A study to guide the design and implementation of a chronic disease management register in a regional health service

Dominic Robin Guda

Australian National University

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Declaration

Except where otherwise indicated, this Thesis is my own work carried out while studying at the Centre for Health Stewardship, College of Medicine, Biology and Environment of
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Dominic Robin Guda
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Acronyms

ACIC	Assessment of Chronic Illness Care
ACE	Angiotensin-converting enzyme
ACT	Australian Capital Territory
ACTEDIS	ACT Emergency department information system
ACTHEIM	ACT Health Enterprise Information Management
ACTHDD	ACT Health Data Dictionary
ACTPAS	ACT Patient Administration System
ACTPath	ACT Pathology
AIHW	Australian Institute of Health and Welfare
ANU	Australian National University
APHCRI	Australian Primary Health Care Research Institute
ATSI	Aboriginal and Torres Strait Islanders
BGL	Blood glucose level
CALD	Culturally and linguistically diverse
COC	Cycle of care
CCM	Chronic care model
CD	Chronic diseases
CDM	Chronic disease management
CHF	Chronic heart failure
CDMCN	Chronic Disease Management Clinical Network
CDMU	Chronic Disease Management Unit
CDSR	Central Data Systems Register
ChMP	Change Management Process
CNC	Clinical Nurse Consultant
COPD	Chronic Obstructive Pulmonary Diseases
CRE-PS	Centre for Research Excellence in Patient Safety
CRIS	Clinical Record Information System
DM2	Diabetes Mellitus type 2
e-Health	Electronic Health
EMR	Electronic medical record
GP	General Practitioner
HF	Heart failure

HL7	Health Level Seven
ICD–10–AM	International Classification of Diseases, 10th revision
IOR	Information Outputs Register
ICT	Information communication technology
IT	Information technology
KPI	Key Performance Indicator
MBS	Medicare Benefits Schedule
MeSH	Medical Subject Headings
METeOR	Metadata Online Registry
NEHTA	National E-Health Transition Authority
NHS	National Health Service
NHHRC	National Health and Hospitals Reform Commission
NHMRC	National Health and Medical Research Council
PASW	Predictive Analytics Software
PBS	Pharmaceutical Benefits Scheme
PCA	Principal Component Analysis
QI	Quality improvement
SCIPPS	Serious and Continuing Illness Policy and Practice Study
TCH	The Canberra Hospital

Abstract

Background

The mounting burden of chronic disease associated with population ageing creates a challenge for health systems. Healthcare organisations are addressing this challenge by exploring new ways to improve patient health outcomes, including through the use of information technologies.

Aim

This research aimed to identify key design features of a chronic disease management (CDM) register for the public sector health services provided in the Australian Capital Territory.

Methods and setting

ACT Health, a government agency, is the largest health service provider in the ACT. An organisational analysis of ACT Health was conducted using qualitative, quantitative, and participant observation methods. Three index conditions – Chronic Heart Failure, Chronic Obstructive Pulmonary Disease, and Diabetes Mellitus Type 2 defined information according to the 'International Statistical Classification of Diseases and Health Related Problems: 10th Revision, Australian Modification' (ICD–10–AM) – were chosen for data collection and analysis.

Results

ACT Health policies support evidence-based CDM interventions, but their implementation has been slow and disjointed. This research found that support for CDM in ACT Health is within the 'basic support' range as measured by the MacColl Institute's Assessment of Chronic Illness Care (ACIC) survey. The survey revealed continuity of care as a concern. On the positive side, factor analysis of the survey results identified a novel 'patient empowerment' factor that was strength within ACT Health. This patient empowerment factor is somewhat more than a concept; it is one of the powerful predictors of positive outcomes for CDM interventions, and has policy importance in this particular regional health system for working toward CDM goals.

In the participant observation aspect of this research, these findings were taken up to enrich the design features for an effective CDM register by incorporating the views of health professionals, patients and their carers. This research identified five data categories and associated variables required to support a CDM register. These five data categories are patient details, medical details, provider details, prevention details, and case coordination details. The prevention detail category is the centre of a CDM register intervention and consists of diagnostic, therapeutic and behavioural sub-categories. However, the research identified challenges regarding availability and completeness of these data in all five categories. Combining the survey and participant observation suggests that electronically incorporating standardised clinical information into a CDM register should enhance multidisciplinary communication, care planning and coordinated service delivery. A clinical data repository with data extraction and filtration systems compliant with the Health Level Seven International (HL7) metadata standard would enable the organisation to populate a CDM register's data fields from multiple sources.

Conclusion

A health service specific CDM register based on established data standards can actively support effective CDM interventions within the service. Further expansion toward a population-based CDM register would depend on implementation of local and national e-Health initiatives to standardise clinical information for automatic extraction into CDM registers. The research provides policy and design recommendations to further strengthen chronic care processes to benefit patients with chronic diseases, their carers and health service providers.

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Chapter One

Introduction

Chapter outline

1.1 Context

Chronic diseases are simply defined as ‘‘illnesses that are prolonged, do not resolve spontaneously, and are rarely cured completely’’ (Davis *et al.* 1999). In contrast to acute illness, chronic disease management (CDM) is complex because the onset is often slow. Patients are often not aware of the symptoms and even the diagnosis is difficult. In most cases, chronic diseases are linked with multiple causes and exposures in the past. For the majority of cases, prognosis of the problems is difficult and conditions are incurable. Weingarten and others emphasised CDM as an ‘‘intervention to manage or prevent a chronic condition using a systematic approach to care and potentially employing multiple treatment modalities’’ (Weingarten *et al.* 2002).

CDM is a challenge for the health system in terms of time and resources to create a supportive sustainable system (Wagner *et al.* 1996). If we look at the burden of chronic diseases in Australia, it is estimated that one in six Australians over the age of 45 years have Chronic Obstructive Pulmonary Diseases (COPD) and three-quarters of them are unaware of their condition (Abramson 2005), 4% of the population over 45 years old have Chronic Heart Failure (CHF), which is equal to over 300,000 current patients with

CHF in 2000 (Australian Institute of Health and Welfare 2004). In addition the national prevalence of Diabetes Mellitus Type 2 (DM2) is more than 7%—double the rate of 20 years ago (Dunstan *et al.* 2002; Shaw and Chisholm 2003) and 787,500 had been diagnosed with Type 2 diabetes according to 2007–08 National Health Survey (Australian Institute of Health and Welfare 2009).

Australia's CDM challenges are due to demographical changes and changes in disease patterns, the cost and burden of the chronic diseases, allocation of resources, and concerns about the consistent provision of evidence-based health services. The country needs helpful and long-term oriented system supports to address the reform agenda (Armstrong *et al.* 2007). Health care organisations need to focus on and implement modern information management technologies, such as electronic medical records (EMR) and functional data linkages. However, there are still substantial uncertainties about the actual impact of EMR on outcomes of patients with chronic diseases. In addition to the adoption of EMR to record and share information about clinical events, the CDM interventions need to deploy systems to better support clinical decision-making and assessment of patient outcomes. Implementation of the EMR together with the data linkage arrangements for the CDM can help clinician teams during the point of care delivery as well as to implement population-based chronic care management initiatives (O'Connor *et al.* 2005; Young *et al.* 2007).

Multidisciplinary care is inherently accompanied by increased transaction costs arising from the need to share information between a wide range of health and social service providers, or in the alternative, increased costs arising from additional risks to patients resulting from a failure of such communication. In this context, the use of information technology (including registers and EMRs) can mitigate these risks, and offset these adverse outcomes and costs. Clinical information management can play an important

role in successful implementation of sustainable CDM initiatives. One component of clinical information systems is the service specific disease register, which allows providers to:

- identify gaps in care at the population level
- bring quality improvement efforts to practice change and improved outcomes (Zgibor *et al.* 2007).

In addition, the service specific disease registers support recall and reminder systems for providers, assist in developing efficient patient care plans, and strengthen other decision support mechanisms to work together for the systematic improvement of CDM interventions. The availability of web-based management of clinical data and disease registers has the ability to exchange secure clinical data about patients as well as disease-specific information to attract the attention of concerned service units and thus facilitate continuity of care. It also provides control over morbidities and emergency department presentations (Rosser and Schultz 2007). Disease registers can identify relevant subpopulations of patients with illness for proactive care, which includes timely preventive interventions, chronic care reminders and prompts to ensure that patients receive care at appropriate intervals (Martin *et al.* 2004). The EMR integrated with the disease registers can provide a source of patient data and maintain multiple disease registries, but in reality few EMR systems are built with these critical functions (Metzger 2004). With the rapid advances in information management technologies, various clinical information systems have evolved in health institutions. Availability of new technologies and information systems for CDM is critical to achieve recommended clinical outcomes.

The Centre for Research Excellence in Patient Safety at Monash University has taken the initiative and outlined operating principles and technical standards for Australian

clinical quality registries. This document has been prepared in collaboration with the National E-Health Transition Authority (NEHTA). The document presents features of most of the existing registers in Australia and provides the guiding principles for any new initiatives (Australian Commission on Safety and Quality in Health Care 2008). Australian health service organisations' existing registers are not systematically designed with features of a clinical quality register. The National Chronic Disease Strategy of Australia calls for actions to implement a CDM register to reduce the gap between recommended and current management of chronic diseases, and facilitates service integration through expanding the functional roles of clinical information system (Guda *et al.* 2008).

The first step in my research is to investigate the relevance of a service specific CDM register and outline features of a register, including the role of a patient identifier that can link multiple data sources. This process can then serve as a catalyst for clinicians and management staff to gain information on chronic care performances in relation to outcomes for further integration (Joshy and Simmons 2006). The Institute of Medicine in the United States of America (USA) emphasised moving from paper based approaches to an electronic based system as a first step to improve care and patient safety. In comparison with other industries and enterprises, information and communication technology (ICT) is profoundly underinvested in health care sectors. In 2002, a report was prepared by Derek Wanless on the long-term views about the National Health Service (NHS) of the United Kingdom over the next 20 years. The report discussed the cost effectiveness of the overall health care interventions in relation to the investment and allocation of resources. The author made the remark ''without a major advance in the effective use of ICT (and this is a clear risk given the scale of such an undertaking), the health service will find it increasingly difficult to deliver the efficient, high quality service which the public will demand'' (Wanless 2002 pp 102;

Lois and Richard 2005). ICT here collectively refers to the innovations across health and social care services in relation to medications, medical devices, diagnostic techniques and procedures, clinical practice, delivery models and management. In Australia, the National Health and Hospitals Reform Commission in their report 'A healthier future for all Australians' put a recommendation to the Commonwealth Government to introduce patient-unique identifier for coordinated health care (National Health and Hospitals Reform Commission 2009).

Now is the time to advance continuity of relationships between health providers at various levels of the health system and between health care providers and consumers. The relationship in terms of communication between service units and agencies is viewed as strengthening organisational and governance systems and structures to support long-term orientation of care within the health system (NSW Health Department 2001).

1.2 Overall aim and objectives

The overall aim of this research is to investigate how to best design a CDM register in a regional health service (ACT Health) to demonstrate how to link evidence-based guidelines with the register in clinical practices; as well as the implementation strategies for a CDM register to improve CDM interventions in public sector health services. The specific objectives are to:

1. Explore the strategic relevance of registers in relation to CDM interventions in a medium size regional health service organisation
2. Assess the organisation's capacity and state of readiness to implement a CDM register to facilitate cooperation between services in the provision of patient care

and in support of patient self-management

3. Provide insight into the practical development of a CDM register so it will have a positive impact on the health of people with chronic disease.

1.3 Research questions

The following five research questions are posed for the study and are connected to the research objectives. The first three questions are related to objective 1; question 4 to objective 2; and question 5 to objective 3. Table 1.1 shows the research questions for investigation, data sources and anticipated findings.

Table 1.1: Research questions and primary data for investigation

Research questions	Data source	Anticipated findings
1. What are the current policies that support CDM in ACT Health?	Relevant policy documents at ACT and national level.	Chronic care policies, policy opportunities, and issues in relation to chronic care.
2. What are the existing services focussed on CDM in ACT Health?	Documents and websites of ACT Health, participant observation.	Existing chronic care programs, health system responsiveness to policies.
3. How could a CDM register support these policies and services?	Key informants' interview, the Serious and Continuing Illness Policy and Practice Study *(*SCIPPS*)* transcripts.	Strategic relevance of a CDM register, impact of a CDM register on chronic care interventions.
4. How ready is ACT Health to implement a CDM register and integrate it with existing services and patient care support infrastructure?	The Assessment of Chronic Illness Care (ACIC) survey, the Serious and Continuing Illness Policy and Practice Study (SCIPPS) transcripts, and key informant interview.	Organisational capacity and opportunities to implement a CDM register, current provision of planned care and continuity of care, patient/carers experiences and expectations, strengths and opportunities in relation to clinical data and clinical information management systems to introduce a CDM register.
5. What is the best way in which data should be collected, stored and presented?	Participant observation, key informant interview.	Practical insights into ACT Health's information management systems, data and data flow design of the CDM register, governance framework for implementing the register, and additional policies for register implementation.

1.4 Terms used in this thesis

This research frequently uses some specific terms. Table 1.2 displays these terms and their descriptions.

Table 1.2: Terms and their descriptions used in this thesis

Terms	Description
Chronic diseases	Chronic diseases are illnesses that are prolonged, do not resolve spontaneously; and are rarely cured completely (Davis *et al.* 1999; Zwar *et al.* 2006).
The index chronic conditions	This research has collected data in relation to three chronic conditions: which are CHF, COPD and DM2. The intention here was to capture knowledge and understandings of the management and prevention of these conditions and reflect those in the design features of a CDM register.
Chronic disease management (CDM)	CDM is the totality of care provided for a patient's chronic diseases, by health professionals, the patients themselves and their carers.
Chronic care model (CCM)	The chronic care model was developed by Edward Wagner and colleagues at the MacColl Institute for Healthcare Innovation in Seattle (Wagner 1998). The model identifies the essential elements of a health care system that encourage high-quality chronic disease care. These are: (1) resources and policies, (2) the organisation of health care, (3) self-management support, (4) delivery system design, (5) decision support, and (6) clinical information systems. A CDM register is a key part of these clinical information systems.
Register	In this research, the term 'register' is applied to a database of patient information for a specific group of patients. Population-based registers are commonly used for epidemiological studies. Service specific registers of the type being investigated in this research project can be used for service improvement activities, as a source of data for case control studies, and benchmarking quality of care between services (Last 2001; Porta 2008). A CDM register is applied to the service specific register for three index chronic conditions. A CDM registry refers to a system managing a CDM register.

1.5 Organisation of thesis

The thesis begins with the introductory chapter on the topic to guide, design and implement a CDM register in a medium size regional health system. **Chapter 2** provides the findings from a literature review and brings in the overall knowledge base on chronic care, CDM issues and challenges, and the organisational roles in strengthening chronic care. The literature contributed to obtaining significant knowledge and understandings about the roles of a CDM register in optimising chronic disease management.

Chapter 3 presents the methodology used to collect relevant information for analysis. This chapter describes the research settings and details of each data collection method, data sources and data collection instruments. This chapter presents the respondents and their characteristics. Also this chapter outlines the methodological framework for primary and intermediate data analysis.

Chapter 4 presents findings of the key informants' interviews. This chapter explores the strategic relevance of the CDM register in relation to CDM interventions in a regional health system. The results of this chapter mainly address the first and second research objectives. This chapter discusses qualitative data analysis in detail including the data analysis framework and the data coding scheme.

Chapter 5 presents the findings of the MacColl Institute's 'Assessment of Chronic Illness Care' (ACIC) survey. This chapter displays a quantitative assessment of the status of chronic illness care. The specific statistical data analysis methods are discussed in detail in this chapter. The survey findings helped to understand current implementation of chronic care initiatives in relation to CCM components. The findings independently contributed to understanding the capacity and readiness of the health

system to implement a CDM register and they create linkage with key informant interview findings and with patients' and carers' experiences (as mentioned in Chapter 6).

Chapter 6 presents the experiences and expectations of carers' and patients with chronic conditions of interest. In this chapter, qualitative transcripts of the *Serious and Continuing Illness Policy and Practice Study (SCIPPS)* are analysed. SCIPPS was conducted jointly by the University of Sydney and the Australian National University (ANU). This research has used only the transcripts of the Australian Capital Territory research participants. The data analysis has used SCIPPS's existing coding scheme and the codes were selected based on their relevance to the CCM components and findings of Chapter 5. The intention of this chapter is to generate results in relation to the readiness of health care consumers; and their perceptions about the capacity of health systems to support chronic care. The findings of this chapter have complemented findings of previous chapters. Also the findings contributed to gaining insights into how a CDM register and strengthened clinical information system can support current CDM initiatives around patients' and carers' needs.

Chapter 7 builds on the understanding generated in the above chapters and presents findings from the participant observation at ACT Health CDM Unit as well as the key informants' interviews. The findings of this chapter are grouped into three sections: the first section discusses the roles of a CDM register to facilitate chronic care; the second section discusses the data elements of a CDM register, data flow design, and quality control processes; and the third section discusses the management and governance framework for CDM register implementation within the main health system.

Chapter 8 is the concluding chapter. This chapter presents key findings of the research in relation to research objectives and questions. It also discusses the strengths and

limitations of the study. It ends by identifying specific policy opportunities for CDM and implementation of a CDM register; and areas for further research.

1.6 Anticipated contributions

The thesis outlines considerations to improve regional management of chronic diseases. The main contributions are in relation to: 1) chronic care program opportunities, 2) specific policy development to integrate chronic care interventions and 3) design of a CDM register to facilitate secondary prevention of chronic conditions.

The growing burden of chronic disease requires integration of all prevention interventions. Within the supportive policy environment, chronic care interventions in ACT Health are strong. However, these interventions need further integration. The thesis draws on the functional features of the CDM register, which is expected to contribute to building collaboration between service agencies. Also, the register will further strengthen the coordination of prevention initiatives. These features have generalisability to other Australian regional health service providers, and provincial health services in some other countries with health system structure common with ACT Health to design and implement CDM registers.

Last but not least, the benefits of the research will flow to ACT Health staff and their patients with chronic diseases through policy development, implementation of quality improvement initiatives and changes in healthcare processes.

Chapter Two

Literature review

Chapter outline

2.1 Introduction

The literature on chronic care and on e-Health is now quite extensive. In this review I have focused on the burden of chronic disease, and how its management might be improved by organisational change in large health care providers. I conclude by examining more specific literature on chronic care model and the role a CDM register might play.

2.2 The review process

The literature review process involves five electronic databases for published and unpublished articles available only in the English language in relation to care for people with chronic conditions. The e-resources and databases searched are MEDLINE, Ovid,

PubMed, ProQuest Central, and Google Scholar for relevant information available as of 2011. In addition, I have reviewed published and unpublished reports of ACT Health, and relevant web-based information.

Terms used to search relevant documents

The general terms and conditions (used independently or in combinations) include Medical Subject Headings (MeSH) terms for the MEDLINE search:

- General terms (care management, care models, care framework, care coordination, care planning, challenges, collaborative, clinical data, clinical information system, co morbidities, chronic care, chronic conditions, chronic diseases, chronic care model, data, decision support, disease management, empowerment, evidence-based guidelines, guidelines, health, information management, information technologies, integrated care, interdisciplinary, long-term conditions, management, multidisciplinary, multiple morbidities, meta guidelines, organisation, patient, patient discharge, pathways, prevention, primary prevention, quality, readiness, register, registry, roles, secondary prevention, risk, self-management, success factors, system, and so on).
- Conditions (asthma, congestive heart failure, chronic heart failure, chronic lung diseases, chronic obstructive lung diseases, chronic obstructive pulmonary disease, dementia, depression, diabetes, diabetes type 2, diabetes mellitus, heart failure, hypertension, kidney diseases, mental health, stroke, and so on).
- Organisations (ACT Health, Australian Bureau of Statistics, Australian Disease Management Association, Australian Institute of Health and Welfare, Australian Lung Foundation, Disease Management Association of America, Institute of Healthcare Improvement, Kaiser Permanente, MacColl Institute, Monash University

Centre for Research Excellence in Patient Safety, World Health Organisation, and so on).

2.3 Burden of chronic disease

According to Australia's Welfare Report 2011 prepared by the Australian Institute of Health and Welfare (AIHW), the population of Australia is 22.3 million as of June 2010. The population aged 65 years and above comprises 13% of the total population. From 1970 to 2010, the population 65 years and above has increased by three times (Australian Institute of Health and Welfare 2011). In the 2004–2005 National Health Survey (NHS), nearly 77% of all Australians self reported as having at least one long-term health problem. Nearly all people aged 65 years or over reported at least one chronic condition and the majority of them (nearly 80%) reported more than one chronic condition (Australian Institute of Health and Welfare 2006; Caughey *et al.* 2008; Jordan *et al.* 2008). Due to the aging of the population, delivering optimum care for people with chronic disease is a major challenge. This challenge is due to the absence of solutions to minimise the gap between the demand and supply of efficient chronic care (World Health Organisation 2002).

Chronic diseases are prolonged, with slow onset and are rarely curable. In most cases diagnosis of chronic conditions is difficult and complex, and their management requires support from a range of healthcare providers including family members (Davis *et al.* 1999; Weingarten *et al.* 2002).

In Australia, chronic diseases account for 70% of the total morbidities (Dennis *et al.* 2008). In 2000–01 the estimated expenditure for chronic diseases was more than $35 billion (Dowrick 2006) and most of the expenditures were related to large number

of hospitalisations involving huge costs (Australian Institute of Health and Welfare 2006). Many of these hospital admissions are preventable through reform in health services delivery systems (Australian Institute of Health and Welfare 2009; Clinical Epidemiology and Health Service Evaluation Unit 2009).

2.4 Continuum of chronic care across care boundaries

According to the CDM intervention framework, the care planning process helps connect various care providers around the need of a patient. It facilitates multidisciplinary care through assessment of the patients' conditions. The care planning process facilitates the transition of patients from hospital to community. A successful care plan has a strong effect on the continuum of care (Nielsen *et al.* 2008) and on the development of communication channels between providers (Jacobsen and Sevin 2008).

Self-management support elements of CDM programs help to improve patient outcome and to reduce the risk factors, thus improving quality of life. However, few self-management support strategies are effective (Glasgow *et al.* 2008; Williams *et al.* 2011). Integration of acute and primary care sectors can strengthen self-management supports (Scott *et al.* 2004) through the clinical information linkage and implementation of clinical decision support systems (Harris and Zwar 2007). In practice, the self-management component is not rooted in primary care services. It is viewed as a strategy to reduce pressure on the acute care sector (Dennis *et al.* 2008). In the Australian primary care setting, only the Medicare program promotes self-management support (Francis *et al.* 2007). The integration of the Medicare program with primary care also adds a social support component for patients who require other assistance in the management of their chrpnic disease (Swerissen and Taylor 2008).

The clinical information management system links patients and service agencies through clinical data and strengthens delivery of coordinated care. This linkage reinforces implementation of self-management activities and improves patient outcomes (Montori *et al.* 2002). According to the Chronic Care Model (CCM), a service specific disease register is a component of a clinical information management system (Zgibor *et al.* 2007). The CDM register is a service specific disease register that incorporates evidence-based guidelines for patient management (Penn *et al.* 2004) and links disease management strategy with patient care. Evidence shows that provision of clinical information support in therapeutic decision-making is associated with better disease management processes including self-management support (Heisler *et al.* 2007). CDM requires specialised and multidisciplinary coordinated support to achieve patient-centred goals. However, implementation of multidisciplinary care relies on relevant service units' strategic priorities and governance arrangements. The attitude, acceptance and rational flexibility of relevant chronic care disciplines are really important to implement a coordinated model of chronic care (Hindle *et al.* 1995). In relation to organisational contexts, the size of the multidisciplinary teams and associated increase in communication (transaction) costs can hinder the implementation of a multidisciplinary CDM approach (Grumbach and Bodenheimer 2004). However, these complexities may be mitigated by the effective use information and communication technologies. CDM interventions also require performance measurement to prove effectiveness of interventions (Bayliss 2007).

2.5 Need for better measurement

Quality appraisal of healthcare facilities often considers discharge summaries as a proxy for the outcome of care. However, the use of discharge summaries has extreme

dependency on the existing policies in relation to patient transfer (Farsi and Ridder 2006). So, the quality appraisal process should define the methodology and type of outcome data to use (Thomas *et al.* 1993).

Schoenman and others conducted a study and reviewed the strengths and limitations of hospital discharge data (Schoenman *et al.* 2007). The study involved a systemic literature review and telephone interview of key informants. In a hospital setting, the discharge data are a potential resource for learning about care delivery processes. However, discharge data have limitations in relation to completeness, representativeness, and accuracy. The current hospital discharge system receives only limited decision support from information technology. In an ideal situation, the discharge system should include a patient discharge component as well as patient transfer component for the integration of the acute care sector with primary care. Due to the inadequate application of information technology, existing discharge summaries are often of limited quality in terms of comprehensiveness of information and timeliness (Smith 2006).

A variety of data linkage activities have tried to address the above concerns. A population-based health data linkage study in Western Australia is such an example (Holman *et al.* 1999). This study supported outcome research programs utilising a range of administrative databases. The study aimed to investigate the usefulness of clinical information on performance. It further reinforced combining administrative data with medical records for comprehensive evaluation of health system performances. In Western Australia another similar study examined use of hospital morbidity data for heart failure surveillance (Teng *et al.* 2008). In Western Australia, the central morbidity database keeps records of all public and private hospital admissions and separations. The study retrospectively reviewed medical charts of 1006 patients with HF. The study

found that standardised coding of discharge has high predictive accuracy in monitoring trends and epidemiology of HF.

There is a strong need to identify indicators and measurement framework to evaluate patient outcome and quality of chronic care (Rubin *et al.* 2001; Buchanan *et al.* 2006; McKinley *et al.* 2008). A better measurement framework is important for a health system, healthcare providers and patients (Groene *et al.* 2008).

Balas and others evaluated the effectiveness of clinical information management interventions on the process of care in outpatient and primary care settings. The evaluation process involved review of 98 randomised clinical trials. The study concluded that efficient clinical information management interventions can make significant improvements in care processes, treatment plans, recall and reminder (for patients and clinicians) and patient education (Balas *et al.* 1996).

Few studies assessed quality of care when patients receive long-term care from different services. Scholle and others in their study compared the quality scores of ambulatory care with the scores based on the information from all other providers. The study was conducted in the Maryland Medicaid program. The study assessed the quality of two interventions, for what the researcher called 'well child' care for 55 two-year old children, and for asthma care for 70 children and adults. The quality scores of well child care improved over time. However, the study found declining quality scores for asthma care because the clinician had not prepared follow-up care plans. The study concluded that quality assessments vary and depend on individual health care providers' focus on care delivery (Scholle *et al.* 1996).

Despite several initiatives to use administrative data, healthcare organisations are trying to develop sustainable strategies for evidence-based chronic care. The discussion

outlined the usefulness of clinical data and disease registers to support care management efforts. The CDM performance measurement requires a shift from a paper-based to a technology-based system like service specific disease registers with a view to precisely measure processes and strengthen evidence-based chronic care (Keyser *et al.* 2009).

Health institutions have started implementing disease registers using data from different sources. The implementations are not always successful due to technical and resource issues, in creating viable disease registries with multiple data feeds (Solomon *et al.* 2003).

2.6 Need for evidence-based CDM programs

The large gap in evidence-based chronic care drives the growing interest in better chronic disease management. Evidence-based chronic care interventions can prevent many complications and improve the quality of life of patients with chronic diseases. A study in the USA revealed that only 56% of patients with chronic disease received care according to evidence-based guidelines. Only 45% of diabetic patients received recommended care (McGlynn *et al.* 2003). There are several barriers to implementing evidence-based chronic care interventions. The important barrier is the absence of performance management systems for chronic care using clinical data (Institute of Medicine 2001). Time constraints is one among other barriers in primary care to providing preventive services (Yarnall 2003) as well as evidence-based chronic care (Østbye *et al.* 2005).

The sustainability of evidence-based chronic disease treatment and prevention programs is a concern (Bailie *et al.* 2006). Bailie and others conducted a retrospective review of clinical data of Indigenous Australian patients diagnosed with kidney diseases and

hypertension. The authors reviewed clinical data of patients who had enrolled in a specialised treatment program. The specialised treatment program continued for three years and aimed to reduce the incidence of end stage kidney diseases. After three years, the intervention was integrated into the primary health care services. The study found a failure to keep control of hypertension after three years of the specialised program. The study discussed several reasons behind this failure to sustain patient outcomes. The important reasons found were the inability of primary health care services to maintain high-level management roles and use clinical information support to recognise clinical priorities.

Implementation of established disease management guidelines also varies across geographical locations. Clark and others conducted one study to determine the level of difference in CHF management in Australian rural and urban primary care settings. The study found a lower than recommended use of pharmacological treatment e.g. angiotensin-converting enzyme inhibitors and less use of diagnostic tests e.g. echocardiography in rural areas compared to metropolitan areas (Clark *et al.* 2007). This finding is similar to other studies in relation to under-use of evidence-based guidelines for heart failure treatment and diagnosis (Fonarow *et al.* 2007; Swedberg and Ekman 2005). These findings call for adoption of disease management monitoring systems. A recent study also identified under-use of spirometry as a diagnostic tool for COPD management in the primary care setting. In relation to patient education, a smoking-cessation program was also not common. The author identified one of the barriers is insufficient time (an average of 15 minutes per patient) to improve clinical care performance (Moore 2007).

The care for patients with chronic disease in primary care settings has improved but the quality of care is below the optimal standard, for reasons that include inadequate

incentives, inadequate participation of relevant disciplines in the management of chronic conditions and under-use of clinical decision supports to attain optimal practice change (Harris and Zwar 2007). Simpson in his paper referred to the inability of the health system to identify the patient population in need of care, which is one of the factors that affects service planning and quality improvement of chronic care (Simpson 2006).

To improve chronic care interventions, patient empowerment appears as a new dimension within the concept of self-management. The overall outcome of 'empowerment and self-management' is how patients with chronic diseases self-manage their illness. Patient empowerment is a modern concept to support patients with their chronic diseases (see Section 2.7 for discussion on patient empowerment). Patient empowerment emphasises patients' ability and power (autonomy) to take control over their illnesses (Cooper *et al.* 2003; Aujoulat *et al.* 2008).

Within the CDM environment, the interaction gap is common between health care providers, patients and their families when attempting to institute active self-management roles (Yen *et al.* 2011). Different studies evaluated the quality of chronic care at hospitals and primary care settings and found gaps in care coordination among service agencies (McGlynn *et al.* 2003 ; Rutschmann *et al.* 2004; Bourbeau *et al.* 2008; Rafter *et al.* 2008). Even hospitals have few initiatives to adequately coach patients with chronic diseases about how to manage their care at home (Clark 2006).

Under the self-management support strategies, the care planning process has scope to improve evidence-based and multidisciplinary coordinated care. According to the paper by Shortus and others, the existing care planning processes could not establish genuine collaboration between providers and patients. Primary care physicians do not often discuss care plans with other providers. The care planning process could not adequately

influence approaches in disease management for coordinated care (Shortus *et al.* 2007). Little evidence has been identified to define the effective use of community resources to support CDM in primary care (McDonald *et al.* 2004). Multidisciplinary care planning requires involvement of other health care providers to contribute to the plan. In the majority of care plans, two or more clinicians or health care professionals are involved. But it is difficult to know the extent to which they contribute, because of inadequate tracking of processes and outcomes of care (Vagholkar *et al.* 2007). In addition, inadequate health literacy also contributes poor compliance from the patient side for uncontrolled chronic conditions (Safeer *et al.* 2005).

Health policies to support CDM require strengthening primary care systems to maintain overall coordination within the continuum of care for patients with multiple and complex chronic conditions (Department of Health and Ageing 2009; Boult and Wieland 2010). In addition, strengthened policies are needed to focus disease management programs for patients who are at moderate level of risk (Wagner *et al.* 2001; Department of Health 2005) and self-management interventions for low risk groups of patients (Gately *et al.* 2007).

2.7 Patient empowerment and CDM

Contemporary CDM initiatives use the term ‘patient empowerment’. Patient empowerment refers to multifaceted learning and action process, which helps patients with chronic diseases to promote their well-being, strengthen their self-management capacity and decision making. This concept enables patients to become partners with their treating teams for disease management decisions (Anderson *et al.* 2000; Santurri 2006).

The preparation of a collaborative self-management plan or care plan is one of the core initiatives on the way to patient empowerment. A collaborative self-management plan transforms the traditional self-management supports into a patient-centred approach to create informed and responsive patients (Funnell and Anderson 2004; Anderson and Funnell 2005).

A collaborative self-management plan actively involves the patient and strengthens their self-management skills. An ideal patient-centred arrangement requires health system supports in relation to tailored educational sessions, productive interactions between providers and patients, availability of a care coordinator, portal for sharing clinical outcome data between providers and patients, and an efficient appointment system involving multidisciplinary providers to reduce individual patient visits (Ledlow 2000; Renders *et al.* 2001; Glasgow *et al.* 2002; Coleman and Newton 2005; McCorkle *et al.* 2011).

A strengthened clinical information management system has specific roles to improve patient-centred chronic care and thus the care delivery processes (Fromer 2011). Barnes and others in their study (Barnes *et al.* 2006) presented notable improvements in a diabetes program through sharing data on patients' glycemic control among the patients and their provider teams. The authors conducted a randomised controlled trial with 350 patients with type 2 diabetes mellitus (DM2) as the intervention group and 350 patients with DM2 as the control group in the Grady Health System (GHS), Atlanta, Georgia. The trial used a simple computer application to graphically display the status of glycemic control of the patients within their existing EMR system as an intervention. The trial called this intervention a 'roadmap'. The trial found that this roadmap inspired the patients and helped them to evaluate how they were managing their DM2. This intervention was also a very convenient decision support tool for the providers.

Within the disease management processes, the concept ‘patient empowerment’ emphasises the creation of active and informed patients through collaborative interactions with their providers. The CCM framework supports these collaborative interactions to achieve optimum clinical and prevention outcomes (Wagner *et al.* 2001). The patient-provider interaction strengthens the self-management education processes and helps patients to improve quality of life (Bodenheimer *et al.* 2002). Aujoulat and others conducted a thematic analysis of 55 articles, and examined the relationship of the term ‘patient empowerment’ with specific chronic care interventions. The results suggested that the patients’ knowledge about their diseases contributes the power to make chronic care programs successful. Patient empowerment is a direct outcome of the negotiation between the providers and individual patients to identify their service needs (Aujoulat *et al.* 2007).

Improved information and communication technologies support clinical decisions, and involve patients in the disease management processes. The empowerment concept is interrelated both to healthcare organisations and patients with chronic diseases. The presence of a seamless communication environment assists concerned service units to set up a coordinated appointment system for planned chronic care services. However, clinical data linkage between multidisciplinary service units requires more policy supports when the service units are under different governance frameworks. The sharing of patient-specific clinical outcome data makes service units more accountable for acting on data that are brought to their attention. On the patient side, the patients can better correlate the clinical outcome data to understand the status of their disease conditions. All these boost up patients’ confidence to strengthen their self-management ability and their choices to select relevant chronic care supports (Marc 2010).

The development of a CDM register can build a platform for patient empowerment by strengthening the underlying clinical information management system to make data more available not only within the multidisciplinary team, but also to the patient and their carer(s). However, the issue of patients' privacy and confidentiality requires appropriate policies in relation to sharing and accessing relevant patients' data. The relevant policies provide the power and control to the healthcare organisations and patients for a continued and coordinated chronic care.

2.8 Assessing the capacity of healthcare organisations to improve chronic care

Better patient outcomes rely on collaborative models of care and organisational commitments (McKay and Crippen 2008). A healthcare organisation with infrastructure support is associated with sustainable quality improvement (QI) initiatives. The clinical information system helps with deeper implementation of QI initiatives to identify problems and benchmark changes in healthcare processes (Perrin *et al.* 1999; Alexander *et al.* 2006).

The concerns related to routine CDM processes result from organisational as well as system level problems rather from those of individual physicians (Institute of Medicine 2001). Healthcare organisations face resistance to accepting new technologies for improvements in processes and performances (Li *et al.* 2004). Introduction of new technology requires clear communication and organisational commitment to attain collaboration between care delivery teams (Dean 2006; Hughes 2008) and improve practitioners performances (Garg *et al.* 2005). Clinical practice improvement is not possible without the trend data analysis of patient population in a particular health system (Diamond *et al.* 2009).

Jessup in her article defined organisational readiness for change as depending on ‘‘the program's need for improvement in clinical practices and administrative functioning, training needs, and pressure for change’’ (Jessup 2007). Organisational change mostly depends on the leadership approach to creating an environment for change as well as the communication between management bodies and staff (Lehman *et al.* 2002; Krause 2008). The communication leads the level of motivation for change, which can manipulate the organisation’s culture and businesses (Chen 2007). The motivation generally depends on the appropriateness of any new initiative compared to the need for change, the effectiveness, and the management support (Simpson 2002; Holt *et al.* 2007).

Most Australian healthcare organisations use clinical audit, incident reporting, inquiry and other qualitative methods as performance improvement approaches (Wolff 1994; Allison 2006; Barr *et al.* 2006). Quantitative approach using performance and outcome indicators is now considered central to quality improvement (Mainz 2003; Duckett *et al.* 2008). The CCM aims to involve patients, their families, and health care providers through active interactions. These interactions are more productive when treating teams use clinical data for clinical decision as well as for planning appropriate prevention interventions. The CCM improves the quality of disease management activities incorporating process and outcome data through a clinical register (Wagner *et al.* 1999; Wagner *et al.* 2001).

The clinical information system establishes reliable systems to monitor patient care. The clinical information system links various patient care data and gives useful information about clinical care. This helps both management staff and the treating team to better understand their care delivery processes (Menachemi *et al.* 2008). The measurement of current organisational strengths and opportunities can direct the implementation of a

CDM register within the health system. The assessment may include measuring the organisation's leadership and management capacity, clinical information system management, implementation of evidence-based guidelines and prevention interventions. If we consider CDM intervention as a service business, then process analysis can help understanding steps needed to improve quality of chronic care (Eitel *et al.* 2008). There is growing evidence to apply process reengineering in health services to improve efficiency of care (Masso *et al.* 2010). The findings from organisational assessment and process analysis can demonstrate opportunities to implement a CDM register in the health system.

2.9 CDM frameworks and models

Newton and others reviewed literature to evaluate the impact of collaborative methodology on the management of patients with HF and chronic cardiovascular disease. The study found that implementation of collaborative methodology had improved the patients' outcomes. The assessment considered quality improvement as the basic principle to describe the collaborative methodology (Newton *et al.* 2006). The organisational arrangement for physicians working as integrated teams with shared understandings on chronic care has a positive impact on quality of chronic care (Kern 2007; Mehrotra *et al.* 2006). Jackson examined diabetes care in relation to organisational features of Veterans Affairs primary care clinics. The study findings suggested that integrated teams of physicians actively support implementation of evidence-based diabetes guidelines. Physicians in integrated teams also facilitate engagement of patients to improve clinical outcome. This integrated approach is in line with the CCM framework (Jackson *et al.* 2005).

Amoroso and others examined the role of the clinical audit process on chronic care performances in general practice (GP) settings. The clinical audit process involved a practice level feedback report, which was sent to the participating general practices. The study explored some useful organisational elements to enhance chronic care performances and quality. The clinical audit process, as a quality improvement method called for further supports to balance the demand of patients with chronic diseases and evidence-based chronic care (Amoroso *et al.* 2007).

The Geriatric Ambulatory Practice at Boston Medical Centre, Boston's safety net hospital used CCM framework to improve cardiovascular diseases and DM2 management. This multifaceted intervention developed disease registers that centralised clinical information. The initiative covered 283 eligible patients for 39 months who had cardiovascular diseases, diabetes mellitus type 2 or both. The results showed significant improvement of all clinical measures over time (Caruso and Clough-Gorr 2007). The intervention showed an overall decrease in mean HbA1c level, more frequent measurement of HbA1c and more frequent foot examination.

The Louisiana State University Health Care Services Division (HCSD) conducted a study using an electronic data repository for CDM programs. The hospital and population centres of southern Louisiana implemented these CDM programs. The study followed up patient data of eight chronic conditions for a period of 10 years. The study tracked improvements in the proportion of patients who followed recommended medication, and achieved target levels for HbA1c and low-density lipoprotein (LDL). The study primarily focussed on process and outcome improvements for adult Diabetes, Asthma and congestive heart failure as well as modification of risk factors (Horswell et al. 2008). Healthcare organisations adopted the disease management approach in the latter half of the 1990s to provide cost-effective and high quality chronic care. The

Disease Management Association of America defined this particular approach as a coordinated health care approach with communication with patients and their families to assist self-management practices (Faxon *et al.* 2004). The structure of the intervention is similar with that of CCM (Villagra 2004).

Singh and Ham conducted a review of different chronic care frameworks and service delivery models implemented in United Kingdom (UK) and other international settings (see Table 2.1). The authors compared the impacts of these frameworks and models. They defined a framework or model consisting of elements to effectively address evidence-based care for chronic conditions and their prevention (Singh and Ham 2006). Table 2.1 below shows the authors' review findings on the evidence or impact of different chronic care frameworks and models. The authors in their review suggested that CCM has the most relevant components for the management of people with long-term conditions.

Phillips and others in a report mentioned that the Australian healthcare organisations need to implement CCM components in existing chronic care programs. The authors prepared the report on the National Institute of Clinical Studies (NICS) Heart Failure Forum 2004. The authors emphasised the need to reform chronic care processes and enhance roles of patients in the care planning process (Phillips *et al.* 2004).

Table 2.1: Chronic care frameworks and service delivery models

CDM frameworks and service delivery models	Program elements	Evaluation findings
Chronic care model (CCM), USA	• Organisation of Health care • Resources and policies • Self-management support • Delivery system design • Decision support • Clinical information systems	There is little comparative evidence of the effectiveness of CCM components compared to other frameworks. The model has significant effects in the improvement of care processes and quality of chronic care.

National Health Service (NHS) and Social Care model, UK	• Case management • Multidisciplinary teams • Self-management	The review could not find any specific evidence of the effectiveness of this model.
Innovative Care for Chronic Conditions model, World Health Organisation (WHO)	• Patients and their families • Health care organisations and community • Policies	The review could not find any specific evidence of the effectiveness of this model.
Public Health Model, USA	• Policy • Community activities • Health services: prevention and continuing care	The review could not find any specific evidence of the effectiveness of this model.
Kaiser Model, USA	• Risk assessment • Case management • Self-management	It has the ability to integrate services; and reduce hospital admissions.
Evercare and Pfizer Models, USA	• Identification of high risk cases • Nurse-led case management (Evercare) or telephone support (Pfizer)	The model has effects on reduction of healthcare costs.
The Strengths Model, USA	• Patient empowerment • Recognise capacity and skill of patients	The review could not find any specific evidence of the effectiveness of this model.
Veterans' Affairs model, USA	CCM components for specific patient population.	Same as CCM.
Guided Care, USA	Nurse-led care for older patients with multiple chronic conditions	The review could not find any specific evidence of the effectiveness of this model.
Program of All-Inclusive Care for the Elderly (PACE) model, USA	• Care for elderly patients • Integrated primary care • Specialist medical care	The authors considered this model with possible roles to reduce hospital admissions.

The CCM (Figure 2.1) was developed by Edward Wagner and his team in the US in 1998. Healthcare organisations in many different settings are implementing CCM to a variable extent (Wagner *et al.* 2001; Siminerio *et al.* 2005; Stroebel *et al.* 2005). The quality improvement approach is an essential component within CCM (Bodenheimer *et al.* 2002a). The CCM framework involves following six areas of change:

1) Organisation of health care
2) Resources and policies
3) Self-management support
4) Delivery system design

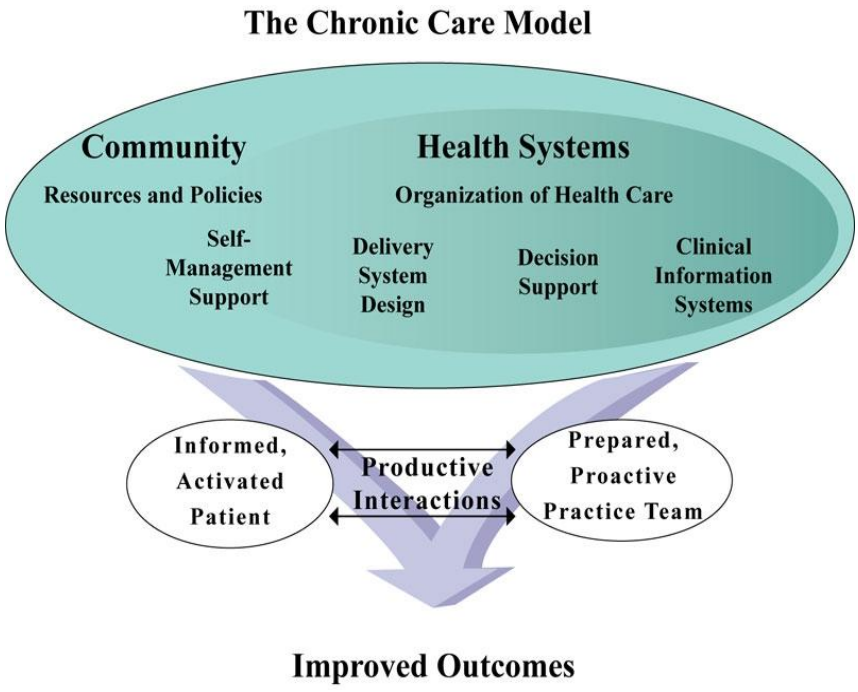
5) Decision support

6) Clinical information systems.

The CCM implementation is effective in many chronic care program settings. Some programs experienced mixed and ineffective results (Coleman *et al.* 1999; Solberg *et al.* 2000; Olivarius *et al.* 2001; Bodenheimer *et al.* 2002b; Schonlau *et al.* 2005).

Minkman and others reviewed integrated care models like the European Foundation Quality Management (EFQM) Excellence model (Excellence award models) and the Malcolm Baldrige Quality Award (MBQA) model with CCM. The authors found that all the models have some level of similarities in relation to intervention elements. The CCM appears as an evidence-based model for improved performances in relation to care delivery process and outcomes, but there is no specific conclusion (Minkman *et al.* 2007).

Figure 2.1: The Chronic Care Model (CCM)



2.10 Effectiveness of the CCM

The CCM provides a conceptual framework to redesign care delivery processes for patients with chronic conditions. There is now considerable evidence on the impact of the CCM from observational and experimental studies. These findings contribute in organising the framework for the remaining chapters in this thesis. In addition to previous discussions, Table 2.2 presents notable evidence in relation to the effectiveness of CCM components in improving the outcomes of CDM interventions. As part of the continued discussion on the clinical information system component of CCM, Section 2.11 presents more evidence in relation to the implementation of a CDM register intervention.

Table 2.2: Evidence in relation to CCM implementation

Authors	Intervention/Study design	CCM component(s) examined	Findings
Asch *et al.* 2005	Evaluation of the quality of care for patients with CHF through a quasi-experimental study. The study involved four organizations participating in the Institute of Healthcare Improvement's Breakthrough Series (IHI BTS) collaborative, and four organisations as the control group.	All six CCM components examined. The intervention included leadership commitment to promote rapid changes in CHF, collaborative provider interaction, roles of a care manager, provider training on quality improvement processes, and use of a CDM register (with processes and outcome indicators) .	The patients in the intervention group had higher use of evidence based medications (e.g., ACE Inhibitor, lipid lowering medications). The intervention significantly improved counselling and education for patients, which resulted in higher level patient activation to improve care compared to control group.
Piatt *et al.* 2006	Randomised controlled trial at 11 primary care practices, Pittsburgh, Pennsylvania.	All six CCM components examined. The trial included community partnerships, patient education, problem solving and goal-setting strategies for patients with diabetes.	The patients in the intervention group showed improved self-management knowledge and skills, and better HbA1c control.

Coleman *et al.* 2009	Review of 944 articles published from 2000 to 2008 in relation to the effectiveness of CCM-based interventions on clinical care and health outcomes.	All six CCM components examined.	The review findings suggest that the CCM-based chronic care interventions are generally linked with improved care delivery processes and patient outcomes. The improvement in care delivery processes and patient outcomes in relation to the implementation of a particular CCM component within the chronic care intervention vary among healthcare settings. The implementation of CCM-based chronic care interventions for a single chronic condition is not usually viable unless it embraces other chronic illnesses and other motivated organisations.
Delon and MacKinnon 2009	Implementation of expanded CCM in Alberta province. Descriptive study.	The provincial health system incorporated all CCM components. The key initiatives include the development of CDM performance indicators, care planning and self-management support, linkage with primary care and community organisations, and a CDM registry.	The intervention reported improvements in certain clinical outcomes. Improvement in HbA1c control of 17%, hospital admission decreased by 19% for patients with a COPD, overall hospital admission decreased by 41%, and emergency department visits decreased by 34%.
Khan *et al.* 2010	Prospective study of 1,098 patients with diabetes at an urban safety net public hospital in Chicago.	Organization of health care, self-management support, delivery system design, and clinical information systems	The study found the relevance of CCM-based diabetes care to lower the HbA1c, blood pressure, cholesterol and weight. The intervention also increased the use of evidence-based medications (ACE Inhibitor, aspirin, and statin).
Stroebel *et al.* 2005	Pilot project, which adapted CCM components at the Salvation Army Free Clinic. Uncontrolled.	Healthcare leadership, delivery system design, and a CDM register.	The shift in the leadership focus improved chronic care delivery at the Salvation Army Free Clinic. This pilot project introduced the roles of care managers, and a chronic disease registry. The project had 149 enrolled patients with hypertension, diabetes, and hyperlipidaemia. A total of 79 patients achieved significant clinical improvements in at least one chronic condition.

Vargas *et al.* 2007	Assessment of the influence of a CCM-based diabetes care on reduction of cardiovascular disease risk among patients with diabetes (613 patients from intervention sites and 557 patients from control sites). Controlled pre and post intervention study.	The intervention implemented proactive follow-up, planned visits, patient education sessions, and active involvement of patients in preparation of care plans.	The intervention group patients had a 2.1% (95% CI -3.7%, -0.5%) greater reduction in risk for cardiovascular events compared to controlled group.
MacLean *et al.* 2004	Cluster randomised controlled trial with 7,412 patients with diabetes in 64 primary care practices in the Vermont and adjacent New York State.	Evaluation of the roles of a chronic disease register and A reminder system (for providers and patients).	The intervention successfully implemented evidence-based laboratory testing processes, and enhanced the laboratory monitoring in primary care. The patients in the intervention group showed improved HbA1c control. However, the improvement was not statistically significant.
Peterson *et al.* 2008	Group randomised controlled trial in 24 practices in Minnesota. The study assessed the implication of a multicomponent diabetes care intervention.	Electronic diabetes registry, patient visit reminders and provider alerts, and a case manager function.	The practices under the intervention group showed significant improvements in clinical outcome for systolic blood pressure, HbA1c, and low density lipoprotein.
Adams *et al.* 2007	Systemic review 32 studies published in 37 articles on COPD management interventions. The review aimed to identify the strength of CCM components to prevent COPD complications.	Predominantly self-management of COPD conditions.	The patients under COPD interventions with two or more CCM components revealed lower rates of hospitalisations and emergency presentations, and shorter length of hospital stay.

Schillinger *et al.* 2006	Assessment of the effects of patient centered self-management support strategies among randomly assigned patients with poorly controlled diabetes. A total of 339 outpatients were enrolled in a three-arm trial.	Predominantly self-management support (interactive weekly self-management support through telephone and monthly group medical visits with clinicians).	The trial measured changes in relation to patients' experiences in relation to the care delivery system, patient-provider interaction, and patient outcomes. The study found improvements in self-management behavior and quality of life among the patients in the intervention group. The patients who had weekly telephone support showed more improvement. However, the study could not establish any change in relation to HbA1c.

The above findings provide substantial evidence about the impact of CCM-based chronic care interventions on the care delivery processes and chronic care outcomes. Assessment and comparison of the effectiveness of different chronic care interventions are complex. They are interpreted and applied in varying ways by the program administrators and researchers.

Overall, CCM implementation relies on healthcare leaders to identify the focus and strategies for practice change. Healthcare organisations that implement CCM components in combination, produce stronger impact on chronic care outcomes (Tsai *et al.* 2005; Coleman *et al*. 2009). The implementation of a CDM register as part of strengthened clinical information systems can facilitate more patient-centred interactions, which further help patients and the clinicians to achieve progress on behavioural interventions and achievement of clinical goals.

2.11 Challenges to implementing effective chronic care management programs in hospital and in community

In Australia, the proportion of older people is growing. The aged population group is more prone to exposure to and accumulation of risk factors for chronic conditions over

time. As a result, multiple morbid conditions become an issue. The economic burden is considerably higher in dealing with chronic conditions when multiple chronic conditions exist. It involves more primary care consultations, emergency admissions, increased hospital bed-days and disability (Cornoni-Huntley *et al.* 1991; Hoffman *et al.* 1996; Wilson T *et al.* 2005).

The CDM requires a coordinated model of care with the support from service delivery teams and healthcare institutions. Most healthcare organisations put effort into implementing a coordinated model of care to improve quality of life and reduce unplanned hospital admissions. However, assessments of these interventions could not establish an adequate relationship with the intervention outcomes (Smith *et al.* 2002; Brand *et al.* 2004).

Patients with chronic diseases move through the transition of care and receive care from multiple providers. This transition places the patients under vulnerabilities especially when patients move from hospital to community service providers (Coleman and Berenson 2004) due to lack of information portal and continuity (Bodenheimer 2008). Care coordination depends on sharing of information between concerned service providers. However, information linkage between primary care, specialists and hospital is inadequate, and discharge summaries frequently contain insufficient information (Forrest *et al.* 2000; Gandhi *et al.* 2000; Kripalani *et al.* 2007).

Many studies attempted exploring CDM challenges in relation to the integration of chronic care with the usual care delivery process. These efforts helped with designing different models of care and interventions. Wagner and others conducted a survey of 72 interventions. The authors found that most of the programs had limitations in relation to achieving the desired outcome. This had happened because the interventions could not

establish adequate linkage with primary care, and self-management practices (Wagner *et al.* 1999).

Literature concerning disease management interventions suggests that patient education and involvement of multidisciplinary care teams are related to reduced hospitalisations. But these studies could not establish any relationship with mortality and quality of life (McAlister *et al.* 2001; Akosah *et al.* 2002; Villagra and Ahmed 2004). Singh and Ham in their review mentioned that there is a varying degree of achievement in terms of quality improvement initiatives (Pearson *et al.* 2005; Singh and Ham 2006). Tsai and others in their review of 112 studies on CCM components concluded that improved chronic care processes and outcomes are associated with at least one element of CCM (Tsai *et al.* 2005). However, it is difficult to say which component is the most effective (Bodenheimer 2003).

Self-management supports include educational programs, behavioural support programs, monitoring of symptoms, and management of symptoms. Self-management support strategies build a patient-centred collaborative approach as an important element in CDM. The patient-centred collaborative approach connects patients and relevant health service providers for treatment decisions, assists patients in managing challenges of living with chronic conditions and reduces exacerbation of symptoms (Lorig 1993; Goldstein 2004; Lorig and Holman 1993). The evaluation of the implementation of self-management supports depends on several indicators. These indicators may include achievement of clinical outcomes (e.g. blood glucose level, blood pressure, HbA1c etc.), patients' knowledge about symptoms, patients' capacity in managing symptoms, and indicators on behaviour change (e.g. exercise, adherence to treatment, smoking etc.). However, limited evidence reflects implementation of self-management strategies in relation to healthcare utilisation and improvements in quality

of life (Barlow *et al.* 2002; Gibson *et al.* 2002; Riemsma *et al.* 2002; Chodosh *et al.* 2005; Kennedy *et al.* 2007; Steuten *et al.* 2009). More health system research activities can uncover hidden challenges, and help in knowing the sustainable self-management components to improve patient outcome.

The current gaps in delivery of recommended chronic care are due to an inadequate process monitoring system (Institute of Medicine 2001). Sometimes this gap results from providers' lack of awareness about the existence of evidence-based guidelines in clinical management (Rutschmann *et al.* 2004). The other reasons are inadequate communication, insufficient documentation of risk factors (Rafter *et al.* 2008) and inadequate health system supports for self-management (Bodenheimer 2005).

Coexistence of more than one chronic condition is a major challenge in implementing evidence-based clinical decisions (van Weel *et al.* 2006). The management of multi-morbidities needs to focus on individual patients as a whole rather than on diseases (Starfield *et al.* 2003). The usual diagnostic and treatment strategies normally ignore existence of co- morbid conditions and even introduce more issues when implemented (Boyd *et al.* 2005). It is important when a patient receives multiple medications for multiple conditions at a time. The combination of medications put patients in more risks of adverse health outcomes (Hajjar *et al.* 2007; Junius-Walker *et al.* 2007). The meta-guidelines or pharmacotherapy helps in clinical decisions and therapeutic supports. However, this is not always enough to overcome challenges to managing patients with multi-morbidities. An efficient doctor-patient communication and self-management supports can bring solutions for better management of patients with multi-morbidities (Marx *et al.* 2009).

The discussion on the concerns and challenges are mostly related to organisational and professional leadership capacity because the performance measurement is not sufficient

at current health system level (Berwick *et al.* 2003). Continued CDM advancement requires more research, performance management of care processes and implementation of prevention programs (Davis *et al.* 2000).

2.12 Need for an integrated database

Based on the discussion in this chapter, chronic care and secondary prevention requires monitoring of care management processes and intervention outcomes. The CCM is the most acceptable approach where a service specific disease register is the central feature to manage population and individuals with chronic illnesses (Bodenheimer *et al.* 2002a). The use of a service specific disease register has roles to tailor CDM interventions according to the need of patients and health care professionals (Benedetti *et al.* 2006).

The implementation of an evidence-based guideline, reminder system, patient self-management support and a service specific disease management register are collectively known as care management processes (CMPs). The CMP elements are integrated in the CCM to support delivery of chronic care and prevention interventions. Healthcare organisations with a CDM register are more capable of generating actions than those without a register (Schmittdiel *et al.* 2005). However, except for diabetes, the concept of disease registers had not been implemented for other common chronic conditions on a wide scale.

Substantial evidence demonstrates that a disease-specific register is an important system element to make sure of implementation of evidence-based chronic care. A CDM register incorporated within a health system also facilitates service planning (Penn *et al.* 2004). A CDM register links clinical data with other relevant service databases and

enhances insights into the effectiveness of clinical and prevention interventions (Ivanov 2001).

The study 'Organized Program to Initiate Lifesaving Treatment in Hospitalized Patients with Heart Failure (OPTIMIZE-HF)' evaluated a national hospital-based initiative on quality of care for HF patients. The initiative used a web-based register and collected both outcome and administrative data. Under this study, 259 US-based hospitals participated and submitted data on 48,612 patients. The reports from the web-based register helped when comparing performances between hospitals and provided feedback to treating teams (Fonarow *et al.* 2007).

In searching for clinical and financial benefits of information technology (IT) in disease management programs, Bu and others used different IT models. These IT models include disease register, remote monitoring, and self-management support for diabetes patients in the US. The project examined the impact of IT on care delivery, clinical outcomes and costs. The results suggested that IT-based disease management programs assist secondary prevention and appearance of complications (Bu *et al.* 2007). Healthcare demands multi-disciplinary interaction for collaborative diagnosis, treatment assessment, planning and decision-making. These elements need support to a greater degree in healthcare organisations than other sectors. This collaboration can deliver optimum output with the use of clinical data (Hummel 2000; Connell and Young 2007).

IT-based clinical information systems can facilitate CDM processes through setting up reminder systems. The reminder system provides feedback to physicians on performance, and they link primary care teams to comply with practice guidelines. Presence of a disease register within an IT-based clinical information system can assist care teams in efficient service planning and implementation of prevention interventions.

A disease register contains relevant clinical and administrative data of a group of patients with particular chronic conditions of interest (Bodenheimer *et al.* 2002a).

Healthcare organisations with an electronic medical record (EMR) system help providers to easily access and recover clinical records. The EMR supports health care providers at the point of care but has limited roles in the CDM. A disease register is a more affordable and practical tool than an EMR for population-based interventions (California HealthCare Foundation 2004). A disease register can identify the patients with specific illnesses of interest and provides information about care delivery processes in relation to evidence-based guidelines. A CDM register linked with EMR can generate more inclusive information about the patients (Metzger 2004).

Based on the analysis of literature review, an active CDM register is able to

- link between care strategies and patients' care according to CCM
- support evidence-based care
- develop reports on key indicators and their outcomes including trend data for benchmarking continuous quality improvement
- connect health service delivery teams for collaborative and multidisciplinary approach to ensure continuity of care and self-management supports
- establish reminder systems for providers
- support improving health system performance through research and evaluation of chronic care programs
- inform organisational leaders, health policy people and health planners for delivery system redesign in relation to workforce, technology and funding.

A CDM register can help to build epidemiological roles in CDM programs. This approach supports CDM programs and policies to define specific management issues,

identify important program elements and assess the outcomes of interventions. The epidemiological functions of a CDM register can also help organisation leaders and clinicians to prioritise effective prevention elements (Remington *et al.* 2003; López-Pousa *et al.* 2006). Chronic care programs using a CDM register results in a comprehensive venture to evaluate quality of care and address current CDM concerns in an epidemiologically sound manner (Australian Commission on Safety and Quality in Health Care 2008; McNeil *et al.* 2010).

The National Chronic Disease Strategy of Australia provides necessary directions to improve chronic care, and secondary prevention (National Health Priority Action Council 2006). Based on the national strategy, ACT Health has incorporated the CDM register as an action component to strengthen chronic care programs (ACT Health 2008a). The integration of a CDM register in this chronic disease strategy is a result of timely policy support. This further explains the presence of a supportive policy environment, leadership and acceptance by relevant stakeholders in this region.

CDM programs have improved a lot but healthcare facilities are not able to deliver optimum chronic care according to the need of patients. This is due to inadequate use of clinical data as the pathway of communication between clinicians or other allied health providers. The current programs also could not effectively include patients as a part of the treating team. All these have impacts on organisational and individual health providers' ability to offer recommended chronic care (Jacobsen and Sevin 2008).

CDM programs need specific administrative, clinical and prevention indicators for performance management. In reality, physician organisations have low acceptance rates for technology, so introducing a CDM register is a challenge (Green *et al.* 2006). The challenge is also part of the issues in relation to the use of clinical data (Arzberger *et al.*

2004). The other challenges are related to the selection of key indicators, data collection, ways of data analysis, and ways to maintain integrity of patients' data.

Healthcare organisations need to implement a service specific disease register designed for chronic conditions. Most of the existing clinical registers are built for research purposes and have varying degrees of limitations. The existing clinical information system also does not have the capacity to connect independent service databases for efficient delivery of care (Quam and Smith 2005; McNeil *et al.* 2010). Development of a clinical quality register for chronic conditions will help health systems to report on individual patient outcomes as well as effectiveness of chronic disease prevention interventions (Zgibor *et al.* 2007).

Chapter Three

Methodology

Chapter Outline

3.1 Introduction

This chapter describes the research methods in detail. The methods give an overview of the nature of the research and the data. This chapter also describes research settings, research participants, data sources, data collection methods, data analysis framework and ethical aspects of the research.

The aim of the research is to get insights into the appropriate design features of a CDM register and organisational contexts to implement it. The study methods aimed to investigate an organisation's mission and explore the roles of a CDM register to improve chronic care quality, health system performance and care coordination.

The research followed a multi-method approach in a combination of qualitative, quantitative and participant observation approaches. The study was set in a provincial Australian health service (ACT Health) of around 5,000 staff serving a regional population of 500,000. The basis for this multi-method approach is to relate data with existing chronic care interventions, identify design features of a CDM register (Morse and Field 1995) and obtain generalisability of results across methods (Eid *et al.* 2009).

The participant observation method supported both the qualitative and quantitative data to make research results more valuable. The qualitative method helped to understand chronic care processes, inputs (Miller *et al.* 2007) and quantitative illustrations. Similarly, statistical findings and quantitative illustrations helped to interpret qualitative references, expert views and explanations.

The research methods finally evolved in (i) an organisational analysis of ACT Health combined with (ii) a system requirement analysis of a CDM register and (iii) a structural analysis of how the CDM register can be managed.

3.2 Research setting

The research was conducted in ACT Health and based in the Chronic Disease Management Unit (CDMU). The data collection primarily gathered views and opinions of selected ACT Health professionals about the current state of CDM and how a CDM register can support care management processes. The establishment of the CDMU indicates implementation of one of the action items of the ACT Chronic Disease Strategy. Initially the CDMU was placed within the Aged Care and Rehabilitation Services of ACT Health. The aim of the CDMU is to enhance chronic care coordination and prevention supports within the ACT Health jurisdiction. The CDMU has now

moved under the Division of Medicine. The CDMU is working in collaboration with the other services for case management, care coordination and self-management support roles. The development of a CDM register is part of the core activity of the Unit in collaboration with the Population Health Research Centre of ACT Health (ACT Health 2008a).

I enjoyed this great opportunity to use the CDMU as the base set-up for my data collection. The Unit provided me opportunities to work in a CDM environment and interact with many professionals in this specific field. This has provided me with the analytical strength to work with data. I have considered CHF, COPD and DM2 as three index chronic conditions for the basis of data collection and analysis.

Besides ACT Health, I was an observer member of the Serious and Continuing Illness Policy Practice Study (SCIPPS) of the Australian National University (ANU). The Menzies Centre for Health Policy and the Australian Primary Health Care Research Institute (APHCRI) conducted the study. The National Health and Medical Research Council (NHMRC) has funded this study. The study was conducted in the Australian Capital Territory and Sydney West area. The aim of the study was to improve the quality of life of people with chronic illnesses through improvement in health systems performance and policy solutions. The SCIPPS addressed three chronic conditions, namely CHF, Diabetes Mellitus type 2 and COPD. This study only used a qualitative approach and collected data from patients with chronic illness and their carers in 2007 (Australian Primary Health Care Research Institute 2008).

I have used SCIPPS qualitative transcripts, which added patient and carer perspectives in my research.

My research work is based in the ANU. I have received scholarship support from the NHMRC Centre for Research Excellence in Patient Safety (CRE-PS) of Monash University. The Centre has a strong academic and professional background in relation to the development of clinical registers. The Centre has published the 'Guidelines for the Establishment and Management of Clinical Registries' for The Australian Commission on Safety and Quality in Health Care (Australian Commission on Safety and Quality in Health Care 2008). My PhD research received continuous technical support from the Centre.

3.3 Target participants

The target participants were recruited based on participants' eligibility to take part in the Assessment of Chronic Illness Care (ACIC) survey. The ACIC survey has been used for quantitative data collection. I have used the ACT Health organisation chart and identified relevant departments and service units to recruit participants.

Initially 72 eligible staff were recruited as target participants. These participants were directly or indirectly involved with chronic care delivery, planning, management and research activities.

I have further cross-checked participants' job responsibilities using each service specific organisation chart. Finally, 67 staff members were selected as target participants. Table 3.1 displays the list of organisations, departments and units of 67 target participants. From these 67 target participants, 10 key informants were selected for qualitative interviews. Table 3.4 and Table 3.6 present ACIC survey participants and key informants respectively.

Table 3.1: List of organisations, departments and units of target participants

Organisations, departments and units
ACT Health Corporate Office
Allied Health
Government Relations, Planning and Development
Internal Audit and Risk Management
ACT Health Policy Division
Information Services Branch
Population Health Division
Nursing and Midwifery Office
Medical Appointments and Training Unit
Patient Safety and Quality Unit
Health Performance Improvement Innovation and Redesign
Aged Care and Rehabilitation Service
Academic Unit of General Practice and Community Health
Continuing Care Program and Community Health
Capital Region Cancer Service
Mental Health
Medical Assessment and Planning Unit
The Canberra Hospital
Acute Support Program
Medical Records
Endocrinology Department
Cardiology Department including Heart Failure Clinic and Cardiac Rehabilitation Program
Geriatric Department
Thoracic Medicine including Pulmonary Rehabilitation program
Pain Management
Chronic Condition Self-Management Program
Chronic Care Program
GP Liaison
Chronic Kidney
Rapid Assessment of the Deteriorating Aged at Risk (RADAR)
Transition Therapy and Care Program
Heart Foundation ACT Branch
Diabetes Australia ACT Branch
The Australian Lung Foundation

3.4 Research team

The research team comprised me as principal investigator and Associate Professor Paul Dugdale, the Chair of the supervisory panel as associate investigator. We worked together to finalise a methodological framework, target participants, data collection methods and data collection instruments. My other supervisory panel members have played overall advisory roles in the research.

3.5 Data collection methods

Chapter 1 (Section 1.2 and Table 1.1) presented the research objectives and associated research questions. This section presents the research methods and approaches. In later part of this chapter, Figure 3.2 displays the relationship between research questions, methods and the data.

As mentioned earlier, I have followed mixed data collection methods to investigate research questions and have extracted trustworthy findings (Johnson B *et al.* 2003). Table 3.2 displays the snapshot of each data collection method, approach and type of target participants.

Table 3.2: The data collection methods, approach and type of target participants

Data collection methods	Approach	Participants
Assessment of chronic illness care (ACIC) survey	Quantitative	Selected ACT Health staff
Key informants' interview	Qualitative	Selected ACT Health staff
Analysis of SCIPPS transcripts	Qualitative	Patients with chronic diseases and their carers in the ACT region
Participant observation	Observation, project work, system requirement analysis	ACT Health CDMU staff and Chronic Disease Management Clinical Network (CDMCN) members.

3.5.1 Assessment of Chronic Illness Care (ACIC) Survey

The purpose of the ACIC survey is to assess the capacity and readiness of ACT Health to implement a CDM register. Another purpose of this survey is to explore positioning of a CDM register within the system and patient care support infrastructure.

ACIC Questionnaire

The MacColl Institute for Healthcare Innovation, Seattle, USA, developed the ACIC survey questionnaire (Kaissi and Parchman 2006). This is a validated instrument (Bonomi *et al.* 2002), and healthcare organisations mainly use this instrument to track improvements in chronic care delivery. The research used the ACIC survey version 3.5. The ACIC survey is based on the six CCM components (Wagner *et al.* 1999). Healthcare organisations use this instrument to comprehensively assess the strengths and weaknesses of chronic care interventions in relation to the chronic care model components (Bonomi *et al.* 2002). This research used MacColl Institute's ACIC survey (Appendix 3) without any modification for better comparison with other research results.

The survey instrument has a total of 34 variables under 7 components. The first six components represent six CCM components. The seventh component investigates the status of integration of CCM components in chronic care interventions. Each ACIC component consists of a list of questions designed to investigate key aspects of chronic care. Each question is divided into four levels. Each level defines a stage of chronic care using scores ranging from 0 to 11. The survey cover page contains instructions for completing the survey. It also has the space to note participants' current professional background to complete the survey. Chapter 5 describes details about the questionnaire and data analysis.

Subject identification

I undertook several preparatory activities before distributing surveys to the participants. As the first step, I prepared the list of ACT Health divisions and unit heads including the Canberra Hospital and Community Health staff. For this task, I used the ACT Health intranet for organisational charts, service specific organisation charts and directories all of which were somewhat out of date and included various inaccuracies. One Vacation Scholar of CDMU helped me identify initial target participants through discussion with switchboard staff and various sections either by phone or in person. I used a Microsoft Excel file and kept records of participants' contact details.

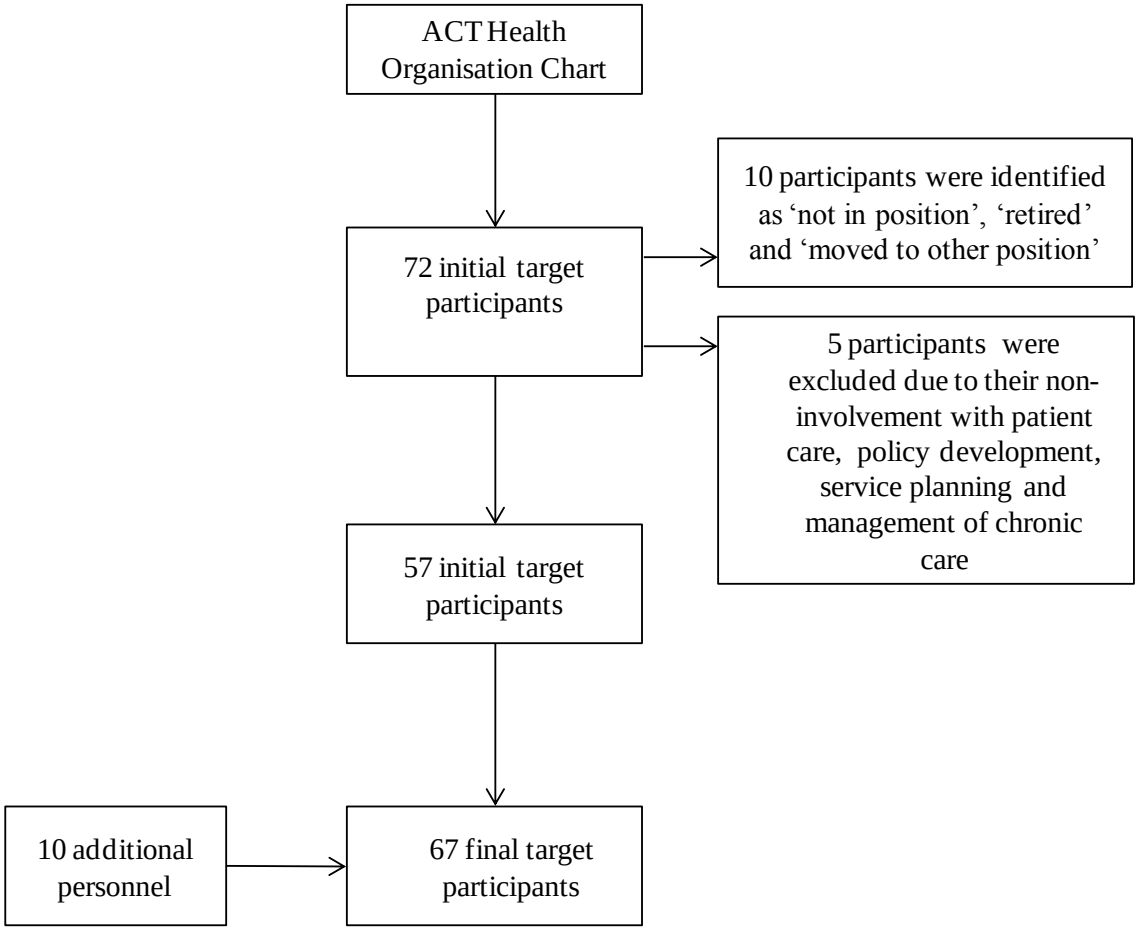
The initial list included 72 personnel, 10 were deleted as I found that they were not in their expected positions. These participants had either retired or moved to another position. This happened because of the time gap between preparation of the participants' list and the initiation of survey data collection. This time gap resulted from the process and delays of getting ethics clearance. A further five personnel were excluded because of their non-involvement (directly or indirectly) with patient care, policy development, service planning or management roles in relation to chronic care. I then identified and added 10 additional personnel of mid level positions who were directly involved with chronic care. This resulted in a final list of 67 potential participants in the survey. Figure 3.1 shows the steps included in identification of target participants.

Survey administration and response

The first step of the survey administration was the submission of a briefing paper to the ACT Health Chief Executive. The briefing paper contained summary of the project and the purpose of the survey. This task aimed to obtain the Chief Executive's approval to

use a formal cover letter signed by him for survey recipients. The Chief Executive approved the request on 2 February 2009.

Figure 3.1: The steps for selection of target participants



During this process, I drafted the participant information sheet (Appendix 1) and consent form (Appendix 2) for the survey package. I also prepared other necessary documentations and submitted my ethics application. Each survey package included paper copies of a (i) a cover letter signed by the Chief Executive (Appendix 4), (ii) a participant information sheet, (iii) a consent form, (iv) an ACIC survey instrument and (v) a return envelope with address.

I identified strategies to improve the survey response overall. The components of the survey response improvement strategy were to:

- send survey packages with the formal letter signed by the ACT Health Chief Executive mentioning Dr Dugdale (my supervisor) and my name
- indicate the response date clearly on the survey
- enclose a self-addressed ACT Health internal envelope enclosed with surveys
- track returned surveys against the list of target recipients each week
- contact with those participants who had not returned surveys through email, phone or in person
- remind them each month for four months.

As mentioned earlier, the first survey distribution aimed for 72 participants.

After the final ethics clearance, I distributed a first set of survey packages to 30 of the initial target personnel between 18 June 2009 and 30 June 2009 through direct mail. I sent this limited number of surveys with a view to receiving feedback from participants. As ACIC is a validated instrument, I did not undertake any initial field test. I did not receive any technical feedback on the instrument from the participants in the first distribution. I then mailed survey packages to the remaining 42 initial target personnel on 17 July 2009.

From this first distribution, I received only 18 responses up to 14 August 2009. I have followed all the steps according to the response improvement strategy. In many cases, I found that the participants were on leave, travelling overseas and attending trainings or seminars. I sent out four reminders to the participants on a monthly basis.

On 14 August 2009, I reminded 54 participants who had not responded through email with the survey package electronically attached to it. In response to this email I received another four responses. I sent a second reminder on 15 September to 50 participants and received another 4 completed surveys. I received a total of 26 survey responses after the

second reminder. At this point, 10 initial potential participants had been identified as not in position, retired or moved to another positions, and a further 5 was not involved with patient care, policy development, service planning and management of chronic care. I then worked through the ACT Health Intranet and identified 10 additional potential participants, giving the final 67.

On 15 October 2009, I mailed the survey packages to 41 participants who had not yet responded and received nine responses. After this third reminder, I had received a total of 35 survey responses. I sent out the final survey reminder with the survey package on 10 December 2009 to the rest of the participants and received another 10 responses. After the fourth and last reminder, the total number of survey responses was 46 out of 67 surveys sent out (Table 3.3 and Table 3.4). The response rate here is defined by number of participants who had sent back the fully completed or partially completed survey and a blank survey. I received 43 fully or partially completed surveys and 3 blank surveys out of 46 responses.

Table 3.3: ACIC survey responses and response rate

Survey response	n
Total participants	67
Survey response	46 (68.7%)

Among 43 eligible surveys, one participant scored '0' for all questions and I have not included this survey for analysis. Table 3.5 illustrates the diseases, specific conditions and areas that 42 target participants considered to complete the survey. Some respondents chose more than one condition or area to complete the survey. I have captured these data from the survey cover sheet information. Most of the respondents also documented their current experiences, professional background and working areas in separate notes. These notes explained the rationale for their complete and incomplete responses to specific survey questions.

Table 3.4: Participants from organisations, departments and units who responded

Organisation, departments and units	Target participants n=67	Participants responded n=46
ACT Health Corporate Office	2	1
Allied Health	1	1
Government Relations, Planning and Development	2	1
Internal Audit and Risk Management	1	-
ACT Health Policy Division	3	2
Information Services Branch	3	1
Population Health Division	1	1
Nursing and Midwifery Office	2	2
Medical Appointments and Training Unit	1	-
Patient Safety and Quality Unit	2	1
Health Performance Improvement Innovation and Redesign	2	2
Aged Care and Rehabilitation Service	7	7
Academic Unit of General Practice and Community Health	1	1
Continuing Care Program and Community Health	4	2
Capital Region Cancer Service	4	1
Mental Health	2	1
Medical Assessment and Planning Unit	1	1
The Canberra Hospital (TCH)	1	1
Acute Support Program	1	-
Medical Records	2	2
Endocrinology Department	4	3
Cardiology Department including Heart Failure Clinic and Cardiac Rehabilitation Program	5	4
Geriatric Department	1	1
Thoracic Medicine including Pulmonary Rehabilitation program	3	1
Pain Management	1	1
Chronic Condition Self-Management Program	1	1
Chronic Care Program	2	2
General Practice (GP) Liaison	1	1
Chronic Kidney	1	1
Rapid Assessment of the Deteriorating Aged at Risk (RADAR)	1	1
Transition Therapy and Care Program (TTCP)	1	-
Heart Foundation ACT Branch	1	1
Diabetes Australia ACT Branch	1	-
The Australian Lung Foundation	1	1

Table 3.5: Disease or specific conditions or areas considered to complete the survey

Diseases, conditions and areas	Number
HF, CHF, Congestive Heart Failure	8
COPD, Asthma	5
Diabetes	8
Cancer	2
Dementia	2
Schizophrenia	1
Parkinson's disease	1
Multiple sclerosis	1
Cerebrovascular disease	1
Chronic kidney disease (CKD)	1
Ambulatory care	1
Chronic pain	1
Cardiac rehabilitation program	1
Continuing Care program	2
Health plan	1
Primary care	1
Information system	1
Chronic disease strategy, Health policy	4
Not specified	7
Total	49

I have tried to get insights about the reasons for non-response through telephonic and personal communication with the participants. My insights are as below:

- Participants not related with care delivery and care management processes were not confident to make comments on service specific questions.
- There was lack of time for the clinicians and other service providers to fill the survey.
- There was failure to communicate to policy, management, and administrative staff participants their role as part of the survey

3.5.2 Key informants' interview

I have conducted the key informants' interviews to collect primary qualitative data for this research. The key informants are drawn from the ACIC survey recipients. The key

informants' interviews provided me with insights into current chronic care programs, their challenges and opportunities to integrate a CDM register into the system. The other aspects of the interviews were to get to know about ACT Health systems and relationships in relation to the CDM agenda. This qualitative method provided necessary clarifications to other method-specific findings. It also helped me in getting insights into data and their data interpretation (Bazeley 2007).

Key informants' interview schedule

I have prepared the key informants' interview schedule or guideline on the basis of the literature review. The key informants' interview schedule reflects discussion topics in accordance with chronic care in the ACT Health jurisdiction. The design of the schedule considered what is important now in ACT Health to strengthen chronic care.

Firstly, I consulted the National Chronic Disease Strategy and ACT Chronic Disease Strategy documents to learn about current chronic care program components. The ACT Chronic Disease Strategy provides the overarching framework to strengthen chronic care and secondary prevention of chronic conditions in this regional setting. It has incorporated CCM components including the CDM register as an action component (ACT Health 2008a; National Health Priority Action Council 2006).

The key informants' interview schedule consists of four sections. Each of the sections has separate topics for discussion. The sections and topics are as below:

- Section A: CDM programs and opportunities
- Section B: Potential for a CDM register
- Section C: Interaction between different units for chronic care
- Section D: ACT Health's capacity and readiness to implement a register.

The interview schedule contains a total of nine main questions under these four sections. Each of the main questions has two to three guide questions to best discuss the main question for clarity. Chapter 4 presents details about the key informants' interview schedule.

The development of the key informants' interview schedule followed a continuous refining process. At the beginning, I listed questions around the concept of a CDM register. Subsequently, I further elaborated the questions to collect key informants' views and opinions about the evolution of the ACT chronic care programs and their current state. Dr Peter Nugus, a Research Fellow of the Centre for Clinical Governance Research in Health (CCGRH) of UNSW provided guidance in the development of qualitative questions. I pre-tested this key informants' interview schedule in the ACT health setting. I did not receive any major feedback about the structure and content of the question but mostly on the interview processes. I finalised the schedule with supervisors' feedback.

Qualitative data collection

As a research team we selected 10 key informants from 67 target participants who received the ACIC survey. The selection of key informants was based on their experience in care delivery, policy, program management, performance improvement and information management (see Table 3.6). I conducted in-depth interviews to collect participants' views and explore opportunities for a CDM register.

I communicated with the key informants concerning their willingness to participate through email and telephone contact. I sent them the interview schedule, participant information sheet and consent form in advance for their necessary preparation for the interview.

Table 3.6: Distribution of key informants by organisations, departments and units

Department/Division/Unit	n=10
ACT Health Policy Division	1
Aged Care and Rehabilitation Service	2
Health Performance Improvement Innovation and Redesign	1
ACT Health Information Services Branch	1
Cardiology Department	1
Thoracic Medicine	1
Primary Care and General Practice	2
Heart Foundation ACT Branch	1

I conducted interviews on a one-on-one basis at key informants' offices with full privacy. Before the interview, I described the purpose of the interviews and linked that with that of the participant information sheet. It allowed me to build rapport with the key informants to discuss on the topics and encourage them to explain their views.

I assured all Informants that all information provided would be treated confidentially, and any names used would be pseudonyms. The duration of qualitative interviews ranges between 29 to 57 minutes. I recorded all interviews using a standard audio recorder upon receiving consent from the informants. I provided an ID for each interview and stored those in the computer to maintain anonymity and confidentiality. As a first step, I did all interview transcripts for analysis. This self-transcription process helped me to understand and conceptualise the issues and views quite efficiently. After completion of three transcripts, I discussed the findings with Dr. Dugdale for necessary guidance and to develop an analytical framework. Finally, I accepted help from a professional transcriber and completed all transcriptions for analysis.

3.5.3 Participant observation

I carried out my participant observation at the CDMU. This method provided me with hands-on knowledge about integration of different chronic care services for CDM and

flow of clinical data to foster care management processes. This method has also given me the practical platform to collect data, explore ideas and concepts for constructing causal explanations (Jorgensen 1989).

I started project work as a participant observer in CDMU at the Canberra Hospital (TCH) in mid May 2009. I followed several administrative steps to enroll into the process. I submitted the 'Clinical placement agreement form for ANU medical students accessing ACT Health placements' at CDMU. This is the first requirement to deal with patients' clinical records. Dr. Dugdale, who is the Director of CDMU, had approved my request. He further assisted in getting the necessary clearance from TCH, and I got a TCH access card. I also got access to the IT system and patient databases and a TCH parking permit. It was a great opportunity for me to get academic as well as professional supervision from Dr. Dugdale to contribute in this research work. TCH has provided me with a work station, computer and access to relevant information about the CDMU. I have completed a TCH online training course on employee code of conduct and ethical practices relevant to the ACT Health environment.

Participant observation method

The purpose of this participant observation was to acquire practical insights into the clinical and administrative data, their strengths and relevance to the CDM register. This method allowed me to deepen my insights into the broad data elements and underlying processes. The expected insights about the underlying processes include knowing data type, data flow, data quality, storage, data acquisition, privacy and ethical aspects. Another purpose of the method was to learn the existing clinical information management infrastructure. Participant observation helped me to interpret SCIPPS patients' and carers' views in the light of existing chronic care programs. I have participated in the following forums and activities as a participant observer.

CDM clinical network (CDMCN) meetings: This services network was formed under the auspices of CDMU by direction of the Deputy Chief Executive of ACT Health (ACT Health 2008d). The service representatives meet on a monthly basis to improve coordination between services and secondary preventive measures for patients with established chronic diseases. The key tasks of the forum are to discuss new and discharged patients, patients who need complex coordination and advanced care directives, and protocols to improve coordination and preventive measures. This network also deals with operational issues and governance of the CDM register. The service representatives present case studies of complex patients to discuss coordination opportunities.

My role as participant observer was to attend the meetings and learn existing care coordination processes and the nature of clinical data. I worked on the existing clinical database, which helped me to find out potential data fields for a prototype register. I have enriched my knowledge in the following areas:

- strengths and limitations of existing systems for care coordination
- clinical information system and data flow
- importance of electronic clinical information flow to facilitate care coordination
- administrative and preventive indicators for a CDM register.

CDM register reference group meeting: This is the CDM register advisory group. This group meets every six weeks. The members provide strategic support to the development and governance aspects of the CDM register. Participation in this group allowed me to get insights into:

- governance and management aspects of a CDM register
- processes related to data acquisition, quality control, access and storage

- design and information outputs of a service specific CDM register
- privacy requirement to use personal health data in a CDM register
- getting views about a CDM register as a business entity.

Meeting with individual service representatives: I had opportunities to meet with individual service representatives who were directly involved with chronic care. I have gathered in-depth knowledge about the strength of clinical data and service specific databases. These meetings also helped me understand existing communication between service units and data flow portals.

Through the above-mentioned forums, I learned about the different chronic care program components and conducted a system requirement analysis for a CDM register. The system requirement analysis employed the 'use case' concepts. IT industries employ the 'use case' methodology for software development and system reengineering. I have used the use case concepts to identify data requirements and data flows for a CDM register (see Chapter 7 for details). This analysis supported positioning of a CDM register into the ACT Health system as a powerful CDM initiative. Finally, the analysis helped to identify a prototype register with technical and management elements.

3.5.4 Analysis of SCIPPS transcripts

Since the beginning of my PhD, I was an observer member of the Serious and Continuing Illness Policy and Practice Study (SCIPPS) at ANU. I have described the study and its aims earlier in Section 3.2. This qualitative study collected views and experiences of patients with chronic diseases and their carer through interviews and

focus group discussion (FGD). The research team transcribed the interviews and FGDs and analysed data using NVivo.

I have included SCIPPS as part of my research setting and used the study transcripts. The SCIPPS transcripts added patients' and carers' component into the research. The study collected experiences and views of patients with CHF, COPD and DM2; and their carers (see Chapter 6 for details). Dr Dugdale was one of the investigators of SCIPPS, and assisted me in getting access to the transcripts. I used the SCIPPS coding scheme but analysed data separately for my research using NVivo. This involved several discussions with SCIPPS investigators. The study collected 29 interviews in the ACT and 26 in Sydney West regions. I have used the ACT based transcripts for analysis. Analysis of SCIPPS transcripts helped to get insights into patients' and carers' expectations in relation to overall chronic care.

3.6 Framework for analysis

Before the data collection, I developed a framework for analysis (Figure 3.2) to visualise linkages of the research methods and data for this research. I refined this framework after completion of each method. Finally this framework shows two types of data.

The first level of analysis of each group of method-specific data produced the primary data. I further analysed primary data to yield intermediate data to answer research questions and objectives. The framework displays the research questions, research methods, primary data and intermediate data in different layers.

Primary data

The methods contributed to a diverse range of data, based on the design and implementation of each method. The research framework put emphasis on existing CDM programs, the role of the clinical information linkages and health system opportunities to implement a CDM register.

The ACIC survey presented evidence of current chronic care in relation to the CCM components. These data are used as a proxy to understanding the capacity and readiness of ACT Health to support a CDM register.

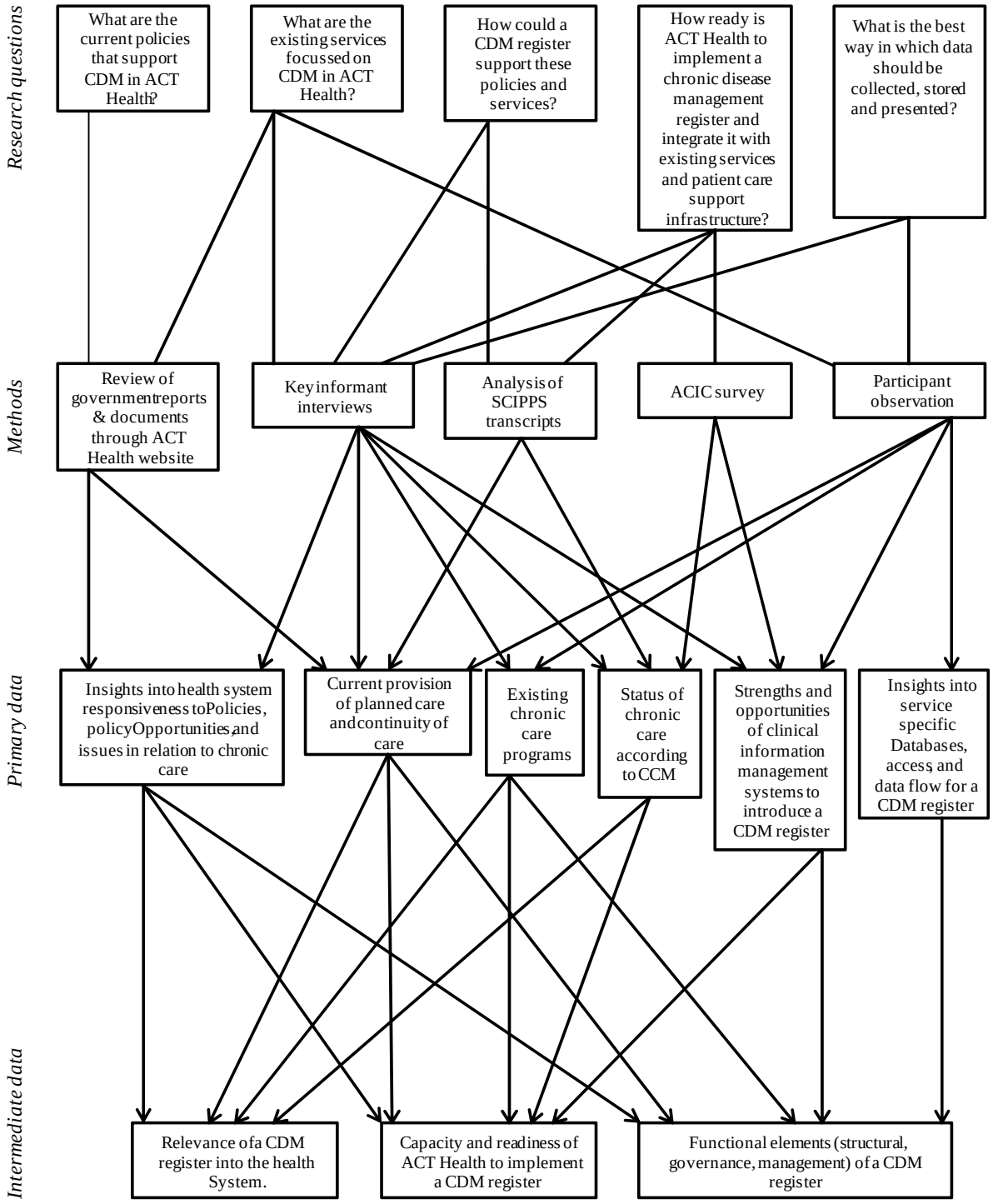
The key informants' interview collected views, opinions and recommendation for a CDM register from the CDM policy and program point of view. The method also gathered Informants' views about care coordination and provision of planned care to engender a CDM register as a care coordination tool.

Participant observation produced two main categories of findings, which include (i) data strength and data support systems and (ii) data element and data flow design of a CDM register.

The SCIPPS data helped to understand patients' experiences, self-management supports and issues in relation to continuity of care. The SCIPPS data also enriched my insights into care coordination, clinical data linkage between hospital and community (e.g. primary care) and with other sectors (e.g. out-patient, emergency department).

The participant observation mostly generated data in relation to care management processes. The method provided insights into functional and technical elements of a CDM register.

Figure 3.2: Framework for analysis



Intermediate data

At this stage, I further analysed primary data to encapsulate objective specific results. According to the diagram, the data analysis helped me to narrow down the results into three categories as below:

- strategic relevance to fit a CDM register into a health system for chronic disease prevention and management
- organisational readiness including strengths and opportunities of the clinical information management to design a CDM register as a planning and management instrument
- structural, governance, and management elements of a CDM register.

3.7 Research management

I received all my administrative support from the ANU Medical School. I carried out overall research management from the ANU Centre for Health Stewardship. The centre provided me with the office setup at the centre with other research fellows and PhD students. I followed research management steps according to ANU guidelines. The steps include finalisation of selection of supervisors, development of the research proposal, a first year seminar and submission of the thesis proposal for review, submission of annual work plans and meetings with supervisors. I had regular meetings with the Chair of the supervisory panel on a weekly basis at the beginning and then each month. I used to meet with other supervisors at six-monthly intervals.

My PhD research is funded by the NHMRC. My research is part of the NHMRC Centre for Research Excellence in Patient Safety (CRE-PS) research program. The CRE-PS works within the Department of Epidemiology and Preventive Medicine of Monash

University. Therefore, one of my supervisors was from the CRE-PS. Initially my research notion was to work on clinical governance around the CDM area. During finalisation of the research proposal with supervisors' comments, I changed the research notion to a clinical register approach from clinical governance focus. Accordingly there was a shift of supervisory responsibility within the CRE-PS to offer proper technical guidance. I presented my proposal at the centre and met with my supervisor when planned.

In relation to a research timeline, I progressed fairly in my first year. I had nearly completed my literature review during this time. In my second year, I could not progress much due to delay in obtaining ethical clearance. The ethics clearance process took more than 7 months. Upon ethics clearance, I started data collection and conducted the ACIC survey and most of the key informants' interviews in 2009. I completed the remaining two key informants' interviews in February 2010 and continued participant observation until May 2010.

I regularly shared my entire manuscript with my supervisors with their feedback incorporated. At the end of first year one article was published by the Australasian Epidemiologist Journal (Guda *et al.* 2008).

3.8 Field work

After the completion of the thesis proposal review, I submitted the ethics applications (see Section 3.10). I received final ethics approval on 9 June 2009 and commenced my field work in the same month. Dr Dugdale continuously guided me during my fieldwork. I used the ANU Centre for Health Stewardship and the CDMU as my field offices. I collected data over a period of 12 months from June 2009 to May 2010.

My field work started with the recruitment and selection of target participants. I drafted and finalised data collection instruments through regular meetings with my supervisors. Shortly after the ethics approval, I conducted field testing of the key informants' interview schedule. I have distributed the ACIC survey to the target participants at the same time on 18 June 2009. I have started my qualitative data collection from August 2009. The ACIC survey data collection started in June 2009 and finished in December 2009, key informants' interviews from August 2009 to February 2010, and participant observation from May 2009 to May 2010.

3.9 Data analysis

Quantitative data analysis

The ACIC survey data is score-based data. I first entered the ACIC data in Microsoft Excel for electronic storage. I double-checked the ACIC data before transfer to STATA 10 software and completed coding of data in STATA 10 for analysis. Finally, I used PASW 18 (Predictive Analytics Software) statistics for ACIC data analysis upon advice from the ANU Statistical Consulting Unit. Many healthcare organisations in USA and Australia (Victoria and Western Australia) are using ACIC surveys. So, I tried to find out what is important in ACT Health and compare ACT Health score with other settings. Chapter 5 presents details of ACIC data analysis and results.

Qualitative data analysis

Initially I transcribed the recorded interviews using Microsoft Word with full attention to covering all conversation. I commenced the transcribing and in the latter stage sought assistance from a professional transcriber service to hasten the process. I processed and analysed qualitative data using NVivo 8 software package. At first I prepared a thematic

coding scheme with the codes and their definitions. As the next steps, I coded transcripts according to the coding scheme for analysed data. Chapter 4 presents detail about key informants' interview data analysis and findings.

For SCIPPS qualitative data, I reviewed the original SCIPPS coding scheme and then selected codes as relevant to my research. I prepared a new coding scheme keeping the codes' definition the same as the original. I have done SCIPPS data analysis solely by myself for this research using NVivo software. Chapter 6 describes the SCIPPS data analysis and results in detail.

Participant observation

The participant observation involved documentation, process mapping and the system requirement analysis. I have gathered knowledge about care management processes through attending CDMCN meetings. I have used that knowledge to interpret the ACIC survey and other qualitative data. I also collected supplementary data from CDMCN members and discuss those in Chapter 7. I used Visio software in the system requirement analysis to prepare different flowcharts.

3.10 Ethical considerations

The study complied with the ACT Health and ANU ethics guidelines. This process involved three levels of ethics clearance. The first level is the endorsement from Survey Resource Group of TCH on 7 January 2009 (Appendix 5). The second level is the approval from ACT Health Human Research Ethics Committee on 27 May 2009 (Appendix 6). The final one is the approval from ANU ethics committee on 9 June 2009 (Appendix 7). I had to follow all these three levels of clearance because TCH was my research setting. ACT Health and ANU ethics committees approved all my data

collection instruments like ACIC survey questionnaire, key informants' interview schedule, participant information sheet and consent form. I have submitted research monitoring reports to the ANU Human Research Ethics Committee.

For this mixed method research protocol, the ethics clearance process contributed more clarity and insights into the whole research process.

Protection of respondents' identities

As a research team, we clearly explained the research objective and data collection procedures to target participants and CDMCN members within ACT Health. For the ACIC survey, the survey package included a formal letter, the questionnaires, participant information sheet and the consent form in a sealed envelope. The participant information sheet contained the summary description of the study with references, the purpose, operational definitions of terminology used in the survey for an understanding about the research. The participant information sheet used plain language suitable for all types of readers. The survey packages were sent to the participants with a formal introductory letter.

For key informants' interviews, I sent the interview schedule along with the participant information sheet and consent form in advance to the participants. I communicated with participants through email and telephone contact to maintain their willingness to participate in the qualitative interview.

Before being asked to participate, the respondents had their choice to participate in the ACIC survey and qualitative interview. I assured participants about the steps to maintain confidentiality of respondents' identity and collected written consents from them. I clearly communicated to them that the participants could withdraw from the study at any time.

I mentioned to participants that only de-identified data and information will be used for analysis and in publications of results once the study has been completed. To do so, I used only codes and pseudonyms to identify subjects in all data. I have conducted all interviews in full privacy and stored all records, transcripts and digital data securely at ANU with electronic and keyed access.

I have performed my participant observation with full compliance to the ANU Medical School undergraduates (ACT Health Clinical Placement Agreement) conditions.

Outcome of participation

In the course of conducting the ACIC survey with 67 target participants, in-depth interviewing 10 key informants, no instances of psychological distress occurred among the participants. The ACIC survey received good cooperation from target participants with several reminders.

Chapter Four

Strategic Relevance of a CDM register in ACT Health

Chapter outline

4.1 Introduction

This chapter presents the key informants' interview findings and their primary analysis. The primary analysis aggregates data around current CDM programs in relation to the chronic disease strategy framework.

The first section describes the components of ACT Chronic Disease Strategy reflecting ACT Health's policy commitment for CDM. Subsequent sections explore the status of chronic care, possible reasons for gaps in chronic care, and policy and program opportunities for CDM.

This chapter aims to explore the necessary factors to optimise CDM programs within ACT Health jurisdiction.

4.2 ACT Chronic Disease Strategy contexts

The ACT Chronic Disease Strategy framework provides an overarching framework for prevention and comprehensive management of chronic conditions within the ACT region (ACT Health 2008a). The strategy framework embraces program elements, which include early detection and treatment of chronic conditions, prevention and risk reduction, service integration, and self-management supports. There is scope within the strategy for program innovations with a view to integrating chronic care services under an umbrella of coordinated care and implementing prevention programs. In response to the strategy, ACT Health established CDMU within the organisation. The CDMU aims to strengthen chronic care coordination, self-management supports and health promotion. The CDMU started building a CDM register for service planning, secondary prevention and benchmark chronic care within the ACT region.

The current health system focuses more on acute care. The strategy incorporates the shift in focus from acute to chronic care. Accordingly the strategy proposes reform in primary care and community based programs to reduce risk for chronic diseases. The strategy also proposes integration of services within government agencies, and primary and community based care to address many of the CDM challenges. Table 4.1 presents the main action areas of the strategy and their descriptions.

4.3 Data Collection

Chapter 3 (Methodology) detailed the key informant's interview as a method. A total of 10 key informants were purposively selected from the list of 67 ACIC survey recipients. Table 4.2 presents the key informants' portfolios, which explains their expertise and professional roles within ACT Health.

Table 4.1: The action areas of the ACT Chronic Disease Strategy

Area	Description
Action area 1: Prevention and risk reduction	This action focuses on behavioural interventions for healthy practices to reduce exposure to risk factors for chronic diseases. The interventions incorporate nutrition, physical activity, alcohol and smoking cessation as program elements.
Action area 2: Early detection and early treatment	Early detection and early treatment interventions include promotion of health check of 45–49 years old population under Medicare Benefits Schedule (MBS).
Action Area 3: Integration and continuity of prevention and care	This action emphasises the integration and coordination of service units. This integration is important to implement care planning processes. The primary care is central to facilitate continuity of care and thus CDM.
Action Area 4: Self-management	This action highlights the role of patients with chronic disease and their carers in the support of CDM. Interventions under this action area bring the community health division to offer a range of educational and life-style modification programs. Self-management supports include patients' informed choice and decision making concerning continue care.
Action Area 5: Research and surveillance	The Research and surveillance component highlights the establishment of chronic disease surveillance and monitoring system. This action area emphasises building a CDM register under the CDM prevention and planning activities.

All the key Informants consented to the interview, without receiving any incentive. The length of the interviews was within the range of 29–57 minutes with the average length of 38 minutes. The key informants received the participant information sheet and key informants' interview schedule two days prior to the date of interview.

The interviews were conducted in full privacy and were audio recorded. I assigned a specific identification number against each key informant' to de-identify the participants.

Table 4.2: Portfolios of the key informants

Key informants	n=10
Senior Executive	3
Clinician Manager	1
Non Clinician Manager	1
Clinician*	2
General Practitioner	2
Non Clinician	1

* Includes staff specialists

Key informants' interview schedule

The intention of the key informants' interview schedule was to investigate findings around the first research objective to 'explore the strategic relevance of registers in relation to CDM interventions in a medium size regional health service organisation' and associated research questions (see Chapter 1 for Section 1.2 and 1.3). Chapter 3 presented details about the development of the instrument. This section presents the themes and the questions. The interview schedule contains four sections and a total of nine open-ended guide questions (Figure 4.1).

4.4 Data Analysis

The data analysis framework reflects action areas of the ACT Chronic Disease Strategy (Table 4.1) and the CCM components (Chapter 2, Figure 2.1). The Chronic Disease Strategy and CCM components guided the coding of interview transcripts in NVivo 8 software. Table 4.3 presents the data coding matrix along with description of each node. This chapter only uses nodes 1–4, 10–14, 18–20 for data analysis. Chapter 7 uses the nodes 5–9, and 15–17 to identify design features and implementation strategies of a CDM register.

Figure 4.1: Key informants' interview schedule

Section A: Discussion on current CDM program and opportunities to improve chronic care

1. Your opinion about the current CDM interventions
    - Reflection of chronic disease strategy and the current CDM program.
    - Key issues of interest in regard to CDM.
    - Current gaps in CDM.

2. What do you think is important in CDM?
    - Opportunities

3. How do you rate the following interventions in terms of the contribution to improving CDM? Why?

    a. Electronic medical records
    b. Quality improvement methods
    c. Web based decision support
    d. Performance management
    e. Care coordination
    f. CDM register

    Scoring:
    5=Excellent contribution 4=Good contribution 3=Some contribution 2=Little contribution 1=No contribution

4. What is your opinion about current performance indicators for CDM?

Section B: Discussion on the potential for a CDM register to improve care of people with chronic diseases

5. Do you think a CDM register will be a useful action component of the chronic disease strategy?
    - Can you identify any potential roles for a CDM register?
    - Can you identify any specific prior steps necessary before implementation of a CDM register?

6. What are your views about the current policy environment for CDM?
    - Policy commitments that still need to be addressed in practice.
    - Policy issues around the use of personal health data in a CDM register.
    - Specific recommendation on the management and governance aspects to build and operate a CDM register.

Section C: Discussion on the level of interaction of different units in CDM

7. What are your views on the interaction between service units for chronic care?
    - Can you comment on existing communication channels between service units and patients including their volume and capacity?
    - Can you comment on current provision of care planning for patients with chronic disease?
    - What additional policy could you see that would help interaction between service units for CDM?

8. What do you think about chronic disease self-management by patients?
    - Current aspects of self-management.
    - What roles can hospital play in better planning for self-management of chronic diseases after discharge?
    - What additional policy could you see that would support CD self-management?

Section D: Discussion on organisational capacity and readiness to implement a CDM register

9. What do you think about the ACT Health's capacity and readiness to implement CDM registers?
    - What are the current strengths and weaknesses of ACT Health's of clinical information technologies?
    - How ready is ACT Health to implement a CDM register considering budget, policy supports, management and governance aspects?

Table 4.3: Key informants' interview data coding matrix

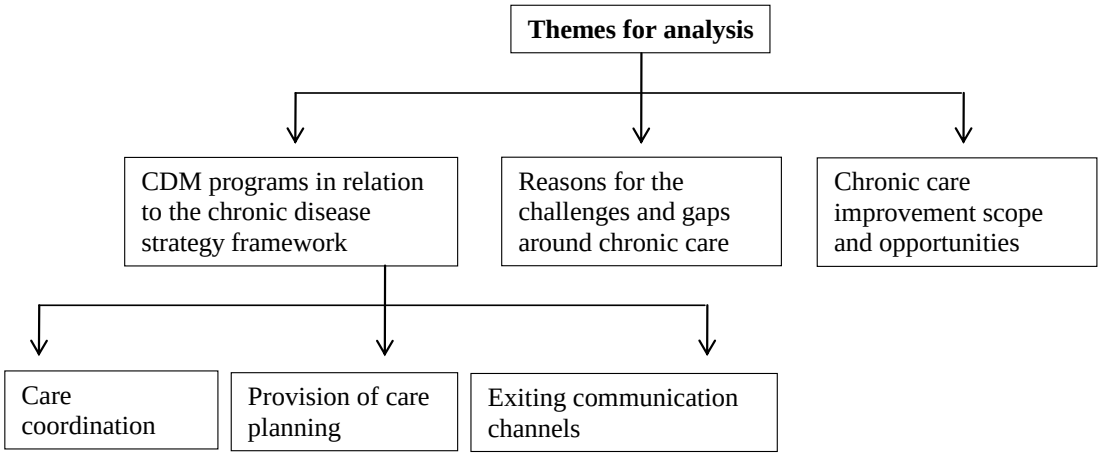
Main Nodes	Description
1. CDM program in relation to chronic disease strategy	Opinion about current CDM interventions and their implementation. This node also describes the implementation of strategy action areas.
2. Status of current CDM programs and intervention	This node aggregates all views about the implementation status of current CDM programs.
2.1. Gaps in current CDM programs	Key informants' opinion about programmatic gaps. This node covers the overall gap as well as gaps in implementation of specific CDM components.
2.2. Issues of current CDM programs	The issues, which are specific problems and concerns of the CDM programs.
2.3. Reasons behind gaps or issues for CDM programs	This node aggregates the reasons for inadequate implementation of CDM interventions.
3. Opportunities for CDM	The term 'opportunity' clarifies all the scopes and possible steps to enhance effective CDM processes.
4. Opinions about evidence-based chronic care interventions to support CDM	These are lists of evidence-based CDM interventions. Key Informants expressed their views about these interventions. The interview schedule contains six sub-node topics for discussion as below. The key informants rated each intervention with justification.
4.1. Care coordination	Importance of care coordination between multiple services and providers to facilitate a continuum of chronic care.
4.2. CDM register	Roles of CDM register to assist disease management processes including disease prevention and risk reduction.
4.3. Electronic Medical Record (EMR)	Informants' views about the roles of electronic medical record as an intervention to assist clinical leadership and clinical decision making.
4.4. Performance management	Performance management processes as a method to explore gaps between the program target and achievements, to identify root causes and develop solutions for service improvements.
4.5. Quality improvement methods	Key informants' views about different quality improvement methods to improve chronic care delivery.
4.6. Web based clinical decision support	Roles of web based clinical decision support system to suplement evidence-based chronic care guidelines and CDM programs.
5. Current performance indicators for CDM	This node aggregates informants' opinions about existing performance indicators and their relevance to improving CDM including services planning.
5.1. Suggestions about potential CDM performance indicators	Specific suggestions to include any indicator as chronic care performance indicators.
6. Roles of a CDM register	Roles and functions of a CDM register in care coordination and secondary prevention of chronic conditions.

7. Prior organisational steps to implement a CDM register	Important management and organisational steps, which are pre-requisite to implementing a CDM register.
8. Prior steps for system level to implement a CDM register	System and technical requirements including data, IT components and other technical inputs to support functioning of a CDM register. This node double entered for prior organisational steps (Node 7).
9. New policy requirement to introduce and implement a CDM register	Additional policy requirement and supportive environment besides the strategy document for functioning of a CDM register. It includes other policies about patient consent processes and ethical aspects of the use of personal health data in a CDM register.
10. Communication channels between service units to support chronic care	Opinion and recommendation to establish communication channel between hospital-based services, and between hospital and community services for clinical decision making.
10.1. Communication issues between service units	Perceptive notes about any issue or challenge that hinders interaction between service units.
11. Provision of care planning	Current status of care planning and involvement of different service units.
11.1. Any policy issues to improve care planning	This is about need for any specific policy content to foster the care planning processes.
12. Status of care coordination	Current state of care coordination and service integration.
13. Policy requirement to foster interaction between service units	This is about additional policy required to enable effective communication and interaction between service units. This node captures all data in relation to the need for additional policies to foster communication and care coordination.
14. Views about chronic disease self-management	Current aspects of self-management and organisational supports for self-management.
14.1. Additional policy support to foster self-management	Specific policy or policy content that is needed to strengthen self-management supports.
14.2. Role of hospital in better planning for self-management	This is about how the ACT Health system can contribute self-management supports. It is more about information linkage for better planning for prevention interventions.
15. ACT Health's capacity and readiness for a CDM register	Key informants' overall comment about ACT Health's strengths and opportunities to implement a CDM register. This node also includes issues and challenges as relevant to the topic.
15.1. Management and governance readiness of ACT Health	Opinions about current status of health services management and governance support for a CDM register.
16. ACT Health's strength to implement a CDM register	These are the strengths, e.g. clinical information system, organisational leadership strength and policy environment to support a CDM register.
17. ACT Health's constraints to implement a CDM register	The constraints are the specific issues and challenges specific to the introduction and implementation of a CDM register.

18. Chronic care policy opportunities	This is a generic node and captures data related to chronic care policy opportunities to strengthen chronic care. It also aggregates key informants' opinions about a new intervention like a CDM register. Double entered for codes related to respondents' opinions about additional policy requirements.
19. Patient discharge system and planning	Current patient discharge system and discharge planning processes in relation to continuity of care. This node also captures important recommendations to strengthen the patient discharge system.
20. Evidence-based guidelines	Respondents' remarks about the status of implementation of evidence-based guidelines to treat and manage patients with chronic diseases.

The data analysis used pre-defined themes in relation to the key informants' interview schedule. The first level of data analysis involved grouping of the relevant quotes according to the coding scheme. At the second level, I rechecked the initial list of quotes and selected a second list of important quotes under the same coding scheme. The third level of analysis iteratively confirmed nodes in the coding scheme using the data query method. Figure 4.2 presents the list of themes for data analysis.

Figure 4.2: Themes for analysis



The discussion of the results used these themes as section and sub-section headings in this chapter. The themes include analysis of related policy contents.

4.5 CDM programs in relation to the strategy

The interview first addressed discussion about the implementation of current CDM programs in relation to the chronic disease strategy framework. This part of the section presents introductory discussion of findings about the current CDM programs implementation status. The sub-sections elaborate specific topics more in-depth.

The ACT chronic disease strategy framework for 2008–2011 is built upon the Wagner's CCM components. The quote below highlights the acceptability of CCM elements into ACT Health's CDM programs. Also it indicates that the agenda for CDM is gaining in importance.

> *We have mapped the elements of the Chronic Disease Strategy in the ACT against the National Chronic Disease Strategy and against the ACT Chronic Disease Strategy and against the Wagner's CDM Program, and we're reasonably comfortable that at least in theory we've got most of the elements of the Wagner's Program well covered.* (Senior Executive).

Structurally ACT Health established the CDMU along with some re-allocation of tasks of certain departments or units the within the health system to support chronic care. The establishment of the CDMU is one of the essential steps in implementing the strategy. In relation to this, one key informant stated that

> *Well the chronic diseases strategy as you know had three or four elements that were part of the initial rollout of which something we were discussing today, the register was one of those components. The four components as I understood were … well I guess firstly before the components were rolled out the evolution of a relationship between the new Chronic Diseases Management Unit, CDM for short, and the other stakeholders in ACT Health, but particularly within The Canberra Hospital and the community, and that's something that [name of a stakeholder] has spent the first six months of the CDM rollout doing.* (Clinician Manager).

The CDMU provides strategic direction and at the same time creates dialogues for concerted efforts from relevant service units.

An efficient CDM program requires a multidisciplinary model of care. The establishment of a multidisciplinary model according to the ACT Chronic Disease

Strategy is very challenging where the governance and management structure are important issues in implementing any new initiative. One participant expressed frustration about the implementation of the strategy. The participant emphasised building shared understandings of the strategy elements and the roles of various units to support it.

> *I think where we're at with implementing the Chronic Disease Strategy is somewhat behind where we should be. I think we are heading very, very slowly in the right direction but I also think there's a lack of understanding or a shared comprehension about where we're heading. And therefore the reality of that is that we ... when we look at ACT Health we can't see or feel a commitment to getting the Chronic Disease Strategy implemented fully.* (Senior Executive).

It becomes clear that the nature of CDM interventions and challenges need resolution for a multidisciplinary care delivery model. The progress of the implementation of strategy elements depend on clear statements about authority and roles and at the same time more coordination of functions to reach towards the chronic care goals.

> *It's really that there's one point of accountability and there's one point of strategic development to which everyone feels they're contributing even though this spans across different services. You see this is the problem, that traditionally medical services here and everywhere have been split in two divisions – are split into sub-specialties. Especially this place because there's no general medicine. It's very sub-specialty based.* (Clinician Manager).

It is obvious that the care delivery systems are separated because of the initial set-up focusing on acute care. Chronic care and disease management processes require the collaboration of relevant services.

ACT Health has a supportive policy environment including the e-Health agenda, which is a strength to connect service units. The e-Health agenda is very relevant to establishing functional linkages between service units.

> *I think getting some rungs on the board is really important for us. So progressing the establishment and roll out of the register is critically important for us. Progressing home tele-monitoring is critically important for us. And getting the governance right around CDM across the whole of ACT Health is right. So while we've got the dots joined up informally, I think it's really important for us to get them formally connected. And I think we're heading in the right direction, but slowly.* (Senior Executive).

> *The next six months were then, as I see it and this is just my perception, were about getting the more specific things established. That is to get the Chronic Diseases Register, the prospect of home tele-monitoring, the enabler of telephone coaching, and then the ITIM (Information technology and information management) platform which needed to be present to facilitate all of this in place, and to then elaborate the model of what we all thought should happen with Chronic Diseases Management with respect to the initial starting of chronic disease areas which were heart failure, chronic airways disease, diabetes, and subsequently others will come along.* (Clinician Manager).

The above two quotes pointed out two important aspects, which are (a) establishment of a common information portal including a CDM register, and (b) governance and management of CDM interventions.

Chronic care within the ACT region is developed a lot within some specific services. The chronic care pathway requires specialised services to work together with primary care, community health and social support networks. The presence of an appropriate communication channel is necessary to connect multidisciplinary providers. Below is a comprehensive view about one CDM intervention.

> *I think the chronic heart failure service that's in Canberra is not ideal. The multidisciplinary component to our heart failure service is important and that doesn't exist in Canberra. There is just the heart failure nurse and she has no opportunity to refer to other people – psychologists, dieticians, etc. I think it's just really touching the tip of iceberg. The people who are able to access what heart failure services there are in Canberra quite small so there are a lot people who are missing out on any form of heart failure program. I think some of the people with a milder form of heart failure are going through the cardiac rehab program, which again is probably not ideal because the cardiac rehab is very much geared to people who have had heart attacks and people with coronary heart disease rather than heart failure so sometimes lectures that they receive, they are not relevant, and they don't always have the capacity to provide the extra bits that the heart failure people require. So I think there certainly needs to be a multidisciplinary care component to the program which is lacking. There is also problem of the linkages with general practice as well in the heart failure program. They have a lot of trouble I think with communication between the program and general practice as well and also the management of patients in general practice as well impacts on the their ability to help keep those patients out of hospital as well if they are not being managed as well as they could be in general practice. I think that area needs to be improved on as well.* (Non-clinician Manager).

The above example illustrates some concerns about CDM programs. The current health system needs reform for a clinical data linked coordinated service delivery model to implement the chronic disease strategy within ACT Health systems.

4.5.1 Chronic care coordination

As mentioned earlier, an effective CDM intervention requires involving multidisciplinary providers to offer coordinated care. A successful care coordination model links patients with a range of clinicians and social service providers of different organisations. The care coordination requires a formal referral system and clinical decision support system. This means that the patients get the central focus within the continuum of care (Kibbe 2001; Institute of Medicine 2004).

In the current health system, the implementation of CDM components is viewed as a challenge. One key informant described this as challenge because the service units implement CDM services without adequate integration. The finding below calls for a specific care coordination intervention to link service units.

> *It's always a challenge because there are components of chronic disease prevention and management across the continuum of the health system, and yet management responsibilities run in silos typically. So you need a cross-matrix sort of coordination system to capture all that activity.* (Senior Executive).

The implementation of shared roles depends on functional relationship within the structure.

> *Now that was a strategic decision that was taken by ACT Health to make sure that everyone was aware that they were all responsible for chronic disease and I think that's an admirable view. However, the reality of that is that that creates a system that is dependent on effective relationships, and that's not how it always looks. So you can work very hard and still not actually achieve the outcomes you need to achieve cooperatively because you don't have an effective relationship. So I think there's merit to it philosophically but I think pragmatically it doesn't work.* (Senior Executive).

The inadequacy of communication exists beyond the boundary of ACT Health's chronic care programs. The coordination of chronic care services does not adequately exist within primary care practices, and between primary care and hospital settings.

> *Care coordination, I think it doesn't exist… The coordination of care between the practice and other primary care services and ACT Health, if you're going to scale it from '1 to 5', it would be a '1'.* (General Practitioner).

The current communication channel between the acute and chronic care programs needs strengthening. The quote below does not mean that the acute care sector is running independently, but there are gaps in the linkage. One clinician participant said

> *I think there should be better communication between the people who are actually doing the chronic care program and us who are providing the more acute service.* (Clinician).

The ACT Health chronic care programs have varying levels of coordination. The key informants' emphasised the role of communication to facilitate the care coordination processes. A strengthened communication portal can connect the service units although the care coordination roles and responsibilities are critical within different management spans of provider units. The service units face complexities dealing with patients with multiple chronic morbidities compared with patients suffering from a single chronic condition. The second quote presents the complexity in relation to medication decisions.

> *It's important though that people identify that they are part of a chronic disease primary and secondary prevention management team and that they will try to work collaboratively across the silos, because many patients will be seen by multiple clinicians for their various sub-conditions. So from the patient's point of view it should be a seamless world.* (Senior Executive).

> *If we've got a client who's a mental health client who has chronic disease as well they [Mental Health Department] have a completely different information system. So we can't see it unless you actually work in mental health. That's problematic if the patient has an exacerbation of their chronic disease, or indeed if their medication changes in mental health care we don't know about it.* (Senior Executive).

In the above quote, the key informant raised the point that the patients expect an ideal patient journey within and between services. ACT Health has potentials to utilise a clinical information portal to carry out strategic reform and establish care coordination.

> *There are opportunities within primary care and allied health and community organisations and the acute sector in hospitals to actually integrate – and clearly their electronic records help that, but there should be better opportunities for care coordination within the ACT and improving, and making it best practices across the board.* (Non-clinician Manager).

If the hospital or acute care setting is a point of care in the patient's journey, the

findings suggest that there are opportunities to establish linkages of chronically ill patients with primary care and allied health services for illness management, prevention and to improve quality of life. The clinical data linkage is the appropriate resource to facilitate referral and communication between service units for management of these patients.

4.5.2 Current provision of care planning

According to the ACT Chronic Disease Strategy, the primary care sector has the key roles for CDM. Besides the clinical care, the primary care physicians have opportunities to prepare patient care plans in accordance with specific Medicare Benefits Schedule (MBS) items. The care planning process facilitates the patient journey involving multidisciplinary care providers through a collaborative approach. The care planning process engages patients and their carers to set specific CDM goals. The care planning process is part of the self-management principle and helps patients to understand the nature of the disease or condition, risk factors and treatment plan. It helps patients to take part in decision making with multidisciplinary care teams, to ensure continuity of care and to improve quality of life (ACT Health 2008a).

The patient care planning MBS items were introduced in 1999. Initially known as the Enhanced Primary Care (EPC) package, this included comprehensive written care plans for chronically ill patients according to their needs, and required formal input from other providers. In July 2005, two new items replaced this multidisciplinary care package. These two items were general practitioner (GP) management plans (GPMPs) and Team Care Arrangements (TCAs). Under the GPMPs the general practitioners prepare care plans with the patients and the TCAs authorise care from other providers (Vagholkar *et al.* 2007) to also be billed under relevant MBS items.

Some of the key informants mentioned the existence of fabulous care planning process and excellent care within the main health system for some patients. One senior executive mentioned that the current implementation of care planning process is insignificant and disjointed.

> *Current provision of care planning, I think it's done piecemeal. It's done in little vortexes of activity that are disconnected, and I've said this right from the start – that you have care coordination teams about chronic disease that are separate from CDM Unit, that are separate from the Community Health nurses who actually deliver care, that are separate from and not connected enough to general practice, that are not connected enough to and integrated with key specialty units, e.g. aged care, cardiology etcetera, although these things are in evolution. But that's the problem. Current provision of care planning is fragmented and it's in little vortexes of activity.* (Clinician Manager).

Based on the quote above, important issues came up in relation to the governance and accountability arrangement of the service units. The issues are specific about how the service units respond to patient care plans and how they talk and collaborate with each other.

In primary care settings, a patient care plan is considered as a tool to assist care coordination process. One general practitioner participant mentioned that the care planning at the primary care level is very comprehensive and patient centred.

> *For care plan we do actually Medicare based mental health care plan and chronic disease care plan. The government gives extra incentive for the GPs because it is time consuming. So when we prepare a care plan, we talk to the patient what to do, what not to do. For the most of the chronic disease plan we ask to see the same doctor in six month time for a follow up and review… At the same time we recommend some other people to involve. It has two parts a team care plan and a GP care plan.* (General Practitioner).

The above-stated quote pointed out the purpose of the care plan. In an ideal situation, care plan preparation involves consultation with patients. The care plan includes other service providers and carers for services and supports for patient care. It has a clear direction for follow-up and review of patient's clinical status. Care plans if implemented at primary care level, would offer great supports for patient in the community care setting. The next quote presents a real scenario and barriers to

preparing and implementing the care plans.

> *The practice is actually hot under the collar about care plans. Two of us do them, but the other ten doctors do them sometimes and I think our big objection was really the care plans as they are written from a bureaucratic point of view. It's all about you've got to get all the people involved with the patient's care, first of all, you have to get them all to agree that they are, and then you have a chat to the patient and everyone has a chat to the patient and then we all decide on the plan. And then we move on whereas from a GP point of view there would be I meet the patient, we're going to talk about what you need, this and that, and then I would invite whatever the services are and they say yes or no and hopefully, it would be really nice if I could just press a button and lights up in their rooms and they can say yes or no so I can immediately get a reply, very handy. And then we move on from there and then we tell the funders that we've all agreed to do this. That's what happens now with, say, the mental health plan, if you do the mental health chronic pain system thing.* (General Practitioner).

The above quote explains the process more elaborately. According to the participant, the preparation of paper-based care plan is complex. The same participant further explained the steps to prepare a care plan.

> *There are lots of steps to fill in the form. I was doing it with a patient and one of them was 'What's the goal of treatment?' And if you have a patient next to you there and you're sitting there and you say the patient's finally accepted they've got depression, 'I've got depression', and what treatment do you want? They want to go to a psychologist or something and then they say well what the goal of all this treatment is? And the patient says well I'd like to get better. What else is anyone going to say? My goal is to undermine the system and not turn up. It's a waste of time, it really is, and when you are depressed actually, sure you get better, but if you want to be specific about that, that's actually part of the treatment... We want the referral and we'd like to pare back as to what the outcome of that referral.* (General Practitioner).

The enhanced primary care (EPC) multidisciplinary care planning (Shortus *et al.* 2007) could not establish partnership between patients and providers due to some administrative barriers.

> *At the moment things like Medicare, the way Medicare is structured in primary care is a real disincentive to good care because it is all of these bits of paper work… I defend the poor care in that primary care sector. It is not about doctors not wanting to provide best practice care; it's about what are the systems that are barriers to that.* (Non clinician Manager).

So, there are some real differences between purpose and implementation of a care plan. The current preparation of a patient care plans is time consuming. The process needs revision for simpler and outcome-oriented care planning. The above two findings indicates that the existing care planning system or processes if they could utilise

electronic system, would be easier.

The patient discharge planning process from and within the acute care units is another important area. The discharge planning process is the part of care planning within the hospital system for a guided transition of patients to the community. Discharge planning within the hospital environment is adequate but poorly documented and implemented.

> *Discharge planning is poorly developed presently in ACT Health. There's a good policy in place but it's been poorly implemented and a discharge planning toolkit that was developed was never implemented. So there is variable practice in discharge planning...It's a constant irritant for general practice in particular that they receive poor or inadequate discharge information. And I think in some circumstances that actually place patients at risk through things like medication errors or failure to follow up.* (Senior Executive).

People with chronic problems usually come to the emergency department with acute exacerbations. Ideally, the patient discharge plan should be in place from the first day of admission to have a better CDM plan and self-management support.

One clinician participant raised the issue about shortage of workforce – shortage for efficient discharge planning.

> *It's [Discharge planning] patchy as well. Some have done better than others... Discharge planning to start on when the patient, basically even before they're admitted on day one. And from that you'd have clearly a better CDM plan. I think that would be ideal. Difficult to get with the current workloads for the junior staff but that doesn't mean you can't strive for it. But I think that would absolutely be ideal, so better planning for self-management.* (Clinician).

The inadequate discharge planning process leads to limited documentation of patient management processes and outcomes, and impacts on the referral processes. So, when the patients go back in the community after hospital care, seamless transfer of patients to other providers with appropriate clinical data and instructions remains as the challenge.

4.5.3 Exiting communication channels

The qualitative interview explored the status of communication between service units. The findings are gathered and grouped around ACT Health's service units and primary care sector. The findings indicate that the communication within the ACT Health service units follow a self-governing pattern.

> *ACT Health is famous for its silo mentality for each little area being independent of the other… The service for the renal unit as opposed to the service for the cardiology unit as opposed to say the services for podiatry and say services for aged care are all independent. Any idea of a patient going from one to the other, both physically is impossible from the patient's concern often, and also that the information flow from one to the other.* (General Practitioner).

So, the clinicians' clinical decision making depends on the clinical presentation of the patients. The system is not able to help the clinicians or service units for integrated care through sharing the clinical data. It also indicates that each service unit prepares a clinical management plan and referral plans separately. The clinical management decisions depend on patients' movement with their own clinical data along with themselves. The ACT Health services have limited communication with other service areas including the primary care.

> *The greatest deficiency presently is the silos between general practice and the hospital information systems. So we've got a major bridge to create to enable continuity of care across that system. And within the hospital itself there are a number of boutique clinical systems that manage discreet conditions that don't talk to each other. So even within our own systems there are challenges to integrate information and even an even greater challenge to reach out to the community-based services.* (Senior Executive).

The gap is in the use of technology as a vehicle to access clinical information for clinical decision supports. This theme is common for both ACT Health and primary care settings.

> *We have big gap sometimes… Everyone has their own strategy or view but no holistic approach and no holistic system either in traditional way or advances in technology. We don't have CDM-wise or information wise any tool or vehicle to get easily any information or we can use the information.* (General Practitioner).

This finding indicates a need for a system for clinical data linkage. The data linkage can

support quick assessment of patients' clinical conditions without duplication of effort.

The services or clinicians communicate as on *ad-hoc* basis for clinical decisions and referral processes. The presence of relevant policy instruments and standard operating procedures and standard protocols can improve formal collaboration and interaction between different clinical streams.

> *There's probably a gap there in terms of policy instruments or standard operating procedures that help and support that collaborative work... I would imagine that there's space for more such detailed protocols because this is a new way of working and there may not be much support for it.* (Senior Executive).

CDM interventions engage multiple providers, different organisations, patients and their carers. The findings indicate existence of some level of organisational barriers for service integration. The other issue is around the difficulties in having the hospital in a home help situation where the interactions do not run smoothly. The presence of a common clinical data portal can connect involved providers of hospital and the community services. The purpose of this common information portal would be to reduce duplication of patient assessment, time involvement for patient re-assessment, augment better coordination of care.

4.6 The reasons behind the gaps or challenges around chronic care

ACT Health has very favourable policy supports in chronic disease management (also see ACIC scores in Chapter 5). The question is why the policies are not in practice. One clinician manager mentioned that poor involvement of clinicians in policy development is one of the reasons for not 'owning or buying into' or not 'becoming aware' of the policy.

> *Whenever you talk to any clinicians around this place and you talk about the chronic diseases managements Strategy and they say, where's the budget held? And you say, well it's in Policy at the moment because it came from Population Health and it's gone to*

> *Policy, but it's about to be devolved we hope... Well they say, so what's our involvement? Why aren't we part of the structural construction of that reality since we deliver the care at the coal face and the assessment and the management strategies? And that's a very sore point. So the connection between initial policymaking and the input from clinicians in that policymaking, which is very meagre in ACT Health, or at least that's the perception of the clinicians.* (Clinician Manager).

Clinicians demand more involvement in the development processes of health policies, which would empower them in implementing actions.

> *The perception of clinicians at the moment means the policy environment is not ideal for the launch of this [ACT Chronic Disease Strategy and CDM register] because of the perceptions of clinicians that they've been divorced from the evolution of the policies. Even if that's not the reality that's their perception.* (Clinician Manager).

> *I think we've overcome a lot of barriers. There was somewhat some reluctance in embracing the philosophical concept about a register in this administration for whatever reason.* (Senior Executive).

The major barriers to building and implementing a CDM register are due to the insufficient understandings of the stakeholders about its public health role in it. There are potential marketing roles to recognising the value of a CDM register for implementation.

> *Unless they [clinicians] all buy into the fact that the register has value then it'll just be a register that's done for public health purposes but has no true impact in the day-to-day conduct of physician in practice.* (Clinician Manager).

At an organisational level, the clinicians are the main users of a CDM register to achieve CDM goals. Although having a positive intention as mentioned in the policy documents to build and implement a CDM register, ACT Health has no active chronic disease registry system currently.

> *We don't have an active CDM Register itself in place. So while we have stated our intention to put a management register in place it's not been implemented as yet. So I think that's a major deficiency.* (Senior Executive).

The following quote explains one of the reasons. The concept of a CDM register creates misunderstandings and doubts among the providers. The impression they got is that a CDM register is a performance monitoring tool. It trims down intentions to comply with

the policy commitments.

> *I think that people generally these days are a little bit suspicious of any register. So what are you using the information for? Is Big Brother watching me? All that sort of stuff. So I think the communication about what it is, what it will be used for, who gets the information, the level of security and privacy, all of that communication about what the hell it really is I think is absolutely paramount. And I think it's the marketing/advertising in a way that people can understand.* (Senior Executive).

The above quote resonates with previous findings. This situation requires proper dissemination of the concept around the usefulness of a CDM register to promote its adoption.

ACT Health needs specific process indicators for monitoring performances of chronic care interventions. One key informant mentioned the need for right performance indicators minimising issues and gaps of chronic disease interventions. The informant opined to include both the clinical process as well as the outcome indicators to track improvements over time.

> *We are very committed to outcome driven sort of care and so certainly I think that there would be a range of process indicators to keep people moving along, and as [people] are developing services and give people some confidence in early wins… Looking at some patient outcome measures, I think would be really important as well. So in terms of health outcomes I think there needs to be a system that allows for both process measures, that there are systems in place and measuring those, but also around patient outcome and measuring that against in looking for improvements in patient outcome, measure against benchmarks that are available.* (Non Clinician Manager).

One key informant opined that the CDM register might satisfy the demand for chronic disease performance indicators.

> *I think what you're saying is that essentially we need to develop new KPIs [Key Performance Indicators] to reflect the structure of what we'd like to deliver and how we'd like to deliver it. So I'd say that that would be my opinion – that they can't continue to be the only KPIs, the ones that are currently there, which are very crude and they don't assume that we've got any of these things, which we should have when we've got a register.* (Clinician Manager).

There are opinions about the features of chronic disease performance indicators.

> *I think they had value as strategic indicators but I think they lack ... when I look at them I can't see what the outcome for a patient is. So for me they're not ... they're not clinical*

> *indicators... I think we can deliver easily all of the things that are the performance indicators for chronic disease without ever making a difference to a patient. And I think we need to have a better accountability framework that delivers outcomes for patients.* (Senior Executive).

> *Do I think we're using the right performance indicators? Well I say we don't make it sexy enough for anyone to actually take a lot of notice of. It's not politically sexy. Emergency departments and their waits are politically sexy. So is elective surgery waitlists and so is deaths in babies. They're the things that get the news. The chronic disease stuff people don't look at and go, 'Wow' or not.* (Senior Executive).

The key informants pointed out that the performance indicators should be attractive and clinical in nature, and have the ability to reflect chronic care performance and patient outcomes. The absence of appropriate performance indicators explains reasons for inadequate implementation of established clinical guidelines. In relation to existing evidence-based chronic care guidelines, one general practitioner made the following statement:

> *I've had a particular, because of research purposes, I was interested in asthma and heart disease and again with asthma I can tell you that there are guidelines, but I don't think I could find them in my practice. With heart failure the guidelines I brought back five years ago from New Zealand that I use, they are from the New Zealand Guidelines Group. I think Australia uses them anyway, so the opportunities are that in our practice we can actually look at certain diseases, but it's not part of the system and I am afraid the whole Australian health system. I think, well it is in a state of flux at the moment, but we are not paid to look at from a disease population perspective.* (General Practitioner).

The above quote highlighted the need for locally tailored and updated regional guidelines for chronic care. Locally tailored clinical guidelines can help in identifying appropriate indicators for a register to benchmark services.

The current health system has a lot more focus on the emergency department and acute care services. Chronic care issues are not very eye-catching. The lack of focus creates issues in chronic care for patients who enter into the system through acute services.

> *I suppose from a system performance point of view where we look at mostly the acute side of the business, and from where I sit so it's only a very personal view, I don't think that there is enough information about CDM anyway. So it's there, it's talked about, but what it actually means – how that can improve for the patient, how it fits with acute services, that sort of stuff – I don't think the normal punter, if you're not involved in a CDM program or it interfaces directly with your work, I don't think people really recognise it a bit. I think it's talked about but I don't know that there's a keen understanding of how we*

> *look at things, like in the Emergency Department that's always on the front foot and everyone's sort of aware of cause it's the front of the house.* (Senior Executive).

The big issue is the absence of unified clinical information system for data repository within ACT Health.

> *The problem, the one that immediately comes to mind is that we don't have one clinical information system. There are multiple facets and often a lack of joined up dots around those clinical information systems.* (Senior Executive).

The operational meaning of 'one clinical information system' is beyond one hospital information system. It should include the primary care sector data as well.

> *We don't have an EHR [Electronic Health Record] that's robust and easily accessible. It's getting there. We don't have personal health record capacity related to the ACT Health system. People may have their own way of keeping their own health records at the moment, but we don't have. We don't have easy connectivity to all GPs, easy connectivity to all GPs or general practices with respect to health information or their access to our records.* (Clinician Manager).

The same informant also raised the privacy issue in sharing clinical data with other providers working at different organisations. There are many CDM prevention interventions currently in place but they require acceptable policies to access patients' clinical records.

> *So the key thing about all these things though, all of the above, doesn't work unless we've got information systems which deliver information at point-of-care, or to all of those that the client gives proxy consent to, or proxy or consent to access that data to optimise their care.* (Clinician Manager).

The following quote refers to the inability of health system capacity to uphold chronic care. Several issues emerged, which include the existence of limited support tools (not specified), referral pathways between hospital and primary care, absence of screening mechanisms to identify patients with chronic diseases, absence of a disease register.

> *We have been working with the division of GPs, certainly over the last year, to start looking at the management of heart disease and there's certainly evidence that there's big gaps, treatment gaps, and that is usually underpinned by the lack of the systematic approaches to CDM so, lack of patient registers around who has heart disease, lack of systematic screening to identify people and then often not have using support tools to support the management of people with heart disease and sometimes limited referral*

pathways so, some GP practices are doing brilliant job, but it's certainly not a consistent picture and a lot of it is due to lack of capacity. (Non Clinician Manager).

The quote highlights the need for systemic attention to linking primary care with the acute care settings and other allied health services for a combined effort.

The above findings suggest giving more focus toward management responsibilities and implementation of the policies in relation to a CDM register. There are governance issues like who will deliver, who will implement and how that relates back to service units and clinicians. The answers to the governance and communication issues will diminish the chasm that currently exists. Clinicians have powerful roles to play to support implementing a CDM register. The interview findings revealed that the clinicians have the perception that they are divorced from the policy development.

4.7 Chronic care improvement scope and opportunities

This section discusses the range of opportunities to address overall chronic care issues and challenges. The content analysis and thematic analysis helped to group interview findings on this topic.

The findings highlighted the role of multidisciplinary care coordination as an initiative to bring improvements. The findings suggested using standard discharge planning protocols and procedures to facilitate care coordination. The standard protocols will ensure essential clinical data sharing with concerned authorities or stakeholders for follow-up actions. Also standard discharge planning has roles to further assist care planning and self-management supports and builds a team approach.

I think some of the ways that we discharge could be better enhanced for people who are already on a self-management plan and I think that's connecting discharge plans with a care plan for chronic disease, which I don't think there's any integration of discharge planning in the ongoing care plan for chronic disease. So I think the connection there could be better. (Senior Executive).

Referral mechanisms for the collaborative projects with other allied health professionals and community organisations are essential to enhance prevention programs, in addition to the clinical management.

> *But how we create the community supports and referral mechanism would enable the life style change. Because that is I guess the issue with chronic disease is that while the medications and the things that the doctors might be able to prescribe are part of the picture. Life style intervention around physical activity and nutrition are also fundamental and need the attention as well. So, connecting all those systems is very important.* (Non Clinician Manager).

The current chronic disease self-management strategy has the potential scope to involve the patients. Patients partnering with their health care team can build greater responsibilities of patients and their carers for managing their own conditions.

> *I think overarching all of this is the need for an excellent marketing strategy [Chronic disease self-management], and I think that's lacking. And I think it's an opportunity for us to actually do hard sell around this stuff. I think that if we were to engage consumers in that marketing strategy who are on board and are able to help us actually sell that message, we could just go such a long way with their support. And I think we miss that at the moment.* (Senior Executive).

One clinician informant mentioned roles of patients or health care consumers in chronic care. The clinical decision making and response to the clinical decisions are dependent on patients' choice and self-management skills.

> *Well, the gap is always the patient. You know, no matter what we think is important and what we try and get done it's always ... the patient is the person who determines whether it's done or not. So there's always going to be a discrepancy between the ideal and the actual management. And we've just got to make allowances for it. Some people can help themselves to a very high degree. Others are not able to, for whatever reason. So I think the human factor is something that has to be allowed for.* (Clinician).

According to the above statement, the self-management knowledge and skills of patients are important abilities in managing their own conditions. Appropriate self-management skills can give power to the patients and thus augment the clinical care by clinicians. This quote calls for more focused patient education programs.

One senior executive informant mentioned introducing web-based modalities for primary and secondary prevention of chronic conditions.

> *I think we could strengthen our chronic disease self-management programs and our chronic disease primary prevention effort. So we are looking to introduce telephone coaching modalities for primary prevention and secondary prevention, and we're looking to introduce web-based modalities for both of those primary and secondary arms as well.* (Senior Executive).

Patient empowerment can assist functional implementation of the self-management strategy and reduce the disease burden on health system.

ACT Health has a supportive policy environment and commitment to strengthen its clinical information system. The future implementation of e-Health will solve many concerns around clinical data linkages and communications between service units. The implementation of an e-Health initiative will provide evidence within Australian health services using patients' clinical data for functional follow-up of outcomes and conditions. It will offer better service planning and coordination of services.

> *Strengths are that they're willing to look at change and are rapidly evolving in the last year with change, and now have a policy which is less elaborated than I'd like to see of where they're going with this e-Health agenda in the next three years.* (Clinician Manager).

> *Look essentially, maybe that's a little bit futuristic because very few places in Australia have linkages between personal health records or for instance monitoring in the home and other things, and what their centralised health record has either as a scan or as electronic or as a paper form. We can do that right now but it's not yet done. And so since we're developing the capacities to have a register and then to use that register to decide who we should have on monitoring or on telephone support or care coordination or whatever, then we should also have in train how we support that in terms of the ITIM platform that creates the connection of that information and flow.* (Clinician Manager).

Future implementation of e-Health strategy has scope for smooth patient transition between services. It will reduce duplication of effort and at the same time offer coordinated support.

> *Each patient should have a unique ID number and we should make it compulsory that all the IT companies use the same coding scheme and that they have systems in place that allows the patient to move from practice to another. That means not just between GPs, but also between GPs and specialists.* (General Practitioner).

> *So the Register and the medical record [electronic]have the potential to be some of the glue that will make things more seamless for patients but we ourselves need communication channels to understand who's doing what and not to duplicate effort.* (Senior Executive).

Within the electronic and web environment, the unique patient ID can connect primary care, specialist care and allied health services and solve many issues.

Certain primary care collaborative projects are trying to address treatment gaps for diabetes and heart diseases. These projects achieved significant positive outcomes. The collaborative projects have opportunities to implement service specific registers for better disease management and set evidences.

> *The primary care collaborative projects certainly do that [systemic care] to a strong degree. There's lots of positive outcomes come from those in relation to diabetes and heart disease. They support practices to develop patient registers and to develop good management plans for those people but that is very short term money and people. Once that money stops and that support for training and people support stops, we are not quite sure what happen in term of sustainability of those activities.* (Non Clinician Manager).

These collaborative projects would benefit from policy and funding supports to bring more positive outcomes in chronic care.

The inclusion of primary care data for a CDM register is important because most of the patients with moderate chronic conditions visit general practitioners. This inclusion can initiate prevention interventions sooner and better care planning. Also this inclusion will help the CDM register to present a more holistic view of CDM data.

> *It's important to continue to work towards the engagement of general practice. That's a critical inclusion, and it may not be achievable optimally initially in the prototype version [CDM register] but I think we should make every effort to expedite that. Because much of the care of people with moderate chronic disease is going to be in an ambulatory setting, often through general practice. And they need to feel that they are part of the treating team and that they have access to the support of the Register as well.* (Senior Executive).

The ACT Health and primary care sector together can bring more positive changes and understandings to deal with CDM challenges.

The quote below explains the operational differences of a CDM register with any surveillance register. A CDM register has potential impact on the quality improvements

in chronic care. Having a positive understanding of a disease register concept, there are opportunities to eliminate policy barriers in the context of privacy.

> *I think having a CDM register would be like the immunisation register with children... As soon as you get a register, the quality improves, it's just magic. It is a no-brainer. And I think the other thing that's happened in this country and happened a bit in New Zealand is that the attitudes and beliefs – and this is all cultural – about privacy has been anti-science, anti any kind of progress towards quality.* (General Practitioner).

The e-Health initiative along with a register approach has roles to streamline governance of CDM interventions.

> *So the Register and the medical record [electronic]have the potential to be some of the glue that will make things more seamless for patients but we ourselves need communication channels to understand who's doing what and not to duplicate effort.* (Senior Executive).

The e-Health and register interventions together can bind service units offering services catering for specific sub-groups of patients in a coordinated way.

4.8 Discussion

The results in this chapter present a primary analysis of key informants' interview findings. The data analysis framework identified the themes, which led to compilation of results relevant to the ACT Chronic Disease Strategy and Wagner's CCM components. This chapter relates results to addressing the first research objective to 'explore the strategic relevance of registers in relation to CDM interventions in a medium size regional health service organisation', and associated research questions.

ACT Health has a supportive policy environment to support chronic care. The chronic disease strategy framework includes specific interventions like behavioural interventions, care coordination and care planning interventions, self-management supports and education, and a CDM register to support CDM initiatives. Though having strong policy supports, the implementation of the interventions are variable.

Establishment of the CDMU is the first step in the implementation of the strategy. The CDMU offers public health and management supports for overall CDM initiatives rather than service delivery. Different service units deliver chronic care components. The result shows that most of the services deliver chronic care independently. The aim of CDMU is to strengthen coordination of service components and bring CDM as a shared role. However, the acceptance of the public health leadership as a separate entity within the clinical leadership environment is a challenge.

Chronic care requires support from a variety of service units and providers. Chronic care governance and management structure requires clear understanding and clarification of roles. As a first step to strengthening care coordination for a multidisciplinary care model, the findings suggest building a communication portal and standardised referral mechanisms. ACT Health's future e-Health initiative will enable setting up of a clinical data linked care model, and thus institutionalise ACT Health's CDM leadership.

The real service integration depends on main health service streams, specialist care, primary care and other community health services working together in a collaborative approach (Bainbridge *et al.* 2010). The care planning process is considered as the main vehicle to link service units in the absence of an efficient communication portal. Some units provide good patient care planning and follow-up services. Primary care practices are mainly responsible for implementing the care planning under national policy with MBS items. However, the implementation of this initiative is variable. In reality the governance arrangement for chronic care between primary care and other service units is not under the same umbrella, which is a significant barrier. The key informants described the current care planning process as a bureaucratic, time consuming and complex process. It is paper based and follow-up is difficult. It fails to create linkages

with relevant service units. Even the discharge planning process within the hospital system is not ideal. The current discharge planning process has limitations for the facilitation of patient transfer from hospital to community and to other providers. Both the care planning and discharge planning need strengthening to support the continuum of care.

These findings prompt a call for a proficient chronic care performance monitoring system within the organisation. The current health system does not have ideal chronic care performance monitoring indicators. This makes it difficult to evaluate the organisation's chronic care interventions and their impacts in relation to the chronic disease strategy. This finding strongly recommends identifying both process and outcome indicators to track progress. ACT Health does not have a unified clinical information system. The data from care plans and their follow-up would have strong inputs for performance monitoring. The CDM register has tactical roles for chronic care performance management and evaluation of patient outcomes in relation to chronic care interventions.

The introduction of a CDM register is part of the ACT Chronic Disease Strategy. The implementation of a CDM register requires the supports of clinical information systems and a simple patient consent policy. ACT Health has service specific databases but does not have a CDM register yet. The reason behind this is the poor involvement of clinicians in policy development and inadequate marketing of the intervention. Unless the clinicians own the program, it is difficult to fully implement the policies.

ACT Health is implementing number of efficient chronic care interventions. Chronic care programs encourage more participation of patients as partners in improving self-management skills and capacity. Partnership of patients with their treating team will create more responsive and empowered group of patients (Heisler *et al.* 2003). This

effort will work in combination to reduce the chronic disease burden and the healthcare cost.

Based on key informants' feedback, ACT Health has reasonably good leadership to deal with CDM challenges. Considering the chronic disease burden, this is the time to anticipate the need for more coordinated care and quality improvements in chronic care. ACT Health will implement the e-Health initiatives in due course. However, the organisation has potential opportunities to implement a CDM register as an early initiative.

ACT Health is implementing chronic care components in a variable fashion and with variable strength. Due to the absence of a common information portal and communication channels for the service units, chronic care coordination is not adequate. Also the current performance reporting system does not have the ability to evaluate chronic care interventions and address chronic care issues. At this stage, a CDM register could help identify patients who need care, facilitate care coordination, implement evidence-based guidelines, implement focused prevention programs, and manage the performance of the CDM interventions. The findings also suggest that proper understanding of the roles of a CDM register can influence and clarify the chronic care management and governance arrangement. This initiative will help make service units accountable for achieving shared CDM goals and translate existing policy commitments into practice.

Chapter Five

Organisational capacity and readiness for a CDM register

Chapter outline

5.1 Introduction

This chapter presents the 'Assessment of Chronic Illness Care' (ACIC) survey findings. The ACIC survey data demonstrate the current status of ACT Health's chronic care initiatives according to Wagner's CCM components. The results of the survey data primarily focus on the capacity and readiness of ACT Health to implement a CDM register.

The statistical illustrations in this chapter provide useful information which supports the findings of the key informants' interviews (see Chapter 4) and the experiences of patients and their carers (see Chapter 6) to understand the overall support and the capacity of ACT Health to implement a CDM register.

5.2 Primary analysis

5.2.1 ACIC survey instrument

The MacColl Institute for Healthcare Innovation, Seattle, USA developed the ACIC survey instrument (Kaissi and Parchman 2006). This research used the ACIC instrument version 3.5. A considerable number of the regional health systems of USA, and Australia use this ACIC instrument to track quality improvements of chronic disease interventions (Bonomi *et al.* 2002; Si *et al.* 2005).

The original ACIC survey instrument has 34 variables. The variables are grouped under seven sub-scales, and these seven sub-scales are divided into three gross parts in the survey questionnaire as displayed in Table 5.1. The ACIC sub-scales are representative of CCM components. The first six ACIC sub-scales represent six CCM components. The seventh ACIC sub-scale presents data about the status of integration of CCM components in a particular health system. Table 5.1 shows the ACIC sub-scales and the number of variables under each sub-scale.

Table 5.1: Number of variables and sub-scales of the ACIC survey instrument

ACIC sub-scales	Number of variables
Part 1: Organisation of Health Care Delivery System	6
Part 2: Community Linkages	3
Part 3: Practice level	
Part 3a: Self-Management	4
Part 3b: Decision Support	4
Part 3c: Delivery System Design	6
Part 3d: Clinical Information System	5
Integration of Chronic Care Model Components	6

The variables for each of the first six sub-scales collect scores that best explain the respective ACIC sub-scale and these variables are mutually exclusive in nature. This chapter uses 28 mutually exclusive variables of the first six sub-scales for multivariate

analysis. The seventh sub-scale has six variables and each variable represents the six respective ACIC sub-scales. These variables of the seventh ACIC sub-scale are excluded from multivariate analysis for their overlapping effect.

In the original ACIC instrument, one variable 'informing patients' about guidelines' (see Table 5.7) was used simultaneously in two separate sub-scales, which are 'decision support' and 'integration of chronic care model components' sub-scales. In the survey package for participants, this particular variable is physically omitted from the instrument under 'integration of chronic care model component' sub-scale to avoid confusion as a duplicate variable. So, the ACIC instrument for this research contained 33 variables.

Note that the data analysis uses this duplicate variable (from decision support sub-scale) only in the descriptive data analysis to present the score of the seventh ACIC sub-scale 'integration of CCM components'. This sub-scale score is used to calculate the overall program score. So, the data analysis covers all the ACIC variables.

To assist respondents in the appropriate scoring of variables, as a research team, we modified part of a variable under the 'integration of CCM components' sub-scale. This is the first variable of this sub-scale. In the original ACIC instrument this variable was described as 'information systems/registry'. We slightly modified the description of this variable to 'information systems/databases'. ACT Health does not have any real disease register, so this modification helped in collecting the current status of any existing databases as a proxy to the concept of a disease register. I communicated with the MacColl Institute for this modification and obtained clearance.

5.2.2 The survey respondents

Chapter 3 presented the list of organisations, departments and units who participated in the survey (see Table 3.4). The data analysis in this chapter uses 42 fully or partially completed surveys. Table 5.2 shows these 42 respondents by their job types.

Table 5.2: Job type of survey respondents

Job types	n=42	%
Senior Executives	5	11.9
Clinician Managers	13	31.0
Non Clinician Managers	6	14.3
Clinicians	15	35.7
Non Clinicians	3	7.1

Table 5.3 shows the methods that the respondents used to complete the survey. Most of the respondents completed the survey individually.

Table 5.3: Methods used for survey response

Methods	n=42
Individually	31
Through face to face meeting	3
Through consultation with others in team	8

5.2.3 Measures

The ACIC sub-scales for measurement represent the CCM components (Wagner *et al.* 1999), which are organisation of health care, community linkages, self-management support, decision support, delivery system design, and clinical information system (see Figure 2.1, Chapter 2)

ACIC is a score based survey on a 0-11 scale for all variables. This scale further describes four levels of chronic care as below:

- 0-2: Limited support for chronic care
- 3-5: Basic support for chronic care
- 6-8: Reasonably good support for chronic care
- 9-11: Fully developed chronic illness care.

In this chapter, I used the following scale to define each level of chronic care.

- Less than 2.5: Limited support for chronic care
- Greater than or equal to 2.5 and less than 5.5: Basic support for chronic care
- Greater than or equal to 5.5 and less than 8.5: Reasonably good support for chronic care
- Greater than or equal to 8.5: Fully developed chronic illness care (score between 8.5 and 11).

According to the survey instruction, the participants marked only one score within the scale for each variable based on the given description. The average score of the variables of each sub-scale makes the respective sub-scale score, and the average of all seven sub-scales' scores makes the overall ACIC program score (Bonomi *et al.* 2002).

Table 5.4 presents the description of each sub-scale according to the ACIC survey instrument (MacColl Institute for Health Care Innovation 2000).

Table 5.4: ACIC sub-scales and their descriptions

Sub-scale	Description
Organisation of the healthcare delivery system	The orientation of the health organisation with specific focus and support for effective CDM programs.
Community linkage	This sub-scale describes the linkages and partnerships between community organisations and other community resources with the health system for CDM.
Self-management	The self-management supports actively involve the patients with chronic diseases, their carers and families to manage and monitor symptoms. Self-management supports aim to reduce complications and symptoms and thus improve quality of life.
Decision support	Decision support refers to the access to patients' clinical data to deliver evidence-based chronic care. The decision support component includes implementation of evidence-based practice guidelines, involve specialist for care, providers' education on population management and self-management, and empowers patients to make provider teams aware of adherence to guideline.
Delivery system design	This shows that the provider teams have defined tasks for patient self-management education, scheduled follow-up according to patients' need, planned appointment for patients' visits to multiple providers at a single visit, service coordination and preventive interventions.
Clinical information system	The clinical information system includes the presence of a disease register, databases of patient sub-groups, a reminder system, a provider feedback system and patient treatment plans.
Integration of CCM components	This sub-scale refers to the functional integration status of the CCM components. This sub-scale uses variables that represent the first six ACIC sub-scales.

5.2.4 Analytical framework

The analytical framework helps to investigate ACT Health's readiness to implement a CDM register. Also this framework helps in exploring the strengths and weaknesses of existing chronic care interventions in relation to CCM components. Table 5.5 shows the data analysis framework.

Table 5.5: Data analysis framework

Type of statistical analysis	Purpose
Cronbach's Alpha	This is the first steps to examining internal consistency of the variables under each ACIC sub-scale and demonstrates how the variables are closely related to represent a particular ACIC sub-scale.
General descriptive statistics	General descriptive statistics include calculation of mean, median, mode of each variable, ACIC sub-scales, and overall chronic care program score. The overall chronic care program score is the mean of all the seven ACIC sub-scales scores. The purpose of general descriptive statistics is to compare results with other organisations that used the ACIC survey.
Factor analysis	The purpose of the factor analysis is to reduce the number of variables, and explain the observed correlations among variables to detect the structure of correlated variables. The factor analysis uses the principal component analysis (PCA) as the data extraction method.
Regression analysis	In this data analysis, the regression technique is only used to confirm that the factor analysis accounted for the variations.
Discriminant analysis	The purpose of the discriminant analysis is to identify the relative importance of the variables that may differ by the job types of survey respondents (Table 5.2).

Most of the studies with the ACIC survey used simple descriptive statistical analysis of survey scores. Some studies used correlation and regression analysis to evaluate effectiveness and quality of specific chronic care interventions (Bonomi *et al.* 2002; Solberg *et al.* 2006 ; Si *et al.* 2008).

In this chapter, the data analysis framework attempts to present an organisational score for chronic illness care as well as explore what is important in the ACT Health jurisdiction.

The data analysis framework in this chapter follows the data analysis concept of a study conducted by Amoroso and others. The authors conducted the study in 97 general practices of 27 Divisions of General Practice of five states and one territory of

Australia. The study evaluated a concise instrument to assess clinical linkages between general practices and other providers for coordinated chronic care. The study used factor analysis as a method to test validity of the instrument (Amoroso *et al.* 2007).

The ACIC survey data analysis framework was developed in consultation with the ANU Statistical Consulting Unit. The data analysis uses PASW 18 (Predictive Analytics Software) statistics.

5.3 Results

5.3.1 Internal consistency of the variables

Cronbach's alpha measurement validates the internal consistency of variables and examines the relationship of variables within each ACIC sub-scale. Table 5.6 below shows the Cronbach's alpha reliability coefficient values of variables by ACIC sub-scales. The reliability coefficient at 0.70 or higher suggests that the variables have relatively high internal consistency. The table shows that all of the Cronbach's alpha reliability coefficient values have high inter-variable correlations and are above 0.80. The result also shows that the variables have a positive covariance and the variables are measuring the same thing (Norusis 2008).

5.3.2 Descriptive statistics

Table 5.7 shows the mean score of each variable under ACIC sub-scale. Each ACIC sub-scale score is the group mean of the respective variables of that sub-scale. The overall program score is the mean of all sub-scales scores.

Table 5.6: Cronbach's Alpha coefficients for ACIC variables

ACIC Sub-scales	Cronbach's Alpha	Cronbach's Alpha if item deleted
Organisation of healthcare delivery system		
Organisational leadership	.928	.915
Organisational goals		.913
Improvement strategy		.901
Incentives and regulations		.908
Senior leaders		.917
Benefits		.932
Community linkages		
Linking to outside resources	.881	.835
Partnership with community organisations		.848
Regional health plans		.811
Self-management		
Assessment and documentation of self-management needs	.927	.919
Self-management support		.895
Address concerns		.922
Effective behaviour change interventions		.884
Decision support		
Evidence-based guidelines	.873	.818
Involvement of specialists		.880
Provider education		.826
Informing patients about guidelines		.829
Delivery system design		
Practice team functioning	.920	.900
Practice team leadership		.901
Appointment system		.892
Follow-up		.908
Planned visits		.917
Continuity of care		.914
Clinical information system		
Registry	.831	.784
Reminder to provider		.783
Feedback		.790
Information about relevant sub-groups of patients needing services		.786
Patient treatment plans		.837
Integration of CCM components		
Informing patients about guidelines	.815	.760
Information systems/database		.798
Community programs		.808
Organisational planning		.806
Routine follow-up for appointments, assessments and goal planning		.772
Guidelines for chronic care		.766

Table 5.7: Distribution of ACIC scores

ACIC sub-scales	Mean	Mode	Std. Deviation
Organisation of healthcare delivery system	**5.8**	**6.2**	**1.9**
Organisational leadership	6.1	6	2.4
Organisational goals	5.5	6	2.1
Improvement strategy	5.5	4	2.2
Incentives and regulations	4.2	2	2.7
Senior leaders	6.7	7	2.1
Benefits	6.4	7	2.1
Community linkages	**5.6**	**5.0**	**2.2**
Linking to outside resources	5.5	5	2.6
Partnership with community organisations	6.0	6	2.3
Regional health plans	5.0	5	2.4
Self-management	**5.6**	**4.0**	**2.4**
Assessment and documentation of self-management needs	5.2	5	2.7
Self-management support	5.6	4	2.8
Address concerns	5.6	5	2.6
Effective behaviour change interventions	6.1	7	2.5
Decision support	**5.3**	**3.5**	**2.3**
Evidence-based guidelines	6.2	4	2.4
Involvement of specialists	4.9	2	3.0
Provider education	4.9	4	2.5
Informing patients about guidelines	5.3	4	2.5
Delivery system design	**5.7**	**3.0**	**2.5**
Practice team functioning	5.7	4	2.7
Practice team leadership	5.8	4	2.9
Appointment system	5.2	2	3.5
Follow-up	5.0	3	3.2
Planned visits	5.8	3	3.0
Continuity of care	6.5	7	2.3
Clinical information system	**4.1**	**2.4**	**2.3**
Registry	3.6	1	3.2
Reminder to provider	2.8	2	2.2
Feedback	4.2	2	3.0
Information about relevant sub-groups of patients needing services	4.5	4	2.9
Patient treatment plans	5.4	4	2.9
Integration of CCM components	**4.4**	**4.2**	**2.2**
Informing patients about guidelines	5.3	4	2.5
Information systems/database	3.2	1	2.8
Community programs	2.9	1	2.0
Organisational planning	3.5	5	2.5
Routine follow-up for appointments, assessments and goal planning	5.2	4	2.4
Guidelines for chronic care	5.4	3	2.4
Overall program score	**5.3**	**1.0**	**1.9**

Table 5.7 and Figure 5.1 show that the ACIC sub-scale scores are within the range of 4.1 to 5.8. The sub-scale scores are: organisation of healthcare delivery system (5.8); community linkage (5.6); self-management (5.6); and delivery system design (5.7). These sub-scale scores demonstrate reasonably good support for chronic care. Among all the sub-scale scores, clinical information system (4.1), integration of CCM components (4.4), and decision support (5.3) sub-scales demonstrate basic level of functioning.

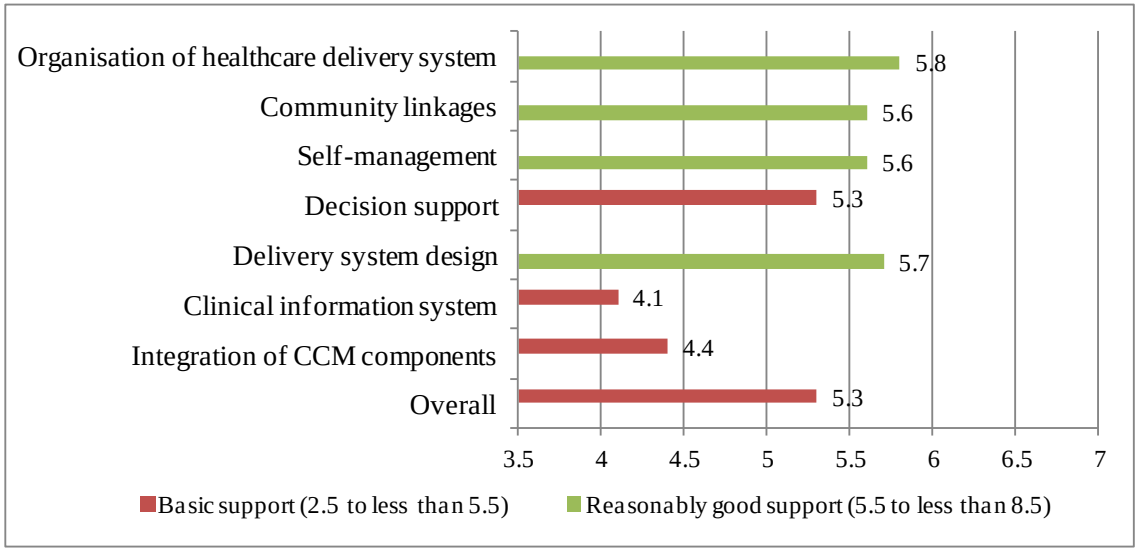
On a scale of 0 (limited support) to 11 (full support for chronic care), the scores are within the basic to reasonably good support for chronic care. The overall program score is 5.3 indicating a basic support for chronic care. The result shows that the clinical information system is least developed. A real disease register and a functional system to remind providers are not in place.

The ACT diabetes and cancer services have well developed service specific databases or information systems, but the real disease register is not available. As a result of the influence of clinical information systems, the overall integration of CCM components showed a basic support for chronic care within ACT Health.

According to the measurement scale and levels, the above-mentioned results provide a gross interpretation of the sub-scale specific scores and overall score. The mode and standard deviation in Table 5.7 provides better explanations about the scores.

The mode in this table extracts common scores recorded by a high number of the respondents and the standard deviation calculates the difference between each variable score with the mean score (Argyrous 1998).

Figure 5.1: Distribution of ACIC scores by level



The interpretation of mean score and mode utilise the descriptions of ACIC variables according to their levels.

Under the 'organisation of healthcare delivery system' sub-scale, the modes for variables like organisational leadership, goal, senior leaders and benefits have clear relationship with the mean scores. The means of these variables are at the lower limit within the scale of 'reasonably good support' band of chronic care. The mean score for the 'improvement strategy' variable lies within the reasonably good support range. However, the mode lies within the 'basic support' level. The mode is lower than the mean because a few respondents gave high scores on the variables comprising this theme (pulling up the mean), but most of the respondents gave scores between 2.5 and 5.5 (and the mode reflects this). Given this, the mode is a more reliable indicator of what most respondents think. According to the description used in the ACIC survey instrument (see Attachment 3), 'basic support' means that the organisation develops strategies on an ad-hoc basis to address chronic care issues as they emerge. The 'incentives and regulations for chronic care' variable score is at basic support level, but most of the respondents scored it at limited support level. This finding suggests that the

incentives and regulations for chronic care are not favourable for providers in achieving patient care goals.

The ‘community linkages’ sub-scale variables have mean scores consistent with their mode. The respondents mostly scored the variables at the upper limit of the ‘basic support’ level except for the ‘partnership with community organisations’ variable. This variable obtained a score at the lower limit of ‘reasonably good support’ level. This explains that ACT Health has supportive programs and policies to create linkage with community resources for CDM. These above two sub-scales describe the organisation’s specific attention to CDM initiatives. The next four ACIC sub-scales’ data present the status of chronic care services.

The self-management sub-scale score shows that ACT Health is implementing reasonably good behaviour change interventions and peer support programs for the patients and their families.

The mean scores of ‘self-management support’ and ‘addressing concern for patients and families’ variables demonstrate that the organisation provides these supports through trained clinical educators.

The mean score of ‘assessment and documentation of self-management needs and activities’ is at 5.2. This finding denotes that the provider organisations do not adequately document patient assessment findings and link that with patient treatment plans. This finding calls for standardised documentation of patient assessment findings to engender next actions.

The mean score for decision support is at ‘basic support’ level. All the variables of this sub-scale, except for the ‘evidence-based guidelines’ have scores at basic support level.

The mean score of ‘involvement of specialist’ variable is 4.9 but the mode is 2. The mode explains that the involvement of physicians or specialists with chronic care is only through the traditional referral process. The physicians or specialists have inadequate participation to enhance the health system capacity to implement evidence-based guidelines.

The ‘delivery system design’ sub-scale has six variables. The variables ‘appointment system’ and ‘follow-up’ have mean scores of 5.2 and 5.0 respectively (basic support level). While looking at the mode of these variables, the distribution of the highest number responses is within the range limited to basic support level for chronic care.

The mean scores of all the five variables of the clinical information system sub-scale lie within the basic support level. However, the mode for first three variables (registry, reminder to provider and feedback) lie within the limited support level.

Table 5.8 shows the means scores of ACIC sub-scales of 42 surveys. In this Table there are some missing values, which denote that the respective respondents had not put any score for any of the variables within that sub-scale.

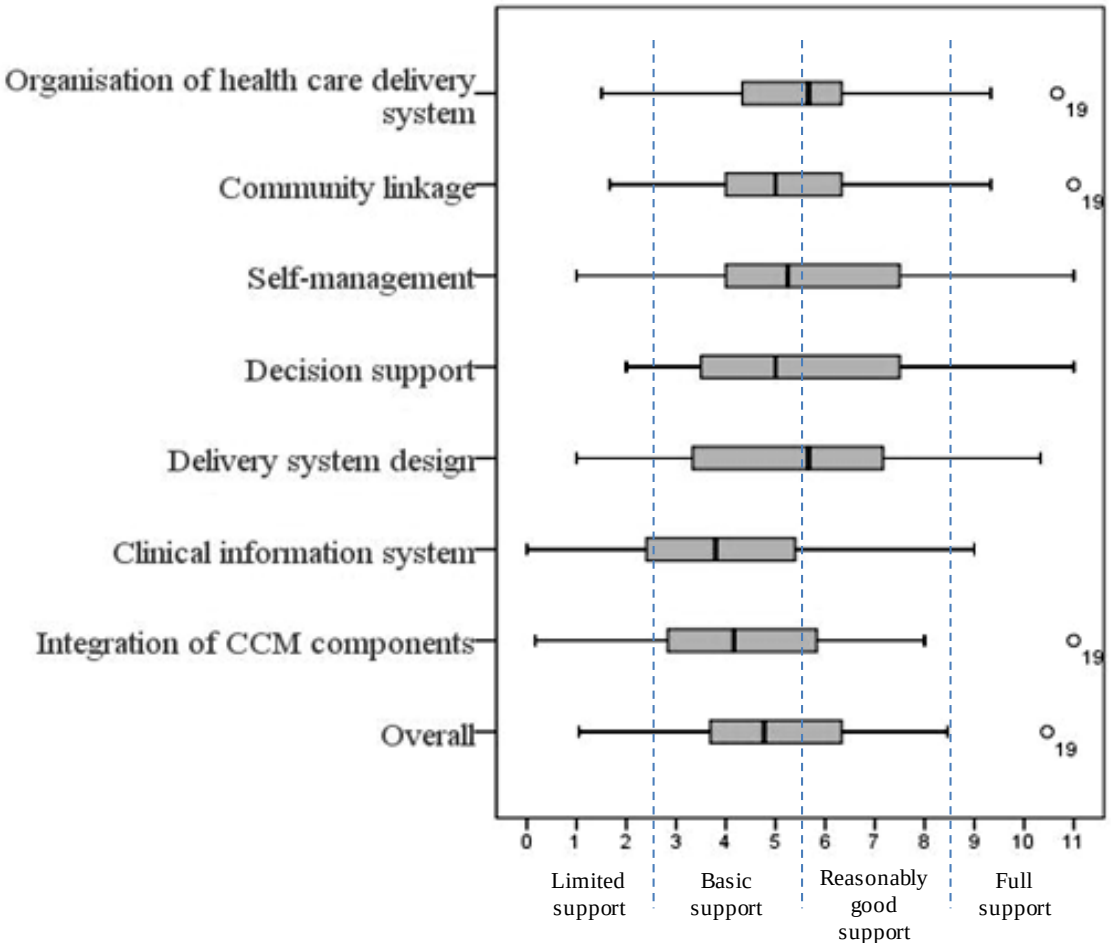
The box and whisker plot in Figure 5.2 shows the range of the distribution of the plot, which is the difference between the minimum and maximum values. Figure 5.2 presents the 25-75 percentile range of scores of each ACIC sub-scale of 42 survey responses. The vertical line within the box is the median and the whiskers shows the extent of scores (Kirkwood and Sterne 2003).

The figure also shows the placement of boxes and median within the four levels of scales.

Table 5.8: Distribution of ACIC sub-scale scores by respondents

ID	Organisation of healthcare delivery system	Community linkages	Self-management	Decision support	Delivery system design	Clinical information system	Integration of CCM components	Overall
1	4.3	5.7	4.0	3.5	4.2	2.4	4.2	4.0
2	4.2	4.0	3.5	2.5	2.8	1.8	2.8	3.1
3	4.0	4.7	6.5	3.8	4.5	4.2	4.3	4.6
4	4.2	5.0	4.3	5.3	3.3	2.4	3.3	4.0
5	3.0	5.5	9.5	8.3	10.0	9.0	5.8	7.3
6	6.3	9.0		8.0			9.0	8.1
7	8.0	5.5			7.0			6.8
8	2.5	2.0	1.0	3.5	1.2	2.8	2.5	2.2
9	9.3	8.7	8.3	8.5	9.5	7.8	7.2	8.5
10	4.8	3.0	5.8	4.8	4.2	2.4	4.2	4.2
11	5.0	5.0	4.8	5.0	4.3	3.6	3.7	4.5
12	6.0	3.7	4.0	5.3	4.2	2.4	2.5	4.0
13	6.3	3.3	2.5	3.3	3.0	2.6	2.3	3.3
14	4.8	8.7	8.5	7.8	10.3	8.2	6.3	7.8
15	4.3	4.7	3.5	2.0	2.7	1.8	1.8	3.0
16	6.3	2.3	8.5	4.5	5.2	1.3	5.3	4.8
17	7.5	6.0	7.3	4.3	6.5	5.0	4.5	5.9
18	6.2	5.0	5.0	5.5	6.3	.	5.0	5.5
19	10.7	11.0	11.0	11.0	9.8	8.8	11.0	10.5
20	8.5	7.3	7.0	5.0	8.2	5.0	5.5	6.6
21	1.5	1.7	1.0	2.0	1.0	0.0	0.2	1.0
22	4.0	5.3	4.3	2.8	3.8	3.6	1.7	3.6
23	6.2	5.3	4.3	3.0	5.7	4.4	3.8	4.7
24	8.3	4.0	6.8	7.8	5.2	5.4	6.7	6.3
25	6.0	10.3			6.2		0.0	5.6
26	3.8	3.3	2.8	3.5	3.3	1.4	3.8	3.1
27	5.8	6.7	7.8	5.0	6.7	5.4	6.2	6.2
28	5.7	7.0	5.3	7.0	6.5	4.8	4.8	5.9
29	5.5	4.3	7.5	7.0	9.2	5.6	5.8	6.4
30	5.5	5.0	2.5	4.3	7.8	4.0	1.7	4.4
31	8.7	8.3	8.0	8.0	8.8	8.0	8.0	8.3
32	2.8	3.7	5.0	3.5	3.0	3.0	4.8	3.7
33	6.8	6.3	4.0	5.3	7.2	3.8	4.7	5.4
34	6.2	9.3	9.0	8.3	8.5	8.0	6.0	7.9
35	6.3	5.3	6.3	5.8	6.7	5.8	6.0	6.0
36	7.3	6.3	7.5	7.5	6.5	5.0	4.2	6.3
37	5.0	5.0	4.0	3.3	2.5	2.8	2.0	3.5
38	5.8	6.0	7.3	8.0	7.2	1.0	3.8	5.6
39	6.2	5.0	5.3	5.3	6.3	4.8	4.2	5.3
40	4.7	5.3	.	2.0	3.0	2.0	4.5	3.6
41	8.8	7.3	7.0	7.8	6.7	2.0	5.0	6.4
42	4.3	2.7	2.5	2.3	3.3	3.0	2.5	2.9

Figure 5.2: ACIC survey of ACT Health showing sub-scale medians, 25–75 percentiles and range



5.3.3 Factor analysis

Using PASW 18, the factor analysis helps to reduce the number of variables through the grouping of characteristically related variables. The factor analysis uses only the first 28 variables of the first six ACIC sub-scales.

The factor analysis uses the principal component analysis (PCA) as the data extraction method and creates a set of factors that explain the observed variances in the initial list of variables.

As the first step, the factor analysis generates the correlation matrix to examine the suitability of the data for factor analysis. Table 5.9 shows the result of the Kaiser-Meyer-Olkin (KMO) Measure and the Bartlett's Test of Sphericity.

The KMO Measure examines the sampling adequacy and Bartlett's Test of Sphericity examines the validity of the factor analysis. The KMO index is more than 0.5 and the Bartlett's Test of Sphericity is highly significant, which indicate that the factor analysis is suitable for these data (Williams *et al.* 2010).

Table 5.9: KMO and Bartlett's Test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		.576
Bartlett's Test of Sphericity	Approx. Chi-Square	914.918
	Df	378
	Sig.	<.0001

Table 5.10 shows the factors using PCA, their eigenvalues, the variance (%), and the cumulative variance of the factors. On PCA, the eigenvalues shows the percentage of variance explained for the linear components, the factors. The eigenvalues decide the number of factors in the data extraction process (Weisstein).

This table shows that the first four eigenvalues explain 73.8% of the variances. The Rotation Sums of Squared Loadings column presents the eigenvalues of the factors after rotation. The rotation process optimises the factor structure.

In Figure 5.3, the scree plot shows a gradual tail from eigenvalue of factor 5. The analysis suggests that the first 4 eigenvalues have significant importance in this analysis (Field 2005).

Table 5.10: The Factors and associated eigenvalues

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	15.400	55.000	55.000	15.400	55.000	55.000	5.476	19.558	19.558
2	2.322	8.294	63.294	2.322	8.294	63.294	5.424	19.371	38.929
3	1.667	5.954	69.248	1.667	5.954	69.248	4.909	17.532	56.461
4	1.278	4.563	73.811	1.278	4.563	73.811	4.858	17.351	73.811
5	.958	3.422	77.233						
6	.890	3.179	80.412						
7	.869	3.102	83.514						
8	.639	2.281	85.795						
9	.594	2.121	87.916						
10	.538	1.920	89.836						
11	.428	1.528	91.364						
12	.390	1.393	92.757						
13	.336	1.200	93.957						
14	.321	1.146	95.103						
15	.267	.955	96.058						
16	.229	.816	96.874						
17	.172	.613	97.487						
18	.156	.556	98.044						
19	.131	.469	98.513						
20	.115	.411	98.924						
21	.103	.369	99.292						
22	.083	.295	99.588						
23	.038	.135	99.722						
24	.033	.118	99.841						
25	.023	.080	99.921						
26	.014	.050	99.972						
27	.007	.026	99.998						
28	.001	.002	100.000						

Extraction Method: Principal Component Analysis

Figure 5.3: Scree plot

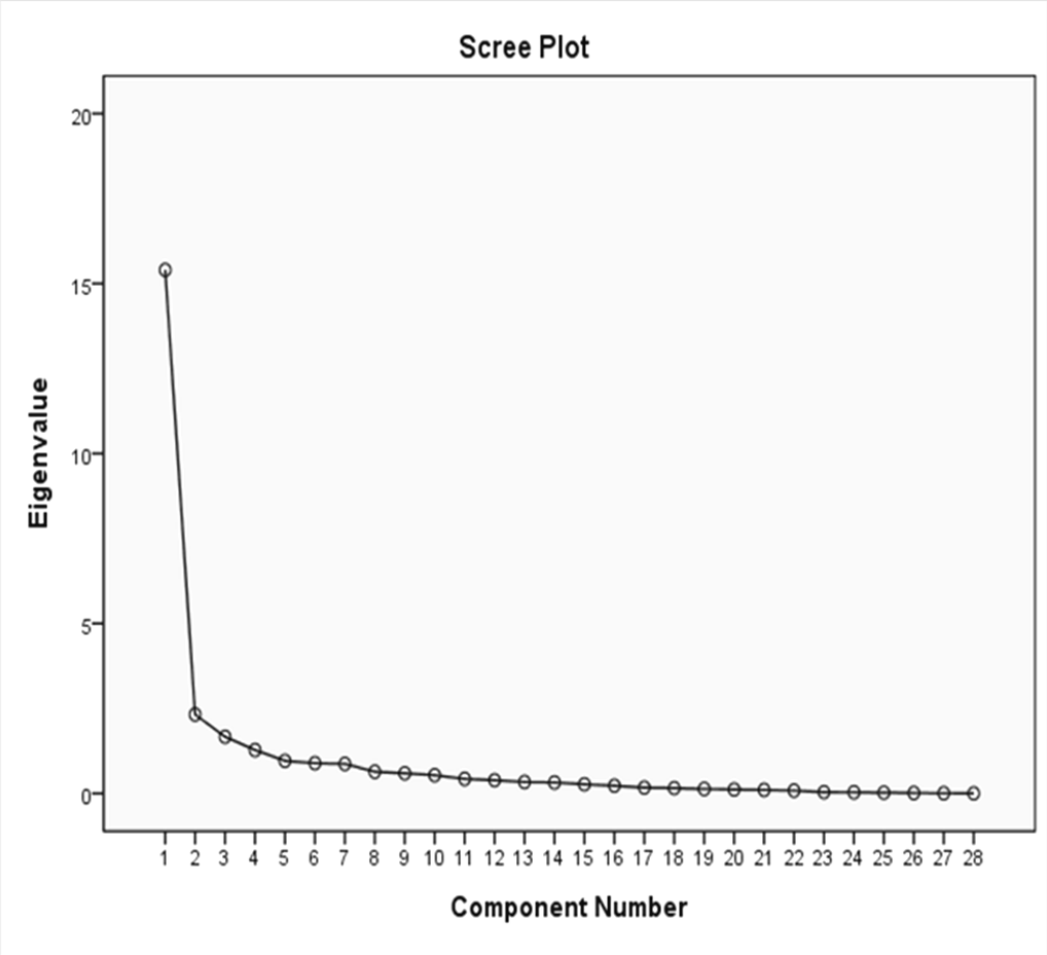


Table 5.11 shows the rotated component matrix. This matrix displays the factor loadings for each of 28 ACIC variables on each factor (linear component). The variables show their order according to the size of the factor loadings. Table 5.11 shows that each of the four factors relates to a number of correlated variables as below:

Factor 1 strongly relates to 5 variables

- Assessment and documentation of self-management needs and activities
- Patient treatment plans
- Self-management support
- Informing patients about guidelines
- Effective behavior change interventions

Factor 2 relates to 5 variables

- Continuity of care
- Practice team leadership
- Address concerns of patients and families
- Involvement of specialists in improving primary care
- Provider education for chronic illness care

Factor 3 relates to 5 variables

- Organisational leadership in chronic care
- Improvement strategy for chronic illness care
- Incentives and regulations for chronic care
- Organisational goals for chronic care
- Senior leaders involvement

Factor 4 relates to 5 variables

- Information about relevant sub-groups of patients needing services
- Registry
- Reminder to provider
- Feedback
- Follow-up.

Table 5.11: Rotated component matrix

Variables	Factors (Linear components)			
	1	2	3	4
Assessment and documentation of self-management needs	.854	.168	.032	.302
Patient treatment plans	.811	.191	.279	.193
Self-management support	.785	.250	.220	.361
Informing patients about guidelines	.749	.394	.210	.131
Effective behaviour change interventions	.624	.480	.369	.217
Benefits	.596	.319	.343	.213
Continuity of care	.305	.783	.120	.255
Practice team leadership	.250	.713	.317	.344
Address concerns	.372	.701	.308	.283
Involvement of specialists	.074	.649	.431	.050
Provider education	.482	.629	.191	.254
Evidence-based guidelines	.506	.598	.282	.204
Practice team functioning	.371	.586	.406	.387
Linking to outside resources	.457	.514	.139	.294
Organisational leadership	.077	.245	.873	.028
Improvement strategy	.250	.238	.834	.235
Incentives and regulations	.266	.232	.795	.195
Organisational goals	.259	.025	.782	.315
Senior leaders	.168	.445	.661	.063
Regional health plans	.204	.411	.505	.420
Information about relevant sub-groups of patients needing services	.158	-.039	.188	.832
Registry	.220	.229	-.081	.816
Reminder to provider	.099	.248	.305	.656
Feedback	.256	.346	.206	.634
Follow-up	.298	.384	.192	.619
Appointment system	.440	.459	.193	.587
Planned visits	.444	.185	.344	.549
Partnership with community organisations	.358	.497	.164	.537

Extraction Method: Principal Component Analysis
Rotation Method: Varimax with Kaiser Normalization. Rotation converged in 6 iterations

In ACT Health context, the loadings of the variables for each factor now exhibit new themes compared to the original ACIC instrument. These newly emerged four factors (see Table 5.12) are named based on the descriptions of correlated variables as below:

- Factor 1: Patient empowerment
- Factor 2: Chronic care delivery

- Factor 3: Organisational support
- Factor 4: Information system

With these four factors, the ‘organisational support’ factor corresponds very closely to the ACIC ‘organisation of health care delivery system’ sub-scale, the ‘information system’ factor corresponds almost as well to the ACIC ‘clinical information system’ sub-scale, and the ‘chronic care delivery’ factor corresponds less closely to the ACIC ‘delivery system design’ sub-scale.

However, in the ACT Health survey this newly named ‘patient empowerment’ factor shows the strongest linear relationship. This factor, based on the first linear component (which explained 55% of the total variance), does not correspond well to any of the specific ACIC sub-scales. Examination of the descriptions of the correlated variables shows Factor 1 relates to the interventions to assist patients to self-manage their conditions including education and behaviour change programs. Implementation of these interventions can enable a patient to be a partner with the treating teams within a specified health system (Funnell 2000). According to the pattern of variables this factor is named ‘patient empowerment’ factor.

The factor analysis using PASW computes the residuals between observed and reproduced correlations. There are 123 (32%) non-redundant residuals with absolute values greater than 0.05, which suggests that the model fit is good. The factor analysis also computes standardised variables. The standardised variables along with the coefficient values from Table 5.13 are used to compute factor scores for each of the ACIC surveys for the selected variables. The factor scores are computed by multiplying the component score coefficient with standardised value of selected variables from Table 5.12.

Table 5.12: Factors and components

Factors	Components
Factor 1: Patient empowerment	• Assessment and documentation of self-management needs • Patient treatment plans • Self-management support • Informing patients about guidelines • Effective behaviour change interventions
Factor 2: Chronic care delivery	• Continuity of care • Practice team leadership • Address concerns • Involvement of specialists • Provider education
Factor 3: Organisational support	• Organisational leadership • Improvement strategy • Incentives and regulations • Organisational goals • Senior leaders
Factor 4: Information system	• Information about relevant sub-groups of patients needing services • Registry • Reminder to provider • Feedback • Follow-up

Table 5.13: Factor score coefficient matrix

Variables	Component			
	1	2	3	4
Organisational leadership	-.075	-.034	.290	-.075
Organisational goals	.026	-.220	.267	.056
Improvement strategy	-.018	-.099	.255	-.009
Incentives and regulations	.000	-.094	.242	-.026
Senior leaders	-.070	.086	.167	-.090
Benefits	.166	-.049	.033	-.061
Linking to outside resources	.050	.115	-.075	-.017
Partnership with community organisations	-.036	.093	-.068	.108
Regional health plans	-.093	.040	.093	.075
Assessment and documentation of self-management needs	.334	-.152	-.081	-.028
Self-management support	.260	-.130	-.021	-.011
Address concerns	-.044	.211	-.035	-.041
Effective behaviour change interventions	.140	.028	.014	-.085
Evidence-based guidelines	.061	.137	-.032	-.083
Involvement of specialists	-.149	.262	.050	-.095
Provider education	.039	.169	-.073	-.056
Informing patients about guidelines	.245	-.011	-.036	-.125
Practice team functioning	-.040	.118	.017	.015
Practice team leadership	-.118	.237	-.030	.004
Appointment system	.004	.042	-.058	.120
Follow-up	-.054	.030	-.039	.167
Planned visits	.068	-.131	.048	.131
Continuity of care	-.081	.307	-.117	-.043
Registry	-.072	-.017	-.124	.301
Reminder to provider	-.133	-.022	.037	.228
Feedback	-.069	.014	-.026	.185
Information about relevant sub-groups of patients needing services	-.058	-.198	.028	.340
Patient treatment plans	.310	-.157	.019	-.084

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalisation.

5.3.4 Regression analysis

The regression analysis uses the calculated factor scores to confirm that the factor analysis accounted for the variations. This analysis considers the overall ACIC program score as the dependent variable. The regression analysis also investigates the effect of

predictor or independent variables (factor scores) on the dependent variable or how well one or more independent variables predict the value of a dependent variable.

Considering the size of the ACIC survey sample and nature of the survey, linear regression analysis option was chosen for this analysis. Table 5.14 shows the quantity of variance explained by the predictor variables. In this analysis the calculated scores of four factors are the predictor variables. The multiple correlation coefficient R has the value of 0.995 and indicates that there is a great deal of variance shared by the predictor variables on the dependent variable. The R Square value (.990) indicates the goodness of fit. This explains that 99% of the variance of the dependent variable is explained by the predictor variables in the model.

Table 5.14: Model summary

R	R Square	Adjusted R Square	Std. Error of the Estimate
.995[a]	.990	.988	.1946

Dependent Variable: Overall program score

a. Predictors: (Constant), Information system, organisational support, patient empowerment, chronic care delivery

Table 5.15 shows the output of the analysis of variance (ANOVA). The large value and small significance level of F statistics suggest that the four predictor variables are not all equal and can predict the dependent variable.

Table 5.15: Analysis of Variance

Model	Sum of Squares	Df	Mean Square	F	Sig.
Regression	103.456	4	25.864	683.220	.000[a]
Residual	1.060	28	.038		
Total	104.516	32			

Dependent Variable: Overall program score

a. Predictors: (Constant), Information system, organisational support, patient empowerment, chronic care delivery system

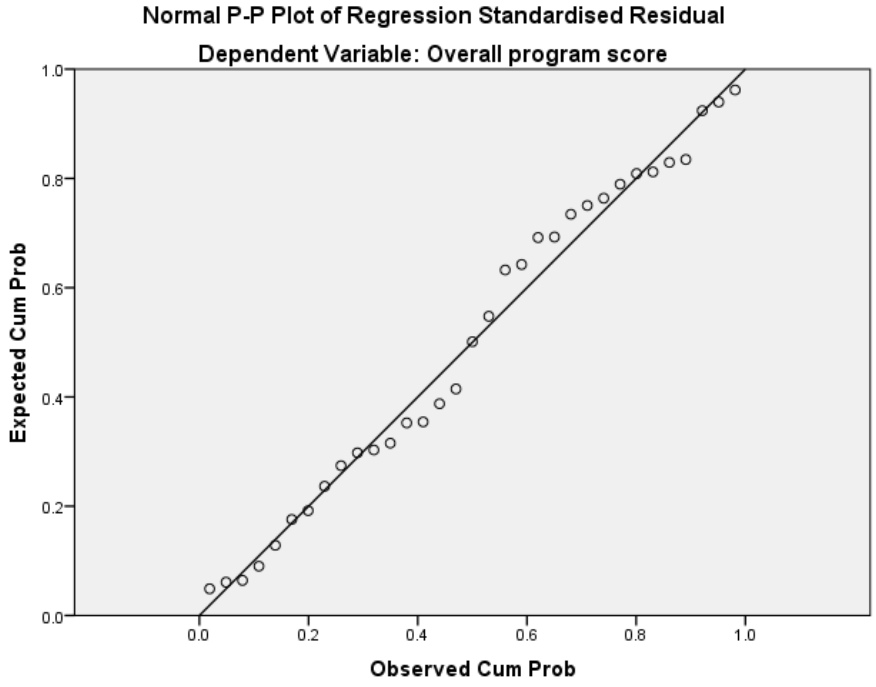
The standard regression analysis (Table 5.16) shows the effects of individual predictor variables. The unstandardised and standardised coefficients are similar in pattern. Except for the organisational support variable, the other three independent variables are good predictors for overall improvement in chronic care. Patient empowerment is obviously the best predictor variable for overall ACIC program score. The table also provides the significance tests for each of the independent variables in this model.

Table 5.16: Standard regression analysis

Model	Unstandardised Coefficients		Standardised Coefficients	t	Sig.	95.0% Confidence Interval for B	
	B	Std. Error	Beta			Lower Bound	Upper Bound
(Constant)	5.202	.034		150.954	.000	5.132	5.273
Patient empowerment	.613	.046	.367	13.253	.000	.518	.708
Chronic care delivery	.624	.057	.330	10.932	.000	.507	.741
Organisational support	.352	.042	.204	8.272	.000	.264	.439
Information system	.551	.048	.289	11.608	.000	.454	.649

Dependent Variable: Overall program score

Figure 5.4: P-P plot of regression residual



5.3.5 Discriminant analysis

The discriminant analysis is a multivariate technique. The discriminant analysis identifies the relative importance of variables that may differ across the job types of the survey respondents according to Table 5.2.

The other purpose of this analysis is to examine whether significant differences exist among the respondents' job types in relation to predictor variables. The analysis uses the multiple discriminant analysis technique because the criterion variable has more than two categories.

The question of interest is whether or not the 'job type' categories can be differentiated in terms of ACIC variables. In this analysis, the five job type categories are the grouping variables and ACIC variables of the first six sub-scales are the independent variables.

Considering the five categories, the analysis extracts a total of four functions. Table 5.17 shows that the eigenvalue associated with the first function (57.768) accounts for 75.9% of the explained variance. Because the eigenvalue is fairly large, this first function has superiority. The second function has a relatively smaller eigenvalue (13.876) and accounts for only 18.2% of the explained variance.

Table 5.17: Canonical discriminant functions by eigenvalues

Function	Eigenvalue	% of Variance	Cumulative %	Canonical Correlation
1	57.768[a]	75.9	75.9	.991
2	13.876[a]	18.2	94.1	.966
3	2.846[a]	3.7	97.9	.860
4	1.625[a]	2.1	100.0	.787

a. First 4 canonical discriminant functions were used in the analysis.

Table 5.18 shows that the four functions together significantly discriminate among five groups. The value of Wilk's Lambda indicates that the group means appear to differ. However, when the first function is removed, the second function is not significant at the 5% level. So the second function does not contribute significantly to the group differences.

Table 5.18: Wilk's Lambda values and level of significance

Test of Function(s)	Wilks' Lambda	Chi-square	Df	Sig.
1 through 4	.000	136.283	108	.034
2 through 4	.007	75.179	78	.569
3 through 4	.099	34.683	50	.951
4	.381	14.477	24	.935

Table 5.19 indicates that the first function has large coefficients for variables like organisational leadership, self-management support, address concerns of patients and families, effective behaviour change interventions, practice team leadership, practice team functioning and reminder to provider.

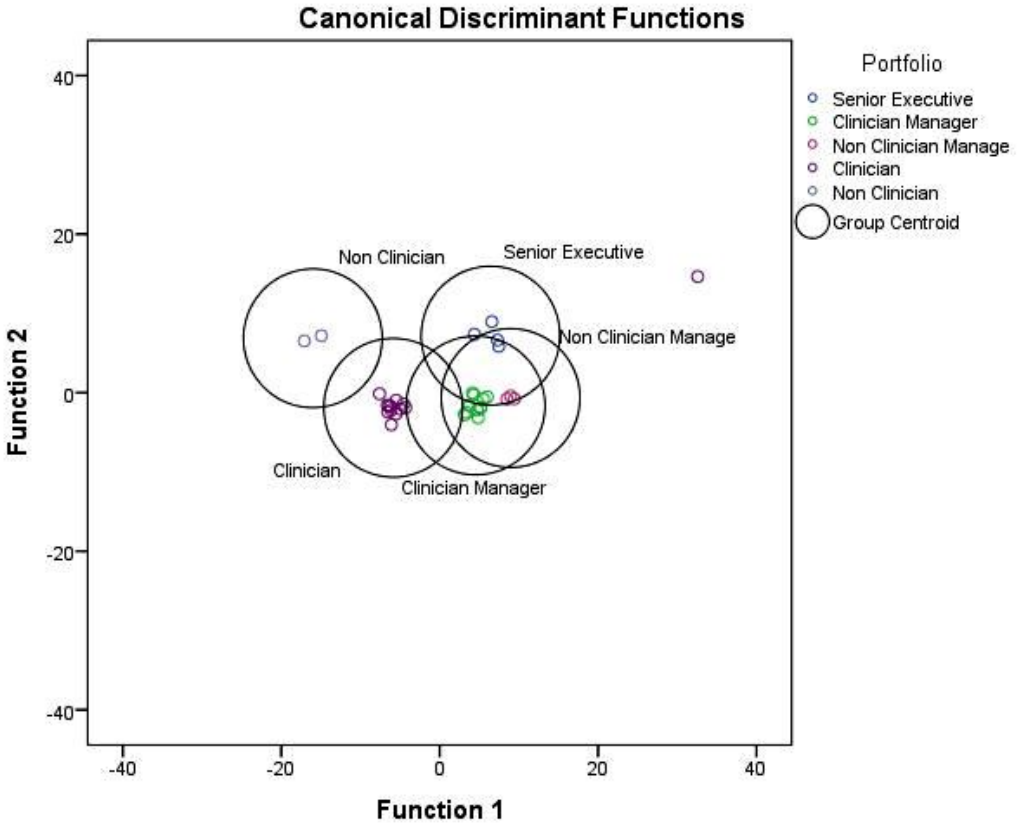
Figure 5.5 shows the group means according to respondents' job types by two functions. This is a scattergram plot of all the job types on first and second functions.

The non-clinician manager job type category has the highest value for the first function whereas the non-clinician job type has the lowest. Therefore the variables with larger coefficients are likely to contribute for the variances.

Table 5.19: Standardised Canonical Discriminant Function Coefficients

Variables	Function			
	1	2	3	4
Organisational leadership	9.533	-4.032	3.268	-.830
Organisational goals	1.283	-.582	-1.694	.664
Improvement strategy	1.136	2.406	-.945	1.502
Incentives and regulations	-1.070	1.566	-.599	-.620
Senior leaders	-5.345	1.654	.712	-.181
Benefits	2.046	-1.899	-.445	.446
Linking to outside resources	-3.667	3.153	-.210	1.068
Partnership with community organisations	2.318	-2.112	-.429	-1.156
Regional health plans	-5.411	2.581	.280	.082
Assessment and documentation of self-management needs	5.134	3.928	.671	1.376
Self-management support	12.425	-11.426	1.468	-2.729
Address concerns of patients and families	9.763	3.140	-.820	1.694
Effective behaviour change interventions	-12.579	.830	.047	-.755
Evidence-based guidelines and peer support	4.590	-14.497	3.376	-1.769
Involvement of specialists in improving primary care	-6.240	4.271	-2.122	.296
Provider education for chronic illness care	-5.973	-2.652	-1.601	1.027
Informing patients about guidelines	-6.098	12.838	-.978	-.276
Practice team functioning	-17.435	8.352	-3.556	2.784
Practice team leadership	15.124	-10.823	4.398	-1.917
Appointment system	4.669	-6.111	2.939	.100
Follow-up	-4.285	11.364	-3.288	.706
Planned visits	-2.544	.096	-.241	-.268
Continuity of care	4.905	1.424	-.129	-.175
Registry	-2.829	2.278	.665	.179
Reminder to providers	7.724	-3.496	.205	-.032
Feedback	-2.098	1.043	-2.534	-.557
Information about relevant sub-groups of patients needing services	-3.930	-.769	1.572	-.085

Figure 5.5: Combined group plot



5.4 Discussion

The ACIC survey analysis quantitatively draws results in relation to the second research objective 'to assess the organisation's capacity and state of readiness to implement a CDM register to facilitate cooperation between services in the provision of patient care and in support of patient self-management' and associated research question. The ACIC sub-scales scores reveal the status of chronic care in ACT Health region according to Wagner's CCM components. The data analysis explores the strengths and opportunities of ACT Health's chronic care elements. Although the sample size is small, it covered a wide range of participants and perspectives (diseases, conditions, service areas and so on) to confirm the survey results.

The ACIC sub-scales scores, on a scale of 0 (limited support) to 11 (full support for chronic care), range from 4.1 to 5.8. The clinical information system score (4.1) and the decision support score (5.3) are at the basic level of support. These two sub-scale scores contribute to lowering the overall program score to 5.3 (basic support for chronic care range). The pattern of ACIC sub-scales score and the overall program score is similar to other Australian health care organisations that have used the ACIC instrument (Si *et al.* 2005; Beer and Forster 2010).

ACT Health has a reasonably good policy environment and organisational leadership in chronic care. Within the policy contexts, the policy on providers' incentives for chronic care requires further strengthening to support them to achieve patient care goals. The clinical information system is least developed and a real disease register is not in place. The low score of the clinical information system sub-scale has direct influences on the integration of ACT Health's chronic care interventions according to the CCM components. Examining individual ACIC surveys, diabetes and cancer services have functional service specific databases and systems to remind providers.

The result suggests that a strengthened clinical information system can support evidence-based management of chronic conditions, establish systems to implement a CDM register, and remind providers (Bodenheimer *et al.* 2002a). ACIC data in this research shows that these roles of the clinical information system are the least developed.

Of the variables grouped under the original six ACIC sub-scales, the factor analysis identified four intelligible factors. I have given these four factors names based on the respective correlated ACIC variables of which they are composed. Among these four factors, the organisational support, information system and chronic care delivery factor correspond closely to the ACIC's organisation of health care delivery system, clinical

information system; and delivery system design sub-scale respectively. The patient empowerment factor does not correspond to any of the specific ACIC sub-scales. This patient empowerment factor can be considered as a validated and new sub-scale within ACIC to track progress toward the CCM. This patient empowerment factor derives from three different ACIC sub-scales variables as below:

Self-management support sub-scale:

- Assessment and documentation of self-management needs
- Self-management support
- Effective behaviour change interventions

Decision support sub-scale:

- Informing patient about guidelines

Clinical information system sub-scale:

- Patient treatment plans

The patient empowerment factor becomes the fundamental concept in this analysis. This is important because it drives the achievement of chronic disease management goals by encouraging patients to be active and informed. The composition of the variables and their descriptions also suggest that a strengthened clinical information system can enable linkage between the clinical management processes and self-management supports to achieve CDM goals.

The ACIC survey results explore the opportunity to implement evidence-based chronic care in this region. This is achievable through strengthening the clinical information system and implementing a CDM register. Despite upgrading isolated CCM

components, the effectiveness of ACT Health's chronic care initiatives requires comprehensiveness and integration according to the CCM framework. The improvement of the capacity of the current clinical information system can connect service delivery units for better organisational planning for chronic care. On the other hand, the introduction of a CDM register will enable the system to improve chronic care performance management and remind the providers.

The ACIC survey provides the baseline data about ACT Health's chronic care interventions. This ACIC instrument can be further used to track improvements in chronic care and integration of chronic care elements in relation to the CCM framework in this regional health system.

Chapter Six

Potential impacts of a CDM register on chronic illness

Chapter outline

6.1 Introduction

This chapter uses the qualitative transcripts of the *Serious and Continuing Illness Policy and Practice Study* **(***SCIPPS***)** for analysis**.** The SCIPPS collected views, experiences and expectations of patients suffering from CHF, DM2 and COPD and their carers (Australian Primary Health Care Research Institute 2008). Chapter 3 described the SCIPPS's research setting in detail.

The primary analysis of SCIPPS transcripts provides important insights into the design features of a CDM register addressing patients' and their carers' expectations.

The results also provide the basis from the health care consumers' point of view to better understand the key informants' opinions (Chapter 4) and the ACIC survey findings (Chapter 5).

6.2 Background characteristics of the respondents

The SCIPPS research team interviewed 32 respondents in the ACT region. Table 6.1 shows the background characteristics of the patients and the carers by their age group. Most of the study respondents are within the 65–85 year age group. Nine respondents are female and 13 respondents are male. Only 2 respondents are from Aboriginal and Torres Strait Islander (ATSI) background, and 4 respondents are from culturally and linguistically diverse (CALD) communities. According to the patients' morbid conditions, six respondents reported having CHF, 12 with DM2 and 9 with COPD. Five patients reported suffering from more than one of the three index chronic conditions. In relation to the presence of other co-morbidities, 28 patients reported having other co-morbidities in addition to the above-mentioned three index chronic conditions.

Table 6.1: Background characteristics of the patients and carers

Background characteristics	Age in Years			
	<45	45-64	65-85	Total
Type of respondent				
Patient	0	6	21	27
Carer	1	1	3	5
Sex				
Male	1	2	10	13
Female	0	5	14	19
Status of ATSI				
ATSI	0	1	1	2
Not ATSI	1	6	23	30
Status of CALD				
CALD	0	1	3	4
Not CALD	1	6	21	28
Diagnosis				
CHF	0	0	6	6
DM2	0	4	8	12
COPD	1	2	6	9
DM2 and CHF	0	1	2	3
DM2 and COPD	0	0	2	2
Status of co-morbidity				
Has co-morbidity	1	5	22	28
No co-morbidity	0	2	2	4

Table 6.2 shows the distribution of the types of respondents according to the diagnosed conditions of the patients. The majority of the respondents reported having DM2 as a main chronic condition or with other chronic conditions.

Table 6.2: Patients and carers for patients by type of diagnosed chronic conditions

	Diagnosis					
Type of respondent	**CHF**	**DM2**	**COPD**	**DM2 and CHF**	**DM2 and COPD**	**Total**
Patients	5	10	8	3	1	27
Carers	1	2	1	0	1	5
Total	6	12	9	3	2	32

6.3 Selection of nodes from SCIPPS coding scheme

The data analysis used the SCIPPS coding scheme version 8. After the initial review of the existing nodes' descriptions, I listed down the first set of nodes of interest. The list of the first set of nodes considers their relevance to the CCM components and the framework for analysis as discussed in Chapter 3.

I had several discussions with one SCIPPS investigator and with my supervisor (who is also a SCIIPPS investigator) and prepared the final set of nodes for primary analysis in this research.

The final nodes for analysis preserves the original descriptions as mentioned in the SCIPPS coding scheme version 8. Table 6.3 presents the selected tree nodes and their descriptions.

Table 6.3: Selected tree nodes and their descriptions according to the SCIPPS coding scheme version 8

Tree nodes	Description
1. Coping issues	Purposeful ongoing strategies to help the participant manage the situation. It can be a physical/behavioural action or mental/thought process.
1.1 Acting on risk factors	Changing behaviours or habits based on disease knowledge, e.g., ceasing smoking, maintaining proper diet or maintaining exercise; this includes self-discipline and being in control defined as (obtaining a sense of wellbeing by) actively attempting to manage and control certain aspects of the illness in everyday life.
1.2 Expressing concerns, needs	Being assertive in terms of verbalising concerns/problems or needs when interacting with health care professionals.
1.3 Learning	Learning about the illness, treatment and management, passive learning, or learning through experiences.
1.4 Ongoing monitoring	Checking one's health conditions or symptoms just to make sure everything is okay, which includes ongoing monitoring as a constructive strategy. Overly vigilant monitoring can be double coded as influences.
1.5 Participating in decision making	Participating in decision making with health care professionals.
1.6 Planning	Purposeful actions (either psychological or practical) to plan for ways to improve/better manage one's situation, goal setting. This includes planning for the future, current plans in place and previous plans.
2. Disease descriptors	Physical and psychological symptoms.
2.1 Co-morbidity	Managing other health-related conditions at the same time. This clearly influences the management of the individual's well-being.
3. Health literacy	The person's perceived knowledge about illness and treatment.
3.1 Awareness	Being aware of cause, treatment, management, process, purpose of intervention, own capacity to manage the illness. It also includes being aware of the patient's health condition changing (deteriorating or improving) from both the patient and the carer's perspective.

3.1.1 Illness management mechanism	Demonstrates an understanding of the management of the illness (e.g., knows how to monitor the illness, knows what triggers illness episodes); an understanding of the mechanisms of the illness.
3.1.2 Navigation of the system	Demonstrates an understanding of how to navigate/negotiate the system/services.
3.1.3 The system	Demonstrates an understanding of the health system/services.
4. Health service issues	Issues associated with health care services and the health system.
4.1 Access	Issues relating to access to the health care service, regardless of the participant's knowledge of the availability.
4.1.1 Waiting time	Issues relating to waiting time for any health care services.
4.2 Accountability	Issues relating to health professionals/services taking due responsibility for people who are receiving care/services.
4.2.1 Standards of care	Describes acts of good or poor standards of care or quality of care provided by health care professionals.
4.3. Continuity of care	Issues relating to care delivery over time, including communication between different health services (e.g., hospital and community or GP) and health professionals (e.g., between casual and permanent staff, or between doctor and nurse, etc.).
4.4 Multidisciplinary team	Issues relating to support provided by a multi-disciplinary team.

6.4 Primary analysis

The primary analysis focuses on ‘the patient and the patient empowerment’ as the theme for analysis. This theme emerged as an important factor in Chapter 5 from the analysis of the ACIC survey.

Patient empowerment as a concept maximises the ability of patients to control their own morbid conditions. The terminology explains the capacity of the patients to be part of

the treating team. The patients enrich their capacity (knowledge and skills) through structured education sessions as part of the disease management processes (Festea and Anderson 1995; Begum and Por 2010). The self-management support interventions develop empowered patients and enforce other health system elements to come into action for patient centered care (Tang *et al.* 2010).

The data cover health system components including primary care to explore aspects of current patient centered care. The data also explore elements that influence care management processes including patient empowerment. I used NVivo software for running the data queries for this primary analysis of selected nodes. Four themes evolve through the data query as below:

(a) Care planning and self-management support
(b) Care coordination and communication
(c) Continuity of care
(d) Decision support system

The data analysis on the above-mentioned themes generates two types of results. Section 6.5: Care planning and self-management support explores the health care consumers' readiness in relation to their knowledge and involvement to self-manage their conditions. Sections 6.6, 6.7 and 6.8 explore the health system elements to support continuum of care.

6.5 Care planning and self-management support

'Self-management' describes patients' involvement in managing their own health with involvement of their carers and relevant health care providers. Self-management supports place the patient at the centre of care with resources and skills (Harris *et al.*

2008).

Care planning is an important intervention under the Enhanced Primary Care (EPC) program and patient self-management support initiative. Care planning is integral to improvements in CDM through creating a collaborative model of care (Martin and Peterson 2008). Care planning processes involve patients documenting goals, and they schedule patients' journeys across the services. It documents the patients' assessment records, and ultimately facilitates clinical decision support.

In reality, the patients expect the care model that helps them to understand their conditions including a diagnosis, advice on the management of symptoms and a treatment plan. One patient with DM2 expressed satisfaction enjoying an integrated team approach at primary care.

> *Well, I'm lucky I'm going to the GP 2 (General Practitioner 2) because they actually do have a well-integrated team approach there.* (A patient of 45–64 years with DM2).

It seems that the above respondent is aware of an integrated team approach. This reflects that the patient is familiar with the disease management processes. The respondent also presents the usefulness of a care plan.

> *The care planning is sort of having planned visits for follow up at particular intervals so everyone knows when you're supposed to go and what needs to be done. You know, at twelve months, you need to have your urine test plus liver plus lipid levels or something like that, you know, whereas maybe at three months you just need HbA1c and lipid levels and see the blood glucose or something.* (A patient of 45–64 years with DM2)

The same patient experienced a good follow-up of care from the GP. The follow-up of care helped to control patient's blood glucose level as part of the 'goal' set in the care plan. The quote reflects the implementation of planned visits across other allied health services. The respondent emphasised the role of primary care to reduce hospitalisation.

> *Shortly after the diagnosis, I went to see a dietitian. That was in a separate practice but she was very helpful so the initial management was very good… It was all clear what I had to do and so on and my GP kept a very close eye on me… to make sure that the blood*

> *glucose was coming down… it was going well, that obviated the hospital visit so I guess it's an example of where general practice care avoids hospitalisation. (*A patient of 45–64 years with DM2).

The above quote refers to an ideal situation. It appears that the preparation of the care plan actively involves the patient. This works as a motivational tool for the patient to self-manage the condition.

The following quote from the same respondent highlights the advantages of using the same clinical network for care. This indicates that the patients can know their morbidity status easily when service outlets are under the same organisation.

> *It's important. Even more important with the pathology because if you go to the same firm, you get serial results so the dates overlap and the dates across on the x-axis and results on the y-axis and so you can just follow your progress and for diabetes it's very important.(* A patient of 45–64 years with DM2).

The expression of the above quote helps to understand the reverse scenario when the patients seek care from different organisations. Unless there is a clinical data linkage between the service delivery organisations, the clinical decision making suffers from duplication of assessment and a problematic appointment system.

The role of structured education sessions has a positive impact on patients' and carers' skills to cope with the diseases. One carer for a patient with CHF expressed satisfaction about the current status of educational sessions.

> *I've been quite impressed with the lectures… following cardiac surgery…from dietitians and physiotherapists and they're for the carers as well as the patients. I've been very impressed with all that.* (A carer of 65–85 years for patient with CHF).

Patient and carer knowledge about the diseases or conditions facilitates self-management activities at home and assists them to take decisions. Below is a good example of patient involvement in setting self-management goal.

> *I discussed it [blood glucose level monitoring] with my GP yesterday and we agreed that I do need to take BGL [blood glucose level] in that circumstance and I do need to get my*

> *wife trained in taking the BGL so that's on the agenda.* (A patient of 45–64 years with DM2 and CHF).

On the patient side, care planning and self-management goal setting make the patient and carer accountable to attain CDM goals. In general a proficient care planning process activates patient, carer and other allied health providers for a patient-centred approach.

This section mainly focuses on the patients' and carers' knowledge and understanding about their roles in CDM. All the above findings reflect patients' and carers' knowledge and positive experiences. The findings explain that the respondent patients and carers know what a care plan is and how it should support self-management.

Apart from the positive experiences, the respondents raised some concerns in relation to the health system roles for CDM. The respondents expressed their concerns around the variability of care plan preparation, follow-up, communication and care coordination, which are presented in following sections.

6.6 Care coordination and communication

The respondents have mixed experiences about the care coordination and communication within the hospital system. This section presents the complexities of chronic care coordination within the hospital teams. The complexities come into view more often when patients suffer from more than one chronic condition.

One patient experienced a coordinated care through team approach. Originally the patient was recruited by SCIPPS team as a diabetic patient and had a history of heart attack.

> *They [the heart team and the diabetic team] were involved… because I was a diabetic. They sent an educator to see me and I went to a couple of sessions with different professionals there.* (A patient of 65–85 years with DM2).

Care coordination impacts on comprehensive care delivery and satisfaction. In contrast to the above quote, the following quote presents findings about poor coordination and communication between service units.

> *When this [CHF] cropped up while I was in hospital, it cropped up in an admission for the stomach bleeding and consequent anemia, but it involved the heart issue and could have involved any two or more issues. The issue was poor coordination between departments at the hospital, within the hospital. Poor information was provided. One hand didn't know what the other hand was doing. Tests were uncoordinated. I was sent down from the ward to one diagnosis area, examination area, not everything was quite right so within five minutes I was sent right back again.* (A patient of 45–64years with DM2 and CHF).

The reason for the above situation might be a result of quick patient movement for acute care support. It also reflects that the patient's previous medical records are not easily available.

Initially the same patient had advice for angiogram for heart problems. The patient reminded the gastroenterology department (for treatment of current stomach bleeding) about the heart problems and the advice for angiogram. The gastroenterology department discharged the patient after eight weeks without referring for the angiogram. The patient came home without having any information on a future treatment plan. After three days, the patient developed drastic breathlessness due to fluid in the lungs, and was hospitalised for an angiogram. The patient mentioned that

> *they [cardiology department] could have at least have done the angiogram and possibly avoided it [recurrent admission with drastic breathlessness] with a bit of liaison… The gastroenterology people were told quite clearly, and I reminded them more than once about the angiogram. Now I don't want to point fingers at specialists, doctors or anybody else… but for the lack of communication and the lack of coordination between departments.* (A patient of 45–64years with DM2 and CHF).

The quote illustrates the current status of communication between service units.

Even with a less complicated situation, the patients expect a coordinated care especially when the patient needs to involve more than one allied health provider to manage the condition.

> *The trouble is that it's sort of… the episodes of care are just like that, they are episodic rather than being sort of tied together.* (A patient of 45–64 years of age with DM2).

The above quotes highlight the need for better service planning for chronic care. Care planning has the potential to tie service units offering coordinated care. But it depends on how ACT Health integrates care plans within the relevant services.

6.7 Continuity of care

The concept of continuity of care emerged in the late 1980s in relation to the management of long-term diseases or conditions. Care planning is the pathway for rational and planned care. It also assists implementation of the evidence-based guidelines (Campbell *et al.* 1998).

There is a constant concern about disintegration of chronic care when patients visit multiple health care professionals at different services and organisations. Haggerty and others conducted a multidisciplinary review on the definition of continuity of care. The authors identified three types of continuity, which are informational, management, and relational. The informational continuity links different health care providers through disease- or person-related information. The management continuity is the shared management plans involving a patient and the list of providers for cross purposes in timely manner. The relational continuity establishes association between care providers for future care. Continuity of care is the process that creates a bridge between the interventions, with care providers to cooperatively reach the CDM goal (Haggerty *et al.* 2003).

Continuity of care as a theme considers the above three types of continuity. The preparation and follow-up of the care plan is the key to offering self-management

support by health professionals. According to a patient of 65–85 years with DM2, the implementation of care planning intervention is not at all functional.

> *I mean the idea of what is being there to be achieved is fine, is basically keeping the HbA1c as low as possible but I think that it would be good to actually have a sort of a health care plan that sort of has goals and how often I should attend. Last time I hadn't heard from my GP about my follow-up so I had to ring up and find out, well, when does he want me back again?* (A patient of 65–85 years with DM2).

The above quote gives an overview of all the three types of continuity of care. The preparation and implementation of the care plan is the first step to link to the patient with other allied health providers to support the patient journey. The same patient took their own initiatives to learn the progress of the condition.

> *I think they should follow up sometimes people a bit more… and see how they are at least once in a while… I have gone there and changed my address and everything. I haven't heard anything from them again.* (A patient of 65–85 years with DM2).

This highlights the need for a disease management database system to remind providers. A system with a clinical database can link the patient with the required service units for clinical decision supports.

Most of the respondent patients and carers expressed their satisfaction in relation to the health care professionals at primary care services and hospital services. However, one patient expressed dissatisfaction regarding GP consultation time, and the information she received related to her disease.

> *He [GP] doesn't tell me what I want to know about it [diabetes] and I go in there to his surgery and I'm out in 2 minutes and I've still got a list of questions.* (A patient of 65–85 years with DM2).

Inadequate consultation time as perceived by the patient has impacts on self-management roles when there is a list of unmet questions. The patient considers the consultation time as a proxy for standard of care.

> *I don't know if GPs in general, but him [Patient's GP] in particular is interested in getting through the 10 minutes and getting you out of the office so that they can see the*

> *next person rather than pay close attention to what you want to say to them.* (A patient of 65–85 years with CHF).

'Time' is an important element to establish partnership between health care provider and patient. This patient-provider partnership enhances providers' support and the patients' ability to self-manage their illnesses (Jordan *et al.* 2008).

Waiting time is also an important factor to evaluate the 'access' to health care professionals for consultation. Furthermore, the access issue is important to assess status of continuity of care. A patient with CHF raised the need to streamline the existing appointment system.

> *And I spend my life going to see people, sitting there wondering 'What the hell am I doing here?' It's an important day of my life gone.* (A patient of 65–85 years with CHF).

So, the 'time' is the topic that impacts on the continuity of care. A proficient appointment system can minimise this issue and assist continuity of chronic care. It is important when patients having co-morbidities need to see multiple providers.

The quote below raises the feeling of insecurity when patients return home after discharge from hospital. The quote clarifies the need for more information about the caring roles and responsibilities.

> *There's a huge gap between being in hospital and being at home, in the sense that there's obviously a lot more people to do things in hospital and they have the medical knowledge, but it's almost as if you're on a different planet, you get one set of things happening in hospital and then you're discharged and it's as if you've been set adrift in a boat without oars and an anchor, instructions or whatever. So, I think that there are lots of assumptions about and around the caring role, and about the patient role.* (A carer of 45–64 years for her husband with COPD).

Patients and carers expect more take-home information or guidelines to self-manage their conditions while staying in community.

A patient with co-morbidities expects to have a straight forward system at the emergency department for quick care. The worry is more when a patient suffers from multiple chronic conditions and needs quick care.

> *It worries me that it is probably an intractable issue to get the liaison right and there are probably a lot more people than me experiencing it and I am not likely to end it with one experience with that good experience… I mean, that hospital is a big ship. It takes a long time to turn it around. That's if they have the political will to turn it around.* (A patient of 45–64 years with DM2 and CHF).

This is a typical concern: to get access to quick care. The patient raised this as a health system issue rather than the providers.

> *Getting in to [the] emergency department, which is so overloaded. I don't have the comfort of being assured that I'm going to get the treatment I need at the time I need it in emergency… That's not the result of the individuals, that's the result of the system.* (A patient of 45–64 years with DM2 and CHF).

The findings suggest that the organisation can think about having a clinical data linkage with primary care and the patients who need recurrent visits, and who already have established treatment plans.

6.8 Decision support system

The decision support processes involve clinicians reviewing patients' clinical records (electronic or other) and being prompted to formulate appropriate and evidence-based clinical management plans (Smith *et al.* 2008). This section explores the organisation's clinical decision support arrangements that have an impact on the standard of care.

The quote below from a carer highlights the need for clinical information system supports to retrieve a patient's previous diagnostic data for making clinical decisions. The statement also shows that the patient or carer is knowledgeable about the illness.

> *The worst experience was in emergency when a – I guess he was a doctor, or an almost doctor – and he decided to announce that… [the patient] didn't have a pulmonary*

> *embolism but he did have lung cancer… And he [the doctor] said, 'Well what you think about that?' and I said, 'Well if it's true, it's not very good, and he [the doctor] said, 'Oh our radiologists are excellent', and I said, 'I'm not implying the radiologists are not excellent, I'm just saying have you considered the last x-rays and compared them with these x-rays that have, that you've just come to this conclusion on' and about two and half hours later he [the doctor] came back a bit shamefaced and said…'we've compared the other x-rays and decided that you [the patient] don't have lung cancer'* (A carer of 45–64 years for patient with COPD).

It is important to make clinical data easily available to the treating clinicians to help them take timely decisions.

The quote below is a statement from a carer for her husband with DM2 and other co-morbidities. The carer changed her husband's GP due to some level of dissatisfaction. The concern was around the treating GP's roles in tracking progress of the patient's condition. This finding echoes the necessity to use evidence-based guidelines, disease monitoring indicators, and implement care plans for CDM.

An empowered patient or carer is very focused on his or her illnesses and expects that clinicians will deliver care and follow-up of symptoms according to the guidelines.

> *There was things that – like his [the patient's] blood pressure for instance. I went there [the practice] with him one day and I said to him [the doctor], 'It seems a long while since he [the patient] has had his blood pressure taken,' and he's on medication for blood pressure. Oh yeah, give him a while, you know, so okay we take the blood pressure and what is it? A high. So then we have weekly trips about three weeks to get this blood pressure down and to get him [the patient] all organised. And then we have to do a blood test, he [the doctor] writes out a blood test thing and I said, 'Well what about his [the patient] cholesterol and what about something else?' There were four things that I mentioned that he [the doctor] hadn't put on this [pathology form].* (A carer of 65–85 years for patient with DM2 with other co-morbidities).

The quote again highlights the need for clinical decision support tools for care providers to deal with the patients having co-morbidities.

One patient expressed concerns in relation to the implementation of evidence-based guidelines for diabetes management. The quote also raises issues about the patient's rights while getting care.

> *Well, for example, I go over to him [GP] and I say, all the books say that I should have an HBA 1C every 3 months. He said, no you only need that once a year. Then why is it in the book that I need it every 3 months?.. And then when I go and have a blood test and the results come to him [GP] … I'll say, I want a printout of my blood test. And he'll say, why do you want that? I'll say, because I want to take it home and keep it and keep a recording so I can check it back on my previous blood test which was 12 months ago and see how the two compare and see how my diabetes is progressing, what my cholesterol levels are what my ….and my HDL's and all these things… He'll say you don't need that. I'll say yes, I do. I want it and I'm not leaving here today until you give it to me. And he'll say, oh all right if you want it I'll get it for you… Now I think, I regard it as a right to have the results of my blood test.* (A patient of 65–85 years with DM2).

This quote illustrates the need for tracking relevant prevention indicators according to the guidelines. It is important when a patient visits a specific practice or a service delivery point frequently for follow-up visits. The prevention indicators have big impact on the disease management processes both at the patient level as well as the organisation level. The above quote emphasises the need for more attention to be given to the establishment of prevention indicators. For any deviation in terms of frequency of any pathological test based on specialist point of view, the treating clinician should communicate with the patient. This finding again raises the concerns about preparation and implementation of a care plan.

The SCIPPS collected some specific responses about the patients' or carers' relationship with their GPs, and their perceived feeling about the standard of care. The finding below is not for evaluating a service provider or a person, but to explore the reasons behind the perceived feeling about the standard of care.

This quote is from a patient with CHF, which reflects the respondent's perceived feeling about standard of care. The patient has many limitations to self-managing her own conditions. This patient expected to have the full attention of the GP for current clinical assessments and follow-up.

> *I think in an ideal world… he [GP] would have fewer patients and would know more about me [the patient] and the way I operate and the various ailments that I have. When I go in to see him [GP], he's got a less than perfect recall of the things that he has seen me about before. He's got a folder there with him, he might glance through quickly… what he's treated me before. About 40 years ago I had a kidney removed and I'm always worried*

> *that my other kidney is not going to – is going to stop operating properly, and it's not operating very well at the moment. Now, I constantly have to say to him, 'But remember I've only got one kidney. And I've got arthritis in various joints.' And we'll be talking about exercise and I'll say, 'But I've got osteo [osteoarthritis] that stops me from…'. 'Oh, yeah, that's your knee, isn't it?' But it's not my knee it's my ankle. I've had a hip replacement and he's not too sure of whether it was a hip or a knee and so on. He's never too sure about any of those things, which just makes me – I think I've got to keep my eye on the ball as much as he has because I've got to keep on reminding him of things that I have suffered from or things that are highly important to my health… I only go to the doctor when I have to, and I don't want to have to go along and give a recitation of my illnesses to him. I want to know that he knows what is wrong with me and so he will take all of these things into consideration* (a patient of 65–85 years with CHF).

According to the above quote, the clinical data management of the particular medical practice was paper-based. It could not produce the summary of patient's medical details to assist the GP to conduct the clinical assessment. It seems that the patient had involvement with the hospital and the same GP for a long time, but she needed to remind health care professionals every time to avoid incorrect decisions.

6.9 Discussion

This chapter presents the views of the patients and their carers in relation to chronic care initiatives in the ACT health system. The data analysis provides health care consumers' perspectives to explore the second research objective to 'assess the organisation's capacity and state of readiness to implement a CDM register to facilitate cooperation between services in the provision of patient care and in support of patient self-management'.

The data analysis uses 'patient empowerment' as the main topic, which emerged in Chapter 5. This topic helped selection of relevant nodes from the existing SCIPPS coding scheme. The data analysis themes help grouping of the results onto two specific premises, namely (1) health care consumers' readiness to support CDM initiatives, and (2) patients' and carers' perceptions about the capacity and readiness of ACT Health to support chronic care. Findings of these two premises provide insights into the potential

impacts of a CDM register and strengthened clinical information system on the CDM interventions.

The respondents raise the concept of integrated team approach for better chronic care. The perception of integrated team approach is twofold. Firstly, the patients describe the integrated approach where the patient is as a partner (Holman and Lorig 2000; Torrey 2010) in care delivery processes. The findings suggest that the involvement of the patients is important to implement disease management processes, which include knowing about the diseases, managing symptoms, and implementing care plans. This finding refers to the definition of health literacy as 'the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions' (The U.S. Department of Health and Human Services 2003). Secondly, the perception of the integrated team approach calls for a clinical data linked model of care. The clinical data linked care delivery is envisaged as activating both patients and the broader health system to achieve chronic care goals (Marchibroda 2008; Bodenheimer 2003).

The patients and carers perceive that the care planning process is the driver to optimise self-management activities and health system supports. The respondents expect adequate attention from relevant service delivery organisations to prepare care plans. A health literate patient can achieve the self-management skills through adequate care planning processes. The findings of Section 6.5 on care planning and self-management support reveal that the interviewed patients and their carers have notable understandings about their disease conditions, and the care management processes.

From the health system's point of view, the patients and carers experience variations in care planning processes and follow-up (Abrahams *et al.* 1989). Also the respondents express mixed experiences about the existing communication channels, which affect

care coordination. Insufficient data linkage between services creates a barrier to establishing communication and coordination (Alvarez and Coiera 2006). This finding is important when patients suffer from multiple chronic conditions. The lack of communication and coordination also exists even between chronic and acute care units within the same health system (Siu *et al.* 2009). ACT Health Diabetes service has a better system to coordinate care for the patients with co-morbidities. At this moment the care planning initiative needs integration between hospital, primary care, and allied health services to support continuity of care.

The findings expose that the absence of electronic data linkage hinders quicker patient assessment and clinical decisions. This is an issue for in-hospital teams as well as for hospital-community service delivery teams (National Health and Hospitals Reform Commission 2008). Clinical information is an integral part of a decision support system (Harris and Zwar 2007) and a vital element to bind health care elements to institute efficient care delivery processes (Wasson *et al.* 2003; Kuziemsky and Varpio 2010). According to the findings, the poor linkage of the clinical information system fails to provide sufficient diagnostic details to implement evidence-based disease management protocols.

The patients and carers raise ‘time’ as an issue. The examples are around the consultation time, and patient waiting time. Several respondents experienced inadequate consultation time. They perceived that this inadequate consultation has an impact on their satisfaction and understanding about their self-management roles. The inadequate consultation time together with poor clinical data linkage result in duplication of assessment and delay in making clinical decisions. The waiting time is a proxy indicator to assess the ‘access’ issue to health services, as well as an indicator of health system efficiency. This is important when the patients need to have consultations for multiple

chronic conditions after being discharged from hospital. This finding calls for building an efficient appointment system and reminder system for providers for timely chronic care and follow-up. The recall-reminder system is an expected feature of a CDM register.

The patients and carers show reasonable awareness about the care planning process and self- management roles and responsibilities. The respondents highlighted some concerns in relation to the diagnostic tests at primary care settings. The data show that the patients are willing to comply with recommended diagnostic targets. The patients consider diagnostic tests to monitor their progress to achieve CDM outcomes. Patients and carers expect diagnostic tests to be performed according to recommended guidelines. Unification of clinical databases and evidence-based guidelines can generate needful actions for both patients and providers (Owen *et al.* 2004) to implement chronic disease self-management support strategies. This finding refers to the status of empowerment and readiness of patients, as well as the concept of 'patient as professional'. This concept indicates the appearance of a well informed patient as an expert member of the health care team (Essue *et al.* 2010; Taylor and Short 2010). Involvement of patients within the health care team is viewed as facilitating preparation and follow-up of care plans.

ACT Health needs appropriate (new or modified) policies to implement care planning processes to support patients with multiple chronic diseases (Jowsey *et al.* 2009). The care plan data can be a rich source for behavioural and life style data (Hoy and Hyslop 1995) for the CDM register.

The findings emphasise the role of a clinical information system in creating an integrated model.

Strengthened clinical information systems can make service organisations and patients accountable for achieving chronic care goals. Addressing this challenge can solve many concerns and support patients' journeys within the continuum of care. Though costly, this investment can support timely and quality chronic care, and reduce duplication of effort. The findings suggest that patients and carers have considerable knowledge about their own roles. However, the organisation requires suitable clinical data linkage arrangements to build interactions between these knowledgeable patients and the health system.

My findings about the progress of ACT Health toward effective implementation of the CCM are unremarkable in relation to our generalised understanding of the difficulties faced when trying to improve CDM. However, in relation to the particular situation of ACT Health, the findings are strategically useful, and should help actors in the services to accelerate their progress toward CCM. The broader usefulness of my research is the construction and implementation of a detailed approach by which provincial health services can diagnose their progress toward the CCM in relation to one of its central components, namely a CDM register.

Chapter Seven

Implementing a CDM register in a regional health system

Chapter outline

7.1 Introduction

This chapter presents the findings of the participant observations method and part of the key informants' interviews. The key informants' interview findings provide some opinions about the expected roles of a CDM register in strengthening management and prevention of chronic conditions. Chapter 4 discussed rest of the key informants' findings. The findings of the key informants' interview together with the participant observations help identify the design features of a CDM register. In addition to the data and technical elements, this chapter addresses the management and governance aspects of a CDM register.

The CDMU of ACT Health is building a CDM register. This chapter discusses findings in relation to the current project and policy guidelines of ACT Health to improve

management and prevention of chronic conditions. The findings are cross referenced with the document *Operating Principles and Technical Standards for Australian Clinical Quality Registries* developed by the NHMRC Centre for Research Excellence in Patient Safety (CRE-PS) at Monash University in collaboration with the National e-Health Transition Authority (NEHTA), as a project under the Australian Commission on Safety and Quality in Health Care's information strategy (Australian Commission on Safety and Quality in Health Care 2008).

7.2 Expected roles of a CDM register

This chapter uses two terms which describe a register. These are 'clinical register', and 'clinical quality register'. A 'clinical register' refers to a database that systematically collect health-related information about patients with particular morbidities and procedures. However, a 'clinical quality register' collects key minimum data extracted from the clinical registers. The purpose of a 'clinical quality register' is to force quality improvement, and performance improvement of interventions for improved outcome. While ad hoc data collections are commonly pulled together to support quality improvement projects, ongoing clinical registers and clinical quality registers are not common in Australian health service organisations. According to a classification of registers developed for the Australian Commission on Safety and Quality in Health Care, a CDM register within a regional health service provider can be classified as a 'clinical quality register' (Australian Commission on Safety and Quality in Health Care 2008; Guda *et al.* 2008). A 'CDM registry' is an organisational unit that manages a CDM register (Last 2001). As discussed in Chapter 5, ACT Health services maintain their own service specific databases of variable strengths. The CDMU is currently building a CDM register within the ACT Health system. According to the ACT Chronic

Disease Strategy, a CDM register is the central part of the CDM program to optimise care coordination and secondary prevention of chronic conditions (ACT Health 2008a).

The key informants expressed their perceived views about the roles of a CDM register, and these provide important directions to designing a CDM register. One of its roles is to classify patient population according to their disease conditions. This classification helps providers and patients in the provision of proactive care through reminders and prompts.

> *It [CDM register] allows the stratification of risk and therefore the flagging of individuals at particular risk for clinicians, and for those individuals, the clients, to know where they sit in the general scheme of things.* (Clinician Manager).

According to the same clinician manager, a CDM register assists organisational planning for chronic care services in relation to existing resources. The register data also benchmark chronic care, and help compare chronic care across organisations.

> *Obviously it also helps with planning in terms of … at a higher macro level health planning in terms of what is the burden of at-risk individuals within that? What does that mean in terms of service planning with respect to resources needed, e.g. persons or things? It's also a nice mechanism to look at cross-jurisdiction or cross-health service comparisons. If you don't have it you can't do it. So it helps with those comparisons and therefore potentially benchmarking, because otherwise you just have no basis.* (Clinician Manager).

The periodic reports from a register inform clinicians and management staff about the extent of disease burden. A register can report on achievement of patient outcomes and chronic care performances.

> *I think in terms of establishing an evidence base both on an individual patient level, but on a performance level for our service and a performance level for the health indicators for a community, I think it's [CDM register] an incredibly powerful tool.* (Senior Executive).

A CDM register adds value in performance management of chronic care. It strengthens clinical leadership through the implementation of evidence-based guidelines in practice. A CDM register monitors outcomes for a cohort of patients.

> *It [CDM register] assists clinicians and patients to achieve optimal care. So we build in known clinical protocols for what are the milestones of care for a particular condition over time and the register helps us optimise the achievement of those milestones for a cohort of patients. So it provides clinical feedback to the clinician and it also acts as a reminder to patients about what the steps of care are that they should require. So I think that's the first thing. It's a methodical way, a systematic way of improving compliance with clinical protocols. The other sort of role I guess it has is if there is persistent variation. So if for some reason patients are not achieving their clinical milestones it might lead to a quality improvement or a performance management process that seeks to overcome those barriers.* (Senior Executive).

According to the above quote, a CDM register leads quality improvement processes. It identifies the variations in relation to care delivery processes or outcomes. A CDM register indirectly strengthens the preparation and implementation of care plans to achieve outcomes. The care plans connect patients and the relevant service provider in achieving planned care and targeted outcomes.

> *The Register can ... I guess you need to look at it at two levels, at the individual level and I guess at the disease or population level. We have, I guess, the potential to assist in the management of individual patients making sure they get ... the care plan is met in the timeframes that are desired for best practice and best care. So at the individual level of making sure that they attend all their tests, sending reminders, being able to provide a picture of care to their GPs who can then follow up on gaps or can ... or the Register may flag, not individual results. An individual result the doctor might go, "Yep, whatever," but there may be another result elsewhere that when combined with one the GP has seen may raise a flag. So I think there's an enormous benefit for individual patient management*. (Non clinician).

The above quote displays the role of a register to build communication and coordination between care delivery organisations. However, the communication between service units is a challenge (see Chapter 4). The government's future e-Health initiative is viewed as improving communications using clinical data between hospital and community services. At this moment, the output from a register can benchmark outcomes, which will eventually have an impact on coordination between service organisations.

> *I think it's some real thought about actually how you integrate those communications. But also then again on how, if you have a register, we measure the benchmarking against those so that coordination hopefully will improve, then outcomes for patients, and you can measure those again as well through that process.* (Non clinician Manager).

The above findings suggest that a CDM register has significant roles at individual patient level as well as at health system level. A functional CDM register generates reports on patients' characteristics, their disease conditions, and outcomes. It thus helps service delivery organisations to design and administer appropriate prevention initiatives. A CDM register brings evidence-based guidelines into the clinical practice. Data from a CDM register can evidence how a health service organisation delivers chronic care, and compare performances across organisations. A CDM register helps reminding clinicians, and thus strengthen care coordination and communications between service units. A register combines patients with the health system, and thereby empowers patients to achieve self-management goals and supports.

7.3 CDM Registry: Information system

The CDMU, in collaboration with other service units, is currently leading the development of a CDM register within the ACT Health system. Under the leadership of the CDMU, a Chronic Disease Management Clinical Network (CDMCN) was formed with the representatives of relevant services. The CDMCN acts as a forum to discuss chronic care issues and facilitates care coordination (ACT Health 2008d). I was part of this forum as a participant observer and attended regular monthly meetings. Data collection from this forum added significant value to this chapter to the discussion of data elements, management, and governance of a CDM register. The CDMCN is a separate forum in addition to the key informants.

The CDMU took the initiative to build a CDM register under the guidance of the ACT Chronic Disease Strategy. The primary purposes to build a CDM register were to improve chronic care coordination, and strengthen secondary prevention of index chronic conditions of ACT public hospital based patients. The secondary or derived

purpose was to monitor the performance of chronic care interventions in relation to the evidence-based guidelines (National Health Information Management Group & AIHW 2001; Australian Commission on Safety and Quality in Health Care 2008). The combined purposes behind the introduction of a CDM register are to deliver best possible chronic care, and improve the outcomes of patients with index conditions using chronic care performance data (ACT Health 2010a).

Building a CDM register is a long term investment, and the CDMU comprehensively considered the above purposes to strengthen the chronic care initiatives. ACT Health has some well- developed services. However, on the ACIC survey the organisation's lowest score was for the clinical information system sub-scale (see Chapter 5). A functional CDM register connects existing hospital and community health systems, and may significantly lift the score of this sub-scale. While outside the scope of my doctoral research, it would be interesting to repeat the ACIC survey in ACT Health once the CDM register is in full use to see if this potential has been realised.

At this stage of building a CDM register, it covers the patients who visit public hospitals including their admissions with established diagnosis for index conditions in accordance with the International Statistical Classification of Diseases and Health Related problems 10th Revision, Australian Modification (ICD–10–AM) (National Centre for Classification in Health 2008) data definitions (Appendix 8). The CDMU uses relevant patients' data for the register with their consent.

7.3.1 ACT Health Information Management Systems

This sub-section provides an overview of ACT Health information management systems. Apart from direct patient care data, ACT Health maintains its information

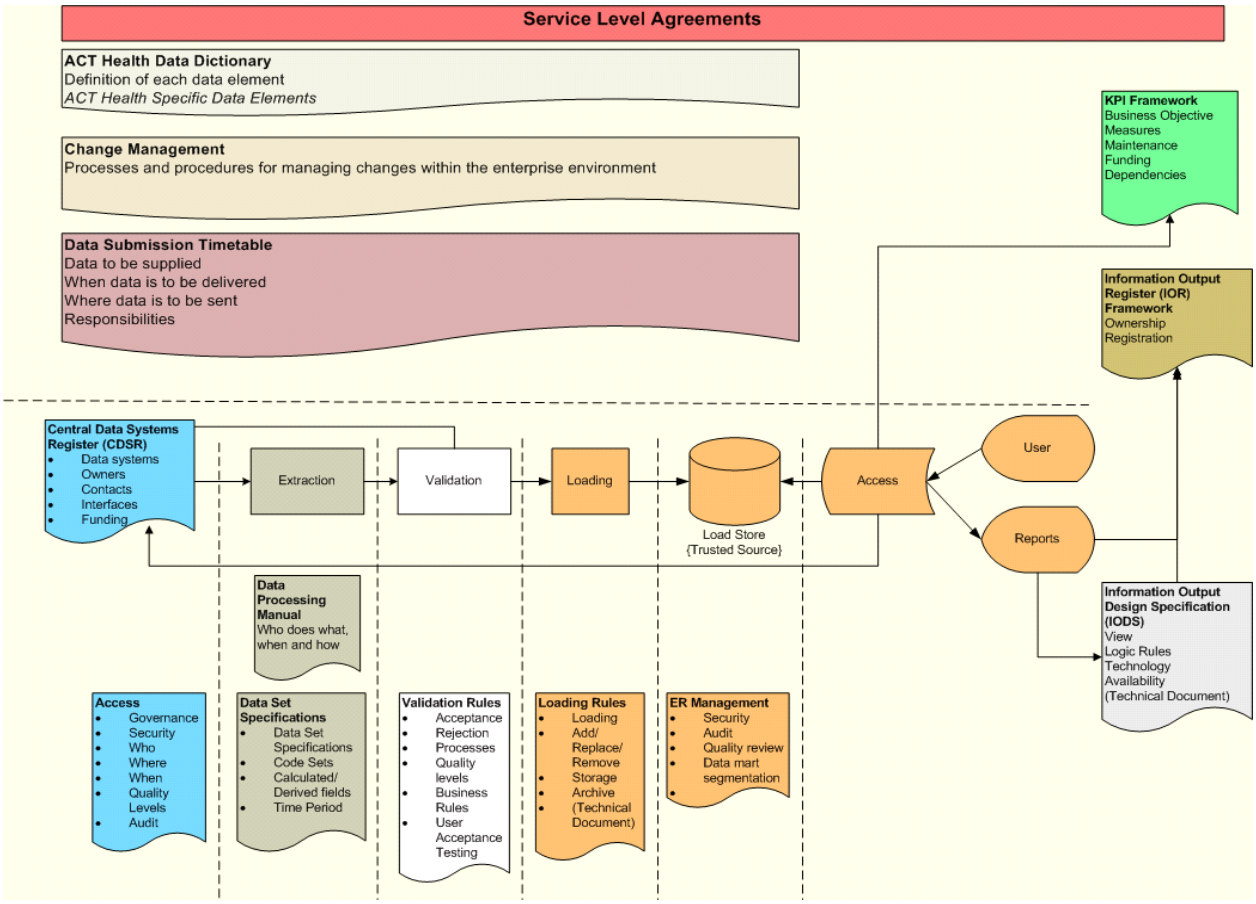
through the ACT Health Enterprise Information Management (ACTHEIM) framework (ACT Health 2010b). Under the ACTHEIM framework, ACT Health's data management strategy covers six main components. These are ACT Health Data Dictionary (ACTHDD), Key Performance Indicator (KPI) Register, Central Data Systems Register (CDSR), Information Outputs Register (IOR), Change Management Process (ChMP), and Service Level Agreements to provide the holistic approach to manage and deliver quality information output. The CDM register is being constructed in line with the ACTHEIM framework.

The ACTHDD defines each data element within the system. The KPI register allows systematic handling of the organisation's performance measurements. The CDSR maintains all data systems within ACT Health. The CDSR is the repository to maintain all patient data including paper copies.

The IOR framework identifies current reports and their reference data sources, and streamlines ACT Health's data management systems. The ChMP component secures information management principles and maintains the standards of the ACT Health's information environment. Figure 7.1 shows the ACTHEIM framework, the components, and processes.

The service units are the points for primary data sources. A CDM register is viewed as capturing selected data from the primary data sources. According to ACTHEIM framework, a CDM register is either part of the CDSR or IOR to facilitate CDM processes.

Figure 7.1: ACTHEIM framework



Source: ACT Health Intranet, accessed on 2010

7.3.2 Development of a CDM register prototype

ACT Health prepared one concept paper as an initial step towards introducing a CDM register for three index conditions. The concept paper elaborated the scope of a CDM register. This was the first generic document to gather preliminary information on case definitions, broad range of variables for a CDM register, and the likely system architecture (ACT Health 2008b). This document considered a set of guidelines to design and implement a CDM register.

At CDMU, I worked with the CDM register project team, and prepared the CDM register data collection format ‘CDM register prototype’. This CDM register prototype

is a Microsoft Excel format with a list of variables under five broad data categories (see Table 7.1).

Table 7.1: Data categories and variables of a CDM register prototype

Data category	Variables
Patient details	Patient unit record number (URN), Name, date of birth, date of death, gender, status of ASTI, address.
Medical details	Diagnosis of medical conditions as per ICD–10–AM codes: CHF, COPD and DM2.
Provider details	Contact details of GPs and specialists, name of CDMCN services with start date (referral date) and finish date (discharge date), name of any other services within the public hospital with start and finish date. Note that the start date is the date of acceptance of a patient into the specific services and the finish date is discharge date from those services.
Prevention details	There are three sub-categories, which contain 18 variables (see Table 7.2).
Case coordination details	Name of case coordinator, date of contact, status of consent signed, status of active client (patient is alive and consented to be part of the register), date of discharge with reasons, status of patient choices signed, patients' status of having documented care plans with goals and their follow-up.

The variables of the case coordination details category are central to patient empowerment, and the establishment of a meaningful patient-provider partnership. These variables reflect in part patient attachment within the health system and its services, as well as patient engagement with providers to support self-management of their own conditions. The case coordination variables reflect patient involvement in shared decision making to take control over their own health and healthcare, rather than be passive recipients of healthcare.

The CDM register prototype is the first representation of a CDM register. The variables in the prototype were finalised in discussion with the CDMCN members. The discussion process also helped in obtaining CDMCN members' agreement for necessary data supply for the register, and their support in achieving the purposes of a CDM register. Except for variables under the prevention category, all other variables are

administrative in nature. The prevention variables were identified through review of national and international clinical guidelines for the management of three index conditions, and developed in consultation with senior clinical staff of ACT Health. For DM2, variables were taken from the Commonwealth Diabetes cycle of care. Table 7.2 presents 18 prevention variables.

Table 7.2: List of prevention variables by three sub-category

Index conditions	Diagnostic	Therapeutic	Behavioural
CHF	Echocardiogram in last 2 years	• Flu vaccination • Beta blocker use	• Salt limitation • Daily weigh • Cardiac rehabilitation
COPD	Spirometry in last six months	• Flu vaccination • Dilator action plan • Optimised Steroids	• Non smoking • Pulmonary rehabilitation
DM2	• HbAIc level annual estimation • Blood sugar level (BSL) tracking • Eye review in last two years	• Flu vaccination • Oral hypoglycaemic agent use • Insulin use	• Dietary support • Physical activity

Note:
Echocardiogram is a sonogram of heart that evaluates cardiac functions.
Beta blocker is the recommended medication for patients with heart failure.
Spirometry measures lung functions.
HbA1c estimation checks whether patient's diabetes is under control or not.
Oral hypoglycaemic agent is the oral medication other than Insulin to lower blood sugar level.

The list of prevention variables further signifies the presence of patient empowerment as a theme within a CDM register through measuring patient compliance and adherence to therapeutic and behavioural interventions. These variables will reflect patients' choices and their confidence to actively participate in specific therapeutic and behavioural interventions. The variables can also provide insights into health system's efforts to improve patient capacity and skills in relation to shared decision making, control, and self-management of their chronic conditions.

To standardise the enrollment of cases into the CDM register, ICD–10–AM provides the diagnostic criteria and data definition of cases (Attachment 8). As mentioned earlier, standardised data definitions are adopted from the Federal Pay for Performance Program for the annual diabetes cycle of care and the Australian National Data Dictionary (Dugdale 2009), the recommendations of the Australian Commission on Safety and Quality in Health Care, the Australian National Heart Foundation guidelines for the management of CHF, and the Australian Lung Foundation. The Director of the CDMU presented the list of prototype variables to the key clinicians at the Canberra Hospital at the Grand Rounds of the Canberra Hospital, and to the CDM team at Priority Partners in John Hopkins HealthCare in Baltimore for peer review and discussion on data definitions.

7.3.3 System requirement analysis for a CDM registry

In this thesis, the system requirement analysis follows the concept and principles of the 'use case' analysis. The use case concept is one of the features of software requirement analysis, which is often used in business process analysis for the purpose of project management (Goss 2007). The use case analysis in this chapter meets ACT Health's system requirements analysis, and the process analysis with a view to implementing a CDM register (Regnell *et al.* 1996). Regnell and others in their article on 'A Hierarchical Use Case Model with Graphical Representations' described the methodological contexts of use case modelling. I used this methodological context as the basis of my analysis to explore the design features and implementation strategies of a CDM register. The system requirement analysis covers current information management system, data flow, data capture processes, data management, the actors and the users.

Booch and others in *The Unified Modeling Language User Guide* explained that every system works together with potential actors or users (human and automated) to produce expected results. According to the authors, a use case 'specifies the behavior [sic] of a system or a part of a system and is a description of a set of sequences of actions, including variants that a system performs to yield an observable result of value to an actor' (Booch *et al.* 1998). This chapter applies the use cases to analyse system behaviour and explore the specification and performance of the CDM register within the ACT Health system. Table 7.3 displays some terms and their descriptions used in this analysis.

Table 7.3: Terms and their descriptions in accordance with ACT Health environment

Terms	Description
The target system	The CDM registry is the target system
The host system	ACTHEIM is the host system. The CDM register is either part of the CDSR or IOR of ACTHEIM.
The users and actors	The users and actors are either part of the target system or the host system or both. The CDMCN members are both the users and actors. Other prospective users are the management staff and care providers who use a CDM register. The term 'user and actor' is relative, and can be defined by their roles.
Events	Events are the steps in the flow diagram, which represents either stimuli (inputs from CDMU to the CDM registry), or responses (inputs from the CDM registry to CDMU and CDMCN providers), or action (intrinsic interaction between CDM registry and ACTHEIM).
Preconditions	These are the initial system requirements to implement a CDM register.
Post conditions	These are the end conditions or characteristics of the target system.

Use case: the concept

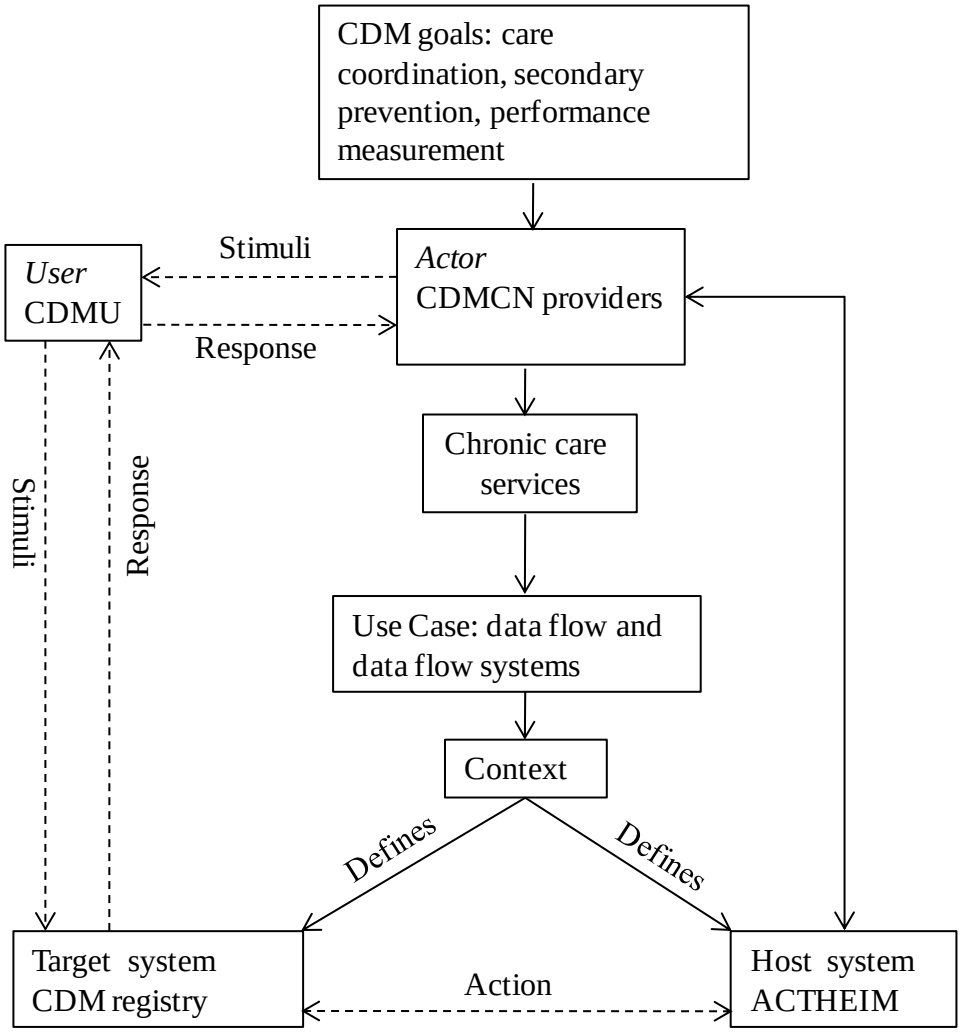
Figure 7.2 shows the conceptual framework for the use case analysis. In this framework the CDM registry is the target system and the ACTHEIM is the host system. The CDMU and the CDMCN members have an agreed understanding on the purposes of a CDM register. Based on the involvement and functions, CDMU here is the 'user' and CDMCN is the 'actor'.

According to my insights into the current chronic care initiatives, CDMCN providers deliver services to the patients from relevant acute, rehabilitative and community service units considering the needs of the patients. So, the CDMCN providers are primarily the 'actors' and service providers in this requirement analysis. However, the CDMCN providers are also the 'users' when they use the data of a CDM register.

The CDMU bears the primary role as 'user' to analyse data and produce reports. The CDMU is also the 'actor' when it maintains the quality of data, and collects data. Both the CDMU and CDMCN are tied together with the CDM goals through the services. The 'use case' here forms the usage situation where the services from the CDM register are used by the users and actors to achieve CDM goals.

The use case displays the contexts, which separate the CDM registry from the ACTHEIM environment. The CDM registry interacts with the ACTHEIM through some intrinsic actions. These intrinsic actions depend on the stimuli or response from CDMCN providers through the CDMU. However, there is a need for further capacity analysis of the host system to maintain the functionality of the CDM registry. The 'response' in this diagram denotes the reports from a CDM registry.

Figure 7.2: Conceptual framework for use case analysis in the context of CDM registry



Adapted from Regnell et al. 1996

The use case analysis

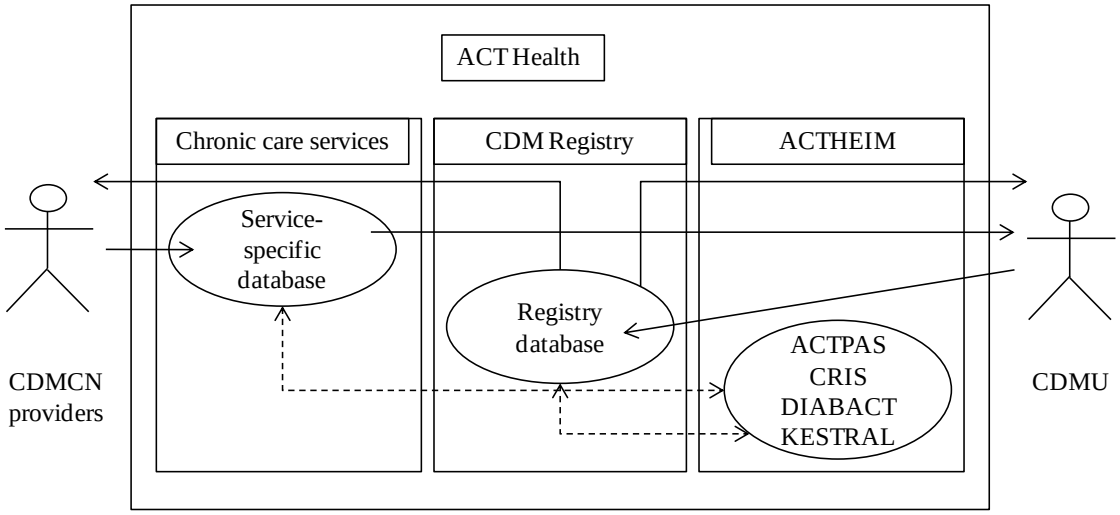
Further based on the conceptual framework, the use case analysis uses data from the participant observation method. The analysis consists of three levels of abstraction. These are (1) environment level analysis, which describes the relationship of use case with CDMU and CDMCN providers, (2) structure level analysis to display the flow of events, and (3) event level analysis to describe detailed flow of events, and their relationship in each use case.

Environment level analysis

The CDMU and the CDMCN providers have a common goal to improve secondary prevention of chronic conditions and strengthen the care coordination platform. The CDMU and the CDMCN providers have defined roles, which demarcate them as being the 'user' and the 'actor'. The data flow here is the 'use case' in the Figure 7.3 below.

The CDM registry gets data from CDMCN service specific databases through CDMU. The CDMCN databases get data support from specific database components of the ACTHEIM. These possible database components are ACT Patient Administration System (ACTPAS); Clinical Record Information System (CRIS); DIABACT for diabetes service information; and KESTRAL for ACT Pathology and diagnostic services information.

Figure 7.3: Positioning of the CDM registry in the ACT Health environment



Adapted from Regnell et al. 1996

The CDMCN providers display linkage with the use case through specific tasks. These tasks provide the inside and outside views of the use case. The CDMCN providers' task to monthly update their service specific databases, is the inside view of the use case. The outside view is sending the updated data to the CDMU. For CDMU, the data management gives the inside view, whereas building data into the CDM register gives the outside view of the use case.

The environment level analysis shows the intrinsic relationship of the use case with the actors and the users. The data flow gives the overall insights into the placement of a CDM register within the health system to facilitate CDM initiatives.

Structure level analysis

Figure 7.4 presents the structure level analysis, and displays the probable events. The events show a downward flow in a hierarchical manner. The hexagon boxes in the diagram display the preconditions (CDM register prototype) and post-conditions (CDM register).

On a monthly basis, CDMCN providers send patients' databases to CDMU. At present CDMU manually enters data into the CDM register prototype on a monthly basis. CDMU enrols patients into the register prototype according to the diagnosis of index conditions as documented in the primary databases.

At present this event does not have a specific process to confirm patients' conditions according to ICD–10–AM definitions. The emerging challenge is to enrol cases in accordance with the ICD–10–AM definitions. The use of patient discharge summaries can help this process. However, this process involves another level of manual coding.

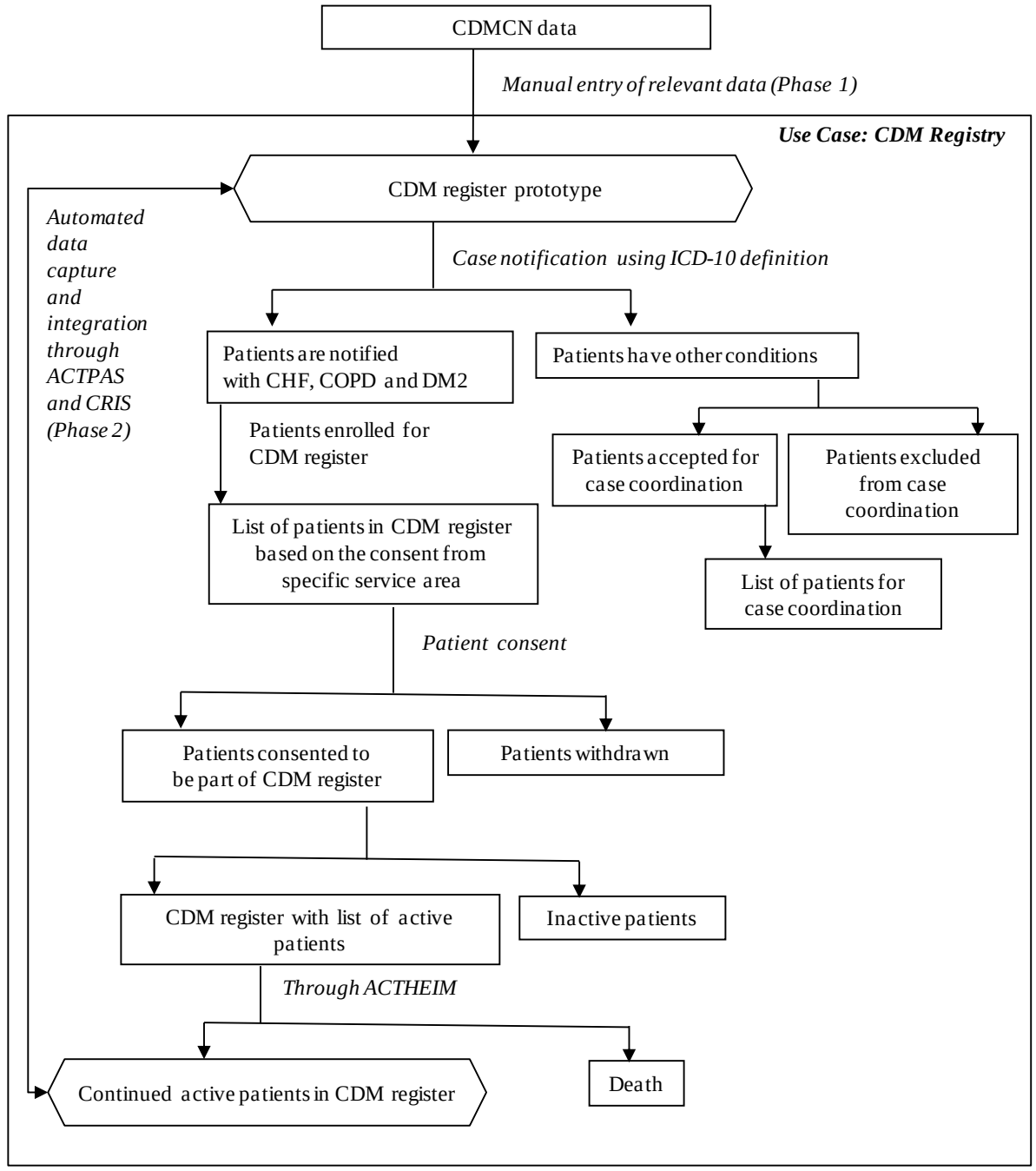
For patients who provide consent, their data flows to the CDM register as a cohort of active patients. However, CDMU is working out how to define the term ‘active patients’ for this initiative. The CDMU also maintains a list of other patients with complex chronic conditions to optimise care coordination through CDMCN providers. Figure 7.4 also highlights future automated data capture processes to reduce errors.

Understanding the nature of current chronic care data

The CDMCN is responsible for overall clinical governance of the CDM register. The network provides data for the register and supports care coordination. The CDMU organises monthly meetings with the CDMCN providers, and provides basic reports from the CDM register prototype. The CDMCN contains 10 services, which are as below:

- Heart Failure Clinical Nurse Consultant (Heart Failure CNC)
- Case Coordination
- COPD Clinical Nurse Consultant (COPD CNC)
- Renal Clinical Nurse Consultant (Renal CNC)
- Diabetes services
- Complex care services
- Transitional Therapy and Care program services (TTCP)
- Home Tele-Medicare
- Chronic Care Self-management services
- Cardiac Rehabilitation services

Figure 7.4: Structure level analysis of CDM registry: Data flow and processes



Existing CDMCN databases include excel spreadsheets and paper copies. As a participant observer, I transferred CDMCN data manually to the register prototype. I experienced some issues in relation to data, which include incompleteness of data, duplication of data, and variability of CDMCN database formats. These issues contributed some level of data transcription errors.

With a view to understanding the issues further, the Registrar of CDMU and I developed a questionnaire with some relevant questions for the CDMCN providers. We distributed the questionnaire to the CDMCN providers. The aim of this questionnaire was to understand the eligibility criteria for inclusion of patients in respective services, sources of clinical data, quality of data, data format they use, care coordination processes, and the referral protocols. We received feedback from five CDMCN providers. Table 7.4 presents the summary findings.

Table 7.4: Summary findings of CDMCN providers' feedback

Area	Findings
Eligibility of cases in CDMCN databasess	The Heart Failure CNC, COPD CNC and Diabetes Services are the three main services that supply eligible patient data to CDMU. For all services, there are difficulties in getting initial diagnosis (except for Heart Failure CNC, COPD CNC, Case Coordination services and Diabetes services). However, CDMU considers patient data from all these services to optimise care coordination and follow-up.
Patient referral to CDMCN	CDMCN receives referrals from a range of services. These services include specialists, allied health, in-patient teams, emergency department, social workers and self referral.
Clinical data collection sources for CDMCN	CDMCN services collect additional relevant clinical data from different sources, which include ACTPAS, CRIS, referral documents, ACT Pathology, other pathology providers, ACT clinical information system (CIS), patients, and clinical providers.
Completeness of existing clinical data	Overall 30–90% (60–90% for majority of the services)
Database formats	CDMCN services use different database formats (Microsoft Excel, ACTPAS format, Microsoft Access and so on).
Case or care coordinators	Three services have either care coordinators or case managers or clinical nurse consultants to assist patient journey and follow-up. Remaining two services do not have any designated care coordinator. The GPs and patients concerned organise their care coordination themselves

According to Table 7.2, CDMCN databases have limited data to support behavioural variables. The CDMCN providers in their monthly meetings highlighted some issues in relation to patient consent processes, current policies around the use of personal health data for the CDM register, and patient referral processes.

Figure 7.5 presents my insights into the strengths and limitations of existing CDMCN data for register data categories (see Table 7.1). Figure 7.5 uses a specific label for each data category as below:

- Patient detail: Data type A
- Provider detail: Data type B
- Medical detail: Data type C
- Prevention detail: Data type D
- Case coordination detail: Data type E

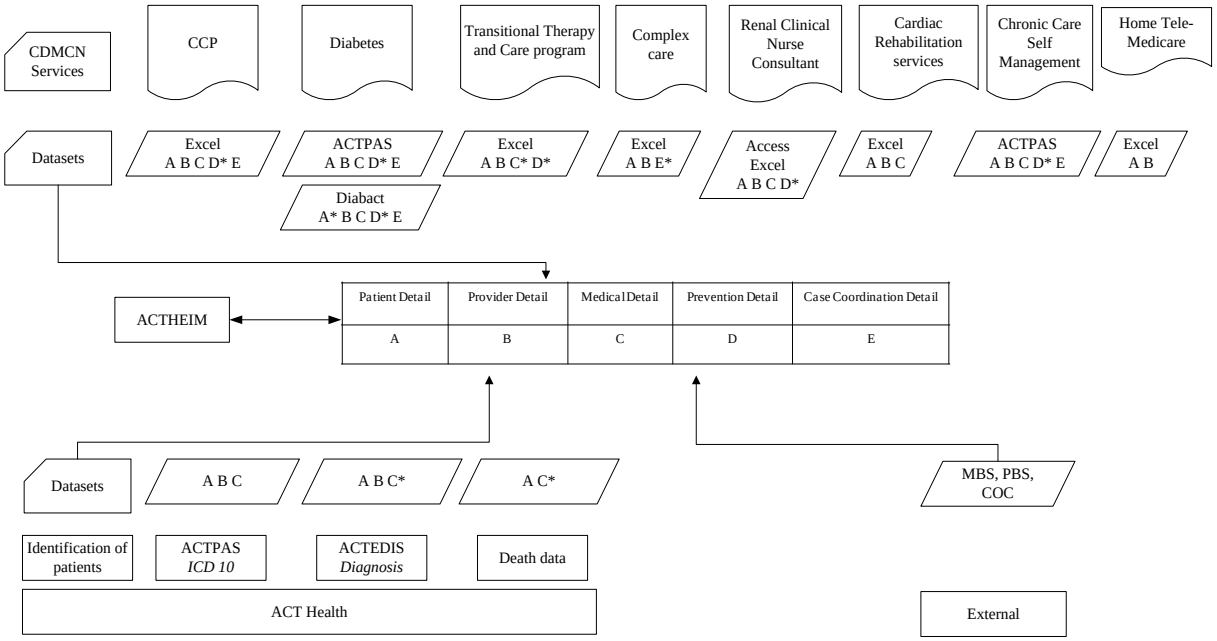
The first level in the Figure shows the services, and the second level shows the database formats including the availability of relevant data type for a CDM register. These two levels explain the current data capacity of each service. The Chronic Care Program (CCP) provides data of three services, which are Heart Failure CNC, Case Coordination and COPD CNC. The CCP, Diabetes services and the Chronic Care Self-management services have required data for CDM register prototype variables except some of the prevention variables (D*). The Figure uses asterisks to the data category indicating insufficient or incomplete data. The CDMCN databases have limitations to supply data on vaccination status under therapeutic sub-category, and almost all variables under behavioural sub-category of prevention variables category.

The analysis identifies some relevant external data sources for prevention category variables. These external sources include Medicare Benefits Schedule (MBS),

Pharmaceutical Benefits Scheme (PBS), carers, health professionals, and cycle of care (COC) data. The Figure explores the challenges to collecting all relevant data for a CDM register.

The structure level analysis explores the data collection processes, completeness of data, and the availability of relevant data within the ACTHEIM system or other external data systems.

Figure 7.5: Strengths and limitations of CDMCN data, host system and external sources data



Note:
Diabact: Diabetes service information system
ACTEDIS: ACT Emergency department information system
* indicates insufficient or incomplete data

Event level analysis

The conceptual framework for use case analysis (Figure 7.2) employs dashed arrows to represent the stimuli, response and action. The generic structure level analysis (Figure 7.4) elaborates these stimuli, response and action in the form of events. The structure level analysis highlights that there are multiple participations of the actors and users to

implement a CDM register. The event level analysis further explores additional steps for data flow to implement a CDM register.

The findings already expose that ACTHEIM does not have all the required data for CDM register variables. The behavioural variables are difficult to track within the host system because chronic care involves other actors outside the ACT Health environment. There are two other elements, namely (a) data linkage, and (b) the feedback loop or reporting to the users and actors that are very relevant to constructing the event level analysis.

> *As we talked about that coordination of care and electronic records, if it's just hospital based, and then can't communicate and/or collect data vice versa and Allied Health and community and primary care, then the usefulness of the data clearly is not and the register is not as useful as it could be. So it needs to be able to be transportable across different areas to make it useful, and that there are privacy issues around how that to make that happen and all those sorts of things as well which you need to look at in terms of a register 'full stop' and also the electronic records as well.* (Non Clinician Manager).

At present the CDM register prototype only captures public hospital based patients' data for the index chronic conditions. However, these patients interact with other community and private providers besides hospital services. Accordingly, implementation of a CDM register requires data flow from other different data sources outside the ACTHEIM. This situation entails exploring the data flow mechanisms from those external information management systems. This can help identify the data linkage process more comprehensively for a CDM register. However, in my research I focused only the CDM registry within ACT Health. According to the discussions with CDMCN providers, one of the feasible approaches is to conduct semiannual or annual clinical audits to collect relevant behavioural variables to fit into the CDM register.

As discussed earlier, CDMCN services use different data formats to maintain their own service specific data. The implementation of a CDM register requires CDMCN services to use a standardised data format to supply monthly data to the CDMU. This is an

important initial step to facilitate easy flow of data into the register database. This will also allow future automated processes to link the register database with the primary data sources, and support interoperability and reliability of a CDM register across the health system (National e-Health Transition Authority 2007). There is a need to identify appropriate data management procedures to ensure completeness and validity of the variables in the CDM register. This task requires creating data interface techniques to capture validated data from the sources.

The presence of a ‘case or care coordinator’ within the CDMCN services is essential to establish a point for patient referral and discharge. The case or care coordinators can significantly contribute by providing up-to-date chronic care data for a register. Analysing the CDMCN data, the services which have case or care coordinators maintain reasonably good chronic care data.

In relation to a future automated data capture process as shown in Figure 7.4, the design of the CDM registry will consider Health Level Seven (HL7) amenable database using Structured Query Language (SQL) server and web front tools. This process involves developing a data integration plan and data integration tools for the CDM register database, as well as other data sources for data harmonisation and standardisation (ACT Health 2010a). The HL7 is the global standardisation body, which assists interoperability of health information management systems. The HL7 receives technical support from major IT and healthcare corporations (HL7 Australia). However, the design of an automated target system requires considering the ‘access permission’ of relevant data providers either as users or actors. This will make sure of building transparency among the data providers, and thus will enable collaborative efforts in achieving CDM goals.

Figure 7.6 displays my insights into the basic data flow design of a CDM register. The Figure shows two data filtration systems, which include data filter 1 for the CDM registry, and data filter 2 for large standing databases within the ACTHEIM. The CDM registry has two main components, which include a data filter 1 and a register database. All local services data inputs will flow to the register database through data filter 1. The aim of data filter 1 is to standardise data variables in accordance with the ICD–10–AM data definitions for case identification, and collect data for prevention variables.

Currently ACT Health is working out how to establish a clinical data repository (Diamond *et al.* 2009) within the ACTHEIM environment. Data from large standing databases of ACT Health will flow to the clinical data repository through the data filter 2. Finally the CDM registry will get data inputs from these large standing databases through the clinical data repository.

The data filter 1 within the CDM registry ensures data standardisation, and data quality. This data filtration mechanism will create possible arrangements for the interoperability of data capture processes for the register database (Fung 2006). This prospective data filtration system would be a new addition within the 'validation' component of ACTHEIM as mentioned in Figure 7.1. The event level analysis helps in exploring the list of data sources as relevant for the CDM registry, as below:

(a) Local services databases

- CDMCN services databases
- ACT Health services databases
- External services databases (primary care, specialist care, other allied health care and so on)
- Ad hoc project data collection (semiannual or annual)

(b) Large standing databases

- ACTPAS
- ACTEDIS
- ACT Path (for pathology data)
- MBS/PBS

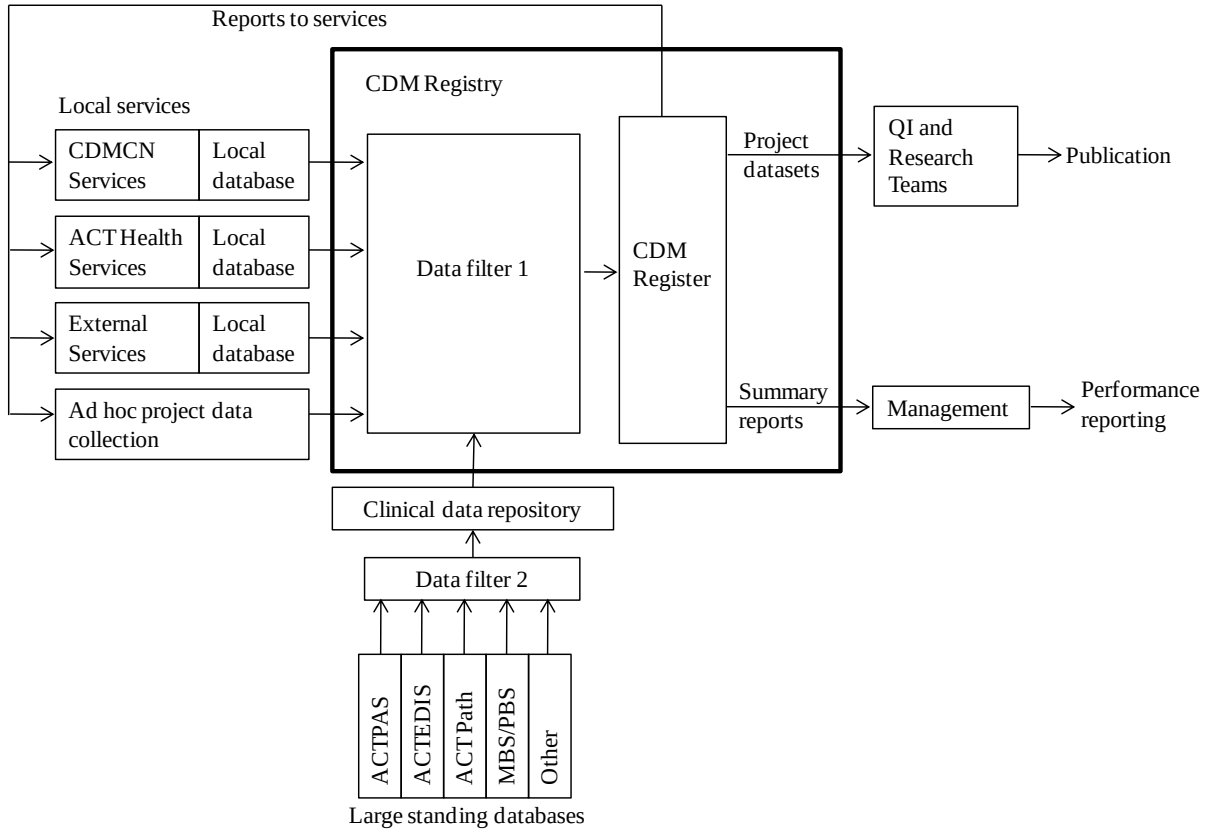
Note that the above-mentioned databases contain most of the register variables. Still there is a challenge to collect the behavioural variables. This may involve semiannual or annual ad-hoc project data collection using survey or clinical quality audits (National Health Information Management Group & AIHW 2001).

Building a CDM registry is a multifaceted process and involves both organisational and technical capacities (Solomon *et al.* 1991). The use case analysis provides some basic system requirement and data flow arrangements for a CDM registry.

A CDM register will generate reports for the CDMCN providers, ACT Health quality improvement (QI) and research teams, and ACT Health management stakeholders. The reports will act as the driving factor for overall CDM performance improvement, and assist in organisational planning for chronic care.

The data linkage arrangement with other providers' databases will help in establishing communication with providers outside ACT Health jurisdiction and will strengthen care coordination.

Figure 7.6: CDM registry data flow



7.4 CDM registry data quality control processes

The data quality control processes involve three intrinsic steps, which include data filtration, data cleaning, and metadata tagging. Besides the data standardisation, the data filtration mechanism cleans data in accordance with the data dictionary for the register. The metadata tagging performs data labeling and tagging, and thus classifies data. This metadata tagging helps in locating a specific data category through computer based or online searching of the CDM register database. This is a proposed structural design to manage output from a CDM register. The automated tagging process is advantageous over a manual process. It also helps in managing large datasets and implements an SQL-based CDM registry. The automated metadata tagging is also helpful for improving searching for a particular dataset for data management (Celaya

2010).

Within the core minimum variables of a CDM register, the variables under patient details and service provider details are epidemiologically sound. The clinical data in accordance with the ICD–10–AM definitions are epidemiologically sound; however, other clinical data may not be (Australian Commission on Safety and Quality in Health Care 2008).

The CDM registry needs specific guidelines for the diagnostic sub-category variables under prevention details. The diagnostic tests results require using specific definitions when the diagnosis is being conducted in multiple settings. CDMU intends to follow AIHW's Metadata Online Registry (METeOR) for standard definition of all metadata and their sources. METeOR is a repository for national metadata standards based on ISO/IEC 11179 standards. METeOR helps in defining standard coding principles, and thus limits the ambiguous nature of data, when the data capture process involves external data sources (Australian Institute of Health and Welfare 2007). The target system can institute a simple data quality control process utilising a sample data audit with that of source data (National Health Information Management Group & AIHW 2001). The use of a standard data return format is the basic step to ensuring that the CDM registry meets HL7 standards (Health Level 7 International).

The prospective data filtration system will perform data synchronisation with relevant data sources, and collect data for all incomplete data fields. In an automated data capture environment, the interfaces for data synchronisation will reduce transcription error and duplication of data.

The introduction of an electronic health record system under the national e-Health initiative, with a universal personal identifier, will streamline the data capture processes.

However, the data collection from the sources outside the host system needs some specific arrangements. This requires collecting data as close as possible to the event of care. Other mechanisms to ensure data quality are regular interaction with the CDMCN providers and the data managers to discuss issues in relation to data collection processes, timeliness of data supply, and data validity.

7.5 Reports from a CDM register

The value of a CDM register relies on its outputs, and how the outputs reflect its purposes. The discussion below provides the basis to outline the list of reporting indicators, and the data analysis framework of a CDM register.

Performance monitoring of chronic care

One of the key functions of a CDM register is to monitor performances of CDM interventions.

> *I think we must move forward with the Register itself. That's absolutely critical in my view. There's still a need to consolidate the evaluation and performance reporting of the elements of the program [CDM programs]. So I think to increase the confidence in the Executive around what's being delivered and what outcomes are being achieved, I think we need a bit more rigour in performance indicators for all those elements… So we will have a cycle of quarterly reporting against a series of performance indicators to the Portfolio Executive… That will help in terms of monitoring our progress but also instilling confidence that we are getting somewhere.* (Senior Executive).

The quote highlights the role of a registry to evaluate chronic care programs and how efficiently these programs improve patient outcomes.

Preventive care for people with chronic diseases

Secondary prevention of chronic conditions is one of the primary reasons to implement a CDM register. Data on the prevention category variables (Table

7.2) is the central part of a CDM register initiative. These variables also have significant roles to identify risks, and strengthen primary prevention measures for another chronic condition(s). Cederholm and others in their study showed the significance of the use of clinical data to identify risk factors and level of risks. The authors examined data of 11,646 participants of the Swedish National Diabetes Register. The study confirmed the role of register data to predict risks of developing cardiovascular diseases in DM2 patients (Cederholm *et al.* 2008).

Implementation of evidence-based guidelines

In many situations, variations exist in the implementation of evidence-based treatment protocols: for example, the use of beta blockers and angiotensin converting enzyme (ACE) inhibitors to treat heart failure patients with co-morbidities. Lainščak and others in their study analysed 10,701 participants' data from the EuroHeart Failure Survey. The study found that 74% of patients with heart failure and associated renal dysfunctions received ACE inhibitors. However, 32% of patients with heart failure and associated respiratory problems received beta blockers. The study found that treatment with spironolactone was not affected with the presence of any co-morbidity. The authors concluded that co-morbidities are often not convincing contra-indications to evidence-based therapies for heart failure treatment (Lainščak *et al.* 2006).

The registry reports on diagnostic and therapeutic variables can showcase the care delivery processes in relation to established guidelines or protocols. The registry reports help in conducting inquiry into streamlining the treatment protocols. These reports serve as an alternative mechanism to measure CDM program outcomes. They also provide grounds for more research activities, and

possible explanations when the achievement of patient outcomes is suboptimal (Australian Commission on Safety and Quality in Health Care 2008).

Care coordination for people with chronic diseases

Continuity of care is another program element that improves patient outcomes. The patients and their carers expect that the service delivery units are well informed about their care management plans, as a means of assuring continuity of care. On the other hand, the health care providers see continuity of care as the application of technical competence and professional knowledge. The perception of continuity of care is different among the patients and providers. A CDM register will strengthen communication between service units and remind them about patients' needs and their respective roles to improve outcomes (Haggerty *et al.* 2003).

The above discussion provides some basis on which to outline the reporting indicators of a CDM register. The CDMU produces preliminary reports and shares with the CDMCN providers in their monthly meetings. Figure 7.7 displays the reporting indicators of a CDM register version 2 (February 2011).

The term 'active patient' describes the number of patients who are alive with index chronic conditions, and who consent to be part of the registry. The CDMU is working out how to further describe an active patient.

As of March 2011, the CDM register database included clinical data of 2,426 patients with chronic diseases, and of whom 1,195 patients have CHF, COPD, DM2 and chronic kidney diseases.

Figure 7.7: Reporting indicators of a CDM register version 2

- Total number of patients in the register database
- Number of patients of each CDMCN service
    - Number of current patients
    - Number of new patients
    - Number of active patients under each CDMCN service
        - Number of patients with index chronic conditions (CHF, COPD and Diabetes)
            - Number of cases diagnosed
            - Number of cases not diagnosed
    - Number of discharges/deaths/ and the patients became inactive
- Number of emergency department (ED) presentations
    - All ED attendances for all active patients
- Number of in-patient admissions
- Number of referrals
- Number of deaths

Shearer and others in their article on hospital public reporting found that the hospital performance reports have two main uses, namely, quality improvement and informing providers about the statistics. Most of the performance reports present data on the hospital utilisation (length of stay in hospital), clinical outcomes (mortality and re-admission), clinical processes (use of evidence-based medications), continuity of care (care coordination), risk adjustments, and trend analysis (Shearer *et al.* 2004). In accordance with the purpose of a CDM register, Figure 7.8 presents a list of probable reporting indicators.

The statistical analysis and charts will provide facts about current status of quality of chronic care. The statistical analysis of register data has more reliability to display changes in patient level outcomes (Duckett *et al.* 2007).

Unlike other clinical registers, the CDM register reports will assist in organisational service planning and health system delivery redesign, to strengthen chronic care in this region.

Figure 7.8: Probable reporting indicators of a CDM register

Patient characteristics

- Demographic characteristics of patients
- Proportion of active patients
- Proportion of patients with confirmed diagnosis of index conditions according to ICD–10–AM data definitions

Continuity of care and care coordination

- Proportion of patients with name of their GPs
- Proportion of patients covered for care coordination (presence in different services)
    - Proportion of patients who gave consent
    - Proportion of patients who have documented care plans with goals
    - Proportion of patients who have placement to another service besides the primary placement
    - Proportion of patients who have placement to more than one service besides the primary placement

CDM and prevention

- Proportion of patients who achieved diagnostic targets by each category of condition
- Proportion of patients managed in accordance with evidence-based treatment protocols, by therapeutic variables by each category of condition.
- Proportion of patients who achieved prevention targets by behavioural variables by each category of condition as on semi-annual or annual basis
- Rate of ED presentations and hospital admissions

Advanced analysis

- Achievement of diagnostic targets adjusted for co-morbidities by each category of condition.
- Achievement of therapeutic targets adjusted for co-morbidities by each category of condition.
- Risk prediction by risk factors analysis using regression analysis of all prevention variables adjusted for each condition.
- Incidence of mortality and adjusted incidence of mortality

7.6 CDM Registry: Management and governance

The CDMU defines a management and governance structure for this new initiative. The management and governance structure involves the referring clinicians, senior management bodies, policy units, researchers, and the patients as partners. It aims to ensure corporate relationship of the partners, and achieve the desirable outcome from the registry. The policies for data standardisation, and data management including data security and confidentiality are imperative in order to build coherent corporate relationships. This coherent corporate relationship will enable ACT Health to demonstrate the scientific benefit of a registry to patients and the wider community for continued funding and support (National Health Information Management Group & AIHW 2001; Williamson *et al.* 2004; Australian Commission on Safety and Quality in Health Care 2008).

This management and governance structure attracts more focus for a CDM. In fact, the healthcare organisations put more focus on the front of the house, which is either the emergency department or acute care. The acute service units have a general self-governing tendency, and this contributes to a disconnection with chronic care.

> *I think a lot of times our focus is on the front of the house and not the back of the house. So therefore the chronic disease management just sort of is being managed without a lot of focus on it. And I think that therefore creates some issues for the patients going through the acute system when they're on a chronic disease program because of what work is being done there and the disconnect between the acute services.* (Senior Executive).

The CDM has a wide breadth, and needs functional collaboration between service units. The patient consent process and the confidentiality issue might have some impact on this disconnection. Getting more focus to CDM issues will put pressure onto streamlining the policies around patient consent processes, and clinical data linkage between service units. Development in this area will further assist data capture processes for a register. The CDMU requires reporting back the reports to its partners.

> *Without the support structures and the feedback loops being defined and well received, that will be a real challenge for us.* (Senior Executive).

The system architecture of a CDM register needs to incorporate the reporting mechanisms to its actors and users. In the absence of an appropriate feedback loop to clinicians, the whole investment will lose credibility. The governance structure helps integration of the registry into ACTHEIM. The next step is to endorse the business use of a CDM register.

> *And I suppose some of that also is dependent on where it sits – the governance etcetera; and it can be overcome with the right education and the right business rules and all that sort of stuff. But how we would actually integrate it, because the register is so much more than just putting names on a database.* (Senior Executive).

The CDMU is responsible for both technical and administrative management of the CDM registry. The CDMU bears the responsibility to disseminate the functions, benefits, and uses of a CDM register to the wide range of actors and users for their support. According to one senior executive, the CDMU proposed governance structure is functioning well, as it actively involves referring clinicians.

> *The clinical governance remains with the referring clinician and the administration of the Register and referral to it is nested within the Chronic Disease Management Unit. I think that's a good way to go forward because we wouldn't want to disrupt the clinical governance responsibilities of the referring clinician. So I think that's a good model.* (Senior Executive).

The CDMU started creating a proper environment for the CDM registry, which means the supportive policy and technological environment. The current policy, budget and IT strategy are favourable to implementing a CDM register. However, it is important to get the governance right and to manage the implementation of how the CDM register would work, and how ACT Health would get the best out of the registry. The right governance structure will create a transparent policy environment to best use of patient information.

> *I think there needs to be very senior accountability and responsibility for managing a register. If we are going to encourage people to trust us, that we will use information in the right way, that this is going to be a useful tool for us, there needs to be very clear governance. … what I mean by governance is responsibility and accountability for the*

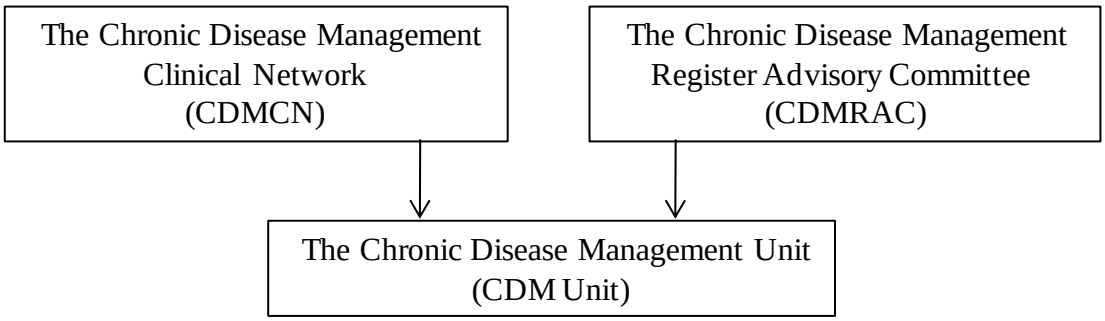
> *information, how it's managed, what it's used for and how it goes forward. So I think that is very important.* (Senior Executive).

The governance of a register needs to include embracing the acute and the primary care sector as well, which will assist data flow for a register.

> *It [CDM register] needs to be across sector, it needs to be integrated with primary care and acute systems.* (Non Clinician manager).

The CDMU outlined three levels of a governance arrangement (see Figure 7.9). The CDMCN is responsible for the overall clinical governance of the registry. The CDMU is responsible for day-to-day operations and management of the registry. The CDM Register Advisory Committee (CDMRAC) provides technical advice on development of a register. The CDMRAC comprised senior staff from ACT Health Policy Division and Information System, Registry Architecture Development Specialist, and staff specialists. The CDMU organises quarterly advisory committee meetings to update and get directions for design and implementation of the CDM registry. The advisory committee guides the development of the registry to uphold the confidence of all stakeholders.

Figure 7.9: Governance structure for the CDM registry



The CDMU has representation in both levels and maintains the liaison between these two levels. According to the structure and roles, the CDMU is the designated data custodian for the CDM registry, and is responsible for data management, storage, data security and release of information. As part of the data management processes, CDMU

facilitates regular data flow from all primary sources including data collection of behavioural variables, data completeness and data quality control processes. The Registrar of the Unit oversees the timely data flow and maintains professional liaison with the CDMCN providers. The CDMU is the vehicle of reporting to the advisory committee and raises the needs for any further policy support to facilitate the implementation processes.

The advisory committee supports setting up the data access and reporting policies in accordance with the data integrity guidelines of the ACT Health Human Research Ethics Committee. The advisory committee also assists in getting collaborative support from other services.

7.7 Prior Steps to implement a CDM register

The key informants' interview provides some considerations about the preceding steps to implementing a CDM register. There is a strong need that relevant clinicians recognise themselves to be part of the overall CDM framework. This will create a supportive as well as a seamless environment to offering chronic care.

The implementation of the CDM register requires that the clinicians or health managers adequately understand the purpose and contributions of a CDM register.

> *Unless people buy into the reality and the need for the register and then can understand what it is being utilised for, or even contribute to a novel thought about how it could be used to better their practice, and that could be just at an individual level or at a departmental level or an all of ACT Health level, then you're not getting the best out of the CDM Register.* (Clinician Manager 01).

This finding is similar to that of the ACIC survey results (see Chapter 5). Although ACT Health as an organisation is centrally prepared, the operational units at the service delivery end are less aware about what registers do and what value they may have in

improving the CDM. The treating clinicians may have some negative feelings towards the CDM register. They sometimes feel that the register might be used for professional performance assessments.

> *They [clinicians] see it [register data] as negative performance data so they feel that they will be subject to criticism or negative comparison with their peers.* (Senior Executive).

This quote emphasises the need for more advocacy on the use of a CDM register. This will reduce gaps, and encourage shared commitment to a CDM register. The advocacy plan should aim at embracing both the clinicians and the patients. It is sensible to include patients to streamline the patients' general consent process in an 'opt-in' arrangement. This will bring the opportunity for the patients to optimise care, receiving more information about their care and health outcomes. The awareness and engagement of the service providers and patients will streamline the referrals from clinicians across the board to CDMU.

> *And then once you got engagement and people being referred you clearly establish your database. And then once you've got your patients coming in then you can look at what you want to monitor.* (Clinician).

The patient referral to CDMU is elemental to maintain data flow to the register, and strengthen coordination of care. This will also help in implementing a standardised referral protocol within ACT Health.

> *Probably there should be at least a form that gets filled out rather than just, 'Hey, see that?' which is what we tend to do, which is very ad hoc and in a way nice for us, but I'm not sure that's the way to go.* (Clinician).

CDMCN providers raised a similar issue in relation to the patient referral process. They took initiatives to develop a standard referral protocol. Setting up a formal referral protocol has more potential to obtain the required data element for the register database.

The implementation of e-Health is essential to automate the data capture processes for the CDM registry. ACT Health is stepping forward with its information and communication technology (ICT) strategy to implement the e-Health initiative.

> *We must have an electronic medical record before we can have a register, so we can pull the relevant information out of the electronic systems.* (Non Clinician).

Besides the key informants' interview findings, the system requirement analysis also highlights some basic requirement for the host system to implement a CDM register. ACT Health has current funding and high level policy support for a CDM register. However, it requires more policies for the ground management of a register including the commitment and support from relevant stakeholders.

7.8 Ethics and privacy

The context behind the initial development of the clinical registries included the identification of a need for reporting the incidence, and analysing trends of infectious diseases. At present, registries are notable for their roles in monitoring outcomes of different therapeutic interventions, surgical procedures, and public health interventions. Participants' enrolment into early registries was simple, without much consideration about informed consent. However, privacy issues have become part of the governance and management aspects of all registries. The management and governance arrangements are very important and crucial to a balance between the privacy and confidentiality issues on one hand, and the public good arising from the implementation of a registry on the other hand (Williamson *et al.* 2004).

The CDM register intends to collect data of public hospital based patients with index chronic conditions. ACT Chronic Disease Strategy Framework specifies the purposes behind the development of a CDM register. However, the implementation process raises

two issues, which are (a) data security and data access policy for multiple providers, and (b) patient consent process. Both are equally important to implementing a CDM register.

The ACT government is very committed to implementing its e-Health initiative. Besides a good policy environment, ACT Health requires more policies to establish the data collection portals for a CDM register. The quote below explains the need for a central data repository. However, the issue here is the data access policies for hospital and community level providers.

> *...so that the hospital and the community and that sort of thing can actually access that health record, and you put in to that and provide information, and on all of those services – so it's not duplicating assessment and that sort of thing. And also for a better coordination of care to incur [occur?], that needs to happen.* (Non Clinician Manager).

A transparent data access policy incorporating the privacy and confidentiality aspects would support data access by concerned professionals. This would support care coordination, and a rich data source for a CDM register (see Figure 7.6).

The patient consent process precedes any data flow to a CDM register. An acceptable CDM register should include more than 95% of the all patients with index conditions to avoid selection bias. The coverage of a considerable proportion of patients is very important for the viability and validity of a CDM register, which relies on the patient consent process (Tu *et al.* 2004).

ACT Health policies for a general consent process allow sharing of clinical data with the treating clinicians of hospital, allied health care provider, and with the designated GPs. According to Health Records (Privacy and Access) Act 1997, the treating team includes the providers involved with diagnosis and treatment for a particular condition. Releasing health information to third parties for the provision of continuing care requires explicit consent from the patients (ACT Health 2008c). However, the overall

data flow arrangements can be designed to obtain explicit consent from patients before collecting or giving information to non-ACT Health service providers. A CDM register incorporates patients' data into the database under this general consent procedure, which minimises any selection bias. The use of patient data for any research activity requires compliance with relevant policies (including ethics approval).

CDMU now identifies suitable patients for its CDM register from CDMCN network services, who may benefit from variety of chronic care interventions. From 2012, CDMU will formalise the process of patient inclusion into the register database. CDMU plans to send an information letter and brochure to suitable patients and their GPs on a monthly basis. The aims of this arrangement are to inform patients and their GPs about a CDM register, and obtain patients' consent in relation to the use of their personal and service related information in the CDM register database. This approach will open the options for patients who may wish to remove their personal details (opt-off) from the register database. For the opt-off patients, CDMU will de-identify these patients' personal details. CDMU will only keep patients' identification number, location postcode, diagnosis, service use and pathology data related details.

The opt-off option will affect the functionality of a CDM register. CDMU as well as CDMCN network services will not be able to communicate with these de-identified patients and their GPs to coordinate care. CDMU will follow this arrangement to comply with the ACT Health Directorate Standard Operating Procedure (SOP) 'General Practitioners – Hospital Access and Sharing of Clinical Information within the Canberra Hospital (TCH) and Health Services.'

The CDM registry governing body needs to inform relevant stakeholders about the access and use of personal health data in the registry database. In addition, this body needs to work on new policies to accommodate advantages and scopes of future e-

Health initiative. The use of registry data for research activities and in publication requires more consideration. The ‘Guidelines under Section 95 of the Privacy Act 1988’, developed by the National Health and Medical Research Council (NHMRC) provide more clarity in relation to the the protection of privacy to conduct medical research involving human participants in Australia (National Health and Medical Research Council 2000). The guidelines provide a framework, and govern the conduct of Commonwealth agencies in their collection, management and use of data containing personal information.

7.9 Evaluation of a CDM register

Dugdale and a group of ANU final year medical students conducted one study and examined clinical data of patients with heart failure. The study aimed to explore the use of beta blockers for heart failure patients (Dugdale and students 2009). They retrospectively analysed clinical data of every 10 consecutive patients in a database since 2006. Among 6526 of cases reviewed, 180 patients had heart failure. The study found that only 27% of the patients diagnosed with heart failure were prescribed beta blockers. This finding is similar to other studies that found variations in evidence-based treatment for patients with heart failure (Krum *et al.* 2001; Fonarow *et al.* 2005).

The above study used a similar clinical indicator (use of beta blocker) that a CDM register uses. This indicator gives a snapshot about the status of evidence-based clinical care. The evaluation of a register depends on how the data flow infrastructure supports a CDM register for relevant variables.

The majority of the ACT Health services employ traditional ways to track and coordinate chronic care. The data structure of a CDM register has the ability to identify

gaps in achieving clinical outcomes. This can help service organisations strengthen the patients' care plans and the provision of other self-management support.

The CDM interventions aim for the totality of care to improve the quality of life. The evaluation of a CDM register depends on how it informs the care providers and assists them in clinical decision making (Dugdale 2009).

> *I think chronic disease management is not just about reducing admissions, which would be nice. I think if anything you might even make them a bit more common. It's about improving a person's quality of life.* (Clinician).

The CDM registry is one of the CDM interventions. It would be good if the CDM interventions reduce hospital admissions. However, it would be better to see the programs reduce significant exacerbations and make sure that the health system is doing something significant for the overall benefit of the patients. Consider COPD management for an example, where one of the big things that leads to the deterioration of patients' condition is depression. Depression leads to poor involvement of patients in care delivery processes, reduced involvement further leads to poor activity which leads to de-conditioning, and again it leads to more depression and social isolation. The power of the CDM interventions takes place when it improves patients' self-management capacity and compliance with therapeutic and life-style advice in reducing exacerbations.

A patient satisfaction survey can show the impacts of CDM interventions. The participation of the patients as partners can bring consumer perspectives for community oriented chronic care.

> *So I think about that qualitative information, about how the patient actually feels about the changes in their care and the coordination of their care is something that we miss a great deal of the time. And the data can say we're doing a better job because more people are surviving for longer, but if they're surviving for longer and actually their quality of life is no better are we actually doing them any favours?* (Senior Executive).

Feedback from patients is important in order to understand the care coordination processes and how the care coordination processes empower patients to coordinate and manage their own conditions. This feedback loop will enable the health system to know how the systems are performing and meeting patients' needs. The efficacy of CDM interventions depends on the presence of appropriate decision support tools. So, the reports from a CDM register in combination with patients' feedback are very important to evaluating the CDM interventions.

The above discussions add topics for the evaluation framework for the CDM interventions, where a CDM register plays an important role to benchmark and compare clinical care. A CDM register keeps prevention variables and drives other CDM components through care coordination, and involves multidisciplinary care teams.

Black and Payne in their article 'Directory of clinical databases: improving and promoting their use' identified ten criteria to assess quality of any clinical database (Black and Payne 2003; Australian Commission on Safety and Quality in Health Care 2008).

The evaluation criteria for a CDM register are based on the above article, the paper on 'Evaluation of a register driven chronic disease management program in a regional Australian health provider' as presented by Dugdale at the Priority Partners in John Hopkins HealthCare in Baltimore (Dugdale 2009), and my insights into the topic.

Figure 7.10 presents twelve criteria to evaluate the design and implementation of a CDM register.

Figure 7.10: Evaluation criteria for a CDM register

Specific to CDM register data, and data analysis

1. The extent of data collection of register variables, specific to ACT public hospital patients
2. The completeness of recruitment of eligible patients having index conditions using ICD–10–AM data definitions
3. The completeness of data for each variable (proportion of variables are at 95% complete).
4. The proportion of variables is defined in the CDM registry implementation guideline
5. The proportions of variables have defined coding principles
6. The reliability of the coding of variables collected from other mechanisms and sources according to Figure 7.6
7. The extent of data validation
8. Identification of any bias associated either with the results or reports from a CDM register

Specific to CDM

9. The achievements of outcomes as indirectly revealed through achievements in diagnostic and therapeutic targets
10. The proportion of patients referred to different CDM programs for secondary prevention of chronic conditions as a proxy to understanding improvements of patients' quality of life
11. The proportion of patients satisfied (using patient surveys to assess care coordination, implementation of care plans, and empowerment of patients to self-manage their own conditions)
12. The proportion of providers satisfied (using provider surveys to assess providers' awareness about its roles in care coordination, and clinical decision making)

7.10 Discussion

This chapter presents the current issues relating to the development of a CDM register, and its design features. The findings are central to answering the third research objective to 'provide insight into the practical development of a CDM register so it will have a positive impact on the health of people with chronic disease'. According to the design features, a CDM register is a 'clinical quality register'. The overall purpose of a CDM register is to underpin continuous improvements in chronic care through strengthening

care coordination and secondary prevention, service planning, and benchmarking outcomes.

A CDM register assists healthcare organisations in identifying the patient population of interest and the patients who are at risk of developing another chronic condition, administering targeted prevention interventions, strengthening care coordination and self-management supports. A CDM register helps with reminding clinicians about actions, monitoring chronic care performances, organisational service planning and resource allocation, quality improvement and research activities, and developing new policies to support chronic care (Evans *et al.* 2011).

The CDM register aims to accommodate ACT public hospital based patients with index chronic conditions. This representation by a CDM register with hospital data will cover only a proportion of patients in the local population, keeping aside a significant proportion of patients who are at risk, visiting specialists and other private providers. However, implementation of a CDM register for the first time justifies the inclusion of ACT hospital based patients only. In any epidemiological study, we look for a well-defined population base, usually defined geographically by place of residence. The purpose of epidemiology in such research is to study occurrence relations (Miettinen 1985) in human populations. An important part of the method of studying this is the use of well-defined population bases in the empirical studies. When the occurrence relation of interest is the relation between the cases provided by a health service and the health of its patients, it is appropriate to use the patients of the health service as the population base for this research. The limitation of this approach is that it is not suitable for making inferences about the relation of the care provided by the health service to the health of the broader population of people that it is supposed to serve. This limitation could perhaps be addressed by conducting representative community population surveys with

a well-defined geographical population base, and using this data in combination with service specific register based data to calibrate the interpretations of the broader relations between care provided and the health of the population. In the current state of discrete holdings of clinical information, it is not possible to know the exact population health surveillance status. The national e-Health strategy has the potential capacity to address this limitation (Australian Health Ministers' Conference 2008).

ACT Health has a reasonably good policy environment to implement a CDM register. The existing registry management and governance structure is also very supportive of the implementation of a CDM register. The CDMU identified the key minimum indicators for a CDM register. The current clinical information system does not have a unified portal to collect selected clinical data for the registry. However, the use case analysis describes the basic design features of a CDM registry within the breadth of ACTHEIM (Young *et al.* 2007).

The CDMCN clinicians are the main actors to implement the register. They send their monthly data to CDMU for the register database. The CDMCN data has some complexities around the diagnosis of index conditions, data quality and completeness. The use case analysis demonstrates how the CDM register data system can identify cases and capture relevant data from various data sources, and maintain data quality (Arts *et al.* 2002). A major concern is the use of ICD–10–AM data definitions for selection of cases for the registry. Only the discharge summary data can contribute to identify cases according to ICD–10–AM data definitions. In addition to ICD–10–AM, the CDM registry may use the SNOMED CT (Systematized Nomenclature of Medicine--Clinical Terms) to describe clinical terms more comprehensively (U.S. National Library of Medicine). The biggest concern is to collect behavioural variables data, which requires ad hoc project data collection or data collection from external sources.

The use case analysis helps to place the CDM registry within the ACTHEIM and identifies a new component 'data filter' within ACTHEIM to standardise data elements of a CDM register. These findings complement ACT Health initiatives to implement the CDM registry according to HL7 standard.

The implementation of a CDM register requires adequate advocacy about its roles and uses among the clinicians, and other actors or users. While information technology support is vital, shared understanding, engagement and acceptance by the stakeholders is central to implementing a CDM register (Greene *et al.* 2009). The current diffuse nature of information management is one of the barriers to implementing the registry. The implementation of the national e-Health strategy will progressively streamline data flow, including relevant policies in relation to privacy and confidentiality issues.

ACT Health services use traditional ways to coordinate care. There are also limited resources to identify variations in management of people with chronic diseases. A CDM register can be a strong facilitator in closing these gaps. The theme 'patient empowerment' as emerged from the factor analysis in Chapter 5, acts as one of the powerful considerations in identifying the data elements of a CDM register. This theme enables the design features of a CDM register to include patients' perspectives. The 'case coordination details' data category incorporates a variable to collect information about patient care plans and their follow-up to track progresses for the novel theme 'patient empowerment' in this jurisdiction. The aim of this inclusion is to activate patients in the processes care, and create linkage between patients and their providers to achieve expected outcomes.

The output from a CDM register will enable service units to provide collaborative support to improve the quality of life of the patients with chronic diseases. The evaluation criteria as outlined in this chapter will help ACT Health to track progress of the implementation of a CDM register and CDM interventions in the ACT Health jurisdiction.

Chapter Eight

Conclusion

Chapter outline

8.1 Introduction

8.2 Key findings

8.3 Strengths of the study

8.4 Limitations of the study

8.5 Policy opportunities for CDM

8.6 Areas for further research

8.7 Concluding remarks

8.1 Introduction

Despite significant advances in health services in Australia since the introduction of Medicare in the 1980s, chronic diseases are a growing challenge due to aging of the population. The main challenge is the allocation of resources and the development of sustainable system support for CDM (Wagner *et al.* 1996; Armstrong *et al.* 2007). This situation is similar to other developed countries where chronic diseases account for most mortality and morbidity (World Health Organisation 2009).

The implementation of Wagner's CCM framework can help healthcare organisations close the gaps around the delivery of chronic care and the needs of patients with chronic conditions (Phillips et al 2004). The CCM recommends implementation of six components (Wagner *et al.* 1999), namely organisation of health care, resources and policies, self-management support, decision support, delivery system design, and clinical information system to achieve CDM goals.

The ACT Chronic Disease Strategy framework endorsed the CCM components to strengthen chronic care in this region. The current CDM initiatives reflect

implementation of the strategy framework, but in many cases these initiatives are disconnected. The strength of the existing clinical information management system is not adequate to connect service units, and integration of CDM elements (Smith *et al.* 2011). The clinical information system is one of six components of the CCM framework, and a CDM register is the central feature of this component. The strategy framework includes a CDM register for prevention, integration, and continuity of chronic care to meet the needs of patients with chronic illnesses.

Research has been conducted by the NHMRC Centre for Research Excellence in Patient Safety research on the use of service specific disease registers. The overall aim of part of this research is to identify the design features of a CDM register, and explore health system elements to implement it within ACT public hospitals.

I conducted my research in the ACT Health setting. The research methods include qualitative (key informants' interview, and analysis of SCIPPS' patients and carers interview transcripts), quantitative (ACIC survey), and the participant observation approaches. The research methods together helped me to conduct an organisational analysis of ACT Health combined with a system requirement analysis, and a structural analysis to design and implement a CDM register. The research methods contribute to the harvesting of the findings from an organisational analysis and articulate results in a practical way.

The organisation of the thesis reflects the data analytical framework in response to the research objectives, and corresponding research questions. This final chapter relates the key findings with the research questions, and discusses the strengths and limitations of this research. Finally it explores policy opportunities to strengthen chronic care, and recommends new research topics for future research.

8.2 Key findings

ACT Health has a reasonably good policy environment to support chronic care. The ACT Chronic Disease Strategy provides comprehensive policy guidelines for chronic care, and incorporates the considerations of current needs. The strategy includes the primary and secondary chronic diseases prevention interventions within the main action streams. As part of the implementation of the strategy, ACT Health established the CDMU to manage CDM interventions. Under the leadership of the Unit, the CDMCN has been formed and is offering overall clinical governance and coordination of the chronic care interventions. The CDMCN mainly supplies clinical data to the CDMU on monthly basis.

The CDM requires connecting both clinical and public health leadership to make it an inclusive effort. The linkage helps in collaboration between primary and acute care units to implement chronic care prevention interventions. ACT Health is implementing evidence-based chronic care interventions and the interventions are part of overall policy components. However, in reality the implementation of these interventions is variable.

The ACIC survey reveals that the chronic care provided by ACT Health is within the 'basic support' range. The ACIC survey instrument collected data in accordance with the CCM framework. The survey results show that ACT Health's clinical information system is least developed, and is one of the barriers to integrating CCM components in the ACT Health jurisdiction. The factor analysis using PCA as the data extraction method identified a new sub-scale 'patient empowerment' as the strongest component of the ACT Health's chronic care interventions. This is an emerging concept in relation to chronic care and is consistent with findings in the published literature. It creates active, informed, and accountable patients, and thus facilitates self-management and

enhances CDM program outcomes.

The research identified two main types of barriers, namely organisational level barriers, and system or technological level barriers. Although there exist patient level barriers, these are the result of inadequate organisational support. As part of the organisational barriers, inadequate acknowledgement of public health thinking within the clinical leadership environment is one important barrier. Another important barrier is the poor involvement of clinicians in the development of policies. These have impacts on less acceptance of the strategy by the clinicians. As a result, the multidisciplinary model of care is not active within the health system due to inadequate communication and coordination between service units, which run in silos.

In relation to the system or technological level barriers, ACT Health does not have a unified clinical information system. Most of the service units maintain independent service specific databases. This contributes to inadequate support for clinical decision making, service planning, performance monitoring, and evaluation of chronic care interventions. The study findings suggest strengthening the organisation's clinical information system to integrate CCM components, and boost up chronic care in this region.

The research findings show that the implementation of care planning is variable, even in the presence of the government's support through incentives. Ideally the care planning processes embrace hospital, allied health, primary care, and other community health services. The usefulness of the care planning interventions is much diminished due to its traditional paper based nature, and absence of modern communication portals. However, patients and carers show realistic awareness about the need for a clinical data-linked model of care, and care planning process to track and inform progress towards achieving desired outcomes. A CDM register informs the service provider about the

pool of patients with chronic diseases, and assists various service units to coordinate care. In Australia, clinical quality registers rarely exist and most of the clinical registers are research focused rather than service focused. Considering the current strength of the information management system, the scopes for a CDM register currently lies within ACT Health public hospital settings.

The research gathered some opinions about the expected roles of a CDM register. The important roles include the ability of a CDM register to know the list of patients and the patients who are at risk of developing another chronic condition, to administer appropriate prevention interventions, to strengthen care coordination and service planning, to remind clinicians and patients, to monitor performance and quality improvement, and to develop new policies to support chronic care.

As part of my participant observation at the CDMU, I contributed to identifying five key data categories and associated variables for the register of patients with CHF, COPD and DM2. These five data categories are patient details, medical details, provider details, prevention details, and case coordination details. The prevention detail category is the centre of a CDM register intervention and consists of diagnostic, therapeutic and behavioural sub-categories. The prevention details category contains eighteen prevention variables under these three sub-categories.

The system requirement analysis suggests placement of the CDM registry within the CDSR or the IOR of the current ACTHEIM framework of ACT Health. At present CDMU receives data from CDMCN and enrols the list of patients with index chronic conditions into the register database. However, CDMCN data have some limitations. The biggest concern is the unavailability of relevant data to confirm ICD–10–AM data definitions for identification of cases. The only source to collect relevant data to meet ICD–10–AM data definitions is the discharge summary reports. Another concern is

around getting relevant data for behavioural sub-category variables. This requires the CDM registry to link with other external data sources and collect data through ad hoc data collection.

The system requirement analysis presents a basic data flow arrangement for the CDM registry. It recommends installing data filtration arrangements into the ACTHEIM to standardise data elements of a CDM register. This will help ACT Health implement a CDM register according to HL7 standard.

According to the current management and governance framework, CDMCN is mainly responsible for the overall clinical governance of the registry. The CDMU is responsible for coordinating day-to-day operations and data management of the registry including its reporting.

The results demonstrate that the introduction of a CDM register will strengthen care coordination from its current traditional patterns. The feedback from the register will enable service units to reinforce collaborative support to improve the quality of life of the patients with chronic diseases. A CDM register provides reports on patients with index chronic diseases, about their care and their outcomes. This will help the ACT Health to improve chronic care performance through exploring variations in care management processes, and their underlying reasons.

8.3 Strengths of the study

One of the strengths of the study is the combination of quantitative, qualitative, and participant observation approaches to conducting this organisational analysis. The key informants' interview, and the SCIPPS' patients and carers interview findings helped me to interpret the ACIC survey findings. Finally my direct involvement with the

chronic care programs as a participant observer helped me to validate the quantitative and qualitative insights, using an ethnographic approach. The study demonstrates commonality between the views of health professionals, the patients with chronic diseases and their carers. Both respondent groups identified similar themes and confirmed the strengths of the data.

Besides investigating research objectives and research questions, the study has exposed some important policy opportunities to foster the implementation of coordinated and multidisciplinary model of chronic care. This is mentioned in my joint publication in the Australasian Epidemiologist Journal: 2008 Vol. 15.3 (Appendix 9)

The qualitative data analysis followed basic theoretical concepts, which finally evolved through a series of analytical processes toward the core concepts and insights. The attention-grabbing part of the data analysis is the theme 'patient empowerment', which emerged from both the quantitative and qualitative methods. This 'patient empowerment' theme became the driving concept to outline data elements of a CDM register. The data analysis brought together the organisational and system elements that I studied from the perspectives of the expectations of patients with chronic diseases. Healthcare organisations, who implement disease registries mostly focus on patients' clinical outcomes, and use the disease registers to optimise the clinical decisions making processes. The ACT Health's CDM register, in addition, incorporates specific data element to track progress in relation to patient-centred care. Under the 'case coordination details' data category of a CDM register, the variables intend to strengthening the coordination of care. This data category enforces presence of a case coordinator, and to obtain patients' consents. This patient consent process will provide support for the e-Health record system to link patients with all of the providers involved in the healthcare. The implementation of this initiative will embrace the patients and

their providers in the continuum of care, and assist in obtaining relevant data in relation to behavioural variables of the prevention category. This ‘case coordination details’ category also intends to collect information about patients’ care plans and their follow-up, to track progresses for the novel theme ‘patient empowerment’ in this jurisdiction. These contributions from this research will help ACT Health to reduce the gaps in relation to the continuity of care, and further assist to increase the coverage of a CDM register to implement it beyond the boundary of the ACT public hospitals.

Despite its limitations, the study provides important insights into how a service specific CDM register and strengthened clinical information system can support CDM initiatives.

Although the results are obtained from a single regional health setting and are subject to the broad limitations of case study research, they appear to be consistent with other health systems in Australia. Given that similar findings in relation to chronic care have been identified in other studies nationally and internationally, it seems that the results of this research are relevant to other health system settings. However, there is much opportunity for research to be undertaken to learn about the practicality of implementing CDM registers. A CDM register according to this research is not a discrete and immediately replicable intervention. It cannot be understood as just a software application that can be taken off the shelf and used in a simple way. It provides a framework within which a healthcare organisation can transform the general ideas of the CCM into a distinctive local application. The generalisability in relation to the implementation of this CDM register framework will vary from organisation to organisation and from country to country, depending on the nature and scopes of different healthcare organisations, and the extent of CCM implementation. Nevertheless, the detailed findings of this research can be expected to be a practically

useful guide for people working in other regional health services who are considering implementing a CDM register.

The research provides significant inputs to the design of a CDM register, including its implementation strategies. ACT Health can use these design inputs to link evidence-based guidelines to clinical practices through this CDM register. The research has shown the value of significant inputs ACT Health staff and their patients with chronic diseases into policy development, implementation of quality improvement initiatives and changes in healthcare processes.

8.4 Limitations of the study

The main limitation of the study is its small sample size, for both ACIC survey as well as for the key informants' interviews. The ACIC survey covered 67 participants from ACT Health. I faced difficulties in getting responses back from the busy professionals. Upon applying the survey response improvement strategy, my survey response rate was 69%. Although the sample size is small, it covers a reasonable mix of respondents. The respondents include senior executives, clinician managers, non-clinician managers, clinicians and non-clinicians as broad categories. The respondents were from health policy, health management, clinical management, information management and primary health care background.

I conducted my research in the ACT Health setting, based at the Canberra Hospital. My ethics application passed through three ethics committees, which include the Canberra Hospital Survey Resource Group, the ACT Health Human Research Ethics Committee, and ANU. Due to the procedures of the ACT Health Ethics Committee at the time of my application (since changed), the ethics approval for the study was delayed. Also there

was delay in getting approval from SCIPPS research team to use patient and carer qualitative transcripts to use in this research. In considering all these delays, I conducted 10 key informants' interviews to meet research progress milestones.

According to MacColl Institute, in addition to the ACIC survey there is another survey instrument for the patients with chronic diseases. The name of the survey instrument is 'Patient Assessment of Care for Chronic Conditions (PACIC)'. The instrument intends measuring patients' experiences around the chronic care delivery system (Glasgow *et al.* 2005). I have not conducted this PACIC survey to include patients' perspectives with chronic diseases, and this is another limitation of this study. However, analysis of SCIPPS qualitative data added the patients' and carers' perspectives in this research.

For ACIC survey respondents, some respondents are from a non-clinical background, and indirectly involved with the care delivery processes. So, there exist some missing values in ACIC data. Considering the missing values and a small sample size, I could not perform regression analysis to predict change in variables based on changes in other variables. The ACIC survey reveals the organisation's overall status of chronic care in relation to CCM components. This research could not separately test efficiencies of any specific chronic care programs, like the Heart Failure program, and Diabetes Service program, for their strengths and weaknesses.

Before qualitative data analysis, I received training on NVivo software. I used the basic and some advanced level of qualitative data analysis techniques using this software. However, I used my knowledge of CCM components as derived from my literature review to construct the coding scheme. There is a possibility of bias reflecting my preconceived ideas in the coding scheme. Similarly, for the SCIPPS qualitative data analysis, I used the existing coding scheme developed and used by the SCIPPS research team. There might be also some influence of the SCIPPS researchers' biases in my

study. I minimised potential biases in my qualitative analysis through using mixed method approaches, and subsequent validation by the participant observation method.

In my participant observation at CDMU, the system requirement analysis identified valuable inputs to the design of a register. However, the CDM register did not reach maturity. I could not test the proposed register data management model due to the limitation of the system to identify cases only according to ICD–10–AM data definitions, and the primitive integration of the ACT Health information systems. The existing CDMCN services also have variable data definitions. The behavioural sub-category variables under prevention category are not readily available.

8.5 Policy opportunities for CDM

The policy opportunities that emerged through this study are not very new. However, these policy contexts are very specific to ACT Health's chronic care initiatives.

The implementation of CDM interventions requires balance between clinical and public health management approaches. The clinicians need to be more actively involved in the future chronic care policy development processes. Clinicians being part of the policy development process will enable them to support the design of a multidisciplinary chronic care delivery model, implement a chronic care prevention framework, and optimise the clinical value through the implementation of a CDM register. There is a need to address the management and governance framework of service units for clear statements on authority, and roles for coordinated functions. This relates to other findings in relation to optimising clinical leadership in chronic care.

At this current stage, ACT Health needs to focus on the development of appropriate chronic care performance indicators to get equal attention on a par with the emergency

department or acute care reporting. This may require ad hoc audits to report patient level outcomes (which the register facilitates) along with some process indicators to track chronic care interventions. The variables of a CDM register are a set of chronic care performance indicators for the chronic conditions of interest. However, the service delivery units need to buy into the concept. A mature CDM register will be able to report on the variations in the implementation of evidence-based guidelines. It will also facilitate further clinical research to explore the clinical basis of such variations, and modify existing guidelines, if needed.

Another important policy context that emerged is the need to strengthen the care planning intervention. Care planning processes activate and empower patients and their carers. The research explored some reasons for inadequate implementation of care planning intervention. Care planning processes require revision for more simplicity and outcome oriented processes. The incentives and regulations for chronic care require further evaluation to support providers to implement care planning interventions to achieve patient care goals.

The CDMCN took initiatives to standarise the referral form and protocols to document relevant patient assessment notes, which may enhance communication between service units. In hospital settings, the patient discharge planning process also needs standardisation in relation to documentation and to further assist patient care planning and follow-up. This will support generating reasonable patient level data for a CDM register. This will in turn contribute to building patients' capacity to self-manage, and strengthen multidisciplinary coordinated care.

Future electronic communication portals will replace the existing bureaucratic and paper-based communication environment. The electronic environment will connect patients with the community level providers and specialised service units. This will

streamline appointment systems, thus supporting the patients' journey within the continuum of the health system, and saving time through from reducing duplication of patient assessments.

ACT Health's clinical data repository agenda is a timely initiative. This unified clinical data portal will facilitate clinical decision making and service planning in service units. However, the privacy and confidentiality of patient data is a complex issue. ACT Health has its current policies on sharing patients' clinical data, which may require more clarification to implement a future electronic health record agenda under the national e-Health strategy. The strategy has identified this area to facilitate uncomplicated data access policies covering privacy and confidentiality issues. Nevertheless, the policy environment around the governance of clinical data is important for the implementation of a CDM register.

ACT Health has reasonable policy strengths in chronic care. It is ready to implement evidence-based chronic care interventions and a CDM register. The above-mentioned considerations can reinforce translation of chronic care policies into practice.

8.6 Areas for further research

In most healthcare settings, ACIC surveys in series are used to track quality improvements in chronic care interventions. The ACIC survey results of this research provide the baseline data about the status of chronic care of ACT Health. ACT Health can conduct follow on ACIC surveys to track quality improvements in chronic care, and evaluate the outcomes of existing chronic care interventions. The ACIC results can make stronger and validated results with the use of PACIC survey, when conducted simultaneously. The PACIC instrument has same basic structure of an ACIC

instrument in accordance with the CCM framework. These two surveys have complementary roles to achieve better understandings about the status of chronic care, and issues around chronic care programs.

In this research, the factor analysis identified a novel 'patient empowerment' sub-scale from the original list of ACIC variables. This new component or factor is important for this particular regional health system. The type of analysis for the survey has not previously been reported. In my study I used SCIPPS qualitative data to get insights about patients' and carers' experiences. The findings of SCIPPS data helped me to understand and interpret ACIC results. This has provided some level of validation of the patient empowerment sub-scale result of the ACIC survey. This patient empowerment sub-scale can now be considered as an additional ACIC sub-scale to measure for organisations using the ACIC survey to track implementation of CCM framework.

In the system requirement analysis, I developed a use case for a CDM register within the existing information management framework. There is scope to elaborate more use cases to explain data interfaces for data from various sources. The use cases for each primary data custodian will help understand data type, its features, completeness, and linkages. The wider application of the use case model could draw out more specific requirements and pathways, and simplify data management processes. This is very specific to system development, but will enrich the features and uses of a CDM register.

ACT Health may use the evaluation criteria the research identified, to evaluate its expected outcomes. Finally, the evaluation of a CDM register will bring forth its importance in improving the quality of life of patients with chronic diseases, and efficiency of chronic care interventions.

8.7 Concluding remarks

Despite the accepted limitation of the study methods, this study investigated the opportunities to implement a CDM register in the ACT Health regional health system. I have given adequate attention, and collated data to reflect my knowledge gained from a literature review on CDM and its challenges. In view of that, I conducted primary and intermediate data analysis to get insights into the data elements, and system requirement for a CDM register.

With the change in demography and aging of the population in Australia, chronic diseases are a growing challenge. There have been considerable improvements in reducing mortality from chronic diseases, for example cancer, chronic heart and lung diseases. However, the incidence of DM2 is increasing with end stage kidney diseases. Regardless of the strengths of ACT Health, continuity of chronic care and tracking progress of patients with chronic conditions are major concerns. The reasons are complex and multifactorial. In this research I presented some determinants in relation to the implementation of a chronic care program from the health system and patients' perspectives. The results show relationships between current policies, patients' and carers' expectations, and health system needs. The chronic diseases strategy is part of the health policies and links broader public policies, so outcome-focused CDM interventions will be useful not only to the health policy makers but to other social and economic policy makers in Australia. The CDM register has the ability to drive changes in this regard.

ACT Health is committed to improving chronic care program outcomes within the supportive policy environment. By moving beyond simply identifying the issues and

challenges, the thesis provides some new and fundamental insights into the development and implementation of a CDM register incorporating expectations from health professionals, patients with chronic diseases and their carers.

The implementation of a CDM register within regional health service settings will allow its implementation for a population defined by service use. The evaluation of this system initiative will support future implementation of e-Health initiatives, and help make progress toward full implementation of Wagner's CCM framework.

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Appendix 1

A study to guide the design and implementation of a chronic disease management register in a regional health service

Participant Information Sheet

Background

We are investigating how to design a chronic disease register. This type of register is a list of patients with chronic diseases. It includes information on the diseases they have and the services they have received. It is used to alert their health care providers about gaps in the care they provide, and to track the quality of care received by the group of people on the register.

Care for people with chronic disease is a major challenge confronting the health system. 77% of Australians report one or more long-term health problems and more than half of those aged 65 years and older have five or more conditions.1 Disease management programs for chronic care have improved considerably, however healthcare organisations are still not adequately equipped for consistent communication between caregivers to deliver optimum care.2 A chronic disease management register is a central feature of the chronic care model3 that ACT Health has adapted.[4] Registers are a proven method to monitor and benchmark clinical data and to facilitate improved healthcare performance.[5]

As yet, there is no agreement on the ideal design of a chronic disease management register. Most existing registers were developed initially as research resources, so they have some limitations. These include: lack of timely reporting; a variable approach to how they are managed; and variable approaches to data analysis.[5, 6]

The Study

The purpose of this research is to explore how to best design and implement a chronic disease management register in ACT Health. We expect the findings to be relevant to other regional health services in Australia and perhaps other countries.

You are invited to participate in this research project. Part of the research is to collect your opinions and recommendations. Your participation in the project will be a valuable contribution to working out how to improve the management of people with chronic disease. By signing the consent form you grant permission for your views and ideas to be used for analysis in this research.

Confidentiality

All information that you provide will be kept confidential. Arrangements will be in place for confidential transcription of the interviews and all responses will be de-identifed. All interviews will be conducted in privacy. All records, transcripts, tapes and digital data will be stored securely within the research offices and archive rooms of ANU College of Medicine, Biology and Environment. In any publication, information will be provided in such a way that you cannot be identified and will be presented only using broad characteristics.

The Research Team

The research investigators, Dominic Robin Guda (PhD student at the ANU Medical School) and Associate Professor Paul Dugdale (Director Chronic Disease Management, ACT Health), will do the primary analysis of the data. Dr Brian Richards (Visiting Fellow, ANU Centre for Health Stewardship) and Dr Sue Evans (Associate Director, Centre of Research Excellence in Patient Safety) will assist in the supervision of the research. This research project is part of a broader research program being conducted by the Centre for Research Excellence in Patient Safety (ANU and Monash University).

If you have any questions, comments or ideas, we would be pleased to hear from you. For further information please contact Dominic Robin Guda on 04 1224 2035 or robin.guda@anu.edu,au and Associate Professor Paul Dugdale on 02 6244 3976 or paul.dugdale@act.gov.au.

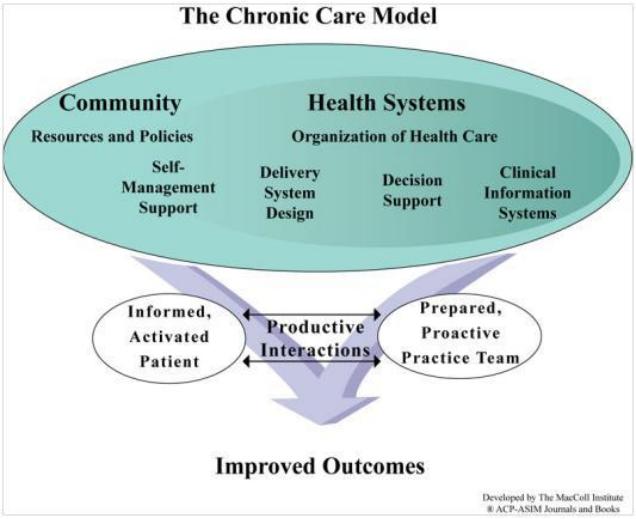
If you have any problems or queries about the way in which this study is being carried out and you do not feel comfortable communicating with the research team, please contact: ACT Health Human Research Ethics Committee, Level 3, 11 Moore Street, Canberra, ACT 2601 Telephone 6205 0846.

Glossary

What is chronic disease management?
Chronic disease management (CDM) is the totality of care provided for a patient's chronic diseases, by health professionals, the patient themselves and their carers.

What chronic diseases are being studied?
Chronic diseases are illnesses that are prolonged, do not resolve spontaneously, and are rarely cured completely.[7] In this research diabetes type 2, chronic heart failure and chronic lung diseases are our main focus.

What is the chronic care model?
The chronic care model was developed by Edward Wagner and colleagues at the MacColl Institute for Healthcare Innovation in Seattle. The model identifies the essential elements of a health care system that encourage high-quality chronic disease care. These are: (1) resources and policies, (2) the organisation of health care, (3) self-management support, (4) delivery system design, (5) decision support, and (6) clinical information systems. A CDM register is a key part of these clinical information systems.



What is a register?
In this research, the term 'register' is applied to a database of patient information for a specific group of patients. Population-based registers are commonly used for epidemiological studies. Service specific registers of the type being investigated in this research project can be used for service improvement activities, as a source of data for case control studies, and benchmarking quality of care between services.[8]

What survey instrument is being used?
In this research we are using the Assessment of Chronic Illness Care (ACIC version 3.5) survey.[9] The ACIC survey is a validated tool to assess and help health organisations move toward best practice in chronic disease management. The survey was developed by the MacColl Institute for Healthcare Innovation specifically to assist healthcare organisations improve the chronic care they provide.

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Appendix 2

Consent Form to Participate in the Chronic Disease Management Register Research Project

I, _____
(Name of participant)

of _____ _____ _____
(Department) (Division) (Organisation)

have been asked to consent to my participation in a research project entitled:

"A study to guide the design and implementation of a chronic disease management register in a regional health service"

In relation to this project I have read the Participant Information Sheet and have been informed of the
following points:

1. Approval has been given by the ACT Health Human Research Ethics Committee.
2. The aim of the project is to is to explore how to best design and implement a chronic disease management register in a regional health service (ACT Health) to improve chronic disease management.
3. Should I have any problems or queries about the way in which the study was conducted, and I do not feel comfortable contacting the research staff, I am aware that I may contact ACT Health Human Research Ethics Committee, Level 3, 11 Moore Street, Canberra, ACT 2601 Telephone +6205 0846.
4. I can refuse to take part in this project or withdraw from it at any time.
5. As part of the research, my opinions and recommendations will be documented and audio taped. All records, transcripts, tapes and digital data will be kept confidentially and only used by the members of the research team for the purposes of the research..
6. I understand that the results of the research will be made accessible through research reports and publications, and that my involvement and my identity will not be revealed.

After considering all these points, I accept the invitation to participate in this project.

Date: _____ **Witness:** _____
(Please print name)

Signature: _____ _____
(of participant/volunteer) (of witness)

Investigator's Signature: _____

Appendix 3

Assessment of Chronic Illness Care
Version 3.5

Please complete the following information about you and your organisation, and return it and the consent form in the envelope provided via ACT Health internal mail by **DATE**.

This information will not be disclosed to anyone besides this research. We would like to get your phone number and e-mail address in the event that we need to contact you/your team in the future. Please also indicate the names of persons (e.g., team members) who complete the survey with you. Later on in the survey, you will be asked to describe the process by which you complete the survey.

Your name:	**Date:** _____/_____/_____ Month Day Year
Organisation & Address:	**Names of other persons completing the survey with you:**
	1.
	2.
	3.
Your phone number: (_____) __ __ __ - __ __ __ __	**Your e-mail address:**

Directions for Completing the Survey

This survey is designed to help systems and provider practices move toward the "state-of-the-art" in managing chronic illness. The results can be used to help your team identify areas for improvement. Instructions are as follows:

1. **Answer each question** from the perspective of one physical site (e.g., a practice, clinic, hospital, health plan) that supports care for chronic illness.

   Please provide name and type of site (e.g., The Canberra Hospital)
   _____

2. **Answer each question** regarding how your organisation is doing with respect to one disease or condition.

   Please specify condition _____

For each row, **circle the point value** that best describes the level of care that currently exists in the site and condition you chose. The rows in this form present key aspects of chronic illness care. Each aspect is divided into levels showing various stages in improving chronic illness care. The stages are represented by points that range from 0 to 11. The higher point values indicate that the actions described in that box are more fully implemented.

3. Place the completed survey and consent form in the addressed envelope provided and return via ACT Health internal mail.

For further information about the survey, please contact:

Dominic Robin Guda
PhD Candidate
ANU Center for Health Stewardship
ANU College of Medicine and Health Sciences
The Australian National University
Tel: 04 1224 2035
Email: robin.guda@anu.edu.au

Assessment of Chronic Illness Care, Version 3.5

Part 1: Organisation of the Healthcare Delivery System. Chronic illness management programs can be more effective if the overall system (organisation) in which care is provided is oriented and led in a manner that allows for a focus on chronic illness care.

Components	Level D	Level C	Level B	Level A
Overall Organisational Leadership in Chronic Illness Care	…does not exist or there is a little interest.	…is reflected in vision statements and business plans, but no resources are specifically earmarked to execute the work.	…is reflected by senior leadership and specific dedicated resources (dollars and personnel).	…is part of the system's long term planning strategy, receive necessary resources, and specific people are held accountable.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Organisational Goals for Chronic Care	…do not exist or are limited to one condition.	…exist but are not actively reviewed.	…are measurable and reviewed.	…are measurable, reviewed routinely, and are incorporated into plans for improvement.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Improvement Strategy for Chronic Illness Care	…is ad hoc and not organised or supported consistently.	…utilizes ad hoc approaches for targeted problems as they emerge.	…utilizes a proven improvement strategy for targeted problems.	…includes a proven improvement strategy and uses it proactively in meeting organisational goals.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Incentives and Regulations for Chronic Illness Care	…are not used to influence clinical performance goals.	…are used to influence utilization and costs of chronic illness care.	…are used to support patient care goals.	…are used to motivate and empower providers to support patient care goals.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Senior Leaders	…discourage enrollment of the chronically ill.	…do not make improvements to chronic illness care a priority.	…encourage improvement efforts in chronic care.	…visibly participate in improvement efforts in chronic care.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Benefits	…discourage patient self-management or system changes.	…neither encourage nor discourage patient self-management or system changes.	…encourage patient self-management or system changes.	…are specifically designed to promote better chronic illness care.
Score	0 1 2	3 4 5	6 7 8	9 10 11

Office use only.	**Total Health Care Organisation Score _____**	**Average Score (Health Care Org. Score /6) _____**

Part 2: Community Linkages. Linkages between the health delivery system (or provider practice) and community resources play important roles in the management of chronic illness.

Components	Level D	Level C	Level B	Level A
Linking Patients to Outside Resources	…is not done systematically.	…is limited to a list of identified community resources in an accessible format.	…is accomplished through a designated staff person or resource responsible for ensuring providers and patients make maximum use of community resources.	… is accomplished through active coordination between the health system, community service agencies and patients.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Partnerships with Community Organisations	…do not exist.	…are being considered but have not yet been implemented.	…are formed to develop supportive programs and policies.	…are actively sought to develop formal supportive programs and policies across the entire system.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Regional Health Plans	…do not coordinate chronic illness guidelines, measures or care resources at the practice level.	…would consider some degree of coordination of guidelines, measures or care resources at the practice level but have not yet implemented changes.	…currently coordinate guidelines, measures or care resources in one or two chronic illness areas.	…currently coordinate chronic illness guidelines, measures and resources at the practice level for most chronic illnesses.
Score	0 1 2	3 4 5	6 7 8	9 10 11

Office use only.	**Total Community Linkages Score _____**	**Average Score (Community Linkages Score / 3) _____**

Part 3: Practice Level. Several components that manifest themselves at the level of the individual provider practice (e.g. individual clinic) have been shown to improve chronic illness care. These characteristics fall into general areas of self-management support, delivery system design issues that directly affect the practice, decision support, and clinical information systems.

Part 3a: Self-Management Support. Effective self-management support can help patients and families cope with the challenges of living with and treating chronic illness and reduce complications and symptoms.

Components	Level D	Level C	Level B	Level A
Assessment and Documentation of Self-Management Needs and Activities	…are not done.	…are expected.	…are completed in a standardised manner.	…are regularly assessed and recorded in standardised form linked to a treatment plan available to practice and patients.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Self-Management Support	…is limited to the distribution of information (pamphlets, booklets).	…is available by referral to self-management classes or educators.	…is provided by trained clinical educators who are designated to do self-management support, affiliated with each practice, and see patients on referral.	…is provided by clinical educators affiliated with each practice, trained in patient empowerment and problem-solving methodologies, and see most patients with chronic illness.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Addressing Concerns of Patients and Families	…is not consistently done.	…is provided for specific patients and families through referral.	…is encouraged, and peer support, groups, and mentoring programs are available.	…is an integral part of care and includes systematic assessment and routine involvement in peer support, groups or mentoring programs.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Effective Behavior Change Interventions and Peer Support	…are not available.	…are limited to the distribution of pamphlets, booklets or other written information.	…are available only by referral to specialized centers staffed by trained personnel.	…are readily available and an integral part of routine care.
Score	0 1 2	3 4 5	6 7 8	9 10 11

Office use only.	**Total Self-Management Score _____**	**Average Score (Self-management Score /4) _____**

Part 3b: Decision Support. **Effective chronic illness management programs assure that providers have access to evidence-based information necessary to care for patients--decision support. This includes evidence-based practice guidelines or protocols, specialty consultation, provider education, and activating patients to make provider teams aware of effective therapies.**

Components	**Level D**	**Level C**	**Level B**	**Level A**
Evidence-Based Guidelines	…are not available.	…are available but are not integrated into care delivery.	…are available and supported by provider education.	…are available, supported by provider education and integrated into care through reminders and other proven provider behavior change methods.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Involvement of Specialists in Improving Primary Care	…is primarily through traditional referral.	…is achieved through specialist leadership to enhance the capacity of the overall system to routinely implement guidelines.	…includes specialist leadership and designated specialists who provide primary care team training.	…includes specialist leadership and specialist involvement in improving the care of primary care patients.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Provider Education for Chronic Illness Care	…is provided sporadically.	…is provided systematically through traditional methods.	…is provided using optimal methods (e.g. academic detailing).	…includes training all practice teams in chronic illness care methods such as population-based management, and self-management support.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Informing Patients about Guidelines	…is not done.	…happens on request or through system publications.	…is done through specific patient education materials for each guideline.	…includes specific materials developed for patients which describe their role in achieving guideline adherence.
Score	0 1 2	3 4 5	6 7 8	9 10 11

Office use only.	**Total Decision Support Score _____**	**Average Score (Decision Support Score / 4) _____**

Part 3c: Delivery System Design. **Evidence suggests that effective chronic illness management involves more than simply adding additional interventions to a current system focused on acute care. It may necessitate changes to the organisation of practice that impact provision of care.**

Components	Level D	Level C	Level B	Level A
Practice Team Functioning	…is not addressed.	…is addressed by assuring the availability of individuals with appropriate training in key elements of chronic illness care.	…is assured by regular team meetings to address guidelines, roles and accountability, and problems in chronic illness care.	…is assured by teams who meet regularly and have clearly defined roles including patient self-management education, proactive follow-up, and resource coordination and other skills in chronic illness care.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Practice Team Leadership	…is not recognized locally or by the system.	…is assumed by the organisation to reside in specific organisational roles.	…is assured by the appointment of a team leader but the role in chronic illness is not defined.	…is guaranteed by the appointment of a team leader who assures that roles and responsibilities for chronic illness care are clearly defined.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Appointment System	…can be used to schedule acute care visits, follow-up and preventive visits.	…assures scheduled follow-up with chronically ill patients.	…are flexible and can accommodate innovations such as customized visit length or group visits.	…includes organisation of care that facilitates the patient seeing multiple providers in a single visit.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Follow-up	…is scheduled by patients or providers in an ad hoc fashion.	…is scheduled by the practice in accordance with guidelines.	…is assured by the practice team by monitoring patient utilization.	…is customized to patient needs, varies in intensity and methodology (phone, in person, email) and assures guideline follow-up.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Planned Visits for Chronic Illness Care	…are not used.	…are occasionally used for complicated patients.	…are an option for interested patients.	…are used for all patients and include regular assessment, preventive interventions and attention to self-management support.
Score	0 1 2	3 4 5	6 7 8	9 10 11

Components	Level D	Level C	Level B	Level A
Continuity of Care	…is not a priority.	…depends on written communication between primary care providers and specialists, case managers or disease management companies.	…between primary care providers and specialists and other relevant providers is a priority but not implemented systematically.	…is a high priority and all chronic disease interventions include active coordination between primary care, specialists and other relevant groups.
Score	0 1 2	3 4 5	6 7 8	9 10 11

(From Previous Page)

Office use only.	**Total Delivery System Design Score _____**	**Average Score (Delivery System Design Score / 6) _____**

Part 3d: Clinical Information Systems. Timely, useful information about individual patients and populations of patients with chronic conditions is a critical feature of effective programs, especially those that employ population-based approaches.[7, 8]

Components	Level D	Level C	Level B	Level A
Registry (list of patients with specific conditions)	…is not available.	…includes name, diagnosis, contact information and date of last contact either on paper or in a computer database.	…allows queries to sort sub-populations by clinical priorities.	…is tied to guidelines which provide prompts and reminders about needed services.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Reminders to Providers	…are not available.	… include general notification of the existence of a chronic illness, but does not describe needed services at time of encounter.	…includes indications of needed service for populations of patients through periodic reporting.	…includes specific information for the team about guideline adherence at the time of individual patient encounters.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Feedback	…is not available or is non-specific to the team.	…is provided at infrequent intervals and is delivered impersonally.	…occurs at frequent enough intervals to monitor performance and is specific to the team's population.	…is timely, specific to the team, routine and personally delivered by a respected opinion leader to improve team performance.
Score	0 1 2	3 4 5	6 7 8	9 10 11

Components	Level D	Level C	Level B	Level A
Information about Relevant Subgroups of Patients Needing Services	…is not available.	…can only be obtained with special efforts or additional programming.	…can be obtained upon request but is not routinely available.	…is provided routinely to providers to help them deliver planned care.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Patient Treatment Plans	…are not expected.	…are achieved through a standardised approach.	…are established collaboratively and include self-management as well as clinical goals.	…are established collaborative an include self-management as well as clinical management. Follow-up occurs and guides care at every point of service.
Score	0 1 2	3 4 5	6 7 8	9 10 11

(From Previous Page)

Office use only.	**Total Clinical Information System Score _____**	**Average Score (Clinical Information System Score / 5) _____**

Integration of Chronic Care Model Components. Effective systems of care integrate and combine all elements of the Chronic Care Model; e.g., linking patients' self-management goals to information systems/registries.

Components	Little support	Basic support	Good support	Full support
Information Systems/Databases	…do not include patient self-management goals.	…include results of patient assessments (e.g., functional status rating; readiness to engage in self-management activities), but no goals.	…include results of patient assessments, as well as self-management goals that are developed using input from the practice team/provider and patient.	…include results of patient assessments, as well as self-management goals that are developed using input from the practice team and patient; and prompt reminders to the patient and/or provider about follow-up and periodic re-evaluation of goals.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Community Programs	…do not provide feedback to the health care system/clinic about patients' progress in their programs.	…provide sporadic feedback at joint meetings between the community and health care system about patients' progress in their programs.	…provide regular feedback to the health care system/clinic using formal mechanisms (e.g., Internet progress report) about patients' progress.	…provide regular feedback to the health care system about patients' progress that requires input from patients that is then used to modify programs to better meet the needs of patients.
Score	0 1 2	3 4 5	6 7 8	9 10 11

Components	Little support	Basic support	Good support	Full support
Organisational Planning for Chronic Illness Care	…does not involve a population-based approach.	…uses data from information systems to plan care.	…uses data from information systems to proactively plan population-based care, including the development of self-management programs and partnerships with community resources.	…uses systematic data and input from practice teams to proactively plan population-based care, including the development of self-management programs and community partnerships, that include a built-in evaluation plan to determine success over time.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Routine follow-up for appointments, patient assessments and goal planning	…is not ensured.	is sporadically done, usually for appointments only.	is ensured by assigning responsibilities to specific staff (e.g., nurse case manager).	is ensured by assigning responsibilities to specific staff (e.g., nurse case manager) who uses the registry and other prompts to coordinate with patients and the entire practice team.
Score	0 1 2	3 4 5	6 7 8	9 10 11
Guidelines for chronic illness care	…are not shared with patients.	…are given to patients who express a specific interest in self-management of their condition.	…are provided for all patients to help them develop effective self-management or behavior modification programs, and identify when they should see a provider.	…are reviewed by the practice team with the patient to devise a self-management or behavior modification program consistent with the guidelines that takes into account patient's goals and readiness to change.
Score	0 1 2	3 4 5	6 7 8	9 10 11

(From Previous Page)

Office use only.	**Total Integration Score (SUM items): _____**	**Average Score (Integration Score/5) = _____**

Briefly describe the process you used to fill out the form (e.g., reached consensus in a face-to-face meeting; filled out by the team leader in consultation with other team members as needed; each team member filled out a separate form and the responses were averaged).

Description: _____

Office use:	
Scoring Summary	
(Bring forward scoring at end of each section to this page)	
Total Org. of Health Care System Score	_____
Total Community Linkages Score	_____
Total Self-Management Score	_____
Total Decision Support Score	_____
Total Delivery System Design Score	_____
Total Clinical Information System Score	_____
Total Integration Score	_____
Overall Total Program Score (Sum of all scores)	_____
Average Program Score (Total Program /7)	_____

What does it mean?
The ACIC is organised such that the highest "score" (an "11") on any individual item, subscale, or the overall score (an average of the six ACIC subscale scores) indicates optimal support for chronic illness. The lowest possible score on any given item or subscale is a "0", which corresponds to limited support for chronic illness care. The interpretation guidelines are as follows:

Between "0" and "2" = limited support for chronic illness care
Between "3" and "5" = basic support for chronic illness care
Between "6" and "8" = reasonably good support for chronic illness care
Between "9" and "11" = fully developed chronic illness care

It is fairly typical for teams to begin a collaborative with average scores below "5" on some (or all) areas the ACIC. After all, if everyone was providing optimal care for chronic illness, there would be no need for a chronic illness collaborative or other quality improvement programs. It is also common for teams to initially believe they are providing better care for chronic illness than they actually are. As you progress in the Collaborative, you will become more familiar with what an effective system of care involves. You may even notice your ACIC scores "declining" even though you have made improvements; this is most likely the result of your better understanding of what a good system of care looks like. Over time, as your understanding of good care increases and you continue to implement effective practice changes, you should see overall improvement on your ACIC scores.

Appendix 4

Chief Executive
Level 3, 11 Moore Street, Canberra City ACT 2601
GPO Box 825 Canberra ACT 2601
Phone: (02) 6205 0825 Fax: (02) 6205 0830
Website: www.health.act.gov.au
ABN: 82 049 056 234

(Correspondent)
(Address)

Dear (Correspondent)

In response to the increasing burden of chronic disease in the ACT, ACT Health developed the ACT Chronic Disease Strategy 2008-2011 to support individual living with chronic disease.

An important part of the strategy is the development of a Chronic Disease Management Register, which will provide data to drive quality improvements, and facilitate increased communication and coordination by care providers.

To enable optimum implementation of the Register, researchers from the ACT node of the Australian Centre for Research Excellence in Patient Safety, Associate Professor Dugdale and PhD scholar Dr Guda, are assessing the ACT Health's capacity and readiness for a Chronic Disease Management Register. The enclosed survey is part of this research.

Participating in this research by completing the enclosed survey ensures your views and experiences are represented in the research results and provides you with the opportunity to contribute to improvements in chronic disease management for the patients of ACT Health.

I encourage you to complete and return the enclosed survey within the next week to the Chronic Disease Management Unit.

Yours sincerely

Mark Cormack
Chief Executive

2 February 2009

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Appendix 5

CANBERRA HOSPITAL
A division of ACT Health

Survey Resource Group
Research Office
Canberra Hospital
Yamba Drive, Garran ACT 2605
PO Box 11 Woden ACT 2606
Phone: (02) 6244 4043 Fax: (02) 6285 3020
Website: www.health.act.gov.au

Dr Zsuzsoka Kecskes
Chair
Survey Resource group
Canberra Hospital

To: Mr Dominic Robin Guda

Date 7th January 2009

Approval of survey: **Service Specific Chronic Disease Registers to Improve Chronic Disease Management Interventions in Public Sector Health Services**

Dear Mr Guda,

Thank you for submitting your survey to the Survey Resource Group of the Canberra Hospital.
On behalf of the Group, I am pleased to advise you that the survey has been approved.

For your information:

Please notify the committee of any changes you make to your survey during the course of your study.

The validity of the current approval is 2 years maximum from the date of this letter.

Please submit a brief report to the Survey Resource Group when you complete or cease working on the survey.

On behalf of the group, I would like to wish you all the best with your study.

Yours sincerely

Zsuzsoka Kecskes, Dr med FRACP PhD

Chair Survey Resource Group
Clinical Director, Department of Neonatology
Associate Professor
Australian National University Medical School
The Canberra Hospital, Woden, ACT, 2605
Australia
Tel: (02) 6244 4056
Fax: (02) 6244 3112
E-mail: zsuzsoka.kecskes@act.gov.au

Appendix 6

ACT Health Human Research Ethics Committee
Level 2, 11 Moore Street, Canberra City ACT 2601
GPO Box 825 Canberra ACT 2601
Phone: 02 6205 8223 Fax: 02 6205 1884
Website: www.health.act.gov.au
ABN: 82 049 056 234

File No: ETH.1/09.111

Robin Guda,
PHD Student
Centre for Health Stewardship
ANU College of Medicine Biology and Environment
Medical School
The Australian National University
ACT 0200

Dear Mr Guda

Thank you for your letter of 25 may 2009 addressing the concerns raised by the Committee in respect of the proposed:

(Low Risk) Service Specific Chronic Disease registers to Improve Chronic Disease Management Interventions in Public Health Services.

Ethics Committee Submission No ETH.1/09.111 refers.

I am pleased to advise you that the study has received out of session approval, including the:

- Assessment of Chronic Illness Care (Version 3.5);
- Key Informant Interview Schedule

I attach for your records an Outcome of Consideration of Protocol form.

I confirm that the ACT Health Human Research Ethics Committee is constituted according to the National Health and Medical Research Council Guidelines and operates in compliance with applicable regulatory requirements and the International Conference on Harmonization Guidelines on Good Clinical Practice.

You may recall that the ACT Health Guidelines for Submission of Application require you to complete payment of the levy when approved by the Ethics Committee.

Please forward **$27.50** levy fee to the Secretariat, ACT Health Human Research Ethics Committee, GPO Box 825, Canberra ACT 2601 as soon as possible. An invoice is attached for your attention.

A copy of your application will be sent to ACT Insurance Authority for consideration. Please note that this may take up to four weeks for more complex matters.

The study cannot commence until you receive written approval from the Insurance and Legal Liaison Manager, Mr Simon Fenton, who can be contacted on (02) 620 50928. Any enquiries regarding insurance matters must be addressed to Mr Fenton.

Yours sincerely

Dr Elizabeth Grant AM, Hon LLD *Monash*
Chair
Ethics Committee

27 May 2009

Appendix 7

THIS IS A SYSTEM-GENERATED E-MAIL. PLEASE DO NOT REPLY. SEE BELOW FOR E-MAIL CONTACT DETAILS.

Dear Mr Dominic Robin Guda,

Protocol: 2008/428

A study to guide the design and implementation of a chronic disease management register in a regional health service

I am pleased to advise you that your Human Ethics protocol received approval by the Deputy Chair of the HREC on 05/06/2009.

For your information:

1. Under the NHMRC/AVCC National Statement on Ethical Conduct in Human Research we are required to follow up research that we have approved. Once a year (or sooner for short projects) we shall request a brief report on any ethical issues which may have arisen during your research or whether it proceeded according to the plan outlined in the above protocol.

2. Please notify the committee of any changes to your protocol in the course of your research, and when you complete or cease working on the project.

3. Please notify the Committee immediately if any unforeseen events occur that might affect continued ethical acceptability of the research work.

4. The validity of the current approval is five years' maximum from the date shown approved. For longer projects you are required to seek renewed approval from the Committee.

All the best with your research,

Kim

Ms Kim Tiffen
Ethics Manager
Office of Research Integrity
Research Office
Chancelry 10B
The Australian National University
ACTON ACT 0200
T: +61 2 6125 3427
F: +61 2 6125 4807
Kim.Tiffen@anu.edu.au or
human.ethics.officer@anu.edu.au
http://anu.edu.au/ro/ORI/Human/human_index.php

CRISCOS Provider Code: 00120C

Appendix 8

ICD–10–AM codes for case definitions:

Chronic Obstructive Pulmonary Disease			
	ICD code		**Definition**
Includes	J40		Bronchitis not spec as acute or chronic
	J41		Simple & mucopurulent chronic bronchitis
	J42		Unspecified chronic bronchitis
	J43		Emphysema
		J43.2	Centrilobular emphysema
		J43.9	Emphysema, unspecified Unspecified chronic bronchitis
	J44		Other COPD
		J44.0	COPD with acute lower resp infection
		J44.1	COPD with acute exacerbation unspecified
		J44.8	Other specified COPD
		J44.9	COPD unspecified
Excludes	J45		Asthma
	J46		Status asthmaticus
	J47		Bronchiectasis
Diabetes			
Includes	E10	E10.00	Insulin-dependent diabetes mellitus with coma, not stated as uncontrolled
		E10.01	Insulin-dependent diabetes mellitus with coma, stated as uncontrolled
		E10.10	Insulin-dependent diabetes mellitus with ketoacidosis, not stated as uncontrolled
		E10.60	Insulin-dependent diabetes mellitus with other specified complications, not stated as uncontrolled
		E10.70	Insulin-dependent diabetes mellitus with multiple complications, not stated as uncontrolled
		E10.80	Insulin-dependent diabetes mellitus with unspecified complications, not stated as uncontrolled
		E10.81	Insulin-dependent diabetes mellitus with unspecified complications, stated as uncontrolled
		E10.90	Insulin-dependent diabetes mellitus without complications, not stated as uncontrolled
		E10.91	Insulin-dependent diabetes mellitus without complications, stated as uncontrolled
			Excludes IDDM malnutrition related, neonatal, pregnancy childbirth and the puerperium
	E11		Non-insulin-dependent diabetes mellitus
	E13		Other specified diabetes mellitus (excluding IDDM)
	E14		Unspecified diabetes mellitus
Excludes	E12		Malnutrition-related diabetes mellitus

Chronic Heart Failure		
Includes		
	I11.0	Hypertensive heart failure
	I25.5	Ischemic cardiomyopathy
	I42	Cardiomyopathy
	I50	Heart failure
	I13.0	Hypertensive heart and renal disease with (congestive) heart failure
	I13.2	Hypertensive heart and renal disease with both (congestive) heart failure and renal failure
	I43	Cardiomyopathy in diseases classified elsewhere
Excludes		
	I51	Complications and ill-defined descriptions of heart disease
	I25	Chronic ischaemic heart disease (bucket code)
	I44	Atrioventricular and left bundle-branch block
	I97.1	Other functional disturbances following cardiac surgery
	I45	Other conduction disorders
	I46	Cardiac arrest
	I47	Paroxysmal tachycardia
	I48	Atrial fibrillation and flutter
	I49	Other cardiac arrhythmias
	I52	Other heart disorders in diseases classified elsewhere
	I20	Angina pectoris
	I21	Acute myocardial infarction
	I22	Subsequent myocardial infarction
	I23	Certain current complications following acute myocardial infarction
	I24	Other acute ischaemic heart diseases

Appendix 9

Round Table: Epidemiology & health policy

Considerations in the design of service specific chronic disease management registers

Robin Guda, Paul Dugdale, Sue Evans and John McNeil

Centre for Research Excellence in Patient Safety Research, Department of Epidemiology and Preventive Medicine, Monash University, Melbourne, Australia

Email: robin.guda@anu.edu.au

In Australia chronic diseases currently account for 70% of the total burden of ill health and a correspondingly high proportion of health care expenditure. Even with recent improvements in chronic disease management, there is a significant gap between recommended and actual treatment, care coordination and provision of supports for self management. In Wagner's Chronic Care Model, a chronic disease management register can facilitate individual and population management of chronic diseases and help build partnerships for collaborative diagnosis, treatment planning and care tracking. Various chronic disease management programs currently use chronic disease management registers as a component of their clinical information management systems and there is some evidence that these have contributed to improved chronic disease management. Such registers are relatively uncommon in Australia but may soon proliferate, in part because they have been called for by the National Chronic Disease Strategy. This paper presents suggestions for optimising the utility of chronic disease registries and advancing the agenda for reform in chronic disease management in Australia.

Background

Chronic diseases are a growing problem in Australia as the population ages. They currently account for 70% of the total burden of ill health and it is projected that this will increase to 80% by 2010.[1] More than half of those aged 65 years and older have five or more conditions.[2]

Challenges facing chronic disease management

Currently in Australia and internationally, there is recognition that a significant gap exists between recommended and current management of chronic diseases. Reasons for this wide and persistent evidence-practice gap are likely complex[3] and are thought in part to be the result of a lack of proper monitoring and appropriate health system components.[4]

There are uncertainties and difficulties in the management of chronic diseases due to the natural history of the diseases with many possible causes, gradual onset, asymptomatic status of patients at diagnosis and lifelong duration.[5] Australia's chronic disease management challenges also arise from changes in demography and disease patterns: the extent of the disease burden: costs: supply and distribution of workforce, and concerns about the quality and safety of health services.[6]

Within the health care setting, chronic disease management is hampered by a lack of consistent communication among caregivers, which affects practitioners' ability to provide excellent evidence-based care.[7] Even though the quality of care provided in primary care has improved, nearly half of patients do not receive optimal care where lack of information systems and decision support systems have been identified as important factors.[8] In addition, data to monitor the extent and quality of chronic disease care are extremely variable in quality.[1]

The large gap that separates actual clinical outcomes of patients with chronic disease from optimal outcomes has spurred calls for action whatever the state of knowledge on effectiveness.[9] In terms of execution of care plans, current programs need to strengthen genuine coordination between providers and patients to increase evidence-based multidisciplinary collaborative care for patients with chronic diseases.[10]

Strategies to improve chronic disease management

A range of initiatives is required to prevent and delay the chronic diseases and reduce their health impact when they do occur.[11] There is a recognised need to reduce the impact of established disease through improvements to the processes of care and through re-design of health care arrangements to create effective and sustainable chronic disease management programs.[12] Systematic review of the literature has suggested that outcomes should be routinely assessed, provided to clinicians during the clinical encounter, and used for population-based care management.[13]

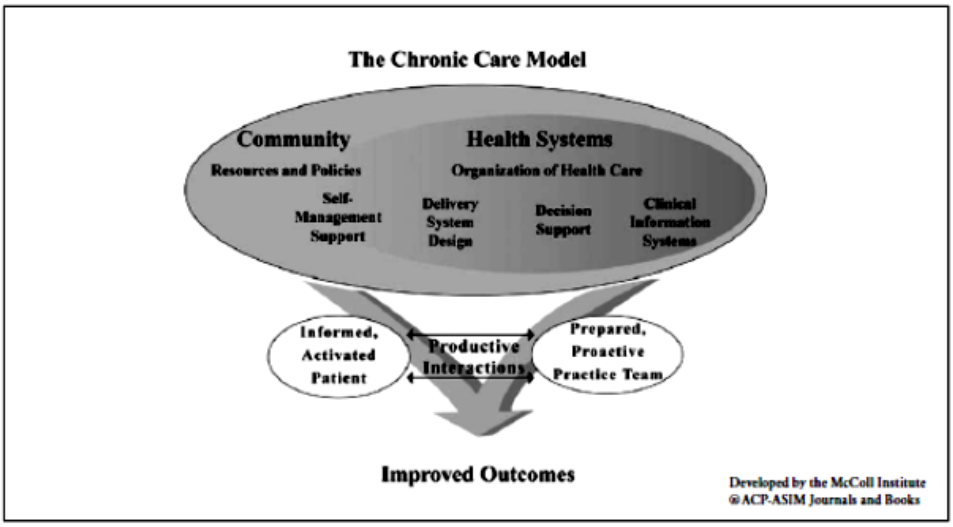
Wagner's Chronic Care Model[14] outlines a comprehensive integrated strategy to facilitate improvements in processes and outcomes of care for people with chronic diseases. In this model six areas of organisational change are discussed: (1) community resources and policies (2) health care organisation, (3) self-management support, (4) delivery system design, (5) decision support, and (6) clinical information systems (*Figure 1*).

Implementation of Wagner's Chronic Care model has been effective in some settings but has produced mixed or ineffective results in others.[15,16,17] Those organisations that have made substantial improvements in their chronic care systems through the explicit implementation of CCM elements have focused principally on improving information support and follow-up as steps to redesign the care delivery system.[18] This includes the deployment of clinical information systems which (1) remind primary care teams to comply with evidence based guidelines: (2) provide feedback to physicians about performance: and (3) facilitate the planning and conducting of individual as well as population-based care.[14]

In Boston, a safety net hospital used CCM elements to restructure and improve the service quality of cardiovascular diseases and diabetes mellitus type 2.[19] The intervention prospectively followed-up 283 patients for 39 months with the first 12 months considered as the baseline. Simple clinical indicators like measurement of HbA1c, diabetic foot examination, lipid profile, and blood pressure measurement were included to track improvements. The intervention showed an overall decrease in mean HbA1c level, more frequent measurement of HbA1c and more frequent foot examination, independent of the frequency of visits.

In another study, the Louisiana State University Health Care Services Division (HCSD) implemented chronic disease management programs at hospital and clinic complexes at eight population centres in Louisiana and used a web-enabled electronic registry to facilitate benchmarking of performance.[20] The study focussed on process and outcome improvements for adult diabetes, asthma and congestive heart failure as well as on prevention and risk factor modification. With 10 years follow-up, the study has tracked improvements in the proportion of patients achieving target levels for HbA1c, LDL and evidence based medication use including for aspirin, carvedilol or metoprolol, corticosteroids, and leukotriene modifiers.

Figure 1. Wagner's Chronic Care Model



In determining clinical and financial benefits of information technology (IT) enabled disease management programs in the US, Bu D et al conducted a 10-year computer simulation using diabetes registries, computerised clinical decision support systems (CDSS), remote monitoring and self-management technologies, and payer-sponsored technologies for diabetes management data.[21] The researchers used standard techniques and systematic review methodologies adapted from Stanford University's Evidence-Based Practice Centre. The measurement indicators were HbA1c, systolic blood pressure, cholesterol, and compliance with foot, eye and microalbuminuria screening. The simulations showed that, while all forms of IT-enabled diabetes management improved processes of care, prevented development of complications, and generated cost-of-care savings, clinical registries provided the most benefit by way of reducing risk factors and improving screening practices.

The challenge of better management of chronic disease has been well documented. However, solutions that result in demonstrable better outcomes are more elusive. While there is little level one evidence that such an intervention actually improves outcomes, there are a number of reasonably well documented examples and studies that give cause for optimism.

The role of registries in optimising chronic disease management

Clinical registries are most commonly used to monitor outcomes of people treated with defined procedures or diagnosed with acute conditions where the outcome of interest occurs relatively quickly and can be reasonably linked to quality of care within a defined episode of management. Chronic disease registries are different, in that outcomes are often very delayed and difficult to link to any particular episode of treatment. For this reason, the focus of chronic disease registries is typically on compliance with guidelines pertaining to processes of care.[22]

Chronic disease registries work by collecting high quality epidemiologically sound data to assess and compare clinical performance between contributing organisations. They can also be used to support clinical audit[1] and facilitate population health monitoring, service planning and provision.[23] Through clinical information sharing they have been used to support partnership models to improve practitioner performance in collaborative diagnosis, treatment assessment, planning and decision-making.[24] They do this by providing clinically credible data back to clinicians to drive practice improvement. Chronic disease registers as one element of a clinical information system can improve quality of care by linking clinical data with rule driven analyses to provide insights into prognosis, as well as into the effectiveness and efficiency of clinical interventions.[25] Information can also be used to design preventive interventions.[26] While they may not provide the level of evidence of randomised controlled trials, registers in clinical settings do provide an accurate account of real world clinical care.[27]

Registers linked to electronic medical records (EMR) provide a potentially powerful tool in generating comprehensive information about population problems, health history, care and outcome.[28] This requires that high quality data are collected in the EMR.

Despite recognition that disease registries can improve chronic disease management, active registers are relatively uncommon in physician organisations.[29] Where they have been developed, they have generally evolved from research activities. As such, many existing registry systems have limitations, which include lack of timely reporting; highly variable governance and data audit approaches; and incompleteness of recruitment of the eligible population.[22,30]

In recognition of gaps in current practice, Operating Principles for clinical registries have been developed.[22] These guidelines contain detailed elaboration and attributes of registry system including standardised data elements (a minimum data set); data collection; and data capture processes.

Advancing the agenda for reform in chronic disease management

As outlined in Wagner's Chronic Care Model, the advancement of chronic disease management demands an integrated approach across primary and acute care. Disparate and ineffective information systems need to be reformed and fortified to optimally support proficient service delivery.[31] In order to measure the effectiveness of strategies to improve chronic disease management, consensus clinical pathways for managing chronic diseases appropriate quality indicators need to be implemented and tested. Integral to improving chronic disease management is the need to build up the role of the patient in their own care. The current gap in knowledge regarding how clinical information systems can be used to support consumer-led care needs to be addressed.

There is a need for an overarching framework and policy direction to improve chronic disease care and prevention in Australia. The National Chronic Disease Strategy of Australia, established in 2006 provides leadership in this area.[32] It supports the development of chronic disease registers as an action component for the integration, prevention and continuity of patient care for chronic illnesses. Given this directive, more work is needed to develop chronic disease registries in Australia. For this to occur, issues such as appropriate governance and funding structures need to be resolved. Methods to optimise functional communication channels between multidisciplinary care providers, so as to support coordinated and quality chronic care need to be investigated. In addition, the development of chronic disease registers demands a responsive policy environment to manage eventualities that arise from register data analysis so as to ensure appropriate chronic illness care interventions.

Under the broad umbrella of clinical information systems, chronic disease registers act as tools to understand basic chronic disease epidemiology for the registered population. If implemented successfully, they can also support program and policy development through identification of specific problems, exploration of epidemiologically sound approaches to dealing with these problems, prioritising of action and evaluation of the effects of different interventions.[22,33]

In this article we outline the arguments, in line with the National Chronic Disease Strategy, that Chronic Disease Management Registers should be established within health services – particularly larger health services. The decision to implement chronic disease management registers is based on a strategy of improving the capacity for scientifically informed quality improvement and better coordinated management of chronic conditions.

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