidable, URVs associated with more serious conditions are appropriate because hospital treatment is a safer option than treatment in the community.

In summary, the literature indicates that URVs are usually associated with age, minor conditions and chronic co-morbidities, many of which can be prevented. Limited access to alternative services was implicated in the occurrence of URVs. The purpose of this study was to identify the factors associated with URVs in a regional hospital using routinely collected hospital data with a view to assisting in the development of strategies to reduce their occurrence. Our hypothesis was that URV patients as a group had different characteristics from the rest of the
patient population and that URVs may be associated with poor access to alternative services such as primary care.
Methods

This study consisted of a retrospective analysis of data from the emergency department collected in 2008 at a publicly funded 150-bed regional hospital in south eastern NSW, Australia. The hospital served a local population of around 100,000. The study focused on the factors associated with URVs, defined as unplanned return visits to hospital within 28 days of the original presentation for the same complaint. The data source was de-identified patient presentation data from the Emergency Department Information System (EDIS) used in NSW public hospitals.

Outcome variable

The categorical outcome variable was whether the presentation was an unplanned return visit within 28 days or not.

Predictor variables

The original variables were: patient identifier number, age, gender, date and time of arrival, country of birth, ICD-9 diagnosis, level of urgency based on the Australian Triage Classification [50], type of visit and mode of separation (treated in emergency or admitted). Type of visit is a local code referring to the type of emergency presentation: normal, planned return and unplanned return within 28 days of the original presentation. A visit is designated as an unplanned return visit within 28 days (URV) if the patient returns to hospital for the same condition as the previous visit, the index visit, within 28 days. URVs are those return visits which are unforeseen at the previous discharge and related to a condition previously treated occurring within 28 days. A return visit is designated as a planned return visit if the patient is specifically instructed by a clinician to return to hospital. In this study, unplanned return visit within 28 days is termed URV.
Each patient presentation was accorded one primary ICD 9 diagnosis based on the major reason for the presentation. A categorical variable was constructed from the Triage classifications of each presentation. Urgent presentations were those classified as Triage 1 and 2 and non urgent presentations were Triage categories 3 to 5. Date and time of arrival variables were converted into hour (business or non-business hours), day (weekend or not weekend) and season of arrival (spring, summer, autumn, winter).

The analysis

The data was analysed either from the perspective of presentations in row-for-each-presentation format or from the perspective of patients in a row-for-each-patient format with nested data for each patient. The primary research question to uncover the patient characteristics associated with URVs required the row-for-each-patient format. However, preliminary univariate analysis was performed on the row for-each-presentation format on the variables for which there were different or potentially different, values for each presentation: hour, day and season of arrival; urgency and diagnosis. Univariate analysis included the variables which were constant for each presentation: age, gender and country of birth.

Regression models and manipulation of predictor Variables

The logistic regression model for multivariate analysis was constructed with the binary dependent variable with categories patients with URVs and patients with no URVs. The independent variables were transformed by counting the number of occurrences in the nested variables for each patient and dividing by the total number of presentations for that patient resulting in a variable of the proportion of occurrences and used in the multivariate analysis. As the values in the proportion variables ranged from zero to one, they were treated as continuous
covariates. The independent diagnosis variables included the proportion of the most common ICD 9 diagnosis codes for presentations resulting in URVs.

Logistic regression was considered the best option for analysis because the dependent variable demonstrated Poisson distribution rendering linear regression models inappropriate [11, 12]. A backward elimination approach was adopted in the interest of achieving a parsimonious model [13, 14]. The categorical variables, male gender, born in Australia and three or more admissions in the year met the criterion of a minimum of ten cases in each category [14].

We used the Holm [15] variation of Bonferroni in the univariate analysis to correct P values for multiple comparisons. Statistical analyses were performed using SPSS statistical software (Version18; SPSS, Chicago, Illinois, USA). Two-sided P values of less than 0.05 were considered statistically significant.

To evaluate the predictive value of the logistic model, receiver operator characteristic (ROC) curves was constructed and areas under the curve was calculated using SAS (SAS Institute, Inc., Cary, NC).

The University of Wollongong/South Eastern Sydney Illawarra Health Service Medical Human Research Ethics Committee approved the research study (approval HE07/271).
Results
The study environment
The study was based at a 150-bed publicly funded regional hospital in an urban coastal area in south eastern NSW, Australia. The hospital website [16] describes the hospital role as:

"[the hospital] provides acute care, emergency, specialist surgical, medical and mental health services as well as a satellite dialysis unit. The hospital provides a lead role in the provision of family midwifery services together with gynaecological, breast, laparoscopic and ophthalmic services for the southern Illawarra."

The service environment is a relatively low socio-economic [17] population with a paucity of general practitioners [18] and poor public transport services [19].

Results of analysis
There were 21,956 presentations by 15,806 patients attending the emergency department in the study year and 5% (787) of patients presented with URVs. The admission rate from emergency for this hospital was 20%.

The comparison of the characteristics of the total presentations and URV presentations by univariate analysis are shown in Table 1. Significant differences were seen between the groups in a number of variables after correction the P values for multiple comparisons. URVs were significantly less likely to be for repeat prescriptions (V681), unspecified follow-up (V679), other orthopaedic aftercare (V548), dressings/sutures (V583), anxiety states (30000), neurosis (3079), all non-psychotic presentations (3000-3190), abdominal pain (7890), renal colic (7880) and unspecified chest pain (78650).

The results of the multivariate analysis are shown at Table 2. Stepwise backward elimination of variables in decreasing order of p values was undertaken on the full model with all variables.
The parsimonious model with the fifteen variables shown in Table 2 was statistically significant with a $\chi^2$ value of 316.07 (15 degrees of freedom, N=15806, p<0.01) indicating the model was able to distinguish between URV patients and non-URV patients. As a whole, the model explained up to 6.3% ($R^2$ Nagelkerk value) of the variance [20, 21] in the dependent variable. As in univariate analysis, patients with urgent conditions were significantly less likely to present as URVs. An additional check of the model was carried out using the area under receiver operating characteristic curve (AUROC) which is a measure for discrimination. The value was 0.6829 indicating that the model was able to distinguish between URV patients and non-URV patients.
Discussion

The purpose of the study was to determine patient factors associated with URVs. The results of the multivariate regression model show that in this hospital, URVs are associated with a number of patient factors, including a range of conditions.

Older age had a significant impact on URVs. A study by Ross et al. [8] reported no age difference between URVs and the total presenting patient population, but the sample of patients was drawn from an emergency observation unit and would be expected to be more uniform in age. Other studies reported older age was a factor in predicting URVs [3, 5-7].

The finding that patients with three or more readmissions were significantly more likely to return for a URV might be linked to the fact that frequently readmitted patients in this hospital [22] were more likely to have chronic disease, including neurosis (ICD 9 code 3079). Patients with neurosis may present as URVs because of the undersupply of GPs [23] and community based mental health services in the area. The work in the USA by Frosch et al. [24] on the emergency department usage patterns by young people with non-psychotic mental health problems is relevant to this study. The findings of Frosch et al. suggested that possible reasons for continued use of emergency rather than community mental health services is influenced by the attitudes of patients and their families, particularly in relation to perceived stigma of using a specific mental health service. Patient beliefs could also be influencing choice of emergency department services for people with non-psychotic mental health problems in this study. Indeed, further work is needed to elucidate the reasons behind observed service usage patterns in this hospital for all conditions.

URVs were associated with chronic conditions such as chronic pulmonary disease, heart failure, angina, pneumonia and bronchiolitis [3] in another Australian study. The lack of chronic
conditions in the URV group of patients in this study could be explained by long hospital stays for people admitted with chronic conditions which would preclude them from returning to hospital within 28 days of discharge.

In line with the study reported by Foran et al [5], patients in our study with conditions of a minor nature were significantly more likely to present as URVs. Our findings may indicate that the treatment and advice given to patients at the first visit for the relatively minor conditions of unspecified follow-up, repeat prescriptions, dressings and sutures, and other orthopaedic after care was not adequate. Another possible interpretation of this finding is that as patients with minor conditions are unable to access other primary care services, return to the emergency department is the only option. Patient preferences might also come into play in URVs. It is possible that patients believe it is more appropriate to return to hospital than to access community-based services. The availability of general practitioner and other community-based services in the area was considered inadequate for the needs of the community by clinicians working in this hospital [18, 25], suggesting that access to other services might be an issue.

However, Australian studies by Nagore et al [26] and Richardson et al [27] reported that there was no evidence that after-hours general practice clinics reduced low acuity emergency department patients. Further work needs to be done to clarify the contribution of access to alternative services to the URVs.

The solutions to unplanned returns to emergency such as longer observation periods in emergency, increased physician coverage, faster diagnostics and admission procedures reported by other researchers [10] are not directly applicable for minor and low urgency conditions found in this study.
The underlying issue for the high prevalence of minor conditions in unplanned returns can be linked to the role of the emergency department. Many contend that emergency is the right place to treat minor conditions because general practice is ill-equipped to deal with these complaints [28].

Both abdominal pain and renal colic are often associated with unpredictable recurrence of symptoms which would explain the high proportion of URVs. Unplanned return visits for these conditions are clinically appropriate.

It is noteworthy that this group of patients who returned as URVs to emergency demonstrated different characteristics from those of frequently readmitted patients [22] at this hospital. Older age and neuroses were, however, associated with both frequently readmitted and URVs. URV patients were characterised by relatively minor conditions such as repeat prescriptions, unspecified follow-up, other orthopaedic after care and dressings/sutures, while frequently readmitted patients had chronic conditions and an urgent triage classification. Frequently readmitted patients diagnosed with urgent conditions require hospital treatment.

Limitations of the study are that it relates to a single hospital. The range of alternative services in the hospital area is an important factor in URVs. However, the results may provide insights for other regional hospitals in areas with similar under-supply of primary health care services in the local area. Although access issues were discussed, data on the accessibility of the full range of alternative services was not collected. The univariate analysis included correction for multiple comparisons which conferred additional predictive value to the analysis. The robustness of the regression model may also influence the strength of the study. Although the Nagelkerk index value is low, other studies have reported low values [29, 30]. The robustness of the model was also strengthened by the application of the area under the receiver operating characteristic curve.
(AUROC). The accuracy of the primary diagnosis collected in the EDIS might be questioned as the results of tests to confirm the original diagnosis are not available at the time of data collection[31]. This would be particularly in patients with comorbidities. The strengths of this study are the demonstration of a method for a multivariate model for analysis of routinely collected hospital data and the links to possible strategies for reducing URVs.
Conclusion

Minor conditions contribute to the unplanned return visit rate. The reasons behind patient choice of emergency department services for these conditions need to be further elucidated.
Table 1. Univariate analysis showing the differences in frequencies between the non-unplanned return visits presentations and URV presentations.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Non_UNRV presentations</th>
<th>Presentations as URVs N=987</th>
<th>P Value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Repeat prescriptions V681</td>
<td>2.12%</td>
<td>6.98%</td>
<td>0.00167*</td>
</tr>
<tr>
<td>Unspecified follow-up V679</td>
<td>1.07%</td>
<td>6.40%</td>
<td>0.00172*</td>
</tr>
<tr>
<td>Other orthopaedic after care V548</td>
<td>0.23%</td>
<td>1.17%</td>
<td>0.00179*</td>
</tr>
<tr>
<td>Dressings/sutures V583</td>
<td>0.64%</td>
<td>1.92%</td>
<td>0.00185*</td>
</tr>
<tr>
<td>Anxiety states 30000</td>
<td>0.42%</td>
<td>1.39%</td>
<td>0.00192*</td>
</tr>
<tr>
<td>Neurosis 3079</td>
<td>0.03%</td>
<td>5.50%</td>
<td>0.00200*</td>
</tr>
<tr>
<td>All non-psychotic presentations</td>
<td>0.81%</td>
<td>1.92%</td>
<td>0.00208*</td>
</tr>
<tr>
<td>Abdominal pain 7890</td>
<td>5.25%</td>
<td>7.79%</td>
<td>0.00217*</td>
</tr>
<tr>
<td>Renal colic 7880</td>
<td>0.48%</td>
<td>1.39%</td>
<td>0.00227*</td>
</tr>
<tr>
<td>Unspecified chest pain 78650</td>
<td>4.48%</td>
<td>2.35%</td>
<td>0.00238*</td>
</tr>
<tr>
<td>Persistent vomiting 5362</td>
<td>1.42%</td>
<td>2.45%</td>
<td>NS</td>
</tr>
<tr>
<td>Winter presentation</td>
<td>24.21%</td>
<td>27.32%</td>
<td>NS</td>
</tr>
<tr>
<td>Constipation 5640</td>
<td>0.64%</td>
<td>1.17%</td>
<td>NS</td>
</tr>
<tr>
<td>Mean age</td>
<td>40.69%</td>
<td>40.60%</td>
<td>NS</td>
</tr>
<tr>
<td>Australian born</td>
<td>82.84%</td>
<td>81.43%</td>
<td>NS</td>
</tr>
<tr>
<td>Male</td>
<td>52.17%</td>
<td>52.76%</td>
<td>NS</td>
</tr>
<tr>
<td>Urgent (Triage 1&amp;2)</td>
<td>6.03%</td>
<td>2.56%</td>
<td>NS</td>
</tr>
<tr>
<td>Weekend</td>
<td>31.11%</td>
<td>32.76%</td>
<td>NS</td>
</tr>
<tr>
<td>After hours</td>
<td>48.89%</td>
<td>50.69%</td>
<td>NS</td>
</tr>
<tr>
<td>ACS rapid</td>
<td>3.99%</td>
<td>2.56%</td>
<td>NS</td>
</tr>
<tr>
<td>ACS chronic</td>
<td>1.32%</td>
<td>0.96%</td>
<td>NS</td>
</tr>
<tr>
<td>Autumn presentation</td>
<td>24.95%</td>
<td>24.55%</td>
<td>NS</td>
</tr>
<tr>
<td>Spring presentation</td>
<td>24.96%</td>
<td>24.76%</td>
<td>NS</td>
</tr>
<tr>
<td>Summer presentation</td>
<td>25.87%</td>
<td>23.37%</td>
<td>NS</td>
</tr>
<tr>
<td>Respiratory distress 78609</td>
<td>2.33%</td>
<td>1.81%</td>
<td>NS</td>
</tr>
<tr>
<td>All Psychotic presentations</td>
<td>0.71%</td>
<td>1.07%</td>
<td>NS</td>
</tr>
<tr>
<td>Other arthropod born diseases 0088</td>
<td>0.94%</td>
<td>1.17%</td>
<td>NS</td>
</tr>
<tr>
<td>Unspecified backache 7245</td>
<td>1.28%</td>
<td>1.28%</td>
<td>NS</td>
</tr>
<tr>
<td>Headache 7840</td>
<td>0.81%</td>
<td>1.28%</td>
<td>NS</td>
</tr>
<tr>
<td>Other unspecified non-infectious gastroenteritis &amp; colitis 5589</td>
<td>0.59%</td>
<td>1.07%</td>
<td>NS</td>
</tr>
</tbody>
</table>

NS = not significant

*significant value after adjustment for multiple comparisons using Holm procedure.
Table 2. Binary logistic regression assessing the impact of the independent variables on patients with unplanned return visits.

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>P value</th>
<th>Odds ratio</th>
<th>95% Confidence interval for odds ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>.025</td>
<td>1.003</td>
<td>1.000 - 1.006</td>
</tr>
<tr>
<td>Patients with under three admissions in the year</td>
<td>.000</td>
<td>7.910</td>
<td>5.362 - 11.670</td>
</tr>
<tr>
<td>P(^1) Urgent conditions (triage 1 &amp; 2)</td>
<td>.007</td>
<td>5.546</td>
<td>.353 - 84.5</td>
</tr>
<tr>
<td>P(^1) Abdominal pain (7890)</td>
<td>.000</td>
<td>1.745</td>
<td>1.294 - 2.353</td>
</tr>
<tr>
<td>P(^1) Unspecified follow-up (V679)</td>
<td>.000</td>
<td>12.235</td>
<td>7.556 - 19.813</td>
</tr>
<tr>
<td>P(^1) Repeat prescriptions (V681)</td>
<td>.000</td>
<td>12.175</td>
<td>7.849 - 18.886</td>
</tr>
<tr>
<td>P(^1) Neurosis (3079)</td>
<td>.001</td>
<td>1.945</td>
<td>1.320 - 2.864</td>
</tr>
<tr>
<td>P(^1) Persistent vomiting (5362)</td>
<td>.012</td>
<td>1.975</td>
<td>1.159 - 3.366</td>
</tr>
<tr>
<td>P(^1) Dressings/sutures (V583)</td>
<td>.000</td>
<td>8.821</td>
<td>3.631 - 21.430</td>
</tr>
<tr>
<td>P(^1) Renal colic (7880)</td>
<td>.026</td>
<td>2.436</td>
<td>1.112 - 5.339</td>
</tr>
<tr>
<td>P(^1) Headache (7840)</td>
<td>.029</td>
<td>2.110</td>
<td>1.081 - 4.118</td>
</tr>
<tr>
<td>P(^1) Constipation (5640)</td>
<td>.026</td>
<td>2.471</td>
<td>1.114 - 5.482</td>
</tr>
<tr>
<td>P(^1) Orthopaedic after care (V548)</td>
<td>.001</td>
<td>5.480</td>
<td>2.017 - 14.889</td>
</tr>
<tr>
<td>P(^1) Winter presentation</td>
<td>.007</td>
<td>1.272</td>
<td>1.069 - 1.513</td>
</tr>
<tr>
<td>P(^1) After hours presentation</td>
<td>.009</td>
<td>1.251</td>
<td>1.059 - 1.478</td>
</tr>
<tr>
<td>Constant</td>
<td>.000</td>
<td>.030</td>
<td></td>
</tr>
</tbody>
</table>

\(^1\) P = proportion of patients with

Note: The final parsimonious model includes all significant independent variables in the multivariate analysis.
Acknowledgments, Competing interests, Funding

The cooperation of the staff and patients of Shellharbour Hospital is gratefully acknowledged.

There are no competing interests.

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What distinguishes clinicians who better support patients for chronic disease self-management?

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Abstract. Many frequent readmissions due to acute exacerbations of chronic disease could be prevented if patients self-managed. This study explored factors involved in patient activation for chronic disease self-management by qualitative analysis of interview data from hospital and community-based clinicians and patients. All clinicians reported that many frequently readmitted patients did not readily take up referral to chronic disease self-management services. This reluctance was compounded by system or access barriers. Clinicians who had a defined role in chronic disease management and patient-centred and behaviour change skills reported that although some patients were more resistant than others, patients could be persuaded to adopt self-management behaviours. Hospital clinicians and GPs were more inclined to attribute blame to clinical, social and personal patient factors, such as difficulty with support at home, social circumstances and reluctance to take responsibility, investment in extending the skills and role of hospital clinicians and GPs to take a more supportive role in patient uptake of referrals to chronic disease self-management services would reduce hospital readmissions. Improvements in access to chronic disease self-management and GP services are also needed to address failure to take up chronic disease self-management.

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Background
Clinicians and hospital managers agree that the large number of people using hospital services for the treatment of acute exacerbations of chronic disease puts pressure on scarce hospital resources. Accordingly, state governments in New South Wales (O’Callaghan 2008), Victoria (Government of Victoria Department of Health 2007) and South Australia (Government of South Australia 2004) have introduced specific strategies to increase diversion of chronic disease patients from hospitals to alternative community-based services. In line with these initiatives, Commonwealth Government policy detailed in the National Health Priority Action Plan places great emphasis on improving chronic disease management (National Health Priority Action Plan 2007).

Chronic disease self-management (CDSM) is a process by which people monitor and manage the symptoms of their disease as well as other aspects of their health, using knowledge of their condition and management. CDSM involves: monitoring and managing signs and symptoms of the condition; managing the impact of the condition on physical, emotional, occupational and social functioning; adopting lifestyles that address risk factors and promote health by focusing on prevention and early intervention; having access to, and confidence in, the ability to use support services.

This is a complex process involving a considerable level of skill on the part of the patient. CDSM supports what health professionals, carers and the health system do to assist patients to manage their condition. CDSM support requires clinicians to have specific skills and competencies that cut across broad categories of patient-centred and disease-specific treatments. These include: communication (especially with older people), clinical skills, education and training, information technology, care coordination, and research into specific conditions.
related in access and external factors in the community. If we want more people to self-manage, thereby avoiding hospital, we need to understand how these factors work. Under the Chronic Care Model, clinicians 'activate' patients to take up CDSM by giving them confidence, information and support to self-manage. Is this reason for chronic disease patients returning to acute care setting indicative of a failure of activation for CDSM? Many theories help us to understand health behaviours. Behaviours are influenced by what people think and feel. The theory of planned behaviour (Ajzen 1991) postulates that the factors that influence people to take up a behaviour are that they believe it is achievable (intent), that they have the time and energy and that they believe it will work for them. In line with this theory, patients who use hospital services to manage their chronic diseases, for example, believe it is reasonable to manage their disease by restricting hospital frequently, they see others managing by frequently attending hospital and they believe resistance for hospital care works.

Hedlund's (1977) self-efficacy theory can also be applied to managing chronic disease, it specifies that patients adopt healthy behaviours for similar reasons, but with an important addition; as well as persuasion they need to have confidence in their own ability to act. Both the theory of planned behaviour and self-efficacy theory highlight the importance of a range of attitudinal factors that come into play when people consider adopting a particular behaviour. Work by Hlobana and Mabuza (2010) has shown that successful experiences of health Behaviours can help people to build confidence and lead to activation of self-management. This also means that, including clinicians, can activate patients by building their confidence and self-efficacy.

These theories can be applied to clinicians (as well as patients) who encourage patients to take up CDSM. Analysis of the important correlation between clinicians' skills and patients adopting self-management suggests that the better the partnership between patients and health professionals, the more confidence patients have in caring for themselves (Powell et al. 2009). Clinicians can be influenced to change their behaviour through showing them evidence that CDSM works, increasing their confidence and supporting them with strategies to develop CDSM skills in their patients. Report that GPA/AM (Zerbe et al. 2005) and other community-based clinicians (Lever et al. 2008) are more likely to provide self-management advice to patients whom they believe to be ready for or with both planned behaviour and self-efficacy stimuli.

Other aspects in the literature provide evidence of the importance of patient and clinician attitudes, behaviour and skills. Using patient and clinician attitudes in acute and long-term care, Asai (1999) pointed out that physicians need to move in a more equal relationship, where patients manage their own illness, to achieve better outcomes in chronic disease care. Weekes and co-workers argued for a more comprehensive approach in CDSM, involving a range of health professionals across the health sector to support CDSM and maintain agreed standards (Weekes et al. 2003). There have been strong arguments put forward that simply providing advice is not enough to convince patients to self-manage. These changes advocated involve introducing, or upgrading, clinician skills as well as changing, clinician attitudes.

Frequently malnourished patients (FRP) represent a difficult group of high-needs patients for most hospitals. In spite of hospital policies on evidence-based disease patterns on CDSM services, many FRP are diagnosed with acute conditions of chronic disease (Kathy et al. 2010). We sought to identify clinician, patient, and service factors involved in CDSM uptake. CDSM research provided the framework and pointed the way to influences that might be important. We asked whether the clinician's treatment of an apatient was influenced by perception of the patient's circumstances as well as by the clinician's skills in the areas of patient-oriented care, behavioural change and organisational improvement. This case study analysed the information collected from patients and clinicians at a regional hospital to ascertain the factors that promote CDSM uptake and prevent patients returning to hospital.

Methods

The study was based at a publicly limited 156-bed regional hospital located in a coastal urban area in south-eastern New South Wales, Australia, with a leader population of around 100,000 people. Clinicians were invited to take part in a semistructured interviews about their patients with chronic disease. Clerkship of 18 clinicians, recruited on the basis of their involvement in the treatment of people with chronic diseases, was deliberately drawn from both hospital and community settings to explore potential differences in attitudes and skills relating to the treatment of chronic disease patients. The clinical settings included the hospital catchment area with a goal to cover those patients with whom they felt comfortable.

The sample of 38 patients was drawn from two groups: those who had been referred to CDSM but were returning to hospital when they experienced symptoms they found unmanageable (U6P, n = 16) and those who had taken up referrals to CDSM services and were managing by consulting with their CDSM clinicians (self-managing patients, SMP, n = 22). FRP were recruited directly from the emergency department or inpatient ward, SMP from the respiratory outpatient clinic (RSPIC) or chronic heart failure service.

To ensure that it was clinically useful for the interview to take place and that no patient felt pressured into participating in the study, each prospective patient participant was approached by a known clinician and asked about being involved in the project. Recruitment was undertaken after patient informed consent was obtained. All participants wrote informed consent as their first language. After participant consent, interviews were digitally recorded and later transcribed for analysis. Patients gave consent for access to medical records to enable information on service usage and clinical data to be collected. Data were stored electronically in a password-protected file.

Clinician interview questions focused on the clinician's skills and attitudes in relation to people with chronic disease, the patient–clinician relationship and CDSM. Patient interview questions focused on the patient–clinician relationship and referral to CDSM services. Care was taken to avoid mentioning labels about hospital service use and a judgmental stance about patient choice of management approaches.
The interviews data were analysed as they were collected (Kvale 2007). Coding using NVivo 8 (QSR: International, Sage, LA, USA) built on the interview questions, but was then reflective and interactive, enabling continuous modification of the analysis in accommodative new data and new insights about the data. As the analysis progressed, queries were posed to: (i) elicit deeper analysis and interpretation, and (ii) to the data. Interviews with both clinicians and patients were semi-structured to provide the participants ample opportunity to present their views as well as insight into questions. In the first interview session was unstructured and descriptive. The next round of analysis were deeper into the data to interpret clinicians and patient attitudes, to identify links between attitudes to the reasons for frequent hospital use and failure to take up CDSM. The third level of analysis focused on clinicians' skills, knowledge and understanding, the orientation of the clinician to a directive relationship with the patient and to system barriers and enables. Issues of trustworthiness in analysis were addressed through regular discussions between the authors to check on the consistency of data interpretation and application of the theoretical models. Findings were also discussed with CDSM clinicians and self-managing patients to check for accuracy of interpretation.

The University of Wollongong and South Eastern Sydney Illawarra Health Service Medical Human Research Ethics Committee approved the research study (approval HEO/7271).

Sample details

Comparison of the two patient groups showed no apparent differences between FRP and SMP in terms of age, sex, living arrangements, educational level achieved or comorbidity (Table 1). The groups differed significantly in the frequency of presentations and admissions to hospital, with FRP showing a higher hospital usage rate. The clinician types included in the study ranged across community and hospital settings (Table 2). Approximately one-third of clinicians were under 40 years of age and one-third were male. Those in two-thirds of clinicians were medical or nursing and one-third were allied health. Clinicians working in CDSM services, two physicians and one psychologist, saw their role as providing information and education about CDSM, making referrals to CDSM services and supporting CDSM. The clinicians working in the hospital service saw their role as medical stabilization or supporting discharge to home.

Findings

The focus in promoting uptake of self-management services arising from the analysis of interview data related to: (i) difficulties in the service environment and access to services; (ii) the process of referral to and uptake of CDSM services; and (iii) the level of trust and disclosure in the patient-clinician relationship from the perspective of both the patient and the clinician.

How clinicians described the service environment

Referral to CDSM services

The CDSM services were located at facilities outside the hospital. The hospital policy was to refer chronic disease patients to the appropriate CDSM service, such as pulmonary or cardiac rehabilitation, chronic heart failure, stroke or diabetes. This was activated as a written referral before discharge. The most usual form of referral to CDSM services in general practice was by the provision of written or oral information about the service. Physicians, emergency department clinicians and GPs all reported that they referred patients to CDSM services when clinically appropriate. Emergency department clinicians acknowledged that lack of privacy in the emergency environment was a barrier to finding out about patient circumstances and factors that might influence lack of CDSM uptake.

All clinicians agreed that one of the major barriers to CDSM uptake was the lack of resources to follow up CDSM referrals. They suggested that changes in procedures, such as making appointments with CDSM services before patient discharge and reminder phone calls to patients, would improve uptake and prevent some readmissions.

"I don't have the manpower to follow them all up as there's a long waiting list. They are given the education package on the ward. It's up to the patients to phone the chronic heart failure service. They very rarely do. So I will then say: 'Yes, I've been meaning to call.'" (female, 55–60 years)

Table 1. Analysis of clinical and personal patient characteristics and service usage comparison of the two patient groups: frequently readmitted patients (FRP) vs attending chronic disease self-management (CDSM) and self-managing patients (SMP) attending CDSM.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>FRP (n = 14)</th>
<th>SMP (n = 17)</th>
<th>P-value Mann–Whitney U-test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average age (years)</td>
<td>72 (range 47–89)</td>
<td>70 (range 41–91)</td>
<td>NS</td>
</tr>
<tr>
<td>Male (%)</td>
<td>7</td>
<td>10</td>
<td>NS</td>
</tr>
<tr>
<td>Post-secondary education (%)</td>
<td>2</td>
<td>3</td>
<td>NS</td>
</tr>
<tr>
<td>Lives with family (%)</td>
<td>9</td>
<td>7</td>
<td>NS</td>
</tr>
<tr>
<td>Lives alone (%)</td>
<td>4</td>
<td>8</td>
<td>NS</td>
</tr>
<tr>
<td>Received support services at home (%)</td>
<td>7</td>
<td>3</td>
<td>NS</td>
</tr>
<tr>
<td>Average Charlson Comorbidity Score</td>
<td>6.6</td>
<td>6.2</td>
<td>NS</td>
</tr>
<tr>
<td>Took up CDSM ref/visits (%)</td>
<td>3</td>
<td>17</td>
<td>P &lt; 0.05</td>
</tr>
<tr>
<td>Average number of hospital admissions over the last 5 years (%)</td>
<td>3</td>
<td>2</td>
<td>P &lt; 0.05</td>
</tr>
<tr>
<td>Average number of emergency presentations over the last 5 years (%)</td>
<td>16</td>
<td>3</td>
<td>P &lt; 0.05</td>
</tr>
</tbody>
</table>

Publication 4 – What distinguishes Clinicians...
This clinic highlighted the problems of long waits for a place in CDSM services, lack of follow up of referrals to CDSM and the seeming reluctance on the part of the patient to make contact with CDSM services.

Access issues

All CDSM services had waiting times of several weeks or sometimes months, indicating that they were insufficiently resourced to cope with demand. Clinicians reported that they thought low uptake of CDSM referrals could be related to the long waiting times for services. The dispirited way in which some clinicians talked about the CDSM waiting time suggested that they felt referral was a lost cause and there was little hope that patients would take up referrals. However, neither hospital clinicians nor GPs reported that support was provided to patients during the wait for CDSM services. Although there was clear need for improvement for patients waiting for CDSM, their workloads were such that it was not possible for them to identify and support all patients requiring CDSM.

Another access barrier in the patient journey to self-management was the undersupply of GPs in the area. Many GPs were reluctant to provide CDSM services and CDSM referrals in the area. As a result, the patient had to travel to the nearest town to receive CDSM services. All clinicians pointed to the shortage of GPs in the area as playing a major part in patients attending the emergency department.

They try the Dragon at the desk and can’t get in – that’s what she is trained to do. (male, 55–60 years)

Furthermore, the GP undersupply would impose large workloads on GPs in the area, restricting the time they could offer for support for CDSM referrals and uptake. The issue identified by clinicians related to resources for following up referrals and access to CDSM and GP services. In summary, there were access and referral barriers to patients taking up CDSM.

How patients described their encounters with clinicians

None of the patients interviewed said that they had a poor relationship with the clinicians who treated them. Despite reporting that there were periods before adopting self-management during which they were not communicating effectively with their clinicians, SMP linked their uptake of CDSM to the strength of communication and confidence they had in the clinician.

I was unable to do a few things so I went to the doctor [GP]. I was saying “good” for years when people asked me how I was. Until I asked him [GP] for a disabled sticker he had no idea how sick I was. Then [name of physician] put me on the school for poker. (SMP box 6, male, 86 years)

This patient had been seeing his GP regularly, but not talking about the restrictions his breathing difficulties imposed on his life. In spite of the regular visits, it took a long time for the GP to gauge the seriousness of the condition and refer to the outpatient respiratory clinic, indicating a low level of patient–GP communication. The patient started self-managing after attending the outpatient respiratory clinic, with the support of the respiratory physician. He also attended a 6-week course at the pulmonary rehabilitation course (“School for Puffers”). The patient had been self-managing with the assistance of the physician in whom he had trust and confidence. He looked back on his experience in self-managing and was prepared to put up with the change in his behaviour and attribute it to the help from his physician.

Twelve of the 17 SMP had been through periods of frequent admissions or presentations to hospital before adopting self-management. They commented that the close relationship with their CDSM clinicians activated them to engage in self-management and that this was reinforced by attending the group pulmonary rehabilitation or chronic heart failure service. The activation to self-management was similar to that described for the respiratory patient above, in that these patients could look back on their experience and identify the time at which they changed their behaviour to self-manage with support from their clinician.

The effectiveness of the patient–clinician relationship in activating patients to become SMP was further, and dramatically, evidenced in a patient who said he had presented to hospital many times in the previous year. He described how her encounter with an ambulance officer convinced her to self-manage.

I was for an ambulance and it came: and a very nice young lady came. She told me her troubles and I told her mine (laughing) – she advised me to stay at home. She said ‘hospital is not the place for you.’ (SMP box 9, female, 83 years)

The relationship between the ambulance officer and the patient was the stimulus for the patient to be convinced that self-management was the best option. In spite of many encounters with hospital clinicians in the preceding year, the encounter supported self-management uptake. What was special about it? “She told me her troubles and I told her mine” – two-way communication, which engendered trust and encouraged the patient to stay at home and avoid hospital. All SMP recalled the occasion during which they were activated to self-manage by their clinician. All SMP were in regular contact with their CDSM clinicians to manage symptoms and reported that they had recourse to a range of strategies, developed with the help of CDSM clinicians, to deal with symptoms and restrictions on daily life. They also indicated that when necessary they were able to obtain advice from clinicians, sometimes by telephone, to manage changing symptoms.
What was different about FRP and their relationship with clinicians? It was clear that some FRP had developed a relationship of trust with their clinicians in the hospital and with their GP. However, the patient–clinician relationship had not resulted in activation to self-management. All FRP handed over management to clinicians believing that it was the clinician’s responsibility, rather than the patient’s:

They [clinicians] should keep you well (FRP 10, female, 59 years)

Another FRP reported that hospital was like home because she was so well known there by clinicians. This patient had a close relationship with hospital clinicians and trusted them but, from her description, the clinicians were focused on getting her to the point of safe discharge rather than encouraging her to self-manage. Although she had a regular GP, she reported that it was difficult to get appointments, making her more dependent on the support she received in hospital.

In spite of the policy to refer chronic disease patients to CDSDM services on discharge, the failure rate for referral uptake was high. Only four FRP reported contact with CDSDM services. Two patients who had attended the pulmonary rehabilitation course indicated that they found it useful in helping them to manage their breathing difficulties but did not have regular contact with the service and continued to attend hospital for managing symptoms. No FRP were attending CDSDM services at the time of interview. Some indicated a definite reluctance about attending CDSDM services.

I’m not even thinking about it [attending the chronic heart failure service]. If they want me to go up there they have to sort it out (FRP 1, male, 74 years)

This patient showed that he thought the clinicians should sort it out for him but did not take up the offer of community transport to the service. Others indicated that they waited for clinicians to contact them, rather than make contact themselves.

Although FRP were in frequent contact with their hospital clinicians and GPs and often had developed a relationship of trust with them, they had not been activated to self-management.

The clinician’s perspective

Clinician role

Although all clinicians generally supported the notion that readmissions could be prevented if more chronic disease patients were self-managing, their clinical role was important to determine the extent of their involvement in CDSDM and their attitudes (Table 3). For example, hospital directors and nurses saw their role as medical stabilisation and management of the patient to facilitate discharge. Hospital allied health professionals, physiotherapists, occupational therapists and social workers saw their role as assisting in bringing the patient to the point where barriers to discharge, such as housing, family support and mobility, were overcome. GPs felt that their role with regard to CDSDM was to provide information, to refer CDSDM services and to support CDSDM. It was the role of the CDSDM clinicians to activate and support self-management. Perceived clinical role, therefore, played an important part in whether clinicians actively encouraged patients to attend CDSDM services.

Clinician knowledge and skills

Hospital clinicians generally had a relatively poor knowledge of services available in the community for patients with chronic diseases. This was a barrier to referral to CDSDM services.

There’s not a lot out there in community to deal with the sense of loss they have. (female, 50–55 years)

GPs reported that they knew about the CDSDM services. Not surprisingly, CDSDM clinicians indicated that they understood CDSDM services and had well developed skills to support patients to accept responsibility. Both GPs and CDSDM clinicians reported that they had skills in supporting CDSDM. CDSDM clinicians additionally reported that their skills in building patient confidence and trust helped patients to accept CDSDM. Their description of their relationships with patients indicated that they had well developed patient-centred and behaviour change skills. They gave high priority to developing rapport with patients and to persuading them to change their behaviour by monitoring symptoms and taking action in line with the agreed management plan.

So I try to give them hope. I say: ‘I can guarantee you’ll feel a bit better and it’ll keep you out of hospital’. I listen to their story – you have to be prepared to listen. (female, 55–60 years)

Clinician attitudes influencing CDSDM referral and uptake

Although the term “frequent flyer” was used commonly by clinicians in the hospital, no clinicians were overtly disparaging about patients with high hospital usage rates. As the discussion progressed, the possible reasons for frequent usage, however, more overt clinician attitudes emerged around the issues of the impact of the patient’s social circumstances and attitudes.

Clinician attitudes: impact of patient circumstances

All clinicians felt that socioeconomic factors and lack of family and other supports played an important part in failure to take up CDSDM.

Yes. We have a frequent flyer, [male], who has a violent son. The mother gives him morphine. We couldn’t medically send him home but she needs to calm down. Yes, they’re medically stable but not going to last long at home. (female, 46–50 years)

This hospital clinician had concerns about the patient’s home situation but demonstrated the focus on medical stabilisation, whether perceived its limited role ending at the hospital door.

Clinician attitudes: impact of patient attitudes

Hospital clinicians and GPs thought that there were distinct groups of patients those resistant to CDSDM who became FRP, and those more willing to accept responsibility and self-manage, thereby avoiding readmissions. The tendency to blame the patient’s attitude for reluctance to CDSDM uptake was evident among hospital clinicians and GPs.
They don’t want to take responsibility. A lot of them think: someone else will look after their health. [they] expect someone else to fix it. (female, 50–55 years)

They also thought that FRP was less likely to keep medical appointments.

Yes, they’re in denial… Yes, FRP don’t go off to see the specialists. I often tell them to go, but they don’t. They don’t go to the GP either. (female, 50–55 years)

Use of ‘tell’ rather than ‘encourage’ or ‘support’ additionally illustrated a directive approach evident in some clinicians.

This directive approach was not evident in CDSM clinicians. In contrast, they contended that although it was more difficult to teach some patients to self-manage, such as people with dementia, cognitive impairment, lack of English language skills, schizophrenia and intellectual delay, all patients could be persuaded over time. Involving the family and/or the facility where the patient lived was important as well. Activating patients by understanding what mattered to them, being patient-centered, was a critical ingredient for successful self-management. CDSM clinicians reported working through patient denial by

winning trust and building rapport, and so negotiating behaviour change.

Cognitive skills are so important as long as you keep it simple. Self-efficacy is important. It’s as if they have decided it’s too hard and they are feeling hopeless about it. I back away and talk about normal things and try to keep the rapport with them. If they say ‘none of this applies to me’ I don’t have any way of this. I just say ‘OK’. I hear it but don’t agree. Then they come back and talk about the possibilities. If I suggest that they consider, say, giving up a little salt and trying the Laos for two days, and I guarantee that they will feel a little better. It may take one session or a few calls or even a few visits. (female, 55–60 years)

The behaviour change skills required to support patients to choose self-management are evident from this excerpt. This clinician working with dementia/heart failure patients was prepared to negotiate; allowing the patient time to change, and to persuade. Similarly, the physician who saw patients in the ROC had established a rapport with patients and spoke with understanding.

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<th>CLINICIAN ENABLERS</th>
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<td>Patient-centred skills</td>
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<td>Behaviour change skills</td>
<td>Adequate access to GP and CDSM services</td>
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<td>Positive belief that patients can be activated</td>
<td>Supported CDSM referrals and follow up</td>
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<th>CLINICIAN BARRIERS</th>
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<td>Poor knowledge of CDSM services</td>
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<td>Lack of clinical CDSM skills</td>
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<td>Negative attitude to high use patients</td>
<td>Inadequate referrals and follow up to CDSM services</td>
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![Fig. 1.](image-url) Clinicians and systems access enable and barriers to uptake of dementia chronic self-management (CDSM).
of his patients’ circumstances and emotions and of supporting them to accept responsibility.

The finding that clinicians and system barriers are summarised in Fig. 1. The summary indicates that clinician attitudes, skills and knowledge, particularly patient-centred skills and behaviour change (navigating) skills, enable them to motivate patients to accept responsibility for self-management. The other key clinician ingredients were the belief that patients could be supported to take responsibility, knowledge of CDSM services and the belief that CDSM services work. On the other side of the equation was the lack of people (clinician) resources and the access issues, primarily of GP and CDSM services. Without the necessary clinician and access modules, the clinical encounter was likely to result in the patient failing to accept responsibility and in repeated visits to the GP and/or hospital.

Discussion

Our findings resonate with another GP study that identified difficulties in communication between GPs and CDSM service providers and that the more directive approach GPs took in guiding patients (Hallinan et al. 2009). There is evidence that other health professionals, such as practice nurses (McDonald et al. 2008), community health nurses (Law et al. 2009) and emergency hospital staff and community health professionals (Kates and Stage 2010), are ill-equipped to manage CDSM. In line with our findings, these reports cite the reasons as (i) lack of skills to engage with patients to establish a more equal relationship; and (ii) inadequate knowledge of CDSM services. Other clinician barriers reported relate to the narrow medical paradigm that works against consideration of the patient’s perspective of the complexity of life with a chronic disease (Thom et al. 2000, Thorne and Paterson 2001; Ryga and Kelsall 2005; Blomke et al. 2006; Nagelkerke et al. 2006; Bourbonnais and Bierlink 2008; Law et al. 2009; Thiele and Russell 2010). These findings also accord with the skills specified as patient-centred skills (Australian Government Department of Health and Ageing 2008). There are several mitigating factors that contribute to the lack of support for hospital clinicians and GPs for CDSM uptake. Role congruence is important: hospital clinicians see their primary role as treating patients and getting them home. A shift in the role of hospital clinicians and GPs to activate and support CDSM is needed. Because GPs and hospital clinicians concentrate on patient throughput, referral to and encouragement of CDSM can fall by the wayside.

Behaviours have been shown to influence clinician behaviour in the management of chronic disease risk factors (Law et al. 2009). Community health clinicians who felt that clinicians were unlikely to take up healthier lifestyle management behaviour were less likely to take action. SME had developed higher self-efficacy through activation and support from CDSM clinicians and GP, without activation and support, had lower self-efficacy in CDSM. Self-efficacy theory (Bandura 1977) suggests that people who lack confidence in their ability to act are less likely to take action. Higher CDSM support might be achieved by working with clinicians to enhance skills and overcome the barriers to their support for CDSM, such as lack of knowledge of CDSM services, the belief that some patients are resistant to taking responsibility, and lack of clarity as to the role in CDSM. Allocation of additional resources to CDSM services to meet demand would improve access. Allowing the

Moreover, clinicians who thought that patients would not be able to self-manage or would not take up referrals would be less likely to make a referral. Clinician beliefs can be modified and skills can be taught. However, training and support to build and maintain skills to strengthen the role of hospital clinicians and GPs to facilitate patients to make a wise and support a time for current patient care activities. The Co-operative care program in the Brisbane South Division of General Practice, based on the UK Health Foundation’s model, developed clinicians’ CDSM skills by providing patient feedback on self-management interventions. This work demonstrates a practical example of how skills can be improved in the general practice environment. We are not advocating that all hospital clinicians and GPs become expert CDSM providers, rather that the skills of hospital clinicians and GPs are enhanced to take the opportunity to activate and support patients to take up CDSM referrals.

Conclusions

This study is the first in a single exploratory case study relating to one hospital and therefore might not be generalisable to other hospitals. It was a relatively small sample of patients and clinicians. However, the clinic sample included a relatively wide range of clinician types. The patient sample was deliberately selected to examine different management strategies and the clinic sample to overcome a wide range of clinical types and settings. There was limited qualitative analysis, with the major focus on qualitative analysis and interpretation of interview data. Future work could include a longitudinal study of patients after discharge to ascertain service destinations and the administration and evaluation of a multidisciplinary team plan preparation (Australian Government Department of Health and Ageing 2011), which can be applied in CDSM. However, clinicians support the patient uptake of CDSM can still be neglected in an overloaded general practice environment.

CONCLUSION

Patients with a chronic disease benefit from clinician activation to self-manage. The clinician skills required to activate were patient-centred and behaviour change skills involving a capacity to understand the patient’s spirit of care and ability to negotiate with patients. Higher CDSM support might be achieved by working with clinicians to enhance skills and overcome the barriers to their support for CDSM, such as lack of knowledge of CDSM services, the belief that some patients are resistant to taking responsibility, and lack of clarity as to the role in CDSM. Allocation of additional resources to CDSM services to meet demand would improve access. Allowing the

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**What is known about the topic?** The Chronic Care Model describes a range of factors which encourage people to self-manage, specifying patient activation as a key element in the uptake of chronic disease self-management.

**What does this paper add?** This study compared two groups of chronic disease patients, those managing by returning to hospital and those self-managing. The study analysed what patients said about the activation to achieve self-management, identifying the elements in the activation process. It provided evidence from a regional Australian hospital-service setting that patients need to be supported through a process of activation for self-management which involves acceptance and ownership, emotional response, changed identity and taking responsibility.

**What are the implications for practitioners?** Activation for self-management is a complex process. Improving the understanding of patient activation might enable clinicians to be more effective in activating chronic disease patients.
Abstract

Introduction
Understanding the factors which activate people to self-manage chronic disease is important in improving uptake levels. If the many frequent hospital users who present with acute exacerbations of chronic disease were to self-manage at home, some hospital admissions would be avoided.

Methods
Patient interview and demographic, psychological, clinical and service utilisation data were compared for two groups of patients with chronic disease: those attending self-management services and those who managed by using hospital services. Data were analysed to see whether there were differences that might explain the two different approaches to managing their conditions.

Results
The two groups were similar in terms of comorbidity, age, gender, home services, home support and educational level. Self-managing patients were activated by their clinician, accepted their disease, changed their identity, confronted emotions and learnt the skills to self-manage and avoid hospital. Patients who frequently used hospital services to manage their chronic disease were often in denial about their chronic disease, hung on to their identity and expressed little emotional response. However, they reported a stronger sense of coherence and rated their health more highly than self-managing patients.

Conclusion
This study shed light on the process of patient activation for self-management. A better understanding of the process of patient activation would encourage clinicians who come into contact with frequently readmitted chronic disease patients to be more proactive in supporting self-management.
Background

The Australian National Health Disease Strategy Chronic Disease Strategy [1] defined self-management as “the active participation by people in their own healthcare” and identified the elements incorporated in self-management as including the following: health promotion and risk reduction; informed decision making; following care plans; medication management; and working with health care providers to attain the best possible care and to effectively negotiate the often complex health system. This definition involves all levels of health care and, importantly, requires the patient to take action. The Chronic Care Model, put forward by Wagner and his team [2], identifies the interaction between “activated patients” and “proactive” health professionals as an essential ingredient in self-management. There is evidence that successfully undertaking a health behaviour can reinforce activation to self-manage [3]. However, achieving activation of patients in chronic disease self-management (CDSM) has proven difficult [4]. Most people-offered CDSM programs do not take them up, women are more frequent adopters than men [4]. Improvement in uptake rates requires an understanding of the factors that enhance and reduce patient activation.

This study arose from the ubiquitous hospital problem of frequently readmitted patients (FRPs). If repeat admissions occur simply because people are very sick then hospital is the right place for them. Clinicians observe, however, that many FRPs are admitted with acute exacerbations of a chronic disease. The Australian National Chronic Disease Strategy [1] specified that improving CDSM uptake would reduce potentially preventable admissions, but that it would involve reorienting the health care system, improving the quality of relationships between patients and health care providers and undertaking research into the barriers which prevent people participating in CDSM programs.
We explored the accepted CDSM models to predict the possible characteristics of FRPs compared to self-managing patients (SMPs). We postulated that if the characteristics of FRPs were known then strategies to reduce potentially preventable readmissions could be developed. The Chronic Care Model and Andersen’s model of health service utilisation [2, 5-7] tell us that socio-environmental and health system factors, including health services outside the control of the individual patient influence patient uptake of CDSM. For example, poor access to CDSM referral and CDSM services would reduce CDSM uptake. Patients who find hospital services more accessible would present to hospital rather than other less accessible services. Therefore access issues are likely to influence patients to become FRPs.

Both systems and psychological CDSM models propose that positive patient-clinician and patient-patient interactions improve CDSM uptake [4, 5, 8]. We predicted that SMPs would have a well-developed relationship with their clinicians and other patients compared to FRPs. The psychological CDSM models postulate that perceived threat, knowledge of and response to symptoms [9], belief that the intervention will work [10], confidence in the patient’s own ability to act, self-efficacy [11] and constant self-appraisal of progress in managing thoughts and feelings about chronic diseases all influence CDSM uptake [12]. We assumed that SMPs would have greater self-efficacy and confidence in their ability to manage and FRPs would have lower self-efficacy.

Bury [13] argued, using a sociological model, that individuals with chronic conditions are agents who are not simply defined by the context of their lives but who take an active role, making choices for their future. Work by Charnaz [14] on self worth for those with chronic disease and by Corbin and Strauss [15] identified the importance of personal agency and identity. Charnaz
demonstrated that living with chronic illness disrupts a person’s biography, with a consequent change in self identity. The sociological models tell us that people’s ability to act, self-agency, and how they define themselves are important in chronic disease management. We predicted that SMPs would have stronger self agency and would change their identity as a result of living with a chronic disease.

Research on the influence of psychological factors measuring how people understand their world and relate to others may also have bearing on CDSM. Sense of coherence, which is a conceptual approach incorporating the three factors of comprehensibility, manageability and meaningfulness, measures how individuals cope with stressors on the health/illness spectrum [16]. A weak sense of coherence is associated with higher morbidity and a higher long-term sickness rate. Evidence from general practice studies indicates that people with a strong sense of coherence are more likely to adopt healthy lifestyle choices [17]. In another study in general practice, Bergh et al [18] reported that sense of coherence was weaker among frequent general practice attenders. SMPs, therefore, would be expected to have a stronger sense of coherence than FRPs. Attachment style may also be relevant to CDSM because there is evidence that people with a more secure attachment style are able to better self-manage chronic diseases like diabetes [19-21] and pain [22]. There is evidence that self-rated health is a reasonable indicator of a person’s clinical health [23, 24]. We were interested to discover, therefore, whether SMPs rated their health more highly than FRPs.

The major focus of the published research on self-management has been on clinical outcomes and patient quality of life. Our analysis of the differences between FRPs and SMPs in personal, clinical, service usage and psychological factors and in the approach to chronic illness and management strategies allowed us to test our predictions about their characteristics. The long
range goal was to provide evidence to help clinicians to promote patient activation to self-management.

In summary, we hypothesised that, compared to ERPs, SMPs would have more positive relationships with their clinicians: greater sense of threat imposed by their chronic disease; belief that they could self-manage, stronger agency and self-efficacy and changed identity. We also postulated that SMPs would have a greater sense of coherence, more secure attachment style and would rate their health more highly.
Methods

We conducted an interview-based study involving both validated sealed items and semi-structured open-ended questions designed to identify the factors which distinguished SMPs from FRPs. The study was based at a publicly funded 150 bed regional hospital located in a coastal regional urban area with a feeder population of around 100,000 in south eastern NSW, Australia.

The sample of 33 patients was sourced from two groups; those who had been referred to CDSM but instead were returning to hospital when they experienced symptoms they found unmanageable (FRPs, N=16) and those who had taken up referrals to CDSM services and were managing by consulting with their CDSM clinicians (self-managing patients, SMPs, N=17).

FRPs were recruited directly from the emergency department or inpatient ward, SMPs from the respiratory outpatient clinic (ROC) or chronic heart failure service (CHFS).

To ensure that it was clinically safe for the interview to take place and that no patient felt pressured into participating in the study, each prospective patient participant was approached by a known clinician and asked about being involved in the project. The researcher (SK) only approached the participant after informed consent had been obtained. All participants spoke English as their first language. After participant consent, interviews were digitally recorded and later transcribed for analysis. Patients gave consent for access to medical records to enable information on service usage and clinical data to be collected and to check that the allocation into the FRP or SMP group was accurate.

Patient co-morbidity information was collected from the medical record and a co-morbidity score determined using the Charlson Co-morbidity score [25]. Co-morbidity scores were determined by the researcher (SK) in consultation with a hospital clinician. Demographic and sealed data
were compared using non-parametric tests. The patient data were stored electronically in a password-secured file.

Data on patient attitudes and perceptions about their chronic disease were collected by interview rather than questionnaire as participants in this study indicated that they were reluctant to fill out questionnaires. The interview format was semi-structured to achieve inter-participant comparability while providing an opportunity for participants to tell their story about their life with chronic illness. Interview questions addressed to aspects of living with chronic disease, services accessed and their relationships with clinicians. Care was taken in the interviews to avoid derogatory labels about frequent service use and a judgmental stance on self-management.

The interview data were analyzed as they were collected [26]. Coding using NVivo 9 (QSR International) initially built on the interview questions, but was then reflexive and interactive focusing on the views expressed by the patients, enabling continuous modification of the treatment of the data to accommodate new data and new insights about those data. Coding was adjusted to ensure the incorporation of the deeper analysis and interpretation and the best fit to the data. The interpretation of the data was discussed during analysis between the authors. Although the sample size was relatively small, it was possible to distinguish between the two groups on the basis of what they said about adjusting to life with chronic disease. The data collection ceased when the interviews ceased to contribute new understanding to the categories and themes developed in the analysis. However, it is acknowledged that further insights could have been gathered by extending data collection to spouses, carers and families of participating patients on clinician performance and trustworthiness, and on preferences for services.
Quantitative information was included in the data collected during the interview by inviting participants to answer the questions in three short validated scales: the four question attachment style scale [27]; the three question sense of coherence scale [28] and the one-question self-rated health scale [23]. Scaled data were collected for 16 of the 17 SMPs and eight of the 16 FRPs. The differences between FRPs and SMPs were developed to postulate the process of transformation for self-management to occur. The activation process was tested by checking against case studies of individual patients and by constructing matrices to check for associations between personal patient factors and the elements of the process.

The issue of trustworthiness of the analysis was addressed in a number of ways. The data were considered in relation to the application of models developed by leading researchers in the CDSM field. Insights from the data were discussed within the group of authors and with other colleagues as the analysis proceeded. Member checking of the conclusions was undertaken with SMPs in the maintenance group for Chronic Heart Failure and CDSM clinicians. The University of Wollongong/South Eastern Sydney Illawarra Health Service Medical Human Research Ethics Committee approved the research study (approval HE07/271).
Results

The results section is divided into quantitative and qualitative findings. Quantitative findings consisted of: demographic patient details and measures of the psychological variables from the validated scales details collected at interview and clinical patient information collected from the medical record. Qualitative findings, analysed from the open ended information about life experience collected at interview, enabled us to develop an understanding of the two different approaches to living with chronic disease.

Quantitative Findings

Analysis of demographic and service utilization data as detailed in Table 1 showed FRPs and SMPs no significant differences in the characteristics of age or gender. The admission history data showed that FRPs had significantly higher emergency presentation rates and readmissions than SMPs, thereby confirming the allocation to the FRP or SMP group. There was no significant difference between FRPs and SMPs in the proportion living with family, living alone and having services at home, thus ruling out living arrangements as having had an impact on frequency of readmission. All patients had co-morbidities, and there was no significant difference in average Charlson co-morbidity scores between the two groups, suggesting that the clinical status does not explain the reason for frequent readmissions. The education level of the two groups was similar and therefore not associated with a readiness to adopt self-management practices. A small minority of FRPs had taken up CDSM referrals, but had not continued.

Results from the psychological scales are shown in Table 2. SMPs were less likely to report a strong sense of coherence, that is, they found life less comprehensible, manageable or meaningful than FRPs. Additionally, FRPs were significantly more likely than SMPs to rate
themselves as healthy. A comparison of the individual Charlson co-morbidity score and self-rated health showed that FRPs were significantly more likely to over estimate their health status than SMPs (see Table 2). Contrary to our expectations, the attachment style scale results showed no significant difference in secure attachment style between FRPs and SMPs. Overall, then, the quantitative findings showed that FRPs and SMPs were similar in their demographic and disease characteristics and in attachment style, but they differed in their sense of coherence and self-perceived health status.

Qualitative findings

Differences in the ways in which FRPs and SMPs represented their illness and their health behaviours were apparent in their:

- Interpersonal relationships
  - Relationship with clinicians
  - Interactions with other patients
- Acceptance and ownership of chronic disease
- Emotional response to chronic illness
- Change in identity
- Taking responsibility for symptom management and lifestyle change

Analysis of the differences is detailed below.

Interpersonal relationships - Relationship with clinicians

All patients reported that they had regular appointments with their general practitioners and specialists. Although all patients claimed that they trusted their clinicians, there were some examples of FRPs withholding information or limiting their relationship with clinicians.
“...there’s a lot of things I don’t tell him (GP) that I should.” (FRP 1, male, aged 74).

“No, no I don’t need them (home visits)...I only want prescriptions. I don’t want to see a doctor.” (FRP 13, male, aged 79).

Most of the SMPs had experienced periods when they were frequently readmitted before being activated to self-management. SMPs reported that encouragement from their clinician was crucial in adopting self-management. All the SMPs spoke of their clinician(s) with trust and even affection; some were close to tears of gratitude when they described what their clinicians had done for them. They were usually on first name terms with their clinicians, with one jokingly referring to the coordinator of the service as “Auntie”.

The development of trust is illustrated in the story told by a patient living with chronic obstructive pulmonary disease who had been hospitalised many times in the previous year. She described her adoption of self-management through an encounter with an ambulance officer:

“Well, I was all tied up in knots and the nurse...... I sent for an ambulance and it came and a very nice young lady came. She told me her troubles and I told her mine (laughing)...... she advised me to stay at home. She said hospital is not the place for you.” (ROC 9, female, aged 83)

During the encounter the ambulance officer engaged with the patient, established rapport and provided information about CDSM. At the time of the interview this patient had avoided the pattern of frequent hospitalisations she had experienced before. She looked back on the encounter with the ambulance officer as being significant in changing her behaviour. It was common for SMPs to have vivid recall of the time at which they took up CDSM because it was clearly a life-changing event.
Interactions with other patients

All the SMPs in the chronic heart failure group (n=7) reported positively on their group experience, talking about the support they derived from other patients, for example sharing jokes about weight loss and exercise, helping each other with loans to cover the payment for community transport and phoning each other in between sessions. They watched out for their friends in the group by telling the clinicians if they thought that things were not going well for one of their colleagues. All SMPs who had attended the CDSM group reported that the friendships helped them to cope with chronic disease. In fact, it seemed that the group experience gave their lives more meaning, by fostering a sense of achievement through learning to master the symptoms and by increasing their contact with others with similar conditions.

“Yes, well you can make a joke. People might say I’m feeling this, then you say so am I!” (ROC 6, male, aged 86)

In contrast, just one of the FRPs talked about the positive impact of other patients with similar chronic disease from her attendance at the pulmonary rehabilitation service. Because FRPs generally were not in regular contact with other patients, they did not report on support from peers.

Acceptance and ownership

Although FRPs saw the recurrence of symptoms as the reason for their repeat admissions, they all needed prompting to provide information on the impact of the chronic disease on their lives. Their attitude to their chronic condition was distant and they appeared to minimize or even be in denial about the extent of their illness.
"First thing with emphysema, it can be hereditary. Mum died from it. At the time it
didn’t worry me. Now it appears that my aunt had it as well. The specialist told me that
it was related to work at the steel works as a boiler-maker’s mate. Forget the smokes -
it’s the fumes and dust from welding that’s 90% of the lung problem." (FRP 4, male,
aged 68).

This FRP distanced himself from his chronic obstructive pulmonary disease by attributing the
cause to factors other than smoking and was not willing to accept and own his disease. Another
FRP with chronic heart failure had been contacted by the CDSM chronic heart failure service,
given advice about her condition but had not attended the service. The following excerpt shows
her unwillingness to accept her condition and her need to push responsibility back to the
clinicians.

“It’s still a mystery to me. I don’t know what to expect. They don’t tell me how to deal
with things.” (FRP 10, female, aged 73).

All SMPs, by contrast, talked openly and frankly about their lives with chronic disease. They
accepted and owned their condition and their symptoms. They talked about what was happening
in their bodies in a personal way and had developed strategies for getting on with their lives.

“... if this is what has to be done, this is what has to be done. It’s sort of like part of me... I
understand that this is my health.” (CHFS 1, male, age 41).

SMPs made the point that their lives had been changed by their chronic disease. FRPs did not
make the distinction of life before and after chronic disease.

**Emotional response to chronic illness**
Patients from the two groups differed in the level of emotion in talking about the diagnosis and how it changed their lives. All FRPs talked about their chronic illness in a fatalistic and unemotional way. For example, some talked about “the heart” or “the chest” as if it was unrelated to their own body and something outside their control, a rogue body part. They needed prompting to describe the impact of chronic disease on their lives.

All SMPs, in contrast, identified the emotional impact of chronic disease on their lives. Their voices were animated when they talked about their condition, describing themselves as having been “shocked” or “knocked out” by the diagnosis, or “feeling I was a nuisance”. They described a range of emotions including fear and anger, loss and grief, periods of despair and even suicidal thoughts because of the things that they could no longer do:

“Yes you get angry with yourself. You feel terrible. My wife, she was cleaning up yesterday, I can’t even move the TV for her, I can wash up all right but can’t put the plates away very easily. Can’t carry them, they’re too heavy. I can’t even do my shoes up.” (CHFS 4, male, aged 69).

This kind of expression of emotions was associated with acceptance of chronic disease.

Change of identity

There were differences in the way SMPs and FRPs described themselves. All SMPs made a sharp distinction in their lives before and after the chronic disease leading to a changed sense of who they were. SMPs acknowledged being a different person, for example, having difficulty getting to the shops, not being able to walk up stairs, to play with grandchildren, help with household duties, go surfing or line dancing.
"I feel like I'm the eternal patient. Sometimes when I look at people in waiting rooms, doctor's surgeries and chemists I remember the days when medications... I remember the days when medications only meant taking them for a couple of weeks (laugh)." (CHFS 1, male, aged 41).

The new identity assumed by SMPs was adapted to the limitations imposed by the chronic disease.

FRPs, on the other hand, did not describe a change in how they saw themselves and gave the impression of hanging on to their identity, wanting their lives to stay the same.

**Taking responsibility for symptoms and lifestyle**

All FRPs and SMPs reported managing their medications and had arrangements with general practitioners and pharmacists for regular prescriptions and delivery of medications. SMPs reported that they had regular medication reviews with their CDSM clinicians. FRPs and SMPs managed symptoms in different ways, however. When they experienced a symptom associated with their chronic disease, FRPs came into the emergency department for assistance, thereby managing their chronic disease in line with advice from their hospital clinicians. Some FRPs thought that they would not be able to see a general practitioner and therefore came straight into the emergency department rather than attempting to see their GP. Others said that the general practitioner would have sent them to the hospital on the emergence of symptoms.

"The advice from GP is, if it's bad pain to come into hospital. The pills (for angina) sometimes take the pain away for a while, but then it comes back and in I come. Yes, I want to come where they will look after me. I've stayed 3 weeks. I once stayed 67 days." (FRP 8, female, aged 47).
Another reflected a fatalistic attitude and handing over of responsibility to clinicians:

“...I get it (information on chronic heart failure) from the specialist, Dr X, from the GP and from the ED. Yes it’s adequate. There’s nothing much I can do,......I’ve had it (heart problem) for 20 odd years so there’s not much chance of improving. I can only go backwards or hold at this level.” (FRP 1, male, aged 74).

All SMPs tried to deal with symptoms as they had been taught by their clinician(s). For example, chronic heart failure patients weighed themselves every day and increased the dose of diuretic when necessary, usually in phone consultation with their clinician. In both the chronic heart failure and the respiratory groups, patients talked about the difficulties of managing smoking, exercise, diet and weight control. They were proud when they were able to say they had given up smoking, lost weight or taken regular exercise. They talked about the strategies to cope with chronic disease such as frequent resting stops when walking, or toilet stops on car trips because of the diuretic treatment for chronic heart patients. They placed a high value on keeping up social contacts with family, friends, neighbours and other patients.

The patient profile for adoption of self-management

The differences between FRPs and SMPs are represented schematically in Figure 1. SMPs had established a relationship of trust with their clinician, accepted the chronic disease, had a strong emotional response, changed their identity and were managing symptoms and lifestyle with clinical support. FRPs did not describe this process.
Discussion

FRPs were more likely to report a stronger sense of coherence and a higher self-rated health than SMPs, in contrast to other studies in which high sense of coherence and self-rated health are associated with self-management. These findings were contrary to our predictions, but, on reflection, fit with the notion that SMPs developed a more realistic appreciation of the impact of their chronic condition on their life. Moreover, FRPs were in denial about their condition and therefore less likely to acknowledge the impact of the chronic disease on their life. This explanation is supported by the finding that SMPs self-rated health was more closely aligned with their co-morbidity score than for FRPs. It should be noted that the self-assessment of health depends on the subject’s personal definition of health and ill health are likely to be influenced by a range of factors. However, self-rated health has been reported to agree with clinically assessed health status in older patients [24]. Data from focus group discussions with patients would have provided insights into the range of views on health and ill health.

Recognition of the difficulties of life with chronic disease could contribute to the feeling that life is unmanageable as reported by SMPs in their weaker sense of coherence. In comparison, FRPs, by handing over responsibility to hospital clinicians, felt that life was more straightforward. The finding that the proportion of SMPs and FRPs with secure attachment style was similar is contrary to our expectation that a more secure attachment style would facilitate more effective patient-clinician interactions and therefore support self-management.

Our prediction from the CDSM models was that SMPs would have more positive clinician relationships than FRPs. Our findings indicated that trust and support from clinicians do help to maintain CDSM as does support from other patients. We found that proactive clinicians had a pivotal role in the activation to self-management [29] as predicted by the Chronic Care Model.
[2]. We also found that SMPs had positive relationships with other patients in their CDSM groups. The influence of others in activating patients to adopt self-management fits with the theoretical models [11, 30-33] which stipulate clinician trust as a key element in CDSM uptake.

We predicted that SMPs would have greater self agency and self-efficacy. Both FRPs and SMPs exhibited agency and self-efficacy in managing their medications. In other aspects of CDSM, however, FRPs and SMPs were different. SMPs had stronger agency and self-efficacy in managing symptoms and lifestyle change. Managing by readmission could be seen as the more passive approach involving lower agency and self-efficacy. SMPS occasionally reverted to frequent readmissions for a period, until they were re-stabilised, and then self-management orientation was re-ignited. This fits with the findings of Gately et al [34] who reported that the life of a person with chronic condition is not static. Agency and self-efficacy break down during periods of readmissions and patients need to be re-activated for self-management and hospital avoidance to reoccur.

Our SMPs change of identity was part of the activation process for self-management, while our FRPs clung to their former selves, not letting go. Other researchers highlight the change in identity with chronic disease. The transformative model put forward by Dubouloz et al [35, 36] specifies triggers which include interaction with health providers and a process of change in which the patient takes on a new identity and constructs new meanings for life with a chronic disease. Aujoulat et al [37], in a study on people living with chronic disease, differentiated between those who “held on” to retain their old identity and those who “let go”. Brink [38] also described patients after myocardial infarct as letting go and changing behaviour to self-manage their condition. Broom [39] described people self-managing diabetes in her study as “constructing an embodied diabetic self”. Our results confirmed those reported by MacRae [40]
that supportive reaction from others, family, friends, other patients and clinicians reinforced acceptance of a new identity in people with chronic disease.

The study population lived in an area at the low end of the socio-economic scale. The level of educational attainment in the people we interviewed was relatively low. Evidence from other studies showed that people of low socioeconomic status tend to use emergency departments for primary care [41-46]. Our data showed that people of low socioeconomic and educational status can self-manage without accessing hospital services if activated by proactive clinicians and if they go through a process of adjustment to living with chronic disease. However, it must be noted that the reasons for use of hospital services might be due to other factors such as access to and affordability of services.

Both FRPs and SMPs managed by attending appointments with general practitioners, medical specialists and they managed their medications. FRPs made a judgement about when to come to hospital. FRPs believed they were managing their chronic disease by presenting to hospital and handing over to hospital clinicians. SMPs made a similar sort of judgement about when they needed to consult their CDSM clinician but they were able to avoid hospital. The lack of affect and tendency to objectify symptoms shown by FRPs is similar to that shown by trauma patients interviewed immediately after discharge from intensive care in a report by Morse [47]. These patients, when referring to the period of trauma and intensive care, also talked in concrete rather than personal terms about the damaged part of their body, as if they did not own it. However, the objectification of the disease and emotional flatness is more permanent in these patients with chronic problems than for Morse’s trauma patients. Emotions play an important part in dealing with chronic disease in Leventhal’s model [12]. In this model, the patient’s thoughts and feelings in response to the illness feed into the process of constant re-
appraisal of their progress in self-regulation. Isla Pera et al. [48] reported that for patients making the adjustment to living with diabetes is like going through the grief cycle. It appears that lack of affect is linked with lower acceptance in FRPs.

Petrie and Weinman [49] reported that it is unusual for patients to talk about their perceptions of their illness in consultations with clinicians. FRPs demonstrated a similar reluctance to talk openly about their chronic illness and their emotions and even withheld information from clinicians, making it more difficult for clinicians to assist with self-management. As suggested by Gately et al. [34], in consideration of policy changes to increase CDSM and to reduce potentially preventable readmissions, our findings confirm that there is need for clinicians to be cognizant of the patients' process of adjustment which leads to the adoption of self-management. Our SMPs reported that the close trusting relationship with their clinicians allowed for discussion of their thoughts and feelings about living with chronic disease and led to the transformative process for self-management.

The strengths of this work are the links to established models of CDSM, the checking of the findings with SMPs and clinicians and the retrospective data on each patient’s service usage. The relatively small sample size and the minimal amount of information about the generalisability of this sample to others in the same location or wider community also limit the value of these findings.

Potential confounding factors in are the duration of illness and severity of complications. One interpretation of the data is that the FRP group simply those with long-standing chronic conditions and severe complications, whereas the SMP group are those recently diagnosed and immediately offered an early intervention style CDSM program. Although duration of illness data were not directly collected, the two patients groups were compared on the basis of
presentation and admission history over the preceding 5 year period. All patients had a primary
diagnosis of chronic disease which was the reason for their presentation to hospital over the
period. Hospital policy dictates that all patients with a diagnosis of chronic disease are referred to
CDSM services. FRPs had significantly more presentations and admissions than SMPs although
their age and co-morbidities were similar. Patient data on the severity of illness were not
collected, but the co-morbidity scores between FRPs and SMPs showed no significant difference.
The diagnosis, presentation and admission history, referral to CDSM, age and co-morbidity
scores support the notion that the FRPs and SMPs are similar in terms of duration and severity of
illness.

Another aspect of patients being frequently readmitted is the relationship between the severity of
the complications of chronic disease and the length of stay in hospital. If FRPs continue to return
to hospital for acute exacerbations of chronic disease but their length of stay is reduced, this is a
positive outcome.

The referral of patients to CDSM services merits further reflection. Although it was hospital
policy for all patients with chronic disease to be referred to CDSM services, it is possible that
clinicians may have decided that some patients were simply not suitable for referral to CDSM
services because they were too sick. It is certainly appropriate that clinical judgment about
suitability for referral is exercised. However, no notation in the patient medical records could be
found to this effect. Clinician attitudes can play a part in the uptake of self-management services
[29, 50-52]. Both groups had survived living with their chronic illness for the 5 year period
covered in the medical record examination.
In addition, this study related to a single hospital with its own special arrangement of ancillary services and the findings may not be generalisable to other hospitals. Scaled data were collected on only eight of the 16 FRPs. While the latter were representative of the larger FRP group in terms of age, gender, co-morbidity, living arrangements and educational level, we recognize this as a limitation of the study. It would be useful to confirm and extend these preliminary findings, for example, by including a measure of health locus of control. Future work could include a longitudinal study of patients after discharge to ascertain service destinations and the administration of an instrument for measuring patient perceptions of how well clinicians have engaged them in self-management [53]. Another limitation is the fact that the sense of coherence, self-rated health and attachment style scales were not administered to all FRPs.

It was clear from the findings of this study that the life with chronic disease is difficult for FRPs and SMPs. Both groups can be seen to manage in different ways: FRPs by presenting to hospital and SMPs by attending or contacting CDSM services. For improvement in the uptake of self-management and a reduction in potentially preventable readmissions by FRPs, clinicians coming into contact with FRPs need to support the process of self-change that leads to CDSM uptake by becoming more aware of changes required for activation of patients to adopt self-management. Clinicians need to learn how to do this. The emphasis in the acute care setting is on throughput of patients at the expense of finding out which patients are repeatedly returning and spending the time on improving self-management to reduce potentially preventable readmissions.

The Chronic Care Model indicates that patient activation by proactive clinicians is a prerequisite for self-management [54]. Hibbard’s [3, 55, 56] work on patient activation has provided evidence of the interventions which improve activation. This study demonstrated aspects of the process of patient activation.
Conclusion

Although the people in this study were of low socio-economic status with a relatively low level of education, some of them had been activated to self-manage with the support of clinicians, thereby reducing potentially preventable hospital admissions. Those who had been activated described a process of accepting the chronic disease, emotional response to their disease, reshaping identity and taking responsibility for symptom and lifestyle management. The group of frequently readmitted chronic disease patients, in contrast, handed over responsibility for managing symptoms of chronic disease to hospital clinicians. Improved understanding of the process of patient activation by more proactive clinicians could reduce the number of potentially preventable admissions.
Table 1. Univariate analysis: comparison of FRP and SMP clinical and service usage patient characteristics.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>FRP (N=16)</th>
<th>SMP (N=17)</th>
<th>P value Mann Whitney U Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average age (range)</td>
<td>72 (47-89)</td>
<td>70 (41-91)</td>
<td>NS</td>
</tr>
<tr>
<td>Male gender</td>
<td>7</td>
<td>10</td>
<td>NS</td>
</tr>
<tr>
<td>Post secondary education</td>
<td>2</td>
<td>3</td>
<td>NS</td>
</tr>
<tr>
<td>Lived with family</td>
<td>9</td>
<td>7</td>
<td>NS</td>
</tr>
<tr>
<td>Lived alone</td>
<td>4</td>
<td>8</td>
<td>NS</td>
</tr>
<tr>
<td>Received support services at home</td>
<td>7</td>
<td>3</td>
<td>NS</td>
</tr>
<tr>
<td>Average Charlson Comorbidity Score</td>
<td>6.6</td>
<td>6.2</td>
<td>NS</td>
</tr>
<tr>
<td>Average number of hospital admissions over the last 5 years</td>
<td>8</td>
<td>2</td>
<td>P&lt;0.05</td>
</tr>
<tr>
<td>Average number of emergency presentations over the last 5 years</td>
<td>16</td>
<td>3</td>
<td>P&lt;0.05</td>
</tr>
<tr>
<td>Number of patients taking up referral to CDSM services</td>
<td>3</td>
<td>17</td>
<td>P&lt;0.01</td>
</tr>
</tbody>
</table>
Table 2. Analysis of Psychological Characteristics of FRPs and SMPs.

<table>
<thead>
<tr>
<th></th>
<th>FRP (N=8)</th>
<th>SMP (N=16)</th>
<th>P value Mann Whitney U Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average Sense of Coherence score(^1)</td>
<td>1.1</td>
<td>2.4</td>
<td>P&lt;0.1</td>
</tr>
<tr>
<td>Average self-rated health (^2)</td>
<td>3.8</td>
<td>2.3</td>
<td>P&lt;0.05</td>
</tr>
<tr>
<td>Number of patients with secure attachment style dominant</td>
<td>4</td>
<td>6</td>
<td>NS</td>
</tr>
<tr>
<td>Over-estimation of health compared with Charlson score</td>
<td>7</td>
<td>3</td>
<td>P&lt;0.01</td>
</tr>
</tbody>
</table>

1. Lower score denotes a greater Sense of Coherence
2. Higher score indicates higher self-assessed level of health
References


Figure 1. Elements in the activation process for adoption of self-management: comparison between SMPs and FRPs.
The purpose of this chapter is to present the findings and demonstrate the overall contribution of this thesis, drawing on the strengths and limitations. In addition, the chapter contains a discussion of the implications for service and policy changes and identifies future areas for research. The chapter is divided into the following sections:

- Summary of findings in relation to research questions
- Revisiting the theoretical aspects of the study
- Overall contribution of the work
- Strengths and limitations
- Implications for policy and practice
  - Policy context
  - A system-wide approach to improving chronic disease self-management uptake
  - The impact of the introduction of Medicare Locals and the restructuring of former Area Health Services into Local Health Districts
  - Implications for research
  - Interventions to improve Chronic Disease Self-Management uptake
- Conclusion
Summary of findings in relation to the research questions

Analysis of emergency department data to identify factors associated with frequent hospital use

Three papers detailed and discussed the findings of the quantitative analysis of emergency department information system data identified the characteristics which separated FRPs, FAs and URVPs. The three patient groups, FRPs, FAs and URVPs, were older than the total patient population and were more likely to present with neurosis. FRPs were significantly more likely to:

- Have conditions requiring more urgent treatment.
- Present with unplanned return visits within 28 days of the first visit.
- Have diagnoses of neurosis, chronic obstructive pulmonary disease, dyspnoea or chronic heart failure, and chronic Ambulatory Care Sensitive conditions.

Frequent readmissions were unrelated to gender, time, day or season of presentation, or country of birth.

Like FRPs, FAs were more likely to present with unplanned return visits and have chronic obstructive pulmonary disease or dyspnoea. But FAs also had different characteristics from FRPs. The other conditions associated with FAs were neurosis, convulsions, repeat prescriptions, follow-up examinations and dressings and sutures. FAs were less likely to present in summer. FAs were unrelated to gender, time of presentation or country of birth.

URVPs were more likely to:

- Have minor and low urgency conditions.
- Present during winter.
- Present after hours.
- Have three or more admissions in the year.

Unplanned return visits were unrelated to gender or country of birth.
The findings provided evidence that:

- frequent hospital users were able to be distinguished from the rest of the patient population on the basis of patient related factors in emergency department information system data (research question 1) and
- FRPs, FAs and URVPs were distinct patient groups (research question 2).

The factors which characterised FRPs, FAs and URVPs were significantly different from the rest of the patient populations. In addition, although the subgroups shared some characteristics, there were significant differences. The findings are summarised in the table below.

**Table 4. Factors which had a significant influence on frequently readmitted patients, frequent attenders and unplanned return visit patients.**

<table>
<thead>
<tr>
<th></th>
<th>Frequently readmitted patients</th>
<th>Frequent attenders</th>
<th>Unplanned return visit patients</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ICD 9 diagnoses</strong></td>
<td>Neurosis, chronic obstructive pulmonary disease, dyspnoea or chronic heart failure, and chronic Ambulatory Care Sensitive conditions, conditions requiring more urgent treatment</td>
<td>Neurosis, chronic obstructive pulmonary disease or dyspnoea, convulsions, repeat prescriptions, follow-up examinations and dressings and sutures</td>
<td>Minor conditions</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>Older</td>
<td>Older</td>
<td>Older</td>
</tr>
<tr>
<td><strong>Urgency</strong></td>
<td>Higher urgency conditions</td>
<td>-</td>
<td>Low urgency conditions</td>
</tr>
<tr>
<td><strong>Time of presentation</strong></td>
<td>-</td>
<td>-</td>
<td>After hours</td>
</tr>
<tr>
<td><strong>Season</strong></td>
<td>-</td>
<td>Less likely in summer</td>
<td>Winter</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Country of birth</strong></td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

The separation of the patient groups is important in developing solutions to frequent and possible preventable hospital use. The finding that older age is associated with FRPs, FAs and URVPs fits with other reports of factors associated with frequent hospital use. It suggests that diverting older patients on presentation to emergency departments to specialised services to treat chronic
conditions associated with old age would assist in achieving improved outcomes and reduce frequent presentations.

FRPs, FAs and URVPs were significantly more likely to present with the diagnosis of neurosis suggesting that access to alternative mental health services outside the hospital might be an issue. Evidence that access to non-psychotic mental health services in the area is poor [163] supports this proposition. However, the clinical psychology service provided by the Illawarra Division of General Practice lends much needed assistance to GPs in dealing with mental health problems.

The findings that chronic obstructive pulmonary disease is an important reason for both frequent attendances and frequent readmissions beg the question of effective interventions in self-management plans. Management of chronic obstructive pulmonary disease focuses on optimising function, preventing deterioration, developing support networks and self management, and managing exacerbation [166]. Whether or not the intervention in the action plan is implemented depends on the patient’s level of confidence, which in turn is influenced by the strength of the relationship between the clinician and the patient.

Minor and low urgency conditions such as dressing and sutures, repeat prescriptions and follow-up examinations were associated with FAs and URVPs. Diverting patients with these conditions to GPs or special clinics in emergency departments would alleviate the pressure on emergency departments. However, the current inadequate supply of GPs in the area [163] means that the capacity of GPs to cope with the additional load of these minor conditions is restricted.

The high proportion of presentations after hours in the URVPs suggests that access to alternative services after hours is a contributing factor for this group of frequent users.

The findings identify the characteristics of the three groups FRPs, FAs and URVPs which provide useful information for possible diversion of these patients to other services to remove the pressure on the emergency department. However, as predicted by Andersen’s model of health service utilisation[41], the findings also raise questions about access to services. Direct information on
access to services was not available in the emergency department information system data. Possible areas for further research are to investigate service access issues such as:

- Collection of patient data by questionnaire or by interview on access to services.
- Analysis of the alternative non-hospital service availability in the area.

The findings on FRPs, FAS and URVPs were in accord with other research in some aspects, such as age and diagnosis. It should be noted that factors associated with frequent hospital use in other studies, ethnicity [39] and socioeconomic disadvantage [22, 44, 50, 70, 76, 103], not investigated in this work. Country of birth data included in the data-set is not indicative of ethnicity per se. There was no measure for socioeconomic disadvantage in the data collected. This study did not reveal differences in frequent use between men and women unlike other studies which reported men were more likely to be frequent users [39].

The quantitative studies achieved the aim of answering the research questions by differentiating between subgroups of frequent hospital users and by confirming that a high proportion of FRPs have chronic illnesses. The findings pointed the way to qualitative studies to explore the reasons why FRPs failed to take up chronic disease self-management and returned to hospital to manage their chronic disease.

**Interview data exploring the reasons for frequent readmissions in chronic disease patients**

**The patient perspective**
Analysis of interviews with FRPs showed that they thought they were managing their chronic disease(s) by presenting to hospital. The fact that they were admitted to hospital indicates that there was a need for acute care. However, the issue which remains unanswered is whether the acute exacerbation which resulted in admission could have been prevented by prior chronic disease self-management. Comparison of the co-morbidity indices for FRPs and SMPs showed no significant
difference thereby ruling out the possibility that FRPs had a greater clinical need than SMPs. FRPs had little understanding of their disease and were in denial about the impact of their condition.

SMPs, in contrast to FRPs, had an understanding of their disease and were able to detail their self-management strategies which they had been taught by a clinician. They described the encounter with the clinician which convinced them to start self-management. The encounter was a significant event to them. SMPs reliance on and bond with the clinician was a common feature of activation to self-management. Work by Hibbard’s team [167] indicates that clinicians can improve outcomes in chronic disease patients by using strategies specifically developed to meet the patient’s needs. The approach is reliant on a close bond and on understanding the patient’s needs. SMPs also described a process of adjustment involving an emotional response, acceptance and ownership of their disease, a change identity and learning to self-manage. FRPs had not formed a bond with a clinician or clinicians and did not undergo the process of adjustment common to SMPs. The results of this study suggest that raising clinician awareness about the process of adjustment which patients go through on the way to activation would improve self-management uptake. Although clinicians understand the concept of activation to self-management, putting it into practice is problematic. Evidence from the work of Blakeman et al [168] in general practice in the UK indicates that the patient’s desire to maintain the pre-chronic disease identity is a barrier to discussing self-management strategies in a general practice consultation. Clinicians working with patients on activation to self-management need to be cognisant of these barriers and to have the skills to move patients into adopting self-management strategies.

FRPs rated their health more highly than SMPs and had a stronger sense of coherence, indicating that they did not perceive the threat of their condition to the same extent as SMPs. FRPs were less likely to take up referrals to chronic disease self-management than SMPs. The findings that there were no differences in home support, co-morbidity index or attachment style between FRPs and SMPs indicated that these factors were not influencing the decision to self-manage. The analysis revealed
clear differences in attitudes of FRPs compared to SMPs which were related to activation by a proactive clinician and understanding of chronic disease.

The findings demonstrate that there were clear differences in attitudes and beliefs between FRPs and SMPs addressing research question 3 - are the attitudes and beliefs of FRPs about living with and managing chronic disease different from those of SMPs?

The findings provide evidence that FRPs and SMPs had different perspectives on adopting chronic disease self-management in answer to research question 4 (what do FRPs and SMPs report about adopting chronic disease self-management?). The differences centred on their encounter and relationship with clinicians. SMPs reported that the support from their clinician was essential in adopting self-management and that they would not have been able to self-manage without the support and encouragement of the clinician. The role of the clinician in the activation to self-manage is in line with patient activation and proactive clinicians. The Chronic Care Model [33] specifies that activated patients work with proactive clinicians to manage their chronic disease. The work by Hibbard and Mahoney on patient activation [169] demonstrated that patients were more activated and managed better with positive reinforcement by clinicians.

Some FRPs remembered that they had been referred to chronic disease self-management services during their hospital stays, but had not acted on the referral. Although they reported that they had confidence in their GPs and hospital clinicians, this did not translate into self-management. Some FRPs indicated a reluctance to attend chronic disease self-management services. These findings indicate that FRPs have a lower level relationship with their clinicians than SMPs. SMPs report a close bond with their chronic disease self-management clinician. The difference between FRPs and SMPs centres on the relationship with the clinician.

The differences between FRPs and SMPs are summarised in Table 5.
Table 5. Comparison of attitudes and beliefs of frequently readmitted and self-managing patients.

<table>
<thead>
<tr>
<th>Attitude/belief</th>
<th>FRPs</th>
<th>SMPs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attitude to chronic disease</td>
<td>Lack of understanding</td>
<td>Understanding</td>
</tr>
<tr>
<td></td>
<td>No emotional response</td>
<td>Initial negative emotional response</td>
</tr>
<tr>
<td></td>
<td>Denial</td>
<td>Acceptance and ownership</td>
</tr>
<tr>
<td></td>
<td>Lack of understanding of threat</td>
<td>Understanding of threat</td>
</tr>
<tr>
<td>Attitude to themselves</td>
<td>Hanging on to self before chronic disease</td>
<td>Changed identity to a person with a chronic disease</td>
</tr>
<tr>
<td>Uptake of referral to self-management service</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Management style</td>
<td>Managing by frequent presentations and/or readmissions Handing responsibility to hospital clinicians</td>
<td>Self-managing by attending and/or consulting with CDSM services and avoiding hospital Joint agents/responsibility with clinicians</td>
</tr>
<tr>
<td>Relationship with clinician</td>
<td>Weaker</td>
<td>Stronger</td>
</tr>
<tr>
<td>Sense of coherence</td>
<td>Stronger</td>
<td>Weaker</td>
</tr>
<tr>
<td>Self-rated health</td>
<td>Higher</td>
<td>Lower</td>
</tr>
<tr>
<td>Attachment style</td>
<td></td>
<td>No difference</td>
</tr>
<tr>
<td>Support at home</td>
<td></td>
<td>No difference</td>
</tr>
<tr>
<td>Co-morbidity score</td>
<td></td>
<td>No difference</td>
</tr>
</tbody>
</table>

The findings can be explained by postulating that the process whereby patient activation to self-management is achieved consists of the elements: open clinician relationship; acceptance and ownership of chronic disease; allowing emotional response and changing identity. These elements are shown schematically in Figure 4. The findings of this study are consistent with the model of care defined in the Chronic Care Model which specifies patients activated by proactive health.
professionals [33] and the patient activation theory [169] and, moreover, shed light on how patients become activated thereby providing a deeper understanding of the activation process.

Figure 4. Elements in the activation process for adoption of self-management: comparison between SMPs and FRPs

The clinician perspective

The system issues identified by all clinicians as contributing to frequent readmissions were the long waiting times for chronic disease self-management services and the under-supply of GPs. They took the view that patients would return to hospital for acute exacerbations of chronic disease if they were not able to access chronic disease self-management services or GPs when symptoms emerged.
SMPS, in contrast, were in regular contact with their chronic disease clinicians which expedited early intervention to control and manage symptoms and reduce readmissions.

Clinicians could be separated into two distinct groups, hospital clinicians and GPs, on one hand, and clinicians involved in providing chronic disease self-management services, on the other hand. The two groups had different attitudes and beliefs about FRPs and their skills in and knowledge and understanding of chronic disease self-management were different.

The differences between the two clinician groups were identified in addressing the research question 5 - what do clinicians think are the reasons for frequent readmissions and chronic disease self-management uptake? All clinicians thought that the system factors contributed to lack of self-management and frequent readmissions. However, there were attitudinal differences. Hospital clinicians and GPs thought that some patients were resistant to chronic disease self-management. The belief that there is a group of patients who were resistant to self-management demonstrates a lack of understanding of the patient activation process and of the potential role of all clinicians who encounter frequently readmitted patients with chronic disease. The belief that there was a group of resistant patients was not shared by chronic disease self-management clinicians. Chronic disease self-management clinicians thought that all patients could be supported to adopt self-management, although some patients might require more time to be persuaded and supported to self-manage. These findings indicate that a deep understanding of the nature of patient activation is necessary to overcome the somewhat negative attitudes towards FRPs expressed by hospital clinicians and GPs.

The difference between the two clinician groups was also demonstrated in the level of skill in and knowledge of chronic disease self-management addressing research question 6 - do clinician skills influence frequent readmissions and chronic disease self-management uptake? Hospital clinicians and GPs reported that they had some knowledge of chronic disease self-management but did not claim expert knowledge and skills. However, hospital clinicians and GPs reported that they agreed with the principles of self-management. Clinicians involved in the provision of chronic disease self-
management services demonstrated a depth of knowledge and understanding of chronic disease self-management and they understood the importance of activating patients and of being proactive. The evidence from this study, which conforms to other reported findings, is that there is a link between clinician skills and attitudes to chronic disease self-management. There is a clear difference between the two groups of clinicians in this study in both skills and attitudes towards patients and chronic disease self-management.

Hospital clinicians and GPs they did not see themselves as having a direct role in chronic disease self-management uptake or support. The clinical role was defined by a medical model of care. Hospital clinicians and GPs saw their role as being restricted to referral to chronic disease self-management services.

The schematic representation of the clinician attributes and system factors contributing to chronic disease self-management uptake are shown schematically in Figure 5. The implications of these findings are that extension of the role of hospital clinicians and GP to a more proactive approach in treating patients with chronic disease self-management to include support for self-management uptake, rather than simply referring patients to self-management services. However, the undersupply of GP services and chronic disease self-management services need to be addressed before the problem of frequent readmissions can be overcome. This is not an argument for transforming all clinicians into self-management experts, but for a role extension into a more proactive approach.

These findings are in line with reports by Hibbard et al [170] that the attitudes of clinicians are critical in the activation of patients to perform better at self-management and that

“clinicians need support to transition to understand the need to support patients as independent actors”. 
The identification of the elements in the process of activation revealed in this study expands on the activated patient – proactive clinician concept specified in the Chronic Care Model [113]. Moreover, it complements and expands on the patient activation theory put forward by Hibbard’s team [169].
Revisiting the theoretical aspects of the study

The study would not be complete without an evaluation of the adequacy of the theoretical underpinnings. Was symbolic interpretivism an appropriate explanatory theory? Symbolic interpretivism [1], the observation and interpretation of the attitudes and values of a patients and clinicians was adopted by putting myself, as researcher, in the place of those being observed to construct a new understanding of service choice, access and utilisation by patients. The theory of symbolic interpretivism can be judged to have fulfilled its role as an explanatory theory on a number of levels:

- the findings aligned with accepted theories;
- the research participants (patients and clinicians) thought that the findings represented a reasonable explanation of their experience and
- the interpretation was checked by other researchers.

However, the limitations of symbolic interpretivism as an explanatory theory are that other interpretations of the data and therefore other understandings are possible. This is because although the issue of researcher bias has been identified and addressed, the argument can be mounted that other interpretations of the same data are valid.

The concepts of agency and identity, as described by Bury [128] and Charmaz [129], proved to be particularly applicable in this work. This study demonstrated that living with chronic illness disrupts a person’s biography, with a consequent change in self-identity involving giving up the old identity. Moreover, a person’s ability to act, their agency, is important in how they live with and manage their chronic disease management, in their adoption and maintenance of self-management. Agency can also be said to come into play in the negotiation of access to services by patients and thereby have an impact on utilisation. What we describe as patient “choice” of services can be deconstructed to
reveal a complex relationship between patient and clinicians, both of whom have agency, and the interface between the organisation of services and patients and clinicians.

How useful were the two systems models? Both were applicable and useful but were insufficient to inform the detail required to improve patient access, choices and inappropriate frequent utilisation. The Chronic Care Model [33] was applicable to this study because it provided an overarching model incorporating important aspects of activated patients and proactive clinicians. The findings shed more light on the processes and skills required for activation of patients and what it means to be a proactive clinician. The framework of Andersen's model of health service utilisation [41] predicted the factors which proved important in frequent utilisation, but was less than adequate in predicting the organisational changes necessary for sustained self-management as shown in both the Chronic Care Model and the Capacity Building Framework [171] and discussed in more detail in page 157 below.

**Overall contribution of the work**

The significant contribution of this work is in the application of the findings to preventing frequent use. There are clear benefits for individual hospitals from analysis of routinely collected hospital data to differentiate between subgroups of frequent hospital users to develop a profile for each group. The methods of analysis used in this work are directly applicable to other hospitals. The findings supported other reports [30, 31] that a high proportion of FRPs were older with chronic disease. The quantitative analyses pointed the way for further studies into the reasons for frequent hospital use by qualitative analysis and raised the question of the influence of patient preference in service choice. Another avenue for fruitful research would be the collection of patient data by interview or questionnaire on patient preferences for hospital services compared with community based alternative services.

The combination of the quantitative and qualitative methods provided answers which would not have been generated by either quantitative or qualitative alone. Quantitative findings showed the
patient factors associated with FRPs and confirmed that many FRPs were older patients who 
presented with acute exacerbations of chronic disease. Analysis of Emergency Department 
Information System data did not provide the reasons why patients returned to hospital to manage 
their chronic disease. However, the quantitative findings provided a basis for speculation about the 
reasons for patients returning to hospital services. The qualitative analysis, by exploring patient and 
clinician attitudes and beliefs, showed differences between SMPs and FRPs and provided reasons for 
SMPs adopting chronic disease self-management.

The theoretical underpinnings of chronic disease self-management and health behaviours formed 
the basis for the interpretation of the qualitative findings. The work contributes to the field of 
chronic disease self-management by highlighting the importance of proactive clinician support in the 
adjustment to living with chronic disease and pointed the way to solutions to improving the 
activation of patients for uptake of chronic disease self-management. The hospital policy of referring 
all patients with chronic disease to self-management services was implemented by handing the 
patient written information about the chronic disease self-management service relevant to their 
condition. It appeared that referral by the provision of written material was not enough to activate 
patients to self-management as the uptake of referrals was low. SMPs reported that they needed 
active support and encouragement from clinicians to take up chronic disease self-management. 
Patients not receiving active support and encouragement were less likely to navigate their way to 
chronic disease self-management services and more likely to become FRPs. Hibbard et al. [169] 
defined activated patients as “those individuals who believe they have an important role in their own 
health and health care and have the knowledge, skills, confidence, and emotional commitment to 
perform this role”. The findings in this study on the attributes of SMPs agree with this definition. 
Clinician attitudes were likely to influence referrals to chronic disease self-management. Hospital 
clinicians and GPs saw their role in chronic disease self-management as being restricted to providing 
referral advice on chronic disease self-management, rather than activating patients and supporting 
uptake of chronic disease self-management. Moreover, clinicians who believe that patients are
resistant to chronic disease self-management are more likely to see referral to chronic disease self-management as a lost cause. A possible improvement would be to upgrade the skills of hospital clinicians and GPs in proactively encouraging and supporting the uptake of chronic disease self-management referrals.

The study, informed by the models of service utilisation and chronic care, provided evidence on why patients with chronic disease were frequently readmitted by identifying:

- Characteristics of frequently readmitted patients.
- Elements of the process of activation to self-management.
- Identifying the skills and attributes needed for clinicians to be proactive in self-management uptake.

**Strengths and limitations**

A limitation of this study is its restriction to one hospital removing the option of direct comparisons with other hospitals. The focus on a single hospital adds weight to the study as the combination of quantitative and qualitative methods provide the basis for solutions directly relevant to the hospital. All NSW hospitals routinely collect and report on Emergency Department Information System data, it would be possible, therefore, to undertake comparative studies across hospitals. There are published reports of findings on frequent hospital users from a regional hospital in NSW [102], a major teaching hospital in Perth WA [172] and the Northern Territory [173]. Although the characteristics of the user population and the range of associated health services may be different between different hospitals, comparisons could provide useful insights into the problem of potentially preventable frequent use.

There were some 20,000 presentations for each year at this hospital. The large sample size allowed for precision in the statistical analysis. A possible limitation in the quantitative analysis applies to the predictive value of the binary logistic regression model. However, the ability of the regression models to predict the factors influencing the outcome indicator of frequent use was demonstrated by the
significance of the $\chi^2$ value and the Nagelkerk Index. A further test for the predictive value of the model, using the area under receiver operating characteristic (AUROC) curve, was performed in the URVP calculations.

Emergency department data may contain inaccuracies in the diagnostic classification because it is collected at the time of triage and therefore not confirmed by diagnostic tests. This is particularly relevant in people with co-morbidities. For example, a patient might present at emergency with shortness of breath. This could be due to respiratory problems or congestive heart failure. If the patient has, say, chronic obstructive pulmonary disease and heart failure, the primary diagnosis is often problematic even after diagnostic test results are available. It is also possible that a diagnosis is assigned to frequent attenders on the basis of the previous presentation. This could result in an inaccurate primary diagnosis [174].

Rigour in qualitative research is the subject of some debate. Although a rigorous approach is highly desirable, Barbour [175] has argued that if used uncritically it can be counterproductive in qualitative research. A limitation relating to the qualitative aspects of this study is that the analyses were carried out by a single researcher rather than a research team. As the study was unfunded access to the resources of research team available in funded studies was not possible. However, supervisors, colleagues and co-authors provided valuable feedback on the coding tree development and the interpretation of the analysis, adding rigour to and enriching the final interpretations.

Another potential bias is the sample selection for qualitative analysis. The sample size was relatively small: 16 frequently readmitted and 17 self-managing patients, and 18 clinicians. This is an acknowledged limitation of the study. However, there was clear differentiation between FRPs and SMPs and between clinicians not directly involved in chronic disease self-management and those with a role in chronic disease self-management. The patient sample was deliberately selected because they were former or existing FRPs. Similarly, clinicians were recruited on the basis that they treated FRPs with chronic disease. Although there was a bias in the sample selection, the comparison
between groups of patients and clinicians provided a contrast to illustrate attitudes that separated
the groups and to link to the frameworks of chronic disease self-management and health service
utilisation that underpinned the study.

The analysis of the data commenced from consideration of the theories of health service utilisation
and the Chronic Care Model [33] [111]. The interpretative approach to the qualitative analysis
allowed the data to speak for itself, with the interview questions acting as prompts for the interview
subjects to talk freely. The analysis proceeded by an iterative refining of the coding of the data to
arrive at deeper interpretations and conclusions. This approach involved the melding of analysis
grounded in the data and drawing from existing theories.

The multi-methods approach is an advantage because it does not rely solely on quantitative or
qualitative methods but draws on the findings of both methods, thereby reinforcing the findings of
each and providing fresh insights in the consideration and discussion of results. Triangulation of data,
using different methods of data collection and comparing the results of analysis, has been claimed to
invest analysis with superior rigour [175] by addressing the issue of internal validity. In this multi-
methods study, both interview and routinely collected hospital data were analysed. The concordance
between the characteristics of FRPs from emergency department data and the characteristics of the
FRPs patients in the interview sample gave weight to the study methods.

The interpretation of the findings was checked with some of the sample of clinicians and patients.
Chronic disease self-management and hospital clinicians agreed with the thrust of the findings,
namely that patients need to be activated for uptake of self-management practices by clinicians who
have the skills and the role to activate and support chronic disease self-management. They also
agreed with the suggested solutions of strengthening the activation of FRPs in hospital to adopt
chronic disease self-management. SMPs in the Chronic Heart Failure Service concurred with the
finding that activation by a clinician was important and that they had gone through a period of
adjustment before embracing chronic disease self-management. Respondent validation by providing rigour added strength to the study.

There are gaps in the evidence for effective ways of improving chronic disease self-management uptake and sustainability of self-management, both of which would benefit from increased understanding of the patient choice and perspective, as foreshadowed in "What distinguishes clinicians who better support patients for chronic disease self-management?" The accepted models of chronic disease self-management discussed in the literature review and in the two qualitative publications (publications 4 and 5) provide the framework for considerations about implementation. This study showed that FRPs had different feelings and thoughts about their chronic disease from those of SMPs. In line with the models, particularly Bandura’s self-efficacy model and Leventhal’s model of self-regulation, the behaviour change from choosing hospital services to manage chronic disease to choosing chronic disease self-management services involved a transformative process supported by a skilled clinician with the elements of acceptance and ownership, strong emotional response, change of identity and management of symptoms. The theoretical basis for this study, drawing on accepted models of behaviour change contributes to the overall strength of the work.

**Implications for policy and practice**

**Policy context**

Several policy initiatives are relevant to this study. One is the Connecting Care program for patients with severe chronic disease [84], currently being implemented across NSW, which aims to reduce repeat hospitalizations due to severe chronic disease. Hospital emergency department data is now being used for case finding by identifying patients who are frequently readmitted [62, 83]. Evidence on their efficacy is not yet available but is likely to be reported soon [62, 83, 84].

The insights into both patient and clinician attitudes from the qualitative findings of this work can be applied to patient and clinician barriers currently preventing the uptake of chronic disease self-
management services by people with chronic disease in all hospitals where the uptake rate is low. This work will add to existing and emerging research.

As reported by O’Connell [62], several hospital avoidance initiatives, which can be seen as system initiatives, are being investigated across NSW. These include emergency medical units, geriatric and aged care assessments and multidisciplinary team interventions, hospital-in-the-home interventions, fast tracking of patient groups in emergency, substitution of emergency medical functions by nurse practitioners, reorganization of medical and nursing workforce, and improved times for diagnostic testing. Although the results of these initiatives show promise, the evidence has not yet been fully assessed or reported in the literature. Qualitative studies of patient and clinician perceptions of these initiatives are much needed in this area to enlarge on the quantitative findings.

The NSW State Government policy on chronic disease management [84] stipulates that

“the challenge for health services is to incorporate the principles of self-management support in all encounters with patients and their carers.”

This study showed that valuable opportunities for chronic disease self-management support were lost in many clinician encounters between FRPs and GPs and hospital clinicians. The NSW chronic disease policy includes a call for more chronic disease self-management interventions to keep people out of hospital and improve health outcomes. Additional funding would need to be allocated to improve access to chronic disease self-management services and to extend the skills of hospital clinicians and GPs in activating and supporting referrals to chronic disease self-management.

Commonwealth Medicare GP items applicable to chronic disease self-management range from preparing and reviewing management plans, Team Care Arrangements, and participating in multidisciplinary team plan preparation [176]. However, clinician support for patient uptake of chronic disease self-management still falls by the wayside in the over-worked general practice
environment. Most clinicians need additional training to put themselves in the shoes of the patient to activate and sustain uptake of chronic disease self-management [177].

A major problem in the implementation of chronic disease self-management relates to the way in which clinicians and health practitioners communicate with each other about their patients [178]. Improved inter-clinician communication for successful of chronic disease self-management would require additional clinician skills, training and systems to maintain it.

**System-wide approach to improving Chronic Disease Self-Management uptake**

The elements involved in improving chronic disease self-management uptake can be identified by applying the capacity building framework [171] which is used extensively in the NSW publicly funded health system. The framework is illustrated schematically in **Figure 6**. The framework indicates that improving chronic disease self-management services to meet the demand would involve a system-wide approach with a prolonged and sustained implementation program and a commensurate commitment on the part of senior leadership in the health system.
The elements of the change required depicted in Figure 6 show that if chronic disease self-management uptake is to be addressed comprehensively, the initiative would need to include each of the key areas for action across the health system:

- Organizational development of the policy framework, such as the Connecting Care program in NSW.
- Development of the workforce to upgrade skills and knowledge in the principles and practice of chronic disease management.
- Allocation of resources to expand chronic disease self-management services and GP services to meet demand, involving both State and Commonwealth Governments.
Strong leadership to ensure that the changes were not only implemented but sustained and to ensure that the partnership between the acute and non-acute sectors was maintained.

Involvement of chronic disease patients in the change process.

Although leadership is of paramount importance, the initiative would not be embraced without clinician buy-in [179]. The current level of competition between the acute and non-acute sectors hinders the coordination and integration of services particularly for people with chronic disease. The lack of integration and coordination is reinforced by the dominant medical paradigm in acute services which excludes the consideration of non-medical factors which contribute to illness, especially chronic illness, and to service use. If frequent emergency department use is seen as a hospital problem and not considered in the wider context of the patient needs and non acute health system resources, patients will continue to use emergency departments inappropriately.

Given the waiting times and general under-resourcing of chronic disease self-management services, more innovative ways of addressing the shortfall include following up patients with chronic disease by telephone reminders or web-based or SMS messages on discharge from hospital to support self-management. This may be a cheaper alternative than face-to-face chronic disease self-management services. However, clinicians need to be trained in these techniques. There is some evidence that telephone reminders and messaging are efficacious [180-182], but further research is needed to consolidate the early findings. Other research has demonstrated that programs that follow patients immediately after discharge are the most effective interventions [183]. Another possible avenue for trial is the involvement of volunteers, recruited from the pool of SMPs, to work with FRPs. Strong evidence of the effectiveness of group interventions in chronic disease self-management [114] suggests that supervised volunteer sessions with FRPs while they are still in inpatient services might encourage them to take up chronic disease self-management.

There are some early indications from the USA that case finding of high risk, high hospital usage (also called super-users or hyper-users) disadvantaged patients can result in dramatic reductions in
hospital usage and improvements in quality of life [184]. The approach has been to utilise hospital records to identify patients and provide intensive multidisciplinary follow-up and support. Data from Camden Hospital in New Jersey, USA showed that 1 percent of patients, or just over 1,000, accounted for nearly 40,000 hospital and emergency visits over a five-year period, costing $46 million (USD) in hospital treatment [185]. Camden hospital employs nurse practitioners to track and support patients at home. The estimated cost of the entire out-of-hospital intervention is less than that of one day in Intensive care. As the savings to be made from this sort of case finding of high users are substantial, a trial of identification and intervention would be likely to bear fruit. The Evercare program in the UK is another example of case finding for high needs patients [186].

The organisational change that needs to be introduced involves not simply the time and attention paid to chronic disease self-management support by hospital clinicians and GPs, but the way in which the patient is supported and encouraged to negotiate service access. Thus, on both sides of the patient-clinician dyad, skills and capacity need to be developed, otherwise inappropriate utilisation will continue. The important link between access and utilisation and the acknowledgement of the way in which patients and clinicians redefine need and eligibility for services has been identified by Rogers et al and Dixon-Woods et al [187, 188].

The impact of the introduction of Medicare Locals and the restructuring of former Area Health Services into Local Health Districts

The Commonwealth Government has developed Medicare Locals, which will replace the GP Divisions, with the aim of improving access and quality of care for their defined populations [189]. There is the potential for stronger partnerships to improve integration of services to improve patient care, including chronic disease self-management. As the Chronic Care model postulates, effective chronic disease self-management requires strong integration of services across general practice and other health professionals. The wide cultural differences between the GP community and other health professionals, particularly those in the public sector, present a significant barrier to integrated care. It is now feasible to adopt a population based approach to improving and supporting self-
management uptake under the auspices of Medicare Locals as foreshadowed in “Patient related factors in frequent readmissions: the influence of condition, access to services and patient choice”.

The relationship between the new NSW Local Health Districts (which replace the larger Area Health Services) and Medicare Locals is collaborative. It appears that Medicare Locals could play a major role in local health district planning and coordination of care. Local Health Districts [190] can provide an appropriate setting for an emphasis on local issues rather than area issues.

“One of the most important outcomes of health reform is the strengthening of local decision-making in the way NSW public hospitals are managed and resourced. The Districts will be administered by a Chief Executive and local Governing Council headed by Chairs that will include clinicians, healthcare management experts and community representatives.”

These initiatives could facilitate real improvements in chronic disease self-management uptake and service development and the significant reduction of avoidable admissions due the chronic disease.

Implications for research

The findings of this work are in line with published research on the characteristics of frequent hospital users. Research based at other regional hospitals with a similar role and feeder population, focusing on patients with high utilisation rates, would lend weight to these findings. It is unlikely that the exact circumstances relating to this hospital and the community services would be replicated. Judgment needs to be made as to the relevance of the conclusions drawn from this study to other hospitals. The linkage of GP under-supply and accessibility of alternative non-hospital services with high hospital utilisation rates needs to be explored for other hospitals.

Extension of the qualitative research to other hospitals would be worthy of further investigation. Patient perspectives on chronic disease self-management uptake and service usages are much needed to explain frequent presentations and readmissions [83].
The patients interviewed in this study were of relatively low socioeconomic status, social
disadvantage and lower educational status. Other studies of the impact of social disadvantage on
service use would be of benefit in determining the influence of these factors on frequent hospital
use. Another aspect worthy of further detailed investigation is whether clinicians are less likely to try
to implement self-management strategies with patients at the lower end of the socioeconomic scale
because they perceive that self-management in this group is too difficult a goal. Moreover, the
association between self-efficacy and disadvantage needs further investigation [145].

A study comparing FRP and SMP scores on the Illness Perception Questionnaire [191] , a validated
instrument for measuring what people with chronic disease think and feel about their condition,
would complement the findings presented in this study. In addition, similar studies comparing the
scores of FRPs and SMPs on the Patient Activation Measure developed by Hibbard et al [122] would
add to the existing evidence on the activation process.

Another fruitful avenue of research would be to link hospital patient records with GP patient records
to obtain a fuller picture of comparative utilisation rates. This would not only answer the question as
to whether FRPs are also frequent users of GP services, but would also shed more light on GP
referrals to chronic disease self-management.

Frequent user patients with a diagnosis of mental health problem or drug and alcohol problem were
excluded from this study. A similar study on this group of vulnerable patients would provide much
needed information of the difficulties they face in accessing health services.

**Interventions to improve Chronic Disease Self-Management uptake**

As foreshadowed above, intervention studies are a logical consequence of these findings.
Streamlining of patients into categories at triage for minor non-urgent conditions, minor procedures,
and chronic disease self-management support are obvious targets. Other possible intervention trials
could include: case-finding for supported chronic disease self-management referrals; supported
referrals to chronic disease self-management services with follow-up; training for hospital clinicians and GPs to improve knowledge of chronic disease self-management; involvement of volunteer SMPs interacting with FRPs prior to discharge and telephone reminders and SMS messaging to support uptake of chronic disease self-management referrals.
Conclusion
This study, which involved quantitative, and qualitative analysis, examined patient and clinician factors influencing frequent hospital readmissions in chronic disease and chronic disease self-management uptake in a single hospital.

The key findings of quantitative analysis of this study were:

- Frequent emergency department presenters could be differentiated from the rest of the patient population on the basis of the patient related factors in the emergency department data system.
- FRPs, FAs and URVPs were distinct patient groups.
- FRPs were significantly more likely to have a chronic disease.

The key findings from the qualitative analysis of patient and clinician interview data were that:

- Hospital clinicians had a relatively poor knowledge of services available in the community for patients with chronic diseases. This was a barrier to referral to chronic disease self-management services.
- GPs reported that they knew about the chronic disease self-management services and that they had the skills to support self-management.
- Clinicians directly involved in chronic disease management indicated that they understood their services and had well developed skills to activate patients to self-manage.
- Hospital clinicians and GPs were more likely to believe that some patients were resistant to chronic disease self-management.
- SMPs who had been FRPs described the process of activation to self-management as dependent on the support of a clinician and involving the elements of acceptance and ownership; an emotional response to the diagnosis of the chronic disease and changing their identity.
- FRPs did not describe this process.
The findings were consistent with the models of service utilisation and chronic care and suggested that patient activation involves a multi-step process facilitated by proactive clinicians. It provided evidence of why patients with chronic disease were frequently readmitted by highlighting the activation process and identifying the skills and attributes needed for clinicians to be proactive in self-management uptake.

The study also provided a basis for speculation on system and access factors which have an impact on frequent readmissions in chronic disease patients.

The study successfully identified the reasons behind frequent readmissions in chronic disease patients have been explored and explained.
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APPENDICES

This chapter contains the supplementary information for the study which is not included elsewhere in the thesis.

A.1 Literature search strategy
A.2 Journals searched
A.3 Ethics approval SESIAHS Ethics Committee
A.4 Information sheets and consent form patients, clinicians
A.5 Scales for patient interviews
A.1 Literature search strategy

The search strategy was twofold. Automatic feeds were set up for the journals listed in Appendix 2 so that new publications were monitored.

In addition, key historical publications relating to the fields of frequent hospital use, health behaviour change, chronic disease self-management, statistical methodology and qualitative methodology.

Publications were stored in an EndNote (EndNote X1 Thompson) library for ease of retrieval and citing.
A.2 Journals searched

Age Ageing Gerontologist
Aging
American Journal of Epidemiology
Australian Medical Journal

Australasian Journal of Emergency Medicine

BioMed Central

British Medical Bulletin
British Medical Journal

BMC Health Services Research
BMC Public Health

Cardiovascular Research
Cardiovascular Systems and Medicine
Chronic Illness
Chronic Respiratory Disease
Diabetes
Emergency Medicine
European Journal of Heart Failure
European Journal of Public Health
Family Practice
Geriatrics
Health Education Research
International Journal of Epidemiology
International Journal of Quality Health Care
Journal of Gerontology B Psychological Science and Sociological Science

Journal of Gerontology A Biological Science & Medical Science
Journal of Public Health
Medical Journal of Australia
PHC RIS Infonet
Qualitative Health Research

Qualitative Research

Science Direct Topic Alert: Geriatrics
Science Direct Topic Alert: Respiratory Medicine
Science Direct Topic Alert: Public Health
Science Direct Topic Alert: Cardiovascular Systems and Medicine
Science Direct Topic Alert Emergency Medicine
The British Journal of Diabetes & Vascular Disease
Topic Alert: Cardiovascular Research
A.3 Information sheets and consent forms

Patients

Clinicians
Patient Attitudes and Frequent Readmissions

Information Sheet For Participants

Semi-Structured Interview - Patients

Thank you for your interest in participating in this study.

Aim of the research

The aim of the project is to explore the attitudes of patients with chronic diseases to frequent readmission to hospital. It is hoped that a deeper understanding of patient attitudes will enable doctors and other health workers to provide more effective care, thereby reducing unnecessary admissions to hospital.

Your Consent

You have been asked to participate in this study by agreeing to be interviewed about your chronic condition. Prior to commencing the study, we ask that you read through this sheet and complete the consent forms if you decide to participate in the study. One copy of the consent form is to return to me, and the other for your own records.

If you have received a package by mail, the signed consent form should be returned to the Medical Records, Department Shellharbour Hospital, in the stamped addressed envelope attached.

If you agree to participate in this study, you will also agree to allowing the researcher to access your medical record to obtain clinical information on your chronic disease(s) and service usage.
Revocation of consent

You are free to withdraw at any time from this study without prejudicing your relationship with Shellharbour Hospital, the South Eastern Sydney Illawarra Area Health Service, the University of Wollongong or the University of New South Wales. A Revocation of Consent to Participate form is attached for you to use if required.

Interviews

Interviews will include questions about your chronic disease(s), hospital admissions and general practitioner and other services. If you would like to have a carer present with you for the interview, this will be arranged. The interviews will be carried out either in Shellharbour Hospital, one of the services you attend, or your home, whichever is the most convenient for you. The interview will take about one hour. The information provided during the interview will be recorded for later analysis to determine the factors which are most important to patients with chronic diseases.

If the interview takes place at Shellharbour Hospital, you will be provided with transport to and from the hospital by taxi at no cost to you for the interview.

Confidentiality

All discussions and data gathered in the research project will be strictly confidential and will be disclosed only with your permission or except as required by law. We plan to publish the results in reports and journals. Naturally, in any publication, information will be provided in such a way that you will not be identified.
Your decision to participate

Your decision whether or not to participate will not prejudice your future relations with Shellharbour Hospital, the South Eastern Sydney Illawarra Area Health Service, the University of Wollongong or the University of New South Wales. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without prejudice.

Complaints about the research study

Complaints may be directed to the Ethics Officer, Research Services Office, Research and Innovation Division, Ethics Secretariat, University of Wollongong on 4221 4457.

Where the research is based

This research study is part of a PhD project at the Centre for Primary Health Care & Equity, University of New South Wales. The study is based at the Shellharbour Hospital. The approval process for the study has involved the Ethics Committee at the University of Wollongong and the South Eastern Sydney Illawarra Area Health Service.

Benefits, risks and costs

The findings of the study will benefit patients, carers and clinicians by providing insights into patient attitudes thereby improving management strategies for patients with chronic conditions and reducing hospital admissions. The participant risk in being involved in the study is the possible distress caused by discussing the chronic conditions in interview. In the event that a participant becomes distressed, the interview will be terminated and the patient will be offered a referral to the appropriate service. There is no cost to the participants in the study.
Sample Questions

The questions you will be asked in the interview have been devised so that you will find them easy to answer and they will provide me with the information I need for the study. The questions focus on how you manage your conditions and what you feel about your care and your condition. You will be asked to select from the options given in the question which answer is best for you. A representative sample of questions is provided below.

Can you tell me what your feelings were when you were first diagnosed with your chronic disease?

How easy is it for you to get an appointment with your general practitioner?

How do you get to services, for example, your general practitioner?
**Relationships with others**  I find it relatively easy to get close to others and am comfortable depending on them and having them depend on me. I don't often worry about being abandoned or about someone getting too close to me.

<table>
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<tr>
<th>not at all</th>
<th>very much like like me</th>
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**More information about the research study**

If you would like more information, feel free to contact me, Sue Kirby (ph: 9385 8387; fax 9385 1513 or email: s.kirby@student.unsw.edu.au) and I will be happy to answer your questions.

You could also contact the research supervisor, Dr Sarah Dennis, Senior Research Fellow, Fairfield Hospital GP Unit, University of New South Wales, SYDNEY 2052, on ph 9616 8520; fax 9616 8400 or email s.dennis@unsw.edu.au.
Please complete and return

Patient Attitudes and Frequent Readmissions in Chronic Disease

Patients and Carers Consent Form

1. I,……………………………….of……………………………………….…………………
……………………………………………………………………………………………………
…………. agree to take part in the study described in the Patient Attitudes and
Frequent Readmissions in Chronic Disease Information Sheet attached.

2. I acknowledge that I have read and understood the Information Sheet which
explains the aims of this investigation. I confirm that the statement has been
explained to me to my satisfaction.

3. Before signing this consent form, I have been given the opportunity to ask any
questions relating to the study. I have received satisfactory answers to any
questions that I have asked.

4. I understand that my decision to participate is voluntary and that I am free to
withdraw at any time without prejudice to my relationships to the University of
NSW, Shellharbour Hospital, the South Eastern Illawarra Area Health Service or
the University of Wollongong.

5. I agree that the research data gathered from the study may be published provided
that my name is not identified in any way.

6. I understand that if I have any questions relating to my participation in this research
I may contact the researcher, Sue Kirby at the Centre for Primary Health Care &
Equity, University of New South Wales, Sydney 2052 NSW, ph: 9385 8387, fax
9385 1513 or email: s.kirby@student.unsw.edu.au or the research supervisor, Dr
Sarah Dennis, Senior Research Fellow, Fairfield GP Unit, School Public Health &
Community Medicine, University of New South Wales, Sydney 2052, on ph 96168
520; fax  9616 8400 or email s.dennis@unsw.edu.au.

7. I acknowledge receipt of a copy of this Consent Form, the Information Sheet, and
the Revocation of Consent Form.

8. I agree to the interview being recorded.  Yes  No
Complaints may be directed to the Ethics Officer, Research Services Office, Research and Innovation Division, Ethics Secretariat, University of Wollongong on 4221 4457.

Please PRINT name: ..........................................................

Signature of participant:..............................................Date..............................................

NAME of Researcher SUE KIRBY   Signature of Researcher..............................
Patient Attitudes and Frequent Readmissions in Chronic Disease

Patients and Carers Consent Form

1. 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I agree to this interview being recorded. Yes No

Complaints may be directed to the Ethics Officer, Research Services Office, Research and Innovation Division, Ethics Secretariat, University of Wollongong on 02 4221 4457.

Please PRINT name: .................................................................
Signature of participant:...........................................Date.....................................

NAME of Researcher SUE KIRBY  Signature of Researcher.........................
Patient Attitudes and Frequent Readmissions in Chronic Disease

Patients and Carers Revocation of Consent Form

I hereby wish to WITHDRAW my consent to participate in the project described above. I understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with Shellharbour Hospital, the South Eastern Sydney Illawarra Area Health Service, the University of Wollongong or the University of New South Wales.

..........................................................  ..........................................................
Signature                Date

..........................................................
Please print your name

This Revocation of Consent form should be forwarded to:

Sue Kirby
Building G27
Centre for Primary Health Care & Equity
University of New South Wales
SYDNEY NSW 2052
Thank you for your interest in participating in this study, patient attitudes and frequent readmissions in chronic diseases. I look forward to working with you on this study.

**Aim of the research**

The aim of this project is to explore the attitudes of patients with chronic diseases to frequent readmission to hospital. It is hoped that a deeper understanding of these patient related issues will enable clinicians who care for people with chronic diseases to provide more effective care, thereby reducing unnecessary admissions to hospital.

**Your Consent**

You have been asked to participate in this study by agreeing to be interviewed about chronic disease and frequent readmissions. Prior to commencing the study, we ask that you read through this sheet and complete the consent forms if you decide to participate in the study. One copy of the consent form is to return to me, and the other for your own records.

**Revocation of consent**

Please note that you are free to withdraw at any time from this study without prejudicing your relationship with Shellharbour Hospital, the South Eastern Sydney Illawarra Area Health Service, the University of Wollongong or the University of New South Wales. A Revocation of Consent to Participate form is attached for you to use if required.
The interview

Clinicians will be interviewed about what they think about chronic disease and frequent readmissions. The interviews will be carried out in Shellharbour Hospital or at the usual place of work which is most convenient to the participant. The 30 minute interview will be audiotaped for transcription and analysis later. You will be asked to agree to the interview being audio-taped. The information provided during the interview will be analysed to determine the factors which are most important to patients with chronic diseases and their carers from the clinician’s perspective.

Sample questions

**Do you think patient attitudinal factors are important in frequently readmitted patients?**

**Do you think frequently readmitted patients can be managed outside hospitals in the community?** what sort of professionals and other workers should be involved?

**What sort of factors keep frequently readmitted patients out of hospital?**

Is self care important? How important is the relationship between clinician and patient? How do you build this relationship? In your experience, are there some patients with whom a relationship is difficult?

Confidentiality
All discussions and data gathered in the research project will be strictly confidential and will be disclosed only with your permission or except as required by law. If you give us your consent by signing the attached form, we plan to publish the results in reports and journals. In any publication, information will be provided in such a way that you will not be identified.

Your decision to participate

Your decision whether or not to participate will not prejudice your future relations with Shellharbour Hospital, the South Eastern Sydney Illawarra Area Health Service, the University of Wollongong or the University of New South Wales. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without prejudice.

Complaints about the research study

Complaints may be directed to the Ethics Officer, Research Services Office, Research and Innovation Division, Ethics Secretariat, University of Wollongong on 02 4221 4457.

Where the research is based

This research study is part of a PhD project at the Centre for Primary Health Care & Equity, University of New South Wales. The study is based at the Shellharbour Hospital. The approval process for the study has involved the Ethics Committee at the University of Wollongong and the South Eastern Sydney Illawarra Area Health Service.

Benefits, risks and costs
The findings of the study will benefit patients, carers and clinicians by providing insights into patient attitudes thereby improving management strategies for patients with chronic conditions and reducing hospital admissions. The participant risk in being involved in the study is the possible distress caused by the researcher observations in clinical settings, or discussing the chronic conditions in interview. In the event that participant becomes distressed, the observation or interview will be terminated and the patient will be offered a referral to the appropriate service. There is no cost to the participants in the study.

**More information about the research study**

If you would like more information, feel free to contact me, Sue Kirby (ph: 02 9385 8387, fax 02 93851513 or email: s.kirby@student.unsw.edu.au) and I will be happy to answer your questions. You could also contact the research supervisor, Dr Sarah Dennis, Senior Research Fellow, Fairfield Hospital GP Unit, School of Public Health & Community Medicine, University of New South Wales, Sydney 2052, on 02 9616 8520 email s.dennis@unsw.edu.au.
Patient Attitudes and Frequent Readmissions in Chronic Disease

Clinician Consent Form

9. I,……………………………….of………………………………………………………………………………
……………… agree to take part in the study described in the Patient Attitudes and
Frequent Readmissions in Chronic Disease Information Sheet attached.

10. I understand that the interview will be audio-taped. I agree to an audio-tape
being used to record the interview.

11. I acknowledge that I have read and understood the Information Sheet which
explains the aims of this investigation. I confirm that the statement has been
explained to me to my satisfaction.

12. Before signing this consent form, I have been given the opportunity to ask any
questions relating to the study. I have received satisfactory answers to any
questions that I have asked.

13. I understand that my decision to participate is voluntary and that I am free to
withdraw at any time without prejudice to my relationships to the University of
NSW, Shellharbour Hospital, the South Eastern Illawarra Area Health Service or
the University of Wollongong.

14. I agree that the research data gathered from the study may be published
provided that my name is not identified in any way.

15. I understand that if I have any questions relating to my participation in this
research I may contact the researcher, Sue Kirby at the Centre for Primary
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of New South Wales, Sydney 2052, ph: 02 9385 8387; fax 02 9385 1513 or
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Community Medicine, University of New South Wales, Sydney 2052, on ph 02
96168 520; fax 02 9616 8400 or email s.dennis@unsw.edu.au.

16. I acknowledge receipt of a copy of this Consent Form, the Information Sheet, and
the Revocation of Consent Form.

Complaints may be directed to the Ethics Officer, Research Services Office, Research and
Innovation Division, Ethics Secretariat, University of Wollongong on 02 4221 4457.
Please PRINT name: ............................................................................................................

Participant signature: ...........................................Agree to audio-tape interview yes no
Date..............................................
NAME of Researcher - SUE KIRBY Signature of Researcher............................................
Patient Attitudes and Frequent Readmissions in Chronic Disease

Clinician Consent Form

7. I,……………………………….of……………………………………….…………………
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Please PRINT name: ...................................................................................................

Participant signature:............................................Agree to audio-tape interview
yes no
Date........................................
NAME of Researcher - SUE KIRBY Signature of
Researcher.................................
Patient Attitudes and Frequent Readmissions in Chronic Disease

Clinicians Revocation of Consent Form

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Signature                Date

.............................................
Please print your name

This Revocation of Consent form should be forwarded to:

Sue Kirby
Building G27
Centre Primary Health Care & Equity
University of New South Wales
Sydney, NSW 2052
A.4 Scales for patient interviews

Please read each of the following statements and circle the one that best describes you or is closest to the way you generally are in your close relationships.

**It is easy for me to become close to others.** I am comfortable depending on other people and having other people depend on me. I don’t worry about being alone or what other people think of me.

Not at all like me A bit like me Very like me
[I_______I_________I_________I_________I_________I_________I_________]

**I am uncomfortable getting close to other people.** I want close relationships, but find it difficult to trust other people completely, or to depend on other people. I worry that I will be hurt if I allow myself to become too close to other people.

Not at all like me A bit like me Very like me
[I_______I_________I_________I_________I_________I_________I_________]

**I want to be completely close with other people, but I often find that other people are reluctant to get as close as I would like.** I am uncomfortable being without close relationships, but I sometimes worry that other people don’t value me as much as I value them.

Not at all like me A bit like me Very like me
[I_______I_________I_________I_________I_________I_________I_________]
I am comfortable without close relationships. It is very important to me to feel **independent and self-sufficient**, and I prefer not to depend on other people or have other people depend on me.

Not at all like me  A bit like me  Very like me

Please read the following statements and choose the answer that best fits what you feel.

Do you feel that the things that happen to you in your daily life are hard to understand?

a. No, never  
b. Yes, sometimes  
c. Yes, usually

Do you see a solution to problems and difficulties that other people find hopeless?

a. Yes, usually  
b. Yes, sometimes  
c. No, never

Do you feel that your daily life is a source of personal satisfaction?

a. Yes, usually  
b. Yes, sometimes  
c. No, never

In general, would you say your **health** is excellent, very good, good, fair or poor? Please circle the one that fits you.

Excellent  very good  good  fair  poor