A study of eHealth enhanced chronic disease management in a large regional health service

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Declaration

I declare that the thesis is my own work which contains no material previously published or written by another person, except where due reference is made in the text.

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Abstract

Background

The health care system is a dynamic environment undergoing constant change, and it has been greatly influenced by modern information and communication technology. Implementing health information technology interventions has become a priority in policy agendas internationally. Healthcare practice supported by digital technologies usually comes under the broad name of “eHealth”. Policy makers around the global have endorsed the use of eHealth technologies to improve health and health care systems. However, despite these best intentions, implementing sustainable and effective e-Health interventions within clinical settings, and in alignment with the existing health education and technology enterprises, remains a challenge.

Aim

Since the development of the Chronic Care Model (CCM) by Wagner in 1998, numerous information management systems have emerged and communication and technology advances have been established. Information and Communication Technology to support clinical care for people with chronic conditions is a particular challenge. The CCM places chronic care "in the context of the community where the person will receive health care services and with the health systems involved in that care" (Wagner 1998). This thesis focused on the adoption of eHealth enhancements of chronic care delivering to achieve effective use of eHealth tools, in a context where both health and efficiency matter. By considering the clinical information systems to accomplish easy data, information and knowledge exchange needed to improve health, and identifying good implementation strategies for eHealth interventions in chronic disease

management. This thesis takes up the challenge by examining the impact of the current establishment of eHealth interventions in chronic care to improve the CCM with clinically efficacious eHealth tools. This study investigates the use and development of certain commonly rewired eHealth tools in a regional health service. The objective is to study the implementation of eHealth enhanced chronic disease management located in a well-funded regional health service committed to the chronic care model in order to generate insights into the more meaningful use of eHealth tools in chronic care.

Setting and method

ACT Health is the largest health service provider in the ACT. The research was conducted in ACT Health and based in the Chronic Disease Management Unit (CDMU). This research project uses three interlinked case studies to address the research questions and combines observations from the case studies with the literature findings. Qualitative methods including participant observation, interview and documentary review have been used.

Results

The study gained insights into implementation of eHealth tools and consider their impact on chronic care management in the regional health service. A number of key findings emerged from this research. The findings from each of the case studies were as follows:

Case Study 1: The implementation of a Chronic Disease Management Register (CDMR) in ACT Health illustrates the user of eHealth interventions for chronic care management. Key enablers included: active support from ACT Health; technological readiness and patient-centered database design. However, the CDMR is only able to contribute to improve care

coordination in a limited way. Key barriers involve: low quality and incomplete datasets; poor technical governance; human resource constraints; inefficient data sharing and limited access; incomplete reports with limited value and a lack of communication for improvement.

Case Study 2: Integration of health care services is bound up with the eHealth transition trajectory over time. The Chronic Care Program with its goal of integrating care is dependent on transformation. The user of electronic clinical forms is an early step towards the proposed fully integrated electronic health record in ACT Health under the Australia National eHealth strategy. This development is still in its preliminary stage, so there has been limited meaningful use of data, and lack of evaluation for services performance and outcome measurement. EHealth tools that are used by the clinical team for data capture, storage and utilization require further design and development. The first step is to develop a person-centered database which is capable of electronic sharing of data within the service, to be followed in due course by integration of records within and between the primary, community and hospital service which supporting multidisciplinary care planning and shared care for chronic disease patient.

Case Study 3: There is a need to improve the use of information technology in Obesity Care in the local health service. This will allow the forthcoming suite of eHealth applications to relieve the overwhelming administrative side burden and best support the patient care they provide. The eHealth interventions demanded by clinicians involve formalization of clinical forms and patient handouts; development of an electronic filing system and development of a case management recall system.

Looking across the case studies to consider the insights gained for the broader aim of the study, we have identified the rationales behind the slow adoption of eHealth implementation in current health care settings, the eHealth innovation impacts on people, environment and contexts in which they exist, and necessary steps for preparing the future IT innovations in a similar

healthcare setting. While these findings are specific to Chronic Disease Management in the ACT Health Service, they are applicable to other similar setting regional health care services from national to local, and to all public health domains.

Conclusion

Healthcare is complex due to its nonlinear, dynamic, and unpredictable nature. As it changes and progresses, it is likely to implement smaller and more networked systems. Implementing new applications and specific services must be needs driven. In most cases, eHealth innovations that are introduced into health care need to interact with pre-existing systems that are likely to be site specific and particular with limited flexibility. A useful eHealth intervention needs to be tailored to local contexts if it is to be effective in implementing a sustainable eHealth solution. The research provides detailed insights and recommendations to further strengthen chronic care management processes.

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1.1 Context

EHealth in general

The definitions of eHealth have evolved in many ways and this term seems to be used without a clear definition. According to WHO, "it is simply the application of information and communications technologies (ICTs) to the health sector" (World Health Organization 2012).

Many countries considered a national eHealth program as a must for development, in order:

- to make the best use of existing systems,
- to provide a solid foundation for innovation and
- to harness ICT for the management of health.

It is necessary to plan eHealth at the national level. However, it is not easy to define a proper eHealth strategy to guide implementation, somewhat like stamping a definition on the eHealth as it is used in a dynamic environment (Scott, Mars and Hebert, Technology enabled knowledge

traslation for eHealth 2012). Consequently, systems frequently adapt their practice from other systems even though these approaches are inappropriate.

We consider eHealth now to be a global trend, yet seldom have health organizations, and countries, had a sustainable eHealth solution that was designed and developed to be long lasting with decreased material consumption and improved care outcomes. The perspective of sustainable eHealth solution might need to be developed within the growing health needs of the population in which it will be applied. But how do we impose implementations that are in alignment with the existing health system, technology enterprises and education level? The answer remains poor and vague, which is a significant barrier to implement sustainable eHealth solution effectively. As experts in implementation across government, Deloitte were commissioned in 2008 by the Australian Health Ministers, through the Australian Health Ministers' Advisory Council (AHMAC), to develop a plan focused on creating and implementing a new strategic framework to guide national coordination and collaboration in eHealth. The strategy allows public and private health sectors to determine their own eHealth implementation within a common framework, while allowing prioritization to maximize benefits and efficiencies. Australia is seeking a more sustainable health system with the help from a national eHealth strategy to respond to ongoing cost and pressures from the health sector (Victorian Department of Human Services 2008).

Chronic disease and its care management

In this research, we would like to place the study of eHealth within the context of Chronic Disease Management. Chronic disease is defined as "illnesses that are prolonged, do not resolve spontaneously, and are rarely cured completely" (Davis, Wagner and Groves, Managing chronic disease 1999). Chronic illness is significant to individuals and costly to society, and it is the leading cause of illness, death and disability in Australia. In 2000, approximately 1 in 6

Australian adults (>= 45 years), have Chronic Obstructive Pulmonary Disease (COPD), and 4% of the population (>=45 years), have Chronic Heart Failure (CHF) (Abramson 2005). Australia's challenges in tackling chronic disease arise from the "change of disease pattern, increased cost and burden, difficulty in allocating resources, and concerns about the consistent provision of evidence-based health services" (Australian Institute of Health and Welfare 2004).

Chronic disease can result from complex causes, and different illness often coexist. The conditions of chronic disease often persist through life and some may never be cured completely. It is the complex nature of chronic disease that forces us to transform the way in which we respond to it. Integrative care approach is considered effective in providing high-quality care for a patient and improving chronic care management as its goal. However, it is resource intensive to bring different entities into unrestricted association, hence increased transaction costs are unavoidable from the demand to share information between a diverse range of health and community service providers. Health care organizational change, along with a strong information and technology component are needed to support and address the reform in chronic disease management.

The foundation for future chronic disease management worldwide is built on the Chronic Care Model (CCM) (Wagner 1998). When systematically implemented, this model has proven to improve health outcomes for people living with chronic conditions. The fundamental philosophy of CCM is placing chronic care in the context of the community, which requires sound organization within an integrated healthcare system. Patients will be informed and motivated, while healthcare teams are prepared and proactive. The CCM (Wagner, chronic disease management: what will it take to improve care for chronic illness? 1998) consists of four important components: "self-management support, delivery system design, decision

support and a clinical information system". It highlights the importance of giving patients the skill and confidence for self-managing their health condition; "promoting a patient-centred interdisciplinary team approach to care; assuring providers and patients have easy access to the updated and relevant evidenced-based guidelines for care" (Matias and Sousa 2016); and accessing data, information, and knowledge needed to improve health. Overall, the essence of CCM is promoting constructive and productive patient and care provider interactions to improve care outcomes.

Chronic care management supported by eHealth

The current CCM is supported by information management systems, telecommunication and technology advancements. It is an enhanced version where each element is improved by clinically efficacious eHealth tools. The "new model" focuses on (Figure 1.1) mobilized community resources to support patient engagement and self-management (Wagner, Austin, et al. 2001). For example, it encourages patients to actively participate in effective community programs, so strong partnerships will form with community organizations and gaps in needed services will be filled with interventions. Patients are supported through community resources for ongoing self-management which emphasize the patients' key role in managing their health. The central strategies in self-management support include regular patient assessment, personalized goal setting, effective care planning and proactive follow up. The concept of community has been branched out to embrace online community and health-related social networks. For example, virtual communities such as "PatientsLikeMe" are supporting thousands of chronic disease patients (Weitzman, et al. 2013). Moreover, virtual community members with chronic condition feel comfortable and supported in the environment where they can ask questions, report personal experiences and find the eHealth literature specific to their condition (Greene, et al. 2011). Such social networking has shown promising results in encourage patient empowerment, where patients have the capability to utilize a combined

knowledge and wisdom for self-manging their health. In addition to a social networking site, other eHealth applications such as telehealth have been provided as a "conduit for self-management support and to promote patient engagement" (Siminerio 2010).

Another component of CCM is the health system itself, which must be "designed to support organizations and providers and enable them to be proactive and prepare and foster productive interactions with patients" (Bodenheimer, Wagner and Grumbach, Improving primary care for patients with chronic illness: the chronic care model, Part 2 2002). Many eHealth interventions play important roles in redesigning health care delivery systems, promoting clinical decision support for both patients and providers, and rapidly expending the clinical information system. The care delivery system has shifted from reactive to proactive with the help of eHealth interventions.

The ability to exchange data and information electronically between health care systems means, access and control over health data is empowered at both provider and patient level. A major development in promoting care coordination is the electronic health record (EHR). Many health systems have successfully implemented interoperable EHR with promising results. Some of them are learning from the implementation to decide what is effective and whether different approaches are needed.

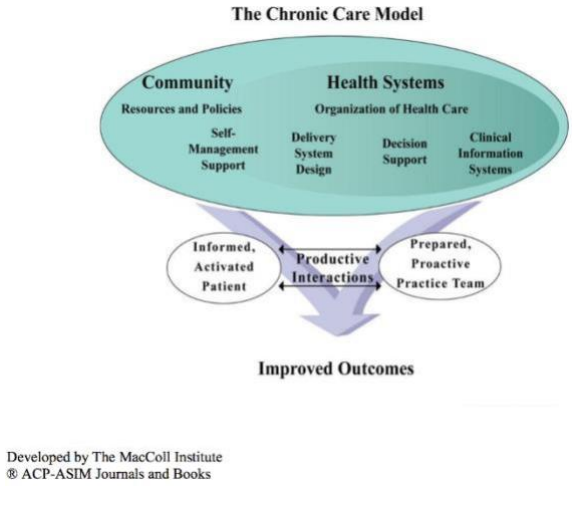
Health care leaders and policy makers are also highly recommending PCEHR (Personally Controlled Electronic Health Records) (Pearce & Bainbridge, 2014) as a care coordination tool for chronic disease patients in which patients manage their own chronic illness through eHealth technologies (PCEHR, mHealth, telehealth, and internet use). Many countries are working on integrated electronic

medical records, with the benefit of interoperability across health care systems and among care providers.

Meanwhile, care providers are supported by clinical decision support applications–computer-based programs that analyze data within EHRs to "assure providers have access to the most current evidence-based clinical guidelines, protocols and standard of care" (Bodenheimer, Wagner and Grumbach, Improving primary care for patients with chronic illness: the chronic care model, Part 2 2002). It has now incorporated patient-specific needs to promote clinical decision support for both patients and providers.

When considering tools such as mHealth apps, mobile devices and telehealth, PCEHR is a logical next step to the expansion of clinical information systems, which were originally focused on registries, databases, and systems that support access to patient identification, protocols and current standards of care. A well-prepared provider team which engages productively with an motivated, informed patient is believed to provide effective care for chronic disease patients

Figure 1.1 The Chronic Care Model (CCM) (Wagner, 2004)



1.2 Statement of the problem

It is a harsh truth that the increase in chronic disease is the biggest health challenge worldwide because of its personal, social and economic impact. With changing lifestyles and ageing populations, chronic disease has become increasingly common and now causes most of the burden of ill health. This requires transformation and structural change in the health care system, from a system that is essential reactive responding mainly when a person is sick, to one that is proactive and concentrated on delivering safer care. The increasing workload in care and needs for empowered chronic disease patients leads to a greater focus on promoting the application of eHealth solutions which give chronic disease patients with superior standard of care. The new model of care should satisfy both patients and health care providers, with the possibility of reducing health care consumption and costs. Although the potential benefits of eHealth are compelling, the evidence in support of these benefits varies greatly depending on the application. It is hard to draw general conclusions about the impact of eHealth on chronic disease management, and "the research focus on clinical outcomes often masks other beneficial effects" (E. P. Talboom-Kamp, et al. 2016).

Australia needs long-term oriented support to address the consistent need for evidence-based chronic care services. It is believed information technology will play a vital role in successfully implementing sustainable chronic disease management initiatives. With the rapid development in information management technologies, regional health service ACT Health has implemented various new IT systems for chronic disease management to achieve recommended models of care and clinical outcomes. The key towards a better model of care is to include integrated and

coordinated care while building collaboration across a multidisciplinary team of care providers. The care plan should include regular follow-up and review which support patient empowerment. However, the impact of current eHealth interventions in chronic disease management, and the extent to which they achieve meaningful use, remains unknown.

The overall aim of this research is to investigate the use of eHealth tools and their impact on chronic care management in a regional health service and to improve their application in eHealth enhanced chronic care. The specific objectives are to:

1. Explore the strategic relevance of eHealth implementations in relation to CDM interventions in a large regional health service.
2. Identify the current eHealth tools implemented in CDMU and identify the facilitators and barriers to their meaningful use; as well as to assess their development within the eHealth transition.
3. Provide insights into the development of sustainable eHealth interventions in chronic care so it will have a positive impact on the CDM

1.3 Significance of the study

This study aims to contribute to the eHealth knowledge base. It examines chronic care management practically in delivery systems and clinical information system design. Specifically, this study chose three sets of small-scale projects within the ACT Health chronic disease management unit to assess the impact of current eHealth interventions and how they perform in terms of meaningful use. As little is known about how, and to what extent, chronic disease management and eHealth interventions inform each other to leverage mutual strengths, understanding the barriers to meaningful use of digital healthcare technologies in chronic

disease management serves as an appropriate starting point. Then we candiscover the potential of eHealth interventions available today to deliver benefits to both patients and providers. The findings and insights from the study of a regional health service will be of interest to other regional health services which are common building blocks to the national health systems.

1.4 Key abbreviations used in this thesis

ACT	Australia Capital Territory
ACTPAS	ACT Patient Administration System
AIHW	Australian Institute of Health and Welfare
ANU	Australia National University
CCM	Chronic care model
CDM	Chronic disease management
CDMCN	Chronic Disease Management Clinical Network
CDMU	Chronic Disease Management Unit
CRIS	Clinical Record Information System
EHealth	Electronic Health
EMR	Electronic medical record
EPR	Electronic patient record
GP	General Practitioner
HITECH	Health information technology for economic and clinical health
HL7	Health Level Seven
ICD-10-AM	International Classification of Disease, 10th revision
ICT	Information communication technology
IT	Information technology

NEHTA	National E-Health Transition Authority
NHS	National health service
PCEHR	Personal controlled electronic health record
PES	Prescription exchange services
PHR	Personal health record
TCH	The Canberra Hospital

1.5 Organisation of thesis

This chapter presents an overview of the thesis. It outlines the context of research, the purpose of the study, as well as stating the research questions, study significance, and defined terms used during the course of this research.

Chapter 2 describes the findings from literature reviews and connects in the overall knowledge base on the development of eHealth in today's health care system, barriers to optimal chronic disease management and the eHealth enhanced chronic care model. The references the literature contributing to obtaining significant knowledge and understanding about the roles of digital technology in optimising health care systems.

Chapter 3 presents the methodology used in collecting relevant data for analysis. This chapter describes the research aim, data collection method, sources and collection instruments. It defines the following: the epistemological framework used in qualitative case studies, the research design and site, researcher positionality, limitations and ethics considerations.

Chapter 4 presents the findings of the first case study. This chapter provides the findings from a literature review on the use of disease registers, and researcher participation and observations from the fieldwork. It describes a study of the use of a chronic disease management register. The findings help us understand the rationale behind the successful or unsuccessful implementation of the CDMR. The findings contributed to an understanding of the contextual barriers and facilitators to meaningful use of a chronic disease register and recommends directions for future improvements.

Chapter 5 presents the findings of the second case study. This chapter provides the findings from a literature review on eHealth adoption in care coordination, care delivery processes, interdisciplinary team communication and care planning within the digital health transition. It describes the researcher participation and observation from fieldwork in Chronic Care Programs and presents a qualitative study of the development of eHealth interventions in CCP to provide continuing care services within the digital health transition. The findings contribute to an understanding of the information collection and storing method, the use of information for care delivery, case load distribution and communication among CCP partners. The findings also contribute to understating how technology impacts people, environments and the contexts in which they exist. The study identified the changes in the CCP workflow and performance of eHealth interventions (e.g. digital form) in improving the quality of CCP service, as well as recommending directions for future improvements.

Chapter 6 presents the findings of the third case study. This chapter recognises the importance of understanding user needs in health IT development and uses the design thinking as a problem-solving approach to uncover the reason behind clinicians' demand for the electronic database. This chapter describes researcher observations from the Obesity Management Service

in ACT Health and defines the problem through qualitative study. The findings helped to identify the problem before attempting to design a digital health solution. The study aimed to prepare for future IT innovation by the obesity management team to enable the appropriate application of professional rationales and expert knowledge.

Chapter 7 builds on the understanding generated in the above chapters and synthesises the findings. It builds a matrix of findings between case studies, literature and specific research questions. It is grouped into five sections: the first discusses the acceptability of eHealth in a health care setting; the second outlines the necessary steps in preparing eHealth for CDM; the third suggests the possible method of measuring the eHealth impact of current implementation; the fourth discusses the interoperability of health information systems in chronic care and the last discusses the updated definition of the "meaningful use" in eHealth-enhanced chronic care.

Chapter 8 is the concluding chapter. It presents the implications for current chronic disease management in ACT Health. It also discusses the strengths and limitations of the study. It ends by identifying opportunities for future research and practice.

Chapter Two

Literature Review

Chapter outline

2.1 Introduction

2.2 Key concepts of eHealth tools in health care system

2.3 Current trends in digital healthcare technologies

2.4 Digital technologies used to overcome barriers to optimal chronic disease management

2.5 Meaningful use of electronic health record (EHR)

2.1 Introduction

The literature on eHealth and chronic care is extensive. In this review, I start by introducing the concept of adopting eHealth tools in a health care system, and the opportunities and challenges they created for the traditional health care information technology industry. Then I review the key factors driving the increased interest in digital health and major trends in its current use. I also include the challenges to current chronic disease management and barriers for eHealth tools attempting to address these challenges. I conclude the chapter by review the "meaningful use" program of electronic health records and its expected benefits to the health care system.

2.2 Key concepts of eHealth tools in a health care system

Our society has been greatly influenced by modern information and communication technology. One of the areas that is increasingly affected is the Health Care System. EHealth is using the

Internet & related technologies to enhance the traditional health information management processes to deliver multidimensional health care improvement to both business and consumers. EHealth is not only the development of health-related technology, it is also the development of a new state of mind. It changes the way of thinking for health care providers, patients and even the whole health system. The adoption of eHealth is a vision and a commitment to improve health care locally, regionally and worldwide.

The health care system is a dynamic environment experiencing constant change. But there is no single technology that can address all the changes. We need a platform to connect different sectors in the health care system and enable information exchange to improve the efficiency of care, reduce costs, empower both the providers and patients, and expand the realm of health care beyond its traditional boundaries (Eysenbach 2001).

The foundation for the eHealth platform is its ability to manage medical data in an electronic form, including diagnostic information and emergency management information, which all play a vital role to build a central clinical repository. The electronic health record (EHR) enabled the development of a wider eHealth platform and created "opportunities and challenges for the traditional health care information technology industry" (Eysenbach 2001).

An EHR, or electronic medical record (EMR), is defined as the "systematized collection of patient and population electronically stored health information in a digital form" (Gunter and Terry 2005). The concept of EMR evolves slightly differently from the EHR, where the former is often used to define the collection of patient records created by health services for set encounters in hospital and ambulatory domain. Traditionally, EMR can be used to generate data

necessary for EHR where longitudinal health information is collected and stored electronically for individual patients or populations (Habib 2010). There is also a personal health record (PHR) widely used as a form of electronic medical record where personal medical data are assessable and controlled by an individual patient and may also be viewed by health providers (Office of the National Coordinator for Health IT 2013). Generally speaking, EHR has been seen as a storage space where all the patient's information is held and all the clinical data can be aggregated for secondary uses (Greenhalgh, et al. 2009). There are other long-established research applications, see the EHR "as a contextualized artifact within a socio-technical system" (Berg 1997).

Many EHR systems in the national and international marketplace are now applying cloud software maintenance and data storage, in place of local network solutions. However, there is no easy option to upgrade a local network EHR with just the power of a cloud server, or web-based architecture. This is hard to implement due to large client bases, development costs and risk (Weaver and Teenier 2014). Questions relating to quality, costs, implementation time, consequences and privacy always arise when considering the implementation of EHR. Even while the majority of U.S. hospitals have now adopted some form of EHR, these issues are still major barriers when implementing the EHR in a large-scale network.

While eHealth interventions such as EHR provide the ability to manage medical data in an electronic form and create the foundation for data liquidity, these are not the only benefits the technology can offer. Current developments in eHealth interventions underpin the healthcare industry in many ways which can be summarized into the following three aspects.

1. *The capability of patients receiving health care remotely*

The healthcare industry is going through a period of fast-track development with the digital experience affecting the actual delivery of medical treatments. With the increasingly ageing population, and persistent emotional and physical distress related to patient chronic condition, the need to expand services that are less rigid, but more patient centered and cost-effective, have been long discussed. Telehealth allows patients to have medical consultations in the comfort of home. The definition of Telehealth according to ISO (International Organization for Standardization) is the "use of telecommunication techniques for the purpose of providing telemedicine, medical education and health education at distance" (Australian Government Department of Health 2015). Telehealth is "having a consultation with a healthcare provider by phone or video call" (The Australian Digital Health Agency 2021), it allows the patient's physiological status and health been monitored remotely which reduce the need for resource and labor intensive human interactions. It is intended to provide better healthcare access by reducing social dislocation, lowering costs in the management of chronic medical illness, and offering greater independence for the ageing population with enhanced quality of life (Nouri, Khoong, Lyles, & Karliner, 2020). Telehealth typically involves both care providers and care recipients in the provision of its services, which encompass preventive education, diagnosis, treatment, and palliative care of healthcare services. (Australian Government Department of Health 2015).

The Australian e-Health Research Centre has done a case study aiming to understand and evaluate the use of telehealth in assisting the ageing population and patients with chronic conditions. The home monitoring of chronic ill patients' study is the Australia's first large scale Telehealth clinical trial, which was designed to determine whether Telehealth can be implemented to reduce hospital admissions for high cost patients by up to 50 per cent (Celler, et al. 2016). The results show a positive impact on patients helped by Telehealth services where chronic disease patients utilize the service and better self-manage their conditions at home.

Moreover, health care providers are able to provide appropriate care interventions at an earlier stage by accessing changes in patients' medical conditions remotely, helping them stay out of hospital. The study concluded health services delivered a "cost-effective, timely and improved access to quality care" through the Telehealth clinical trial (Celler, et al. 2016).

The involvement of industry and government in promoting Telehealth directly impacts the pattern of digital health adoption. Telstra has partnered with Silverchain to roll out the ReadyCare system. People use the system to get in touch with their GP, who is employed by Telstra Health, to provide telephone or video-conferencing consultation. Telstra formed an alliance with the Northern Territory Government and various Aboriginal medical services, to deliver Telehealth service to some of Australia's most isolated communities from its leading hospitals (Health View 2015). In Australia, Telehealth eligible areas, including selected aged care facilities and aboriginal medical services, are able to claim Medicare rebates for video consultations with specialists. The Medicare rebate for remote video consultations is only available for remote, rural and regional areas (MBS Online 2015). Policy making organizations such as national governments play a pivotal role in promoting Telehealth opportunities in various aspects of health care.

Many studies have examined the effectiveness of Telehealth. A recent BMJ study (Steventon, Bardsley , et al. 2013) relates to comparisons on a number of quality of life measures between the 'telehealth' group and the 'control' group and shows "there was no significant difference between the two groups on these measures over the 12 months of the study". Members of both groups had been involved in service redesign to include self-management, education etc. for long-term conditions. A previous paper (Steventon, Bardsley, et al. 2012) had looked at other factors, such as impact on hospital admissions and mortality. The result indicates "Telehealth

is associated with lower mortality and emergency admission rates". However, on the contrary, another study (Steventon, Ariti, et al. 2016) found "telehealth patients had a higher likelihood of an emergency admission, and accident and emergency department attendance, than matched controls". It is clear that we are lacking a national standard for measuring telehealth effectiveness. Having a consistent measurement, and quality metrics will be the key in improving telehealth outcomes.

In conclusion, the development of Telehealth or Telemonitoring service performed satisfactorily by taking into account the patient's particular medical needs, local infrastructure and patient/practitioner preferences. The question that remains is how can we make Telehealth work better?

2. Improved possibilities for transmissions of medical data

Patients often see different health care provides for their expertise through specific, limited and individual interactions. Each health care provider might provide different views of the patient depending on the team member's area of expertise. As a result, the health care providers as a team often provide a fragmented view due to isolated facts and aggregated symptoms. However, advanced medical practices and technologies improve the interactions between different health care providers by providing them with a less fragmented view of patients. This is often achieved through standardizing the communication and information exchange between different health services.

The use of secure messaging and eReferral products have been implemented in many regional areas to provide a common secure messaging product for use by all health, community and social service providers in the region (Findlay and Yen 2015) (Chen, Murphy and Yee 2013).

The notion of ‘integrated care’ assumes a ‘seamless’ health care and many projects have focused on ways to improve cooperation between the GP and specialist (Bal, et al. 2007) (Liddy, et al. 2013) (Nicholson, et al. 2006) which fits the purpose of secure messaging. Implemented solutions have varying degrees of successes, such as reduced wait time, easy access to specialist care, up to date and quality referral communication, more accurate health information transfer and integrated health care systems (Mansour, Davoud and Ali 2015).

The purpose of having an E-prescribing system is to allow prescribers to send patients’ prescription information to pharmacy computers electronically. National electronic prescription exchange services connect the doctors and pharmacists. The Commonwealth has approved prescription exchange services (PES), provided by MeciSecure and Erx Script Exhcnage, to connect with pharmacy and medical practice. Both PES systems are required to meet specified standards relating to security and privacy (Australian Digital Health Agency 2015). Australia is not the only country having the accelerated adoption of E-prescribing technology. In the United States, “national growth in E-prescribing over the period Sept. 2008 through June 2012 increased over 40 per cent, with individual states increasing adoption anywhere from 28 per cent to 70 per cent” (Office of the National Coordinator for Health IT 2012). The adoption of E-prescribing “connected the physician and pharmacy systems, reduced paperwork and the associated mistakes that may occur from reliance on handwritten notes” (Bigler 2012), and “saving on time and cost for all parties involved” (Porterfield, Engelbert and Coustasse 2014).

E-health interventions enhance the quality of health care by providing a unified view of a single patient to the health care providers. Within a single hospital, a large volume of data are often divided into structured data and unstructured data. For instance, the medication information and clinical notes are organized in mixed systems (Analysis Group Health Care Consulting Services

2016). The massive production of health care data from various departments and medical branches across the modern healthcare facility leads to the increased need for a clinical repository which has the ability to provide easy data access, and act as a comprehensive information platform for the health care providers to have easier information exchange and communication.

3. New possibilities for patient self-management and self-education

E-health has been seen as a useful technological tool in achieving self-management and self-education. Evidence suggests that self-management programs can "improve health status while reducing utilization and costs especially in chronic disease and ageing population" (wagner 2000) (Norris, et al. 2002) (Gibson, et al. 2002) (Lorig, et al. 1999). Patients often engage in health-management in many their routine activities of daily living, such as nutrition arrangement and physical activities. The success of this self-management mechanism is associated with patients being motivated, coping, self-efficacious and reporting progress (Bodenheimer, Lorig, et al. 2002), as well as planning and coping with planning (Sniehotta, et al. 2009).

The development of novel wearable intelligent systems assists patient self-management with continuously monitoring the vital signs over a 24-hour period, which in some cases are important for "understanding the progression of chronic symptoms in the elderly" (Poon, et al. 2011). This continuously advanced technology enables patients to manage their health proactively, and potentially transform the future of healthcare by "ubiquitous monitoring of a patient's health condition" (Pantelopoulos and Bourbakis 2010).

Advances in internet speed and social media greatly promote patient self-education and encourage initiative to help others. Patients now have the skills and confidence needed to assert themselves. And there is an increased need for a platform for patients to search information they need and share information with fellow patients (Overberg, et al. 2010). About "69% of US adults reported having access to the Internet for health information in 2007" (Pew Research Center, 2006). Among these Internet users, "5% participated in an online support group, 7% reported blogging, and 23% used a social networking site" (Chou, et al. 2009). There is increasing interest in studying the nature and motivations behind patients who are "interested in connecting with and sharing information with one another" (Ellis, Showell and Turner 2013).

Another aspect of improvement in patient self-education is their ability to acquire trustworthy information about the quality and capability of health service providers. Patients find it hard to decide the accuracy of the internet source, hence there is an emerging trend in developing online reputation and rating systems that support users in making decision based on the group of rating, and communication of obtained reputation scores. In addition, there are methods developed to prevent uncontrolled rating that ensure "only genuine patients of a specific health service can rate that service" (Josang 2008).

2.3 Current Trends in Digital Healthcare

Digital healthcare technologies are helping transform health care delivery and patient care, while reducing the cost of delivery at the same time. Three main factors are driving the increased interest in digital health:

1. Increase in health care cost
2. Increase in growth of chronic disease

3. Increase in the need to provide better and safer medical care especially in the booming ageing population (Comstock 2016).

Trends identified as major driving forces now in digital health can be summarized in the following five aspects.

1.Intelligent Automation

We can take advantage of technological development and merge that with health care providers to make people more productive and also get better results. Virtual care, wearable technology, biometrics, data analytics and artificial intelligence are all part of the intelligent automation shaping the future of care delivery and patient self-care. For instance, remote symptom monitoring could reduce the number of home visits for those patients with long-term conditions; the advanced technology helps patients avoid hospitalization and allows care providers to focus on those in need (Barley 2014). A study in a Southern California tertiary care center analyzed the "effects of remote monitoring systems on activation, self-care and quality of life in older patients with heart failure". Participants in the remote monitoring systems group showed "greater improvements in activation, self-care and quality of life compared with their counterparts" (Evangelista, et al. 2015). Another example of using intelligent automation in health care is internet delivered treatment. SilverCloud Health provides Internet delivered treatment that supports mental health patients between therapy visits. The benefit of this eHealth intervention enables the therapist to increase their client load by a factor of six (Richards, et al. 2015).

2.The Liquid Workforce

The composition of the workforce is gradually changing. We expect to generate a more fluid workforce with help from digital technology that provide help where needed. This will

fundamentally shift the enterprise structure, the way people get trained and culture change with new technology-enabled ways of working (Accenture Consulting 2016). The increased aging and morbidity of our population, particularly in the area of chronic disease, drives up the demand for outpatient visits. This population has strained the system's ability to provide timely, accessible care (Yack, et al. 2004) (Anderson and Horvath 2004). The Department of Veterans' Affairs in Australia introduced a national home Telehealth program to "coordinate the care of veteran patients with chronic conditions and avoid their unnecessary admission to long-term institutional care". It shifts the workforce from outpatient clinic/hospital admission to patients who live independently at home with disease management technologies (Darkins, et al. 2009). The development of mobile devices and the Internet allow the clinicians to have access to patient information when needed with no limitation on the location and time. For example, personal digital assistants (PDAs) offer care provider access clinical data and relevant information remotely at the point of care (Lu, Xiao and Sears, et al. 2005). However, the liquid workforce is challenged by labor laws, availability of broadband connectivity and a reimbursement scheme that places limits on where healthcare workers can work from (Comstock 2016).

3.Digital Platform Economy

In healthcare, the digital platform economy is emerging with the application of big data, new algorithms and cloud computing. The e-health platform opens the way for radical changes in health care by linking the entire healthcare system, from patients to providers to health plans. This platform in the health care system includes the patient, which shifts the balance of power while connecting the health care providers and transforming their way of working. We can imagine digital platforms with different functions and structure in the near future, for instance, a digital platform where healthcare consumers go to one central place to book appointments,

check their electronic medical record, pay for expenses and get options on the treatment plan. Another digital platform where health care providers can track a patient's activity from hospital to home, provide a unified view of the patient and get support on decision making.

The rapidly growing mobile phone app stores "turn a smart phone into a microscope, an ultrasound machine, or a heart rate monitor" (Wac 2012), which is a digitally based new economy-developing power that may be even more formidable than those in the earlier health care industry. These apps can be empowered by an e-health platform technology for consumers to have a streamlined, seamless, and enchanting experience (Mertz 2012).

Diverse health care players who used to be fragmented now benefit from cooperation with emerging network platforms, such as the 'cloud technology' (Felix and Ravi 2016). Philips Health is accelerating its uptake of digital technologies and cloud foundations as the crucial first step to break into the platform world (PHILIPS 2016). Among the benefits of cloud technology are radical reduction in the cost of computing resources and barriers to usage, crucial factors for health services in adopting eHealth intervention when their resources are limited.

Overall, the digital health platform is a mixture of software, networks, hardware and interfaces along with a broad set of users. It is a cultural and structural transformation of traditional healthcare system.

4.Disruption in healthcare structure

Digital technologies and the e-health platform economy make it possible for people who had no role in healthcare to change the nature of it. There is a trend for healthcare to be disrupted

by new innovators, and the disruption is as likely to come from outside of healthcare as from within (Comstock 2016). Non-traditional players are stepping onto the healthcare field. New wearable devices are not being developed by manufactures of traditional wearable products but, mainly, by computer and software companies. Fitness trackers such as 'Fitbit' and 'Garmin' provide wearers with the ability to monitor their personal fitness indicators while other wearable devices provide healthcare professionals with information that improves diagnosis (Davis and Gormez, Wear Next: An Exploration into the Future of Wearable Technology 2016). Not only are historical demarcation lines blurring across industries and new ecosystems are emerging, but also there is increasing shifting and blurring of professional boundaries within the health care system.

A wider range of health professionals have now been included in the primary care workforce and boosted the diversity of the health care approach, shifting from 'task delegation' to 'team care'. It is a global trend but is limited by traditional role concepts, legal frameworks and reimbursement schemes (Freund, et al. 2015).

The digital technology innovations offer nurses, physician assistants, and other professionals opportunities to expand their interactions with patients and gain increased exposure to independent clinical work (Hoff, Sutcliffe and Young n.d.). Healthcare organizations must link up with those outside the industry to seize new opportunities in order to deliver a better healthcare service.

5.Data-driven clinical innovations

With the growing amount of health data, one of the important questions to ask is how to protect the privacy and security embedded in each stage of healthcare services. The expansion of health

care ecosystems involves more players in the digital chain, hence the greater potential risk in data security and privacy breaches. Companies need to build consumers' trust by behaving in a way that's consistent (Comstock 2016).

Big data in healthcare usually refers to the "electronic health data sets that is large and complex which is difficult or even impossible to manage with traditional software and/or hardware" (Raghupathi and Raghupathi 2014). Organizations and policymakers have begun to manipulate the big data platform at different levels of detail. By taking the privacy and security into account, consumer distrust can be reverse engineered with innovative solutions. For instance, the Federal Trade Commission (FTC) in USA issued a report (Federal Trade Commission 2014) on the data brokers focused on the use of data, data collection, compilation and analytics that concluded that the data should be used in the context in which it was shared. If the company is generating health related data, it is expected by a consumer to be used in a health context. Wearable fitness company Fitbit in September 2015 achieved compliance with the Health Insurance Portability and Accountability Act, a U.S. law that protects personal health information (Brown 2016). This is an example of how organization-enabled big data privacy and security can improve user confidence and trust.

Another use of big data analytics is in research and development where data are explored to extract insights for making better informed decisions. It is often challenging to increase the data acquisition for medical research. For instance, the UK National Health Service (NHS) proposed to increase the data acquisition from electronic patient records (EPRs) which caused controversy and uncertainty in public awareness. Williams and his colleagues (Williams, et al. 2015) proposed a possible solution where "the sharing of sensitive health care data can only be done through maintaining public trust in a constantly evolving ethical, legal and political

landscape". It is an active consent model to improve patient confidence and public trust. Patients are informed about the use of their data, and offered a transparent, flexible and user-friendly means of data control.

2.4 Digital Technologies Used to Overcome Barriers to Optimal Chronic Disease Management

It is clear that digital technologies are slowly developing in the health care system with the potential to help overcome the barriers to optimal chronic disease management and deliver benefits as an outcome. However, there are not many studies about how and to what extend do digital technologies optimize the outcomes of chronic disease management.

The Chronic Care Model (Bodenheimer, Wagner and Grumbach 2002) has long been established as the framework for optimal chronic care management and practice movement. There is no question that the CCM improves the quality of chronic disease care according to accumulated evidence over the past decade. The published evidence suggests that "practices redesigned in accordance with the CCM generally improve the quality of care and the outcomes for patients with various chronic illnesses" (Coleman, et al. 2009) (Dennis, et al. 2008). The CCM strengthens the need for communication among the care teams, patient self-management and the clinical information system. However, most practices are not doing so effectively in chronic disease care management, even following the CCM, and it is largely due to the complex nature of health care systems and limitations in human resources. Michael Georgeff summarized the barriers to optimal chronic disease management in his paper (Georgeff, Digital technologies and chronic disease management 2014).

- Lack of human resources: it is a huge burden on health services to carry out regular reviews and follow-ups for chronic disease patients; the limitation in time and resources constrain ways of providing support for patient self-management; there is also the burden of "administrative overheads and red tape associated with meeting Medicare requirements and the corresponding documentation and paperwork".
- Inefficient communication among the care teams: there is large amount of faxing, scanning and telephone tag work needed from health care providers which consumes a lot of their already limited time; It is hard to produce purposeful care plans that are "up-to-date, evidence-based and personalized for the patient" due to the complexity of sharing information among the care teams; The care team often lose track of what everyone on the team is doing; it is difficult to guarantee that duty-of-care responsibilities are properly discharged.

There are promising amounts of digital technologies available today capable of helping overcome the above mentioned barriers and deliver benefits through simpler collaboration and communication; improved care planning; more effective care management; more regular follow-up; better support for patient self-management; and reducing red tape and administration. We can certainly see technologies help reduce the number of barriers caused by limited human resources and information flow.

Take care plan as an example. The purpose of having person-centered care plans is to "facilitate communication, information sharing and collaboration between health care providers, patients and teams" (Thille and Russell 2010). This is important for chronic disease management where care coordinators are often needed to facilitate communication across the health care teams. In Australia, the chronic condition management care plans are required for implementing the

person-centered care framework (National Health Priority Action Council 2006). Barriers to good practices within the context of care planning for chronic disease management often include: closed/fragmented communication between health care teams and patients; overlapping information in the care plan or separate plans from each health care provider instead of one comprehensive care plan; lack of consent from patient or patients– or who are unaware of giving consent; and that the current government funding plan invented "barriers to effective care planning and information sharing" (Simon, Murray and Raffin 2008) (Jowsey, et al. 2009) (Lawn, et al. 2015). Further, in Australia less than 20% of Medicare-rebated care plans are regularly reviewed (Australia Government Department of Human Services 2014). Digital technologies can certainly reduce closed/fragmented communications and help in developing one comprehensive care plan for each patient through robust information sharing.

Another key element in the Chronic Care Model is patient self-management, which is defined as the "ability of the individual in conjunction with family, community and health care professionals, to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions" (Richard and Shea 2011). There are different aspects of self-management in chronic disease, such as self-learning about treatment options; understanding medication dosage, adjusting to changing dietary and physical activity habits; seeking support from others, and setting goals. Self-management is considered important in people with chronic disease given the nature of the disease. It requires patients to regain "a sense of control over their lives and improve their interactions with health care providers" (Barlow, et al. 2002). However, it takes high investment of time and resources to support patient self-management, especially for patients living in rural and remote areas.

Adem Sav and his colleagues have looked at "how health-care professionals and policy makers can support the self-management efforts of people who live with chronic conditions in rural and remote locations" (Sav, et al. 2015). A more creative self-management approach was considered necessary to meet the need for patients living in an isolated geographic area with limited health care providers. This approach focuses on a more collaborative and progressive model, where health care providers continuously work with the rural people from a distance to develop the self-management plan that suit patients' everyday rural living (Furler, et al. 2008). This is where digital technologies and CCM inform each other to leverage mutual strengths. Emails, instant messages, secure Web-based systems and telephone lines were often found useful for distance patient-provider communication to support self-management (Green, et al. 2008) (Gulmans, et al. 2012) (Lyles, et al. 2011). Other eHealth interventions such as preventive health reminders, electronic laboratory test results and patient access to electronic medical records are additional supports to self-management that fit with patient everyday living (MacLean, Littenberg and Gagnon 2006) (Green, et al. 2008).

However, despite evidence suggesting digital technologies give real benefits to health care providers, "adoption of digital technologies in healthcare is far slower than in most other professions" (Georgeff, Digital technologies and chronic disease management 2014). Some very obvious obstacles include a lack of clear evidence for improved care and demonstrated cost-effectiveness of eHealth interventions. Furthermore, the cost for new technologies could be too high for consumers, hence the reluctance to take on the financial risk of adopting new technologies. There is also the extent of behavioral change involved in eHealth adoption where health care providers often deal with insufficient time and resources to rethink practice workflow in a busy practice. Sometimes, health care providers are reluctant to adopt digital technologies simply because they see them as impersonal. Recent studies have found that "rapid

implementation of new medical technology, electronic health records, patient monitoring devices, surgical robots and other tools can lead to adverse patient events when it is not thoughtfully integrated into workflow" (Tahir 2014). The results could be fatal if the interaction between care providers and new digital interventions is not adequately analyzed before implementation. The unanticipated consequences of health information technology are of particular interest today.

The diffusion rate of information technology in health care varies across different sectors. The process is multifaceted in nature, therefore, there should be no single tactic to successfully address all the barriers to eHealth adoption in the health care system (Fernandopulle, et al. 2003). It is suggested that redesign is required for tackling the alignment of digital technologies in chronic disease management. Eventually, change is driven by research evidence of the benefits to health care providers where measures of the changes in health status brought by eHealth interventions, and how health status changes over time following implementation of the eHealth solution.

2.5 Meaningful use of electronic health record (EHR)

The term "meaningful use" was introduced by the U.S. government as part of the 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act. The Meaningful Use program intended to encourage health care providers to show "meaningful use" of a certified Electronic Health Record (EHR) and in doing so, enable eligible providers to receive an incentive payment (Centers for medicare & medicaid services 2011). It is technically a voluntary program where meaningful use criteria should be considered as guidelines only.

However, health services found themselves forced to participate to avoid potential economic penalties.

Eligible professionals have to achieve objectives of meaningful use to qualify for the EHR incentive programs. The objectives are defined with three stages. “Stage 1 outlined requirements for the electronic data capture; stage 2 promoted the use of the certified EHR technology to continuously improve point of care and exchange structurally formatted information; stage 3 as a final rule that modified stage 2, concentrated on improving health outcomes” (Department of Health and Human Services 2010). Following the release of the meaningful use staging, there has been some adjustment made to the timeline and rules to help the program dropouts remain in the program. The changes were intended to ease concerns proposed by the stakeholders and promote sustainable adoption of Certified EHR technology. Before the meaningful use program emerged, EHR implementation rates were dismally low. The incentives have certainly increased interest in use of the technology among clinicians (Wright, et al. 2013). However, it is not clear whether the performance of the meaningful use program in terms of quality, safety and efficiency will further increase EHR adoption.

The intention of the meaningful use program is to achieve better clinical outcomes with “increased transparency and efficiency, empowered individuals and more robust research data on health systems” (Department of Health and Human Services 2010). It is generally accepted that when health care providers have access to complete and accurate information, patients receive better medical care. A national survey (Jamoom, et al. 2012) on doctors who are ready for meaningful use offers important evidence: “94% of providers report that their EHR makes records readily available at point of care; 88% report that their EHR produces clinical benefits

for the practice; and 75% of providers report that their EHR allows them to deliver better patient care".

EHRs are also believed to have beneficial effects on public health outcomes (Kern and al. 2012) (Bell, et al. 2010). For example, improved quality of patient care with higher patient satisfaction; improved quality of care for patients suffering from a specific condition; increased preventive measures for patients at risk with improved care screenings and controlled medications. When health care organizations reach meaningful use of EHRs, it is believed that ultimately this enables the exchange of critical information across a health care system which increases the transparency and efficiency, and improved ability to study and improve care delivery (Chin and Sakuda 2012). Patient empowerment has frequently included as one of the benefits of EHR. A survey of patients viewing and controlling their EHR found that a majority of patients wish to be empowered through viewing their health record (Munir and Boaden 2001), however, there is a lack of evidence in literature that these have actual implications for the development of EHR and its link with patient empowerment. On the other hand, using EHR with its robust clinical data shows promising evidence supporting clinical research studies including the design and execution of clinical trials for new medicines (Coorevits, et al. 2013).

The concept of meaningful use is extremely attractive; however, it remains to be shown that the standards that are being established will result in improvement in health care. It will be helpful to understand the actual meaning of "meaningful use" where it might take the health care system, and the benefits and risks of a rapid transformation from paper to an electronic record system.

Chapter Three

Aim and Methodology

Chapter outline

3.1 Introduction

3.2 Gap in the knowledge and research aim

3.3 Research setting and team

3.4 Methods used to investigate the questions

3.5 Case studies

3.6 Ethical considerations

3.1 Introduction

This chapter describes the research aim and methods in detail. It gives an overview of the research settings and actions taken to investigate a research problem. It answers two main questions: how was the data generated and collected? And, how was it analyzed?

3.2 Gap in the knowledge and research aim

Technology innovation opens a new era for the storage and distribution of health information. The development, collectively labeled eHealth, is claimed to represent "the single-most important revolution in healthcare since the advent of modern medicine, vaccines, or even public health measures like sanitation and clear water" (Silber 2003). In the care of chronic disease patients, eHealth has incorporated aspects of:

- clinical information systems (CIS)
- delivery system redesign
- decision support
- healthcare organization support

All these aspects aim to meet patient needs better and improve chronic disease care management through care and care teams restructure. Many published studies, the majority of which are observational, have reported eHealth enhanced components of the Chronic Care Model (CCM). The conclusion of these studies into clinical practice are that the quality of care is improved through the introduction of eHealth. In the previous chapter, we outlined the common use of eHealth in patient self-management empowerment and improving community resources capacity. The intention of technology development is to empower patients to take control of their health and improve their access to healthcare by providing timely community support and coordination of care. The Washington think tank "e-Health Initiative", the Institute of Medicine (IOM), and the Agency for Healthcare Research and Quality (AHRQ) recommend "the use of eHealth as a tool to support self-management in chronic illness" (Institute of Medicine 2009). The idea of eHealth initiative in chronic disease management is backed up by large systematic reviews conducted by the AHRQ. It had determined that "eHealth tools can improve patient engagement and health outcomes" (Finkelstein, et al. 2012). However, like any other eHealth interventions in the health care setting, there are challenges in developing methods to measure the impact of eHealth implementation and evaluate its outcome.

The implementation of health information technology interventions is prominent in many policy agendas, both nationally and internationally. However, the requirement for complex strategic planning as well as systemic organizational change are barriers to a straightforward

undertaking of such programs (Cresswell, Bates and Sheikh, Ten key considerations for the successful implementation and adoption of large-scale health information technology 2013). The challenge in measuring eHealth ecosystem implementation is it deals with so many values and norms and varying organizational contexts and interests. Moreover, many studies used uncontrolled designs which makes it difficult to conclude whether the changes in patient care are results of the eHealth interventions or from some other unmeasured component. Currently, there are many focuses of interest for evaluating the impact of eHealth intervention. It varies from case to case; we have seen research articles from the macro perspective, such as social economics impacts, policy, compliance with the clinical process, and impacts on general healthcare outcomes. There are also studies focusing down to the system level, such as usability, efficiency, privacy, security and functionality. Hence it is necessary to use many different methods suitable for measuring the evaluation criteria of interest (Marlund 2016).

There are four domains associated with effective implementation of eHealth identified in the literature: Technical, Social, Organizational, and Wider socio-political (Cresswell, Bates and Sheikh, Ten key considerations for the successful implementation and adoption of large-scale health information technology 2013). However, implementation of e-health is a dynamic process where all perspectives need to be included. None of the current frameworks for evaluation are specifically planned to support sustainable e-health implementation. We will need to take the sustainable evaluation as a matter of concrete scientific evidence to inform key policy decisions, rather than political influences, or simply enthusiasm to implement technology because it exists, which is currently often the case. (Catwell and Sheikh 2009).

For eHealth transition to achieve sustainability, the implementation must yield successful outcomes and meaningful use. However, vendors and health services have already “recognized

major difficulties in collecting, calculating, and reporting the measures of care quality, regardless of whether it is inpatient or outpatient". (Classen and Bates 2011). It is never an easy job to evaluate the implementations that will improve care as difficulties in evaluating eHealth interventions have long existed. The paradox is that unless we can integrate technologies throughout the health care industry, and find the best practice to demonstrate the true benefits of using the digital health interventions, we will never have the necessary evidence to support the case for ICT in health Care (Heathfield 1996). Unlike other industries, where complicated information technology systems are often widely tested in a continuing manner after implementation to ensure acceptable performance, most electronic technologies used in the health care system are difficult to retest during routine operation. We need tools for evaluating the eHealth intervention when they are operational, before and after implementation. For example, tools for continuous testing on high-risk applications following system shutdowns or regular updates. Such tools will be needed to facilitate health services in managing self-assessment and refinement of their current systems, as well as ensure meaningful benefit from eHealth implementation. Currently, it is not common for eHealth interventions to go through the development cycle for decades or various stages of trial. It is often developed and implemented in one stage within a few years and is not tested and retested. Moreover, eHealth interventions are often evaluated for their effectiveness without sufficient knowledge of their efficacy (Makai, Melis and Olde-Rikkert 2014). The challenges to developing good implementation strategies for eHealth interventions and evaluation tools after implementation to ensuring meaningful use remain a serious concern.

The adoption of eHealth enhanced chronic care is not a goal in itself; it is the effective use of eHealth tools to achieve health and efficiency that matters. The hardship in developing a good implementation strategy and a sustainable evaluation method lies in the fluidity of health system

networks. One IT intervention can be interpreted differently by different stakeholders and in a different context. It is important to first understand the reason behind the successful or unsuccessful eHealth implementations and examine how eHealth innovation is positioned in the large network of health care settings. The finding may shed light on developing an effective method to identify good implementation strategies and evaluate them after implementation to ensure meaningful use. The research aims to get insights into the eHealth tool and evaluate its impact on chronic care management in a regional health service. The study methods aim to investigate the development and use of eHealth interventions in chronic disease management within the local context and explore the design of possible IT innovation in a similar healthcare setting.

Specific research questions:

1. What are the rationales behind implementation of digital interventions for chronic disease management?
2. How do the current eHealth innovations in chronic disease management unit impact the people, environment, and the contexts in which they exist?
3. How to prepare for the future digital intervention implementation in a similar health care setting in terms of early planning, strategic relationship and groundwork development.

3.3 Research setting and team

The research was conducted in ACT Health where case studies were managed in the Chronic Disease Management Unit (CDMU). The field work was authorized by ACT Health Human Research Ethics Committee (submission number ETHLR.17.066) and ANU Human Ethics

Committee (protocol number 2014/274). The CDMU establishment is part of the ACT Chronic Disease Strategy. The CDMU aims to "enhance chronic care coordination and prevention supports within ACT Health" (ACT Health 2017). The data collection was primarily gathered through selected small-scale case studies within ACT Health and the detailed research setting is outlined in each case study chapter.

The research team comprised YUNLI SHAO as the principal investigator. Associate Professor Paul Dugdale is the Chair of the supervisory panel, who worked with me on this research project as the associate investigator. The methodological framework, case studies topic, target participants, and data collection methods are the teamwork of the supervisory panel and myself. My other supervisory panel members have provided advice during the course of research.

3.4 Methods Used to Investigate the Questions

This study adopts a qualitative approach for many reasons. First, qualitative research methods are particularly useful "in revealing the meaning that people give to events they experience" (Bogdan and Biklen 2003). It deals with data not easily reduced to numbers and the manipulation of numerical data is not the central goal of the research. Specifically, a qualitative study gives the researcher "the opportunity to explore phenomena, such as feelings or thought, that are difficult to extract and refine through conventional research methods" (Strauss and Corbin 1998). Moreover, qualitative research method is the best approach when the study contents exhibit phenomena in their natural setting (Denzin and Lincoln 2003), which is helpful in understanding the social process in context (Esterberg 2002).

This research project uses three interlinked case studies to address the research questions. A combination of methods has been used in this study. The case studies focused on micro-level qualitative research methods (Murphy 2001) include observational studies of naturally occurring interactions in health care settings, non-standardized individual interviews with providers of health care, and analysis of documentary material produced in the health care setting. One of the common methods for qualitative data collection is the participant observation. It requires that "the researcher become a participant in the culture or context being observed". When an observer does not typically try to become a participant in the context and collect the data from a more detached perspective, we refer to this method as a direct observation that is distinguished from participant observation in several ways. A direct observer does "strive to be as unobtrusive as possible so as not to bias the observations" (Research Methods Knowledge Base n.d.). The research will avoid being immersed in the entire context by watching certain sample situations or people rather than taking part. In this study, both observation methods have been used to study current e-Health implementation in the chronic care program. The primary investigator worked as an employee of ACT Health for a year on the study of e-health implementations in a local network for the Chronic Care Program where most of observations were conducted. A chosen set of small-scale projects with 9 participants for the observational studies within the ACT Health was deployed to accomplish the PhD projects.

Qualitative interviews are widely used in studies at the micro-level and have been incorporated in this field study, which involves a straightforward communication between the researcher and a respondent. We won't be using the traditional structured interview in this study because we want the interviewer to be able to move the conversation freely in any direction of interest when needed. Nevertheless, we will still have some initial guiding questions or core concepts to ask, which are intended to gain "access to informant's definitions of their experiences and practices"

eventually. (Secker, et al. 1995). We understand the difficulties involved in analyzing unstructured interview data, especially when combining answers from respondents where a unique set of questions are given.

This study utilizes the qualitative research method as a way to understand the research question as well as to contextualize the underlying research purpose. We consider the qualitative approach as the most appropriate method for this study. It encourages a better understanding of the experiences from different service providers working with the eHealth interventions in the chronic care program and their understanding of how they manage, navigate, and work with these e-Health interventions. This study provides participants with the opportunity to communicate the ways they learn and use electronic technologies in the health care system.

In the context of studying the dynamic landscape of fast-moving digital technology within the healthcare sector, juxtaposed against the relatively slow pace of digital solution implementation within healthcare organizations, a methodological approach that effectively captures this intricate interplay was imperative.

To address this challenge, this research adopts a comprehensive methodology comprising interrelated case studies and qualitative studies. This combined approach enables a nuanced exploration of the complexities involved in both the rapid evolution of digital health technologies and the gradual assimilation of these innovations within healthcare setting. The utilization of interrelated case studies allows for a holistic examination of multiple instances, enabling cross-case comparisons that illuminate patterns, variances, and critical factors influencing technology adoption. Meanwhile, qualitative studies provide an in-depth exploration of the contextual factors, stakeholders' perspectives, and organizational dynamics that contribute to the observed disparities. By employing these intertwined methods, this

research offers a robust framework for unraveling the intricate relationship between the fast-moving digital health landscape and the more deliberate implementation processes within healthcare organizations.

3.5 Case Studies

This section describes the background of case study research, data collection methodology and plan of analysis. Stake described case study methodology as “a strategy of inquiry in which the research explores in-depth a program, event, activity, process, or one or more individuals” (Stake 1995). The researchers managed to “collect detailed information using a variety of data collection methods over a period of time” (Flyvbjerg 2006). Social science has always relied on large numbers of good case studies. In this study, we deploy three case studies for theory building and summarize toward verification. We place more value on practical knowledge compared with theoretical knowledge.

In line with the aim of this study, Actor-Network Theory (ANT) was chosen as a method to evaluate complex IT systems in health service organizations. Despite some limitations, an

Actor-Network Theory-based approach is “conceptually useful in helping to appreciate the complexity of reality and the active role of technology in this context” (Cresswell, Worth and Sheikh 2010). ANT is a sociological theory developed by French sociologist Bruno Latour (Latour, Reassembling the social: an introduction to Actor-Network-Theory 2005), Michel Callon and British sociologist John Law (Law, A sociology of monsters: essays on power, technology, and domination 1991) (Law and Hassard 1999). The essence of this theory is that “the world is constructed of hybrid entities consisting of networks” (Latour, Reassembling the social: an introduction to Actor-Network-Theory 2005). “These networks can include humans, things, ideas, concepts – all of which are referred to as “actors” in the network” (Law 1992). “Tracing of associations or relationships between network components (or actors) is a key activity in ANT” (Latour, Reassembling the social: an introduction to Actor-Network-Theory 2005). “The central idea of ANT is to investigate and theorize about how networks come into being, to trace what associations exist, how they move, how actors are enrolled into a network, how parts of a network form a whole network and how networks achieve temporary stability” (Doolin and Lowe 2002) (Cresswell, Worth and Sheikh 2010).

ANT assumes that “if any actor, irrespective of its position, is removed from or added to the network, as is the case if the technology is introduced into the health care system, then the functioning of the whole network will be affected” (Doolin and Lowe 2002). However, “networks are constantly evolving as a social reality is assumed to be both complex and fluid” (Law 1998). It is the highly dynamic and inherently unstable nature of the ANT that enables us to better understand the alignment between people and technology that stabilizes the health care network to some extent. More importantly, ANT should help us understand “the role of technology and how it can facilitate or negatively impact the work process and tasks” in the health care setting (Muhammad, Zwicker and Wickramasinghe 2013). It is for exactly these

reasons that ANT is used in this study as a rich lens to facilitate a better understating of eHealth interventions and their impact on chronic care management in a regional health service

Three case studies of the selected small-scale project within ACT Health were chosen to generate both descriptive summary and thematic analysis.

Case Study 1: The use of the Canberra hospital and health services Chronic Disease Management Register (CDMR)

Case Study 2: The development of Chronic Care Program (CCP) within the Australia eHealth transition

Case Study 3: Identify the user needs in design thinking-based IT development in Obesity Management Service (OMS)

Case Study Background

ACT enjoys slightly better health compared to the rest of Australia (Australian insititue of health and welfare 2016); however, the prevalence of chronic disease has increased significantly and accounts for approximately "80% of the total burden of disease and injury in 2013" (ACT Government Health 2013). In recent years, we have seen an increasing number of preventable hospital presentations in the ACT that were due to chronic conditions. Furthermore, chronic disease contributed to a large number of the underlying causes of death from cardiovascular disease, degenerative disorders, respiratory disease and diabetes for ACT residents.

ACT Health focuses on health promotion initiatives that "support a preventive health agenda in response to the increasing rate of chronic conditions in the community" (ACT Health

Strategy & Corporate 2011). The known risk factors contributing to poor health, such as smoking, poor nutrition, alcohol, physical inactivity are tackled by the preventive health agenda. In addition, ACT has a dynamic support and advocacy sector for people living with chronic conditions. These support groups work in close collaboration with the chronic disease management unit in ACT to provide expertise and support in chronic disease management, as well as service development. The contribution of these groups plays an important role in service integration for caring for those living with chronic conditions.

ACT Health is committed to providing a patient and careers centered, evidence-informed health system. The patient-centered health system is intended to provide chronic condition patients with appropriate screening and early detection, so the patients chronic condition can be managed with "the right care, in the right place, and at the right time from the right team" (ACT Health 2017). ACT Health understands the importance of actively engaging patients in their care and empowering their self-management by supplying relevant support options and information to stay healthy.

Chronic Disease Management (CDM) is a multidisciplinary team within the Division of Medicine of Canberra Hospital and Health Services whose goal is to promote health, provide education and improve the self-management of people with chronic conditions. CDM comprises the Chronic Disease Management Unit (CDMU), the obesity Management Service (OMS), and the Chronic Care Program (CCP). The ACT Health Directorate, through the Chronic Care Program and the Obesity Management Service, provides Chronic Disease Management Services to residents of the ACT and surrounding areas. The service utilizes the multidisciplinary teamwork to "provide care coordination and clinical support to people with Chronic Obstructive Pulmonary Disease (COPD), Chronic Heart Failure (CHF), Parkinson's

Disease (PD) and other movement disorders, and obesity" (ACT Health 2017). Moreover, ACT Health Chronic Disease Management Service takes advantage of digital technologies such as Home Telemonitoring and Telephone Coaching service to manage the patient with challenging and complex conditions which again highlight the importance of engaging patient self-management. Together with the Chronic Care Program (CCP) that emphasis on people who may need support to manage their health and to understand the ACT health care systems, means the service truly encourages patient self-management at home or in community settings. We can see a mixture of peer-support and technology to provide education to the patient, their carers and family, and assist them with accessing appropriate health and community services. The benefit also extends to communication among the care providers who are involved in the patient's care, which eventually allows for more constructive and prompter tracking of the patient's condition.

Data Collection Methods

Having multiple sources of evidence in a carefully conducted case study ensure the result is as robust as possible. (Yin 2009). In a case study, we need to have more than one method of collecting data, also known as 'triangulation', "as a means to ensure comprehensive results that accurately reflect the participants' understanding and assuring the validity of research" (Denzin, Interpretive Interactionism 1989). Triangulation is a characteristic of qualitative design as it captures different dimensions of the same phenomenon. It allows the researcher to view the problem from multiple angles choose the best approach to analyze data, and extend conversations across a variety of fields of study. For example, in case study 2, I will first collect and review all the relevant documents to understand and substantiate participants' statements. I will then observe clinicians' normal daily work within Chronic Care Program and their

workflow regarding use of electronic forms. I will also interview the clinicians regarding their understanding and feeling towards the use of electronic forms. Having different data collection methods and rich data sets enable the researcher to establish a comprehensive picture. The document reviewing prior to the consultation allows the research to establish the background of the case study, the observation shows what is happening in the chronic care program for electronic form use, and the interviews provide information on how clinicians experienced the electronic form use. Triangulation requires alignment of multiple perspectives across data sets to enrich the understanding of the research question and adds validity to the findings. For example, we will compare the notes from the observations with clinicians' experiences described in the interviews to verify the finding.

Document review was used as a data collection method in research to "clarify or substantiate participants' statement" (Glaser and Strauss 1967), and to provide "insight into the research questions and thick description of the case" (Esterberg 2002) (Merriam 2002). The following core documents were reviewed:

1. ACT Chronic Conditions Strategy – Improving Care and Support 2013-2018
2. ACT Government Health Directorate Annual Report 2015-2016
3. Canberra Hospital and Health Services Chronic Disease Management – Annual Performance Report July1 2013–30 June 2014
4. ACT Health Clinical Repository Implementation Planning Study 2010

Based on the scope of this research, I select interviewing as one of the data collection methods. Drawing from many scholars in qualitative research, interview is a time-intensive method that must be conducted in-depth to ensure the validity and reliability of case studies. There are many aspects of consideration when conducting in-depth interview, including "purposeful sampling,

individual versus a group focus, sample size and appropriate participants to choose for the interview" (Esterberg 2002). Jamshed viewed the in-depth interview as "a controlled conversation which is skewed towards the interests of the interviewer" (Jamshed 2014). It is important for the interviewer to determine from the start who is the "gatekeeper" in relation to knowledge, and can provide access to data sources in order to generate the best result. For case study 1, I identified a project officer and a medical registrar who work in the chronic disease management unit as gatekeepers. For case study 2 & 3, I identified a care coordinator and a clinical specialist who work in the chronic care programs and obesity management service as gatekeepers. There are two reasons I identified them as gatekeepers. Firstly, they are already using electronic interventions in their daily workflow. Secondly, and more importantly, I needed their support and cooperation to develop the in-depth interview over a period of time in order to extract the essence of their contextualized experiences with the eHealth interventions for data analysis.

The nature of an in-depth interviews require the establishment of relationships and rapport, coupled with trust between the interviewer and interviewee. I have prioritized active listening and non-judgmental behaviour when interviewing for case study research. Nine participants, known as the "key informants", were interviewed for this research. They possess particular knowledge about the inquiry setting and have the ability to articulate their knowledge. Their insights are helpful in assisting me, as the observer, in understanding events that have happened and the underlying reasons behind why events happened. The participants in this study were interviewed between October 2013 and December 2015. All interviews were held in participants' offices and conducted face to face lasting from 35 to 60 minutes for each session. Each participant has been interviewed with multiple sessions, and there are 17 interviews in total.

With the participants approval, I took notes during each interview session, which enabled me to highlight important items to be examined later in the interview or to call attention to ideas of certain interest. I used an unstructured interview approach "to elicit rich, detailed materials that can be used in qualitative analysis" (Lofland 1971). The objective of an unstructured interview is to allow respondents to express in their own ways and pace with the aim of gathering what kinds of things are happening in their lives. During the interview, I have a list of topics for the interviewee to talk about and discuss, while I will vary the phrase and order of the questions from one interview to the next. For instance, the first interview might seeks understanding of the experiences leading to the phenomenon under study, while the second interview explores their experience in the moment. In summary, the interview process is mainly determined by the responses from the interviewees.

Plan of Analysis

Qualitative researchers seek to infer meanings underpinning action by observing action in context (Murphy 2001). When we present the rigorous qualitative data analysis of the context in which an innovation took place carefully, it is possible to facilitate application of findings beyond study settings. There is "no particular moment when analysis begins" (Stake 1995). Qualitative research studies involve "a continuous interplay between data collection and data analysis" (Strauss and Corbin 1998). It is an ongoing process throughout the study, rather than being concentrated at the end. Data analysis is based upon detailed filed notes. In making such notes, the objective is to provide a comprehensive record of what is observed in a setting and features of the respondent's understanding. In this study, it means not only finding the meaning in the use of eHealth implementation in chronic care management and making sense of it, but also "identifying and defining the patterns that emerged from that meaning making process"

(Dodge 2011). This is a constantly developing analytical process that moves from the data to analytical concepts, extracting and integrating the concepts when more data becomes available. To refine the observations, I used interview scripts and audio recording to examine interactions with respondents in fine detail. The recorded data are transcribed, using detailed notation that retains words spoken and non-verbal contributions because it is necessary to analyze interview data in terms of what respondents say and what they are doing as they say it.

Esterberg suggested open coding for data analysis, that researchers work intensively with the data and identify the themes and categories that seem of interest. In this study, research data were inspected in depth through the open coding process (Esterberg 2002). Table 3.1 presents 5 categories of data collected from case studies that reduced transcript data to manageable levels and achieved a simple conceptual schema.

Table 3.1 Categories of data collected from case studies and corresponding data collection methods

Categories	**Data Collection Methods**
Background of the eHealth intervention and its setting	Document review
The implementation strategies used for project	Document review & Observations
Identify the personnel background using the IT intervention	Observations & Interview
Key informants' experience with the implementation	Observations & Interview
Impact of eHealth intervention in its network	Observation & Interview

I chose thematic analysis as the approach to delineate the purpose of the study and the method of data analysis. The National Centre for Social Research (Ritchie and Lewis 2003) utilizes the thematic analysis approach to classify and organize data according to key themes, concepts or categories. Each case study has its unique narrative materials of live stories which consist of a

series of main themes and related topics. This context is better described and interpreted with a non-linear analysis process, hence the thematic analysis approach. Moreover, the data analysis process later evolves and is refined as an iterative process through my familiarization with the raw data, for the purpose of search and identification of common threads that extend across sets of interviews.

The processes of data analysis in thematic analysis starts with familiarizing oneself with with data. It involves key steps labelled ‘detection’, ‘categorization’ and ‘classification’ (Ritchie, Spencer and O'Connor 2003) to transcribe data, and noting down initial ideas. Coding interesting features of the data set is the next step where data are collected relevant to each code. The process results in more refined categories with codes collected into potential themes. Different manifestations of the data are incorporated and discriminated before being assigned to new categories where each theme is mapped in relation to the coded extract, with the possibility of generating a thematic map. Descriptive research analysis can be built exclusively at this level of categorization.

3.6 Ethical considerations

Ethical approval was obtained from the ACT Health Human Research Ethics Committee (submission number ETHLR.17.066) and ANU Human Ethics Committee (protocol number 2014/274) in Canberra, Australia. The primary investigator worked as a part time project coordinator in ACT Health for a year in 2017 and the work was conducted in compliance with all data protocols of ACT Health. All identifiable ACT Health information were remained within ACT Health Clinical Repository database and Clinical Record Information System. The results that have drawn from the fieldwork observation and records of interviews are securely

stored on the ANU computer through the use of password protected file. All the interview participants have signed the participant consent agreement, and the primary investigator only report aggregate findings, not individual-level data. The actual interview recording, and transcript will be destroyed and deleted after thesis submission. The work has been conducted in accordance with the ACT Information Privacy Act 2014 (Australia Capital Territory 2015), which requires:

1. Consideration of Personal information privacy. The personal information has been managed in an open and transparent way. And individuals have the option of not identifying themselves.
2. Collection of personal information. The personal information has been collected based on the ground if "it is reasonably necessary for, or directly related to, one or more of the project functions and activities". The primary investigator has taken cautions steps when dealing with unsolicited personal information and ensured that the individual is aware of the fact and the circumstance of that collection.
3. When dealing with personal information, the primary investigator has not used nor disclosed the information for any purpose other than the primary purpose unless the investigator has received consent to use or disclose it.
4. Considering the integrity of personal information, the primary investigator has taken reasonable steps to ensure that the personal information the work collects is accurate, up-to-date and complete. Withholding of the personal information, the primary investigator has taken reasonable steps to protect the information from misuse, interference or loss and from unauthorized access, modification or disclosure. When necessary, the primary investigator has protected the security of personal information by destroying the information or ensuring that it is de-identified.

5. All personal information has been gained from each individual by request except certain circumstances as listed in the Territory Privacy Principles 12.2 (ACT Parliamentary Counsel 2014). The primary investigator has corrected the information to ensure that having regard to the purpose for which it is held, the information is accurate, up-to-date, complete, relevant and not misleading.

The interview consent process is a critical step in conducting ethical and responsible interviews in research where one person seeks to gather information from another. The primary purpose of this interview consent process is to obtain informed and voluntary consent from the interviewee, enduring they understand the purpose, risks, and implications of the interview, and that they agree to participate willingly. Here is a step-by -step explanation of the interview consent process:

1. Interview participation invite were sent out to the potential participants by email. The Participant information consent form was attached in the send out. For those interviews were arranged face to face, I provided the participant consent form on the spot prior to the interview.
2. Once participant agreed to the interview, I then followed it up with date, time, location, and interview method (phone, face to face or email). The participant consent form was collected after the interview.
3. For those who forgot to send me back the signed consent form after the interview, I followed it up with email.

All interviews were conducted in 2017, most of them are within the coverage of the ethics committee approval which granted on the 19th April 2017. There is one interview that was carried out on the 23rd March 2017, one day after the ACT Health Low Risk Sub-Committee meeting which is conducted on the 22rd March 2017.

Chapter Four

Case Study 1 – The use of the Canberra Hospital and health services Chronic Disease Management Register (CDMR)

Chapter outline

4.1 Abstract

The ACT Government, within the 2007-08 integrated prevention for chronic disease budget, funded the establishment of the Chronic Disease Management Register (CDMR). Implementation of the CDMR was recommended under the ACT Chronic Disease Strategy 2008-2011 as a tool to monitor key indicators for people known to be living with chronic heart failure, type 2 diabetes and chronic obstructive pulmonary disease, in order to improve service delivery and health outcomes. The CDMR is seen as the central part of ACT Health's chronic disease management program for optimizing patient care and early detection of chronic disease.

This study examined eHealth initiatives in ACT Health, and why this eHealth solution, CDMR, has not as yet delivered the hoped for results. The study uses Actor Network Theory (ANT) to understand the rationale behind the successful or unsuccessful implementation of the CDMR. In addition, it demonstrates a comprehensive understanding of key enabler and barrier factors.

4.2 Literature review

Disease registers have a variety of purposes ranging from "facilitating longitudinal research" to "providing epidemiological surveillance" (Harris, et al. 2006). A registry is defined as "a file containing uniform information about individual persons, collected in a systematic and comprehensive way, in order to serve a predetermined purpose" (Brooke 1974). Their principal function in primary healthcare is to "facilitate the structured care of patients attending services: supporting the identification of patients at risk, structured preventive care, the provision of care according to guidelines, and the recall of patients for planned visits" (Lazakidou 2006). Disease registers kept at the health organizational level of the services have the benefit of "speeding up data capture, preventing difficulties in data transfer". Registers at the regional level held by a primary healthcare or specialized service have better ability in "data analysis and capability to monitor the care through a multidisciplinary team approach" (Harris, et al. 2006).

Patient data in a disease registry may be recorded and captured in a variety of methods. Historically, data was recorded initially through hard copy forms, which were later entered into a computer database manually. Nowadays, data is often extracted from an electronic medical record and sent to a register using an HL7 (Health Level 7) message which allows seamless interoperability for the communication of clinical data.

There are five types of reports usually generated from the disease register to facilitate its functions (Harris, et al. 2006):

1. Reports for Recall function – generated to remind patients of upcoming appointment or tests that they need to schedule or complete.

2. Reports for Audit function – used to identify areas of improvement and ensure that providers are complying with relevant laws and regulation, as well as best practices for patient care.

3. Reports for Follow-up function – documents that summarize the outcomes of medical interventions or treatments provided to patients, and recommendation for follow-up care or treatment.

4. Reports for Accountability function – provide information about the performance of organizations, providers, and systems, and hold them accountable for meeting specific standards or goals.

5. Reports for Service Management function – provide information about the management of healthcare services and resources, and how they are utilized to provide high-quality care to patients.

A register is different from an electronic medical record in that it collects only a defined minimum data set or data spine, rather than comprehensive patient information. As some chronic disease management registers are designed to be used at the point of care (Bu, et al. 2007), they have similarities with electronic medical records that other types of registries do not share. Most registries can be classified as either a local hospital (or service) registry, central registry or population-based registry (Pedersen 1961). Local hospital (or service) registries capture all patients seen at a particular hospital (or service) with a particular disease. The CDMR most closely matches a local service registry. Central registries pool information from numerous hospital (or services) in a region. The key feature is that if risk adjustment is possible, comparisons can be made between the different hospitals or services. An example is the Australian and New Zealand National Dialysis and Transplantation Registry. Population based registries attempt to capture information on all services they receive (King 2013).

Central registries tend to focus on benchmarking and quality improvement across institution (Evans, et al. 2011), and population registries focus on epidemiological analysis. In contrast, chronic disease registries, which are embedded within a service that has adopted the Chronic

Care Model, are used for tracking patient information and helping physicians and other care providers to identify and reach out to patients with gaps in their care. They can "identify patients with specific illness of interest and provide information such as care delivery processes in relation to evidence-based guidelines" (Metzger 2004). In Australia, ad hoc data collections are commonly used for quality improvement projects. However, ongoing clinical registers are not common (Guda, A study to guide the design and implementation of a chronic disease management register in a regional health service 2012). Such registries are more commonly used in the United States. Where they are used in Australia it is usually in the primary care setting (Zwar, et al. 2006), rather than in the acute care setting.

4.3 The CDMR as an actor

The "ACT Chronic Disease Strategy framework 2018-2022 edition" (ACT Health Chronic Disease 2018) provides "an overarching framework for prevention and comprehensive management of chronic conditions within the ACT region". The strategy "incorporates the shift in focus from acute to chronic care. And proposes reform in primary care and community-based programs to reduce risk for chronic disease" (ACT Health 2013). The CDMR implementation is part of the strategy.

The establishment of Chronic Disease Management Register (CDMR) in ACT Health was funded by the ACT Government within the 2007-2008 budget. The CDMR has been operational since 2010. It is a tool to monitor key indicators for people known to be living with chronic heart failure, type 2 diabetes and chronic obstructive pulmonary disease, in order to improve service delivery and health outcomes. Currently, patients are only identified for inclusion in the CDMR if they have been "discharged from the Canberra Hospital (TCH) with diabetes mellitus (DM), chronic obstructive pulmonary disease (COPD) or chronic heath failure (CHF) or

received care from some of the services that participate in the Chronic Disease Management Clinical Network (CDMCN)" (King 2013). The CDMR is operated by the Chronic Disease Management Unit (CDMU), which is part of the Division of Medicine at the Canberra Hospital and Health Services (CHHS).

The CDMU aims to "strengthen chronic care coordination, self-management supports and health promotion. The CDMU started building a CDMR for service planning, secondary prevention and benchmark chronic care within the ACT region" (ACT Health 2013). The CDMR aims to provide a database of all patients with DM, COPD and CHF admitted to TCH or receiving coordination related service from the CHHS. It collects information that can be used to optimize care for identified groups of patients.

The key human actors in CDMR implementation include board members, senior management, technical staff, administrative, clinicians, patients and clerical staff. There are also non-human actors such as the information for health strategy, medical records and the capabilities of the CDMR suppliers. The CDMR is required to realize a central eHealth strategy aimed at addressing the CDMU's need for seamless patient care, which entails access to track patient information and allows successful implementation of sustainable chronic disease management initiatives.

The implementation of the registry in ACT Health is evidence of using e-health interventions for chronic care management. The following are reasons why the primary investigator chose this project to be one of the case studies.

1. The registry has been operational since 2010. Given it is an established system, it can be succinctly described, with a clear and easily articulated context and a recognizable outcome. Dr Paul Dugdale is the supervisor of this PhD project and the director of the chronic disease management unit. The case studies the primary investigator has chosen are projects currently operational and developing in ACT Health under Dr Dugdale's directorship. Hence, this gives the investigator easier access to the resources and an opportunity for in-depth observation and participation of the projects.
2. Most chronic disease registries are used to support care management for groups of patients with one or more chronic conditions. The development of the registry shifts the practice of medicine from one rooted in episodic care to one that focuses on better managing chronic disease conditions and improving the overall health status of the patient. This e-health intervention is one of the Health IT applications used in CDM programs and studying its implementation can address the research questions in this study.
3. In depth analysis of a case can reveal trends or issues that have not been exposed in prior research or will reveal new and important implications for practice. It is necessary to measure the implementation of the CDMR in ACT health and to reveal whether hidden problems are valid and evidence-based.

4.4 Findings through Participation & Observations

This study explored ACT health digital health initiatives and investigated the reason for CDMR not producing the outcomes as expected. The study uses Actor Network Theory (ANT) to understand the rationale behind the successful or unsuccessful implementation of the CDMR.

Research fieldwork with the CDMR started in May 2013 and lasted for one year. During that period, the primary investigator worked in the CDMU, and was directly involved with routine

operation of the chronic disease register to identify patients who may benefit from a chronic disease-related service. It produced data for audit projects or specific analyses and generated

regular internal feedback reports for the CDMCN. The CDMR focuses on the patients "who visit public hospitals, including their admissions, which established diagnosis for index conditions in accordance with the International Statistical Classification of Disease and Health Related problems 10th Revision, Australian Modification (ICD-10-AM) (National centre for classification in Health 2008) data definitions" (ACT Health 2013).

The Register collects data consisting of a list of variables under five broad categories (Guda n.d.) :

1. Patient details
2. Medical details
3. Provider details
4. Prevention details
5. Case coordination details

All variables are administrative in nature except for variables under the prevention category which are subdivided into three categories:

1. CHF (Echocardiogram in last two years)
2. COPD (Spirometry in last six months)
3. DM2 (Blood sugar level tracking; HbAIc level annual estimation; Eye review in last two years).

The CDMR gets data from CDMCN service, and the CDMCN databases get data support from specific database components of the ACT Health Enterprise Information Management (ACTHEIM). Database components including Clinical Record Information System (CRIS); DIABACT for diabetes service information; ACT Patient Administration System (ACTPAS); and KESTRAL for ACT Pathology and diagnostic services information.

On a monthly basis, CDMCN providers send patients' databases to CDMU using Excel spreadsheets. Once data has been collected, a list of conditions is applied to filter the raw data by demographic, diagnosis, service use and test results. The process of extracting data from source systems and bringing it into the data warehouse is commonly called ETL, which stands for extraction, transformation and loading. Meanwhile, business rules are applied to data, to standardize terminologies, values and ensure data quality. The standardized data then gets manually loaded into the register, which is a pure SQL database, by the database manager. The reports are generated in SQL database and later available as Excel format files manually for the research teams, CDMCN providers and ACT chronic health management stakeholders. The reports operate as the key documents for improving overall CDM performance and assist in service planning for chronic care. The CDMCN clinicians are the main actors of the register implementation. Their monthly data is sent to CDMU for the register database to prepare the extraction process. The database manager uses SQL programming script to transform the data and generate a patient identification report, a monthly report to members of CDMCN, and reports for audit, project or specific analyses. For example, a list of suitable patients included in the Chronic Disease Telephone Coaching Service. The challenge in big data system management is to "integrate, rearrange and consolidate large volumes of data over many systems, thereby providing a new unified information base for health system intelligence" (Lane 2013). Having a well-designed and maintained ETL process is often resource intensive.

As of mid-2014, the CDMR has been used only as an internal chronic disease management tool. More specifically, the main ways it was used to that point were:

1. To identify patients who may benefit from a chronic disease-related service. Since May 2011 the CDMR had been used to identify patients who were suitable for the Chronic

Disease Telephone Coaching Service. After identification by CDMR, letters were sent to these patients to inform them of the service.

2. As a source of data for audit projects or specific analyses, in 2012 the CDMR data was utilized to conduct an audit of chronic disease case management planning and self-management planning among a sample of Health Directorate patients. Analyses of the CDMR patients HbA1C and eGFR results were conducted in 2011 and 2012.
3. To generate regular internal feedback reports for the CDMCN, the reports had been generated since April/May in 2011, but they were not always produced on a regular basis.

At the end of 2012, CDMR began to be used to identify patients for potential inclusion in research projects. It was used to identify patients with poorly controlled DM for inclusion in a medical student research study in later 2012, and to identify patients for inclusion in a national study of home tele-monitoring services for patients with chronic disease in 2013.

4.5 Findings through interview

During in-depth interviews, study participants described their perceptions and experiences with CDMR data handling and reports generation. The research findings that this chapter reports are based primarily on analysis of interview transcripts and are supported by reviewed documents and observations throughout the fieldwork within the Chronic Disease Management Unit.

Participants' Background

The participants of this study were comprised of three staff from the Chronic Disease Management Unit. Participant 1 reported more than 30 years of

system analysis and software developer experience. The other two participants have science degrees, experiences in operating Office and basic IT skills, and they both work as project officers in the Chronic Disease Management Unit. Participant 1 was the main developer of the CDMR and was involved in the development of the CDMR for 12 months, afterwards maintaining and enhancing the registry, including new data feeds and developing new cohorts for three years. Participant 1 left CDMU in April 2016 and since then, no one has managed or maintained the CDMR, and it stopped producing monthly reports.

Participants 2 and 3 have both been working on the Telephone Coaching Project, which uses reports generated by CDMR. They have basic knowledge of how CDMR works having observed participant 1 operating the monthly report routine. They understand what the input source data is and the reports it produces. However, they reported have no actual experience handling the SQL database and CDMR. Participant 3 has since qualified to operate CDMR to extract, transform and load the data, and generate reports.

Participants' Experience of working with CDMR

Since only participant 1 has actual hands-on working experience with CDMR, mainly his view is discussed in this section. The other two participants have contributed their observations and understanding of the CDMR during interviews which are also discussed in this section. Their experiences are discussed in terms of data collection, data analysis and use of the report.

(1) Data collection

This section describes the types of data the registrar collects. Furthermore, it discusses the procedures the registrar used to generate and extract the input data for further analysis.

In general, participants reported that they collect data in three areas once a month: (1) patient list from CDMCN, (2) list of ICD-10 discharge diagnosis codes for COPD, Diabetes and CHF,

and (3) pathology list with chronic disease statistics of GFR & HbA1C. The patient list used for the current month analysis was obtained from the previous month's CDMR database. Each monthly list of ICD-10 discharge diagnosis codes was sent from the medical registrar of other departments through email. Monthly lists of chronic disease statistics for GFR & HbA1C were sent from the medical registrar of the pathology department through email.

The purpose for the above data collection is to produce a CDMR cohort list for an ACTPAS extract which are then used to identify different cohorts. The registrar runs one SQL script to produce the CDMR cohort list and sends it to one administrator in return for the ACTPAS extract cohort list, thus completing the final step of the data collection.

Participant 2 reported that:

> "*It always seemed like an effort to get the data on time and the quality of the data in the other parts of the system feeding into the register is questionable.*"

Participant 3 reported noticing that there was no control of the data collected and feed into the register, including both the data quality and turnover timeframe. In other words, both participants found it hard to trust the quality of the source data and had difficulty in getting the data on time, given the registrar had to wait for the data to be sent from three different departments. Of interest here is the fact that it usually takes around one week for the participant to collect all three datasets. Participant 1 agreed with the point that the current process of data collection is time consuming and inefficient. Participant 1 also said:

> "*We need the control of the source data for housekeeping purposes.*"

Additionally, all participants were concerned that the limited data acquisition, and incompleteness of the dataset, limits the generation of useful feedback reports. For example, participant 1 reported that the CDMR does not contain data from Calvary Hospital (another

major public hospital in ACT) or the private sector and does not collect data on key prevention variables, such as medication use and influenza vaccination status.

(2) Data analysis

Once the source data is collected and ready, the next step is to run the scripts in the SQL database so they can be edited to produce reports. All scripts were written in SQL language but only participant 1 had a sound knowledge background and understanding its meaning, and the ability to manipulate the script in case an error occurred or change was needed. Participant 1 explained:

> "*When running the scripts what they actually do is modulate the data shape of all the services, even though they have difference service entry requirement.*"

The procedure of running the scripts has been documented by participant 1 and me (the researcher) during the fieldwork in CDMU which refers to the CDMR operation manual. It was written in language for the non-IT background users.

> "*There is no need to have a special person with IT background to run the database.*" *(Participant 1, CDMR)*

This however has not been proved by non-IT background user, which is run the CDMR with only the help of CDMR operation manual. Participant 3 received a copy of the CDMR operation manual before participant 1 left the job, and at this time of this study, participant 3 had read through of the manual but never operated the CDMR. According to participant 3:

> "*The handover of CDMR was not done properly, I have only been given notes of running and using CDMR, but if I was ever going to start to use it, I have to contact participant 1 to come and teach me again.*"

In fact, there was a brief period when another person (who has academic background in epidemiology and experience with database operation) was assigned to take over the CDMR

before participant 1 left the job. However, that person never managed to get the registry up and running before leaving. Hence participant 3's comment about "not been handed over properly".

(3) Use of the report

There are two types of report generated monthly in CDMR. One gives a summary on the number of patients for each category, for example, the total CDMR patients registered that month. There are 52 categories in total. The other report details each service in CDMR, which has 11 services in total, such as the total number of active patients recorded in the Heart Failure Clinic service that month. Sometimes, other regular reports are requested for a special project. For example, a patient list is generated every two months for telephone coaching service. The reports provide a quality snap shot of the services making up the chronic disease network.

> *"Since the implementation of CDMR, we have the visibility of people's chronic disease journey, and a new service or an audit of old service can be conducted within the quality context." (Participant 1, CDMR)*

The reports generated by CDMR are stored in an SQL database and manually output as a table in Excel format later to be used by the registrar, clinician or project officer. Again, the reports are required to be written in SQL script, with which neither participant 2 nor 3 have any experience–even though they are users of the reports. In other words, the end users are not able to shape or change the reports in any productive way.

The main purpose for the use of reports is to identify active patients of that month for CDMU. Participant 1 explained:

> "*The big table generated by CDMR is useful for the registrar to work on and report to the management unit for service improvement or to develop new services.*"

Both participant 2 and 3 have been using the report to get lists of patients to invite to the participant Telephone Coaching Service which is "a telephone-based support service provided free of charge by ACT Health. The program will help people with chronic disease improve their ability to self-manage their condition" (King 2013). The CDMR implementation established a pathway for clinicians to get the data in a regular basis. Participant 1 recognized the significance, in his words:

> "*Without the register, you have to negotiate to get feeds of data, and how do you negotiate the data if you don't know what do you need?*"

Participant 3 agreed, and reported:

> "*The monthly report is valuable for telephone coaching, and we see the potential definitely.*"

Although both participant 2 and 3 recognize the patient list generated by CDMR makes the telephone coaching service possible, they think it would be better if they could manipulate the database to get what they want without relying on other people. Participant 3 further explained:

> "*I can access the reports, but whenever I have a doubt with the report and would like to validate its accuracy, I have to rely on someone else who can manipulate the database.*"

Additionally, both participant 2 and 3 claimed that monthly reports are often delivered later than expected if the arrival of source data is delayed. Apparently, users prefer to make their own enquiries from the database and have their report prepared whenever they need. This concerned participant 2, and explained:

> "*A lot of the time, data is very focused on activity such as occasions of service, length of stay, etc. This doesn't tell us anything about the lived experience for the person with their chronic disease management.*"

The monthly summary report is used by registrars to produce quarterly and annual CDM performance reports for a management unit to review. The feedback is useful for management to make future decisions about chronic care management. The monthly detailed report of chronic care services provides a care coordinator with a snap shot of what their patients are doing.

> *"Care coordinators can assess the care efficiency and when there is a change of model of care, they can actually evaluate the change by looking at the report." (Participant 3, CDMR)*

To sum up, the CDMR reports fulfilled many of the uses it was for, according to participant 1:

> "*The register was designed to provide quality and longitudinal data, which can be validated back to the source and keep track of the change over time.*"

However, both participant 2 and 3 thought the report needed further development.

Participants' comments on CDMR and its meaningful use

Each participant was asked to give a short comment on the CDMR intervention and their definition for its meaningful use during interview.

> *"CDMR is an elegant solution, it is patient-centered as opposed to service-centered interventions provided by other registries." (Participant 1, CDMR)*

Patient-centered is a term in widespread use; in the US, for example, the recent movement toward reforming primary care is known as the patient-centered medical home. It is about focusing care on the needs of the person rather than the needs of the service. When a patient-centered disease registry is properly designed and implemented, it should provide a comprehensive view of the health service, patient care outcomes, and comparative effectiveness. Participant 1 recognized that there is no integrated, public performance reporting on Australia's progress in preventing chronic disease. Participant 1 further explained:

"*The CDMR implemented as a system with reporting, however, it needs to be further developed, otherwise it can only be used as a secondary reporting system.*"

In order to achieve its meaningful use, participant 1 thinks:

"*Health intervention should provide right data at the right time to the right person.*"

However, participant 2 expressed concern:

"*I have personally always struggled to understand the value of the CDMR, as far as I know, it has only been used to get lists of people to invite to participate in a telephone coaching service."*

Of interest here, there are several uses for registries, such as: geographically based population registries; registries created for public health reporting without tracking outcomes or listing registries that are used solely to identify patients with particular diseases in clinical practices; but they are not used for evaluating outcomes (Gliklich, Dreyer and Leavy 2014). In participant 2's opinion, although the current CDMR was designed to be patient-centered, it can improve its value by providing assistance in person-focused care which provides a view of patients over time independent of care for a particular disease.

Participant 2 concluded his/her understating of meaningful use:

"*The CDMR should live up to its promise of being used to help better coordinate care for people.*"

On the other hand, participant 3 reinforced participant 1's comment, recognizing that CDMR has its potential, but transitions can be problematic.

"Unless the register can be used to its full capacity, leaders won't see the value for it." (Participant 3, CDMR)

Participant 3 seems to agree with participant 1 and recognized that CDMR will play an active, or even a leading role in encouraging changes in clinical practice that help generate improved health

outcomes. However, CDMR needs to evolve to keep pace with users' needs and address new challenges. Participant 3 observed that management thinks the report produced by CDMR is interesting, but not useful. For management level staff to recognize CDMR's value, maintaining a high level of engagement is especially important for mandated evidence-based reimbursement decisions. In participant 3's opinion, for CDMR to achieve its meaningful use, most importantly:

> "*It should provide accurate data and be accessible across services whenever the user wants.*" *(Participant 3, CDMR)*

This shares great similarity with participant 1's definition of meaningful use.

4.6 Summary of Findings

This section presents the findings of the study. These findings are based on analysis of interview transcripts, reviewed documents and observations throughout fieldwork. Findings were discussed in five sections.

Section one reviewed the ACT Health documented reasons for CDMR implementation. With an increase in chronic disease patients, the CDMR aims to create a register of all patients with DM, COPD and CHF admitted to ACT public hospitals or receiving coordination related services. The information collected can be used to optimize patient care for identified groups of patients. Key objectives for CDMR as documented on the ACT Health website in October 2012 were: (a) identify patients discharged from public hospitals with COPD, CHF and DM, (b) identify patients using services of the ACT chronic disease management clinical network (c) collect information on key indicators for patients' management, (d) provide useful feedback reports to clinicians and care coordinators, (e) provide data for research on clinical care for

patients with a chronic disease, and (f) provide data for new health promotion and disease prevention studies.

Section two reviewed the implementation strategies used for CDMR. It was recommended under the ACT Chronic Disease Strategy 2008-2011. The governance arrangements for the CDMR include a custodian, an operations team (staff in the CDMU) and clinical governance provided by the CDMCN. Technical governance for the CDMR is provided through the Electronic Health Record Steering Committee. The advisory committee should guide the development of the CDMR to "uphold the confidence of all stakeholders" (Guda, A study to guide the design and implementation of a chronic disease management register in a regional health service 2012).

Data in the third section focused on participants' backgrounds and their role in CDMR implementation and operation. Only one participant was involved in the design and implementation of the CDMR, so this participant's perception and experience are vital when looking at the technical part of CDMR, while the other two participants were considered as users of the system who have not direct involved in the development of the system and shared the same academic background with basic IT skills. Their feedback focused more on CDMR's usability.

Section four focused on participants' recognition and experiences with data collection and analysis, as well as use of the reports (ref Figure 4.1). In the area of data collection, participants described (a) the contents of data collected and the data collection methods, (b) how often data are collected, and (c) who collects the data. In the area of data analysis, participants described (a) how was source data being analyzed, and (b) who performed the data analysis. In the area of report use, participants described (a) what reports were generated by CDMR, (b) who uses the reports, and (c) how often reports were generated.

Section five focused on what participants perceived the current performance of CDMR to be and what attributes CDMR should have to achieve its meaningful use. Participants agreed that current CDMR has not reached its full capacity and underperformed. They described their understanding of what CDMR should provide to have its meaningful use, which can be grouped into three categories: (a) quality and comprehensive data, (b) transparent and accessible information, and (c) accurate and person-focused reports.

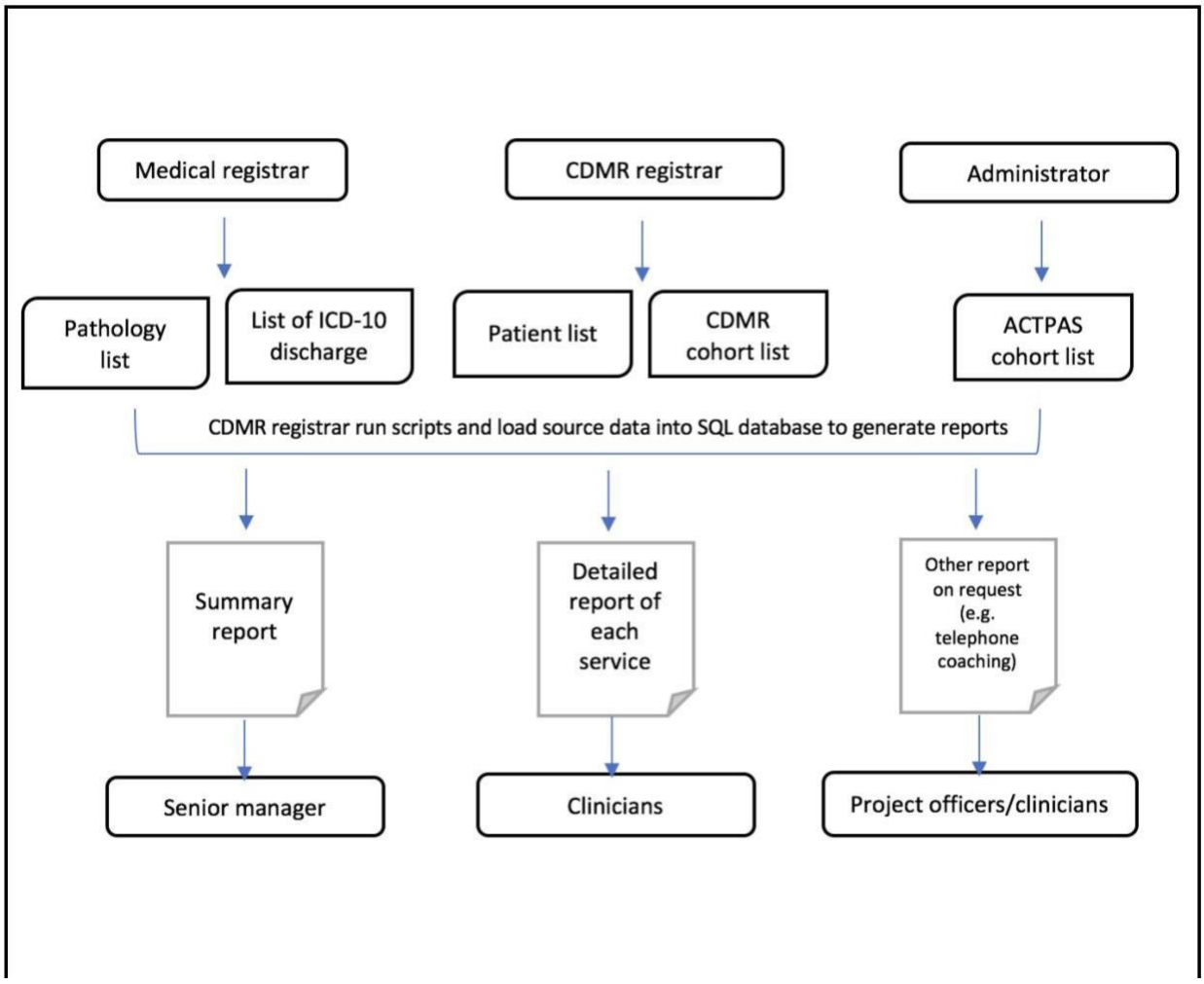


Figure 4.1 A illustration of CDMR data collection and use of the reports

4.7 Discussion

The purpose of this case study was to examine the use of the registry in a regional chronic care management unit. The study was of typically highly dynamic people and technologies that are inherently unstable. They can be stabilized to some extent when people, technologies, standards, procedures, training, incentives and so on are aligned (Greenhalgh, Swinglehurst and Stones 2014). We attempted to achieve this alignment through what Latour called 'translation', which is used to "explain the process of creation of actor networks and formation of ordering effects" (Law, A sociology of monsters: essays on power, technology, and domination 1991).

The formation of CDMR in ACT Health is an example of 'translation' and CDMR registrars are identified as primary actors in CDMR adoption and implementation. This case study identified five major factors to consider to achieve alignment for successful CDMR implementation: Organization, Financial, Technology, Social and People. There are both enablers and barriers existing in each factor, and by analyzing these specific factors using the power of ANT, it becomes possible to appreciate what is required for a successful e-health solution.

Document review and fieldwork established the cornerstone for the study. All participants' voices and views are represented. Further, participants' responses to interview questions often addressed more than one question. In those cases, the interview data are described where they appear to fit most logically. We uncovered three contextual facilitators that give rise to the features associated with effective implementation and use of CDMR, as well as seven contextual barriers that impede the success of meaningful use.

Contextual Enablers in Financial, Organization and Technology

(1) ACT Health recognizes a health service specific CDMR can actively support effective chronic disease management interventions within the service

The chronic diseases included in the CDMR are of public health significance because of the increasing burden of chronic disease in developed countries. ACT Health policies support evidence-based CDM interventions and working toward continuity of care. Leaders recognize the importance of optimizing existing services through enhanced integration leading to the development of the Chronic Disease Register to improve coordinated and proactive care. They are willing to invest the resources needed to develop CDMR to improve care coordination. For example, during CDMR's design and construction phase, it had a specific infrastructure budget and data management funding.

(2) IT-ready for improved chronic disease management

Many chronic disease management projects have used health technology to help both providers and patients access up-to-date information concerning clinical practice, medications and treatment options. Technological innovation combined with automation and miniaturization have triggered an explosion in data production, and the potential for this data to improve health is enormous. In ACT Health, the clinical electronic information already available is sufficient to begin the implementation of a chronic disease registry. Technically, ACT Health has established a good track record in electronic clinical information exchange and can leverage the existing infrastructure of secure messaging and its portal to provide access to the clinical record.

(3) CDMR database is designed and implemented as patient centered

ACT Health had a service-specific database before the implementation of CDMR. However, due to the absence of a complete information portal and communication channel for the services

unit, chronic care coordination has not been sufficient. Meanwhile, the performance reporting system doesn't capture the current chronic care issues and is therefore, not be able to assist in evaluating CDMR interventions. The current patient-centered database allows CDMR to identify patients who need care, adopt evidence-based guidelines, facilitate care coordination, and manage the performance of the chronic disease management interventions.

Contextual Barriers in Technology, People, Social and Organization

(1) Low quality and incomplete dataset

Data quality problems were identified during the interview. For example, there have been problems generating the list of suitable patients for the Chronic Disease Telephone Coaching Service in that patients who have previously been invited to participate in the program are again included in future lists. There have been issues in using the ACTPAS data to define the list of current patients for each service. Furthermore, the absence of a readily available data dictionary is also a concern for data quality. The CDMR does use hospital separation data, coded according to ICD-10-AM standards. However, these data may be inaccurate due to coding errors, which are more likely with complex clinical cases.

The current registry contains a core data set consisting of the essential elements required for the registry to serve its purpose that are epidemiologically sound. However, it is questionable whether the CDMR dataset collected all patients of CHHS who required diagnoses. Moreover, the request to include detailed clinical information to facilitate chronic disease management process tasks has uncovered these issues during interview and fieldwork observation. It may be appropriate to include new data items to reflect improved knowledge of a health issue.

The register was designed to be flexible and adaptive while still maintaining its integrity, security and appropriateness. A comprehensive data management system "determines the utility of the data for meeting the goals of the registry, and data quality aims to assure that the data is collected in accordance with the procedure" (P. R. Lee 2020). If data management system and data quality improvement is not part of an overall and continuous focus on quality improvement, then the CDMR is unlikely to achieve sustainable digital health benefits.

(2) Poor technical governance of the CDMR

Governance is central to make a health system responsive to the needs of people who access and provide services. Poor governance of CDMR was identified during interviews and fieldwork observation. For example, CDMCN did not have the technical expertise to grapple with the issues, hence it was not always engaged with issues relating to the CDMR. Although related ACT Health policies and procedures are already developed, they do not provide the specific information that is required for a CDMR policy on data management, system management, resource application and accountability structure. An appropriate governance structure creates a transparent policy environment and ensures the best use of patient data. It is also important for gaining and maintaining the trust of stakeholders. Improved documentation of policies and procedures, which is also a part of good governance, is important for quality improvement and patient safety. Fieldwork observation and documentation review are also important so that CDMR will always have the potential to progressively increase its scope, such as by adding additional diagnoses or fields. It is important to ensure the good governance on data quality, core functions, outputs and basic processes and procedures of the CDMR are well developed beforehand and are not undermined by adding further functions.

(3) CDMR are limited by human resource constraint

Limited staff capacity is a major impediment to implementing and maintaining the CDMR. Since the implementation of CDMR, it has relied on shared responsibility between one semi-permanent data person and a couple of project coordinators who do not have database backgrounds. Lacking a permanent data-skilled person limited CDMR to perform routine function and it needs to improve its performance. For example, the CDMR data are updated only at the end of each month and if the database builder is on leave, there is a longer delay. Having a permanent data person would facilitate data quality checks and generate timely reports and performance analyses.

When the previous data person left the job, participants found it hard to obtain support to keep the CDMR functional, even with provided documentation and a manual. With no or limited database management background and SQL knowledge, project coordinators found it hard to understand the scripts written in SQL language, maintain standards or make improvements. Moreover, the ACT Health IT unit did not provide systematic support to the CDMR or other clinical unit-specific databases.

(4) Inefficient data sharing and limited access in CDMR

The methods for obtaining source data are still primarily based on email transfer because of the lack of interoperability between applications. Lists of data are collected in a spreadsheet and emailed to the data person for importing to CDMR. This manual process has serious downsides and is not efficient nor appropriate enough for today's health interventions. Moreover, the process of data acquisition was not always done or often not done close to the end of each month. As a result, reports were delayed which limits their value and creates significant barriers for users and management to realize the benefits of CDMR. Efficient and flexible processes for collecting source data are needed and, in addition, timeliness and inflexible report distribution

are a concern to users, impeding CDMR's ability to fulfill its objective for better coordinated chronic care.

Limited accessibility to CDMR contributes to the problem. Currently, only the database builder has access to the CDMR database. Only this person can enter data and therefore update the CDMR. Strong support was expressed from CDMCN members for having access to the CDMR and being able to run reports as needed, rather than being sent them on a monthly basis. Providing relevant staff with access to CDMR will generate reports more appropriate for their requirements.

(5) Reports with limited value to users and incomplete data

The value of monthly reports was questioned by participants during interviews, consultations identified that the format and attributes of the monthly reports for the CDMRCN need further work. They can be difficult to comprehend and missing in detailed information for certain services which limits their usefulness. Strong support was expressed for the matrix in the CDMCN reports that shows what other services patients are using. Currently, the reports are only being used within the CDMU for service-related purposes or performance review. Other users find them interesting but not useful. They would like to see more person-focused reports.

(6) Lack of communication for improvement

Since the CDMR implementation, a review of its performance has only been done once in 2013. This limits timely feedback from the users, and it is well known that effective internal communication is highly important to any intervention. More engaged users can reduce errors and misunderstandings due to poor communication. This also applies to management, where

regular reviews would help provide earlier insights into whether the CDMR was meeting its purpose and objectives.

Document review and fieldwork observation revealed a lack of interactions and communications with other health care sectors which limited the usefulness of CDMR. For example, there is a demand for CDMR to be used to improve coordination of care and integration between the acute and primary care sectors. Without communication with local GPs, there is no way to know whether the information contained in the CDMR is useful for GPs and whether they would benefit from being included in the feedback loop.

Summary

When introducing a new technology, the 'translation' process often involves Callon's "four stages of problematization (defining a problem for which a particular technology is a solution), interessement (getting others to accept this problem-solution), enrolment (defining the key roles and practices in the network), and mobilization (engaging others in fulfilling the roles, undertaking the practices and linking with others in the network)" (Callon 1986). In the case of CDMR implementation, the ACT Chronic Disease Management Committee and stakeholders decided that CDMR is the solution to monitoring people with certain chronic diseases and optimizing care coordination (Guda, A study to guide the design and implementation of a chronic disease management register in a regional health service 2012). The Chronic Disease Management Clinical Network (CDMCN) accepted CDMR as a systematic approach to the care of patients with chronic diseases. CDMCN provides clinical governance for the CDMR. The governance arrangements for the CDMR include a custodian and an operations team with clinical governance provided by the CDMCN. Technical governance for the CDMR is provided through the electronic health record steering committee. The advisory committee guided the

development of the CDMR to uphold the confidence of all stakeholders. It is clear that all the key roles and practices have defined in the network. The rationale behind the successful or unsuccessful implementation of CDMR lies in its mobilization stage where we found hardship in engaging the key actor, the CDMR registrar, in fulfilling their role, undertaking the practices and linking with others in the network. Through identified enablers and barriers, we can see clear tension between each sector which are supposed to help stabilize the network and. As a result, the eHealth solution, CDMR, failed to fully reflect and respond to local needs and priorities.

4.8 Recommendations for future improvement

The CDMR faces a variety of issues in the areas of data management, governance, accountability, communication, resource management, accessibility and sharing. Many of these challenges have been acknowledged in a previous CDMR review done in 2013, but it attracted little attention from the management level. CDMR has not performed to its full capacity and is deficient in communication, so CDMCN is not yet able to fully realize the benefits of the CDMR. Without support from CDMCN and attention from management level, CDMR has limited resources, which inhibit its development and improvement.

The findings of this study point to six recommendations for addressing and improving the meaningful use of CDMR: (1) strengthen governance and accountability, (2) perform regular data audit, (3) automate capture of service data, (4) build user interface, (5) improve CDMR reports and their use and (6) organize regular communication with users and other health sectors.

<u>Recommendation 1: Strengthen governance and accountability</u>

The definition of governance is “ensuring strategic policy frameworks exist and are combined with effective oversight, coalition building, the provision of appropriate regulations and incentives, attention to system design, and accountability” (WHO 2007). Therefore, good governance from that perspective is “understood to be policy-centric including consideration of all factors which impact the health intervention together with transparent rules overseen by strong accountability” (Mikkelsen 2014).

Develop a CDMR policies and procedures manual which in compliance with other relevant ACT Health policies is a priority for reform to create good governance. One key recommendation is to identify where current governance issues are and weigh the individual elements to seek major drivers for “strong” or “weak” governance.

The accountability for current CDMR management is vague and ambiguous. For example, staff are not held to account when absent, and there is a lack of regulation to hold absent staff accountable. Another key recommendation is to have regular meetings of CDMCN specifically focusing on CDMR issues to update its policies and procedures manual.

Recommendation 2: Perform regular data audits to ensure data quality and completeness

The CDMR aims to optimize care for identified groups of patients and its key functions relate to tracking the care of patients and identifying and providing support to patients with gaps in their care. To be able to do this, accurate patient information is crucial. The core dataset needs to be continually reassessed to select the essential items, and additional service related data need to be considered for inclusion to complete the CDMR. One key recommendation is to have a regular data audit or study to assess the accuracy and necessity of the CDMR data. The ACT Health Data Quality Framework would be a useful tool to support the data audit process.

Recommendation 3: Automate capture of service data

Manually capturing data from different service is time consuming, error prone and often delayed due to fluctuating demand, pressure of work or inexperienced personnel. The need for an automated process for obtaining the service data for CDMR had been recognized prior to 2012. However, this need has never been addressed properly. The idea is as simple as its implementation is difficult. With rapidly developed technical capability, it will be IT-ready to assist the automated capture of service data.

The barriers for implementation consist of privacy concerns, challenges to current health data policy, source data not in electronic form, limited resources and lack of knowledge about where data exist and how to access it. Resolving these issues should be achieved by:

1. Defining the scope of use through formal agreements with partner services, such as data sharing agreements, confidentiality agreements and obtaining permission
2. Utilizing resources to prepare the source data in electronic form which is transferable
3. Provide necessary education to staff from different levels and service partners to smooth the transition to implementation.

Recommendation 4: Encouraging innovation to improve usability

The usability concept is critically important in promoting both the adoption and meaningful use of CDMR in CDMCN. Negative impacts of CDMR on efficiency, team collaboration and report errors can all be linked to issues directly related to usability. Encouraging and broadening innovation to better meet end user needs will service CDMR's aims and objective. One recommendation is to implement a CDMR user interface which makes the CDMR more accessible for relevant staff. With improved accessibility, staff can be trained to generate reports

when they want and in a form they like. It can also improve timeliness of CDMR output, which has been constrained by resource limitations. A user interface should make the regular generation of points of care possible, as well as regular clinician feedback reports.

Recommendation 5: Improve CDMR reports and their use

There are three types of report users expect to be generated by CDMR.

(1) a patient report to be used at the point of care,

(2) a report with a patient list which identifies patients for different chronic disease management services,

(3) population reports which provide information about how well the service sector is doing in delivering recommended care to a patient population and potentially also provide information about individual care teams. Current reports of CDMR are inadequate for use in evaluating patient outcomes which need point of care, because the included data does not recognize the health problems experienced by the patient. A key recommendation for improving CDMR reports is to have the data focus on the patient rather than the service.

Recommendation 6: Organize regular communication with users and other health sectors

Increase communication between users and management. For example, consider more frequent meetings of CDMCN, follow up with users to ensure that new development or change in CDMR is useful and set up a CDMR feedback email box. Further, arranging interaction with other health care sectors can develop CDMR for new services and expand its use.

4.9 Limitations

The scope of this case study was limited to consultations with staff from the CDM section, fieldwork observation and participation in the CDMCN. The study was limited in scope because of the time and resources available, and the stage of development of CDMR. It would have been beneficial to consult more widely with electronic health stakeholders in ACT Health.

The CDMR is a unique register in Australia. It is operating at the interface between the acute and primary care sectors. But there is a lack of information about similar registers, and limited information about best practice for such registers.

This study only viewed one disease registry in the case study, which could be considered a limitation. Disease registries often vary greatly from each other, even though they might have the same size, same disease type and same implementation background. Therefore, speculation that the result of this study would be similar to another should be discouraged. In addition, the study focused solely on the use of CDMR, which could be another possible limitation. A broader scope of questions may have given more insight into other complex problems with disease registry. Additionally, the sample in this study consisted of just three staff who agreed to participate; data sources, which included an unstructured interview and a relevant document review.

Chapter Five

Case Study 2 – The development of a Chronic Care Program (CCP) within the Australia eHealth transition

Chapter outline

5.1 Abstract

IT development in healthcare is increasingly shaping health service organizations. We expect the introduction of IT in healthcare to improve the information flow and lead to improved quality of care. However, the result is often not straightforward given the complex healthcare environment. It is important to understand the complexity of the issue and what role technology plays.

The introduction of technology in health care can be viewed as a new component added to the existing network, which means there will be a "new formation of connections and other already established components to re-organize around this new component" (Cresswell, Worth and Sheikh 2010). This is a complex process of change and this study intends to gain deeper insight

into this network of association, so it facilitates the effective integration of technology into the healthcare environment. In the last case study, the primary investigator chose to focus on one aspect of the network, which is individuals directly interacting with technology. And in this case study, the investigator continues to explore how individuals interact with technology as well as existing systems (e.g. a paper-based system) within the Australia eHealth transition. We use findings from aspects of the network to draw conclusions about the wider network without neglecting the whole picture.

In summary, we traced connections among different components in the network of Chronic Care Program in ACT Health to study how technology impacts people, environments, and the contexts in which they exist. We identified the intensity and strengths of associations as well as the resistance to them when they occur. Based on the study, we made recommendations for future integration of technology into the healthcare environment and laid groundwork for the next case study.

5.2 Literature review

It is of particular importance to assure the delivery of proactive, efficient clinical care and self-management support for people with chronic illness. That requires defining roles and distributing tasks among team members. More complex patients may need more intensive management to optimize clinic care and self-management, such as making follow-up a part of standard procedure. One study shows “access to shared clinical information by a multidisciplinary team of providers is likely to support team-based care across geographical boundaries: and lead to improved continuity of care” (Haikerwal 2010). Therefore, making health information available to all providers involved in the care of a patient, such as

implementing electronic medical records in a health care setting, ideally should improve chronic disease management.

Clinical nurses and care coordinators are an integral part of the chronic care delivery process. They produce documentation including material covering assessment, planning, implementation and evaluation. There should be clear evidence of the care planned, the decisions made, the care delivered and the information shared. The electronic patient record has become "an important aspect in the information workflow and using information technology will result in improving patient outcome quality and efficiency" (Cassano 2014).

Patient documentation has always been one of the key requirements for communicating patient information to plan their care according to their needs, even before the digital age. A significant factor in the current care delivery system is the increasing use of electronic documentation as instead of the paper forms used by care providers to document important patient information. Therefore, a well-designed clinical information system is needed to help and supply information for efficient documentation processing. In the beginning, care providers believed that "electronic documentation and information systems were an interruption to their daily workflow and a disruption from bedside care" (Cassano, 2014). Over the years, however, they are "more proficient in all aspects of information technology while maintaining superior levels of patient care" (T. T. Lee 2004).

Shifting to an electronic system from a paper-based system is "widely expected to improve the efficiency, quality, and safety of medical care" (Mekhjian, et al. 2002). Paper documents hold "static information that loses timeliness with age and constitutes an information security hazard" (Kuerman and Gibson 2003). However, analysis reveals "psychological, ergonomic,

technological, and regulatory reasons for the persistence of paper in an electronic environment" (Dykstra, et al. 2009). For example, it is hard to ignore the physical attributes that makes paper particularly effective in collaborative work. Paper will continue to fill the gaps from psychological to technological, to legal with numerous reasons why itis still needed. Meanwhile, as technology evolves with increased functionality and usefulness paper will gradually be replaced. So it is important to implement "carefully designed procedures detailing how temporary paper records will later merge with computer records" (Dykstra, et al. 2009) in a health care setting.

We use the term "inertia" to describe "resistance to change, or a desire to continue the current process" (Wikipedia n.d.). Many clinicians continuing to use paper notes do so because they always have and the practice worked. So financial incentives were introduced in U.S. health care system to "incentivize the conversion from paper to electronic files for medical providers that establish meaningful use of electronic health records (EHRs)". However, results of a survey of 2952 American Hospital Association-member institutions showed that only "1.5% of hospitals had a comprehensive EHR system, another 7.6% had basic systems and 17% had computerized provider-order entry for medications. Of the hospitals that had not installed electronic record keeping, 74% said they did not have the money for an EHR system; 44% had concerns about maintenance costs; 36% pointed to resistance from physicians; 32% cited unclear return on investment and 30% said they lacked adequate expertise in information technology" (Jha, et al. 2009).

The ambitions of the digital agenda have always commendably gone beyond simply making the system paperless. It is the essential tool for meeting the needs of patients, their families, healthcare professionals, and improving the way care is delivered. With government funding,

it is also important to emphasize quality improvement and benefits to patients, so clinicians will come on board. As well as building the workforce, making progress on updating or adopting systems so that they share information in a standardized way is a must. In health care, we use the term “interoperability” to describe the ability of different information technology systems and software applications to communicate, exchange data, and use the information that has been exchanged (HIMSS 2010). The technical capability has long existed to achieve interoperability; however, “a by-product of a fragmented national healthcare system is that vendors lack incentives to make their technologies work in a plug-and-play manner” (Jayanthi 2015). Another challenge is the “lack of interoperability caused by an industry that does not have the same data standards, hence it is hard to mandate that all healthcare organizations utilize the same systems” (Jayanthi 2015). And even with a seamless flow of information around local health care units, it is difficult to sustain a viable model. Patients who desire to direct data to their providers are often given a fax number or asked to print the information so that it can be scanned.

Overall, to develop health care in Australia by adopting eHealth systems, the electronic health information system should have the ability to (National E-Helath Transition Authority 2013):

1. Improve the efficiency of health care service and personalizing the quality of care
2. Streamline multi-disciplinary care management and restructure the business model of health care delivery
3. Improve clinical and administrative efficiency and
4. Maintain high standards of patient privacy and information security.

5.3 Introduction, findings through participation and observations

The purpose of this case study was to examine the development of eHealth interventions in CCP to provide continuing care services within the digital health transition. The following research questions informed this study: (a) What has been changed in the CDM network within the national eHealth transition? (b) What are the components of the CCP work flow and how do they interact with each other before and after the introduction of electronic forms and (c) What are the resistance forces when new associations between old components and eHealth interventions occur.

The Chronic Care Program (CCP) is one of the disciplines of Chronic Disease Management (CDM) within the Division of Medicine of Canberra Hospital and Health Services (CHHS). The Chronic Care Program provides care coordination and/or clinical support to people in the ACT and surrounds. The program targets frequent users of the acute care sectors with Chronic Heart Failure (CHF), Chronic Obstructive Pulmonary Disease (COPD), Parkinson's disease (PD) and other movement disorders. CCP provides services including:

Chronic Heart Failure Service	The Heart Failure clinic provides education, clinical support and care coordination for those patients who are frequent users of the acute care sector with Chronic Heart Failure. The Heart Failure clinic also accepts patients with newly diagnosed CHF and stable HF patients who need to develop self-management skills."
Heart Failure Rehabilitation Course	A 12-week multidisciplinary course incorporating education and exercise sessions for patients with CHF. The Heart Failure Rehabilitation Course aims to educate chronic heart failure patients and their family/carers about their condition; provide appropriate exercise sessions to improve patient quality of life; improve confidence and self-management skills; and reduce the frequency of hospitalizations."

Chronic Obstructive Pulmonary Disease Service	The COPD service is staffed by a Clinical Nurse Consultant (CNC) who provides education and clinical support for frequent users of the acute care sector with COPD. The COPD CNC reviews patients in the hospital and community setting. Clinical Care Coordinators work collaboratively with the CNC to provide support for those COPD clients who require further care coordination, including self- management strategies, education and advance care planning.
Parkinson's Disease and Movement Disorders Service	This service provides "education, clinical support and care coordination for frequent users of the acute care sector with Parkinson's disease, Multiple Systems Atrophy (MSA), Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD)
Chronic Disease Home Telemonitoring Service	The HTM service provides remote monitoring for patients. Daily recording of observations aims to promote self-management and stabilization of the individual's chronic disease, as well as decreasing the incidence of hospitalizations.
The ***Smoking Cession Service*** and ***Care Coordination Service***	These provide individually tailored services including self-management strategies, advance care planning, education, facilitation and coordination of community and other support services". It focuses on those people "who may need assistance to manage their health and to navigate the ACT health care system" (ACT Health 2013)

Clinical nurse consultants provide specialist nursing support for eligible patients in either specialized outpatient clinics or home visits if needed to assist with any medical concerns. They provide patients with education and information about chronic conditions, as well as liaise with patients' GP, Specialist and other health care providers. Moreover, the clinical care coordinators work with the patients to arrange support for them in the community, to help with everyday tasks at home, and plan for patients' future to ensure their conditions are known by everybody involved in the care, e.g., liaise with the GP, specialist and other health care providers about appointments and care.

There has been a significant "increase in demand for Chronic Care Program services" which led to the "expansion of some services, as well as the implementation of new processes to ensure effective and efficient service delivery" (ACT Health 2013). The following are the reasons that the primary investigator chose this project to be one of the case studies.

1. The Chronic Care Program is an established system, and the primary investigator has access to the project with help from principal supervisor Dr Paul Dugdale, who is the

director of the Chronic Disease Management Unit. Therefore, the project can be succinctly described with in-depth observation and participation.

2. It is important to ensure the patient gets care using structured, planned interactions. Digitization is an essential tool to improve the way care is delivered. This is happening in the Chronic Care Program which makes it an excellent case study to investigate research problems.
3. Digital development should drive the roll-out of technology in such a way that it fits better into clinicians' ways of working. This is not the case in the current Chronic Care Program. The investigation in this case study may result in findings that reveal ways in which to resolve an existing or emerging problem.

During field work in the Chronic Care Management Unit, the primary investigator observed there are seven services within the Chronic Care Program and each service has a form template to record the patient information and progress. For example, the COPD assessment form asks for a patient's medical history and measurement of their spirometry, such as blood pressure, during the session. Staff working for the CCP unit will eventually forward the forms to a GP, specialist and other health care providers for better support, decision-making and care planning. These forms were initially developed as paper questionnaires with sections consisting of proposed information for each particular service. They were originally stored as paper documents in a storage unit. With the rise of computer and electronic use, the forms have evolved from plain paper records to Word documents on computer. All seven forms contain at least 23 variables for patient information and a standard electronic form template has the patient label and a unique barcode on the top.

There are three essential parts involved in the current information flow: data services, data transformation and the reports as output.

Data Services

Current patient information was gathered through patient in-clinic visits by clinical nurse consultants or care coordinators inputting information on computer using Word document or written manually on a paper form. Some services were provided through a home visit to record the patient information. Given the total patient size varies and the different nature of the services provided in CCP, each service has its own routine when adding to patient records (Ref Table 5.1).

	HFC	HFR	HTM	COPD	SC	CCPMD	CC
Total Active Patient (August)	134	44	12	123	25	170	80
Electronic or Paper Forms	Electronic	Paper	Electronic	Electronic	Electronic	Electronic	Electronic
Visit Type	In Clinic	Rehab Gym	Home Visit/Telephone	Home Visit/In clinic	In Clinic	In Clinic/ Home Visit	Home Visit/ Telephone /In Clinic

Table 5.1 Total number of active patients in August 2013; methods of record; visit type for each service

Abbreviations: Heart Failure Clinic (HFC); Heart Failure Rehab (HFR); Home Telephone Monitoring (HTM); Chronic Obstructive Pulmonary Disease (COPD); Smoking Cession (SC); Chronic Care Program Parkinson's and other Movement Disorders (CCPMD); Care Coordination Patients (CC)

Most in-clinic or telephone services can record patient information electronically as they have easy access to a computer. However, when service providers required for a home visit or for a service performed in the rehab. gym where a computer is not accessible, they have to use the old method, which is record the information on a paper form and input it into computer after they get back to the office or when a computer is accessible.

Data Transformation

The Chronic Disease Management (CDM) Register is a data model been created using normalized SQL relational tables. It keeps records for patient identification, diagnoses, prevention indicators (specific for each disease), care providers, services, and events. Six out of the seven services provided in CCP are also recorded in the CDM register where the information is extracted from the ACT Patient Administration System (ACTPAS). However, only minimal information from the assessment forms in each service is recorded in the CDM register, which is the patient label (URN, surname, given names, date of birth and gender). The rest of the information on the forms is either stored as a paper document in the storage cabinet or saved on computers as Word document in the CCP unit.

Output

One of the purposes for the CCP is to have the patient progress recorded and available for their GP, specialist and other health care providers to view, which possibly helps in the clinical decision-making or advanced care planning. Therefore, the forms recorded in each session for each service are forwarded to Clinical Research Information System (CRIS) where the data collected for both research and clinical care are accessible to clinical providers. Forms are usually either uploaded to CRIS through Internet or by fax. The best scenario is to have these forms uploaded to CRIS immediately after each visit, when there is a new referral or as

scheduled. Although the care coordinators or the clinical nurse consultants from the CCP try their best to achieve the best scenario, currently, the forms are rarely uploaded to CRIS on time.

5.4 Findings through interview

The aim of this case study is to investigate and understand the impact of digital initiatives had on CCP in terms of change on its interrelationships.

During in-depth interviews, study participants described their experiences with the delivery of clinical care, particularly in the use of electronic clinical forms and the methods used in storing patient information. Moreover, participants talked about their role and communication among team members.

The research findings that this chapter reports are based primarily on analysis of interview transcripts and are supported by reviewed documents and observations throughout my fieldwork within the Chronic Disease Management Unit.

Participants' Background

The participants of this study were comprised of three staff members from the Chronic Care Program.

Participant 1 was the clinical nurse consultant in Parkinson's Disease and Movement Disorders Service for six years. Participant 1's role involved managing a caseload of people with neurodegerative disorders, as well as supporting other members of staff, including care coordinators and junior nurses. Participant 1 was an experienced clinical nurse who provided educational and professional support for other health professionals across Canberra and ACT. Participant 1 has basic knowledge in database, programming and IT development, and showed considerable enthusiasm for the use of electronic methods for the delivery of care to patients.

Participants 2 and 3 were clinical care coordinators who receive patients from COPD, HF and CCPMD after

a clinical nurse consultant has decided they need further care outside their service network. Unlike participant 1, participants 2 and 3 adopted a conservative attitude towards the use of electronic methods in care delivery. They were experienced care coordinators who believed in eye contact with patients. They were happy with the paper-based system and felt discomfort using the computer and typing when with the patient. Both participant 2 and 3 owned basic office IT skills only. There was one clinical nurse consultant working for the Parkinson's Disease and Movement Disorders Service and three care coordinators looking after patients from all services. The reason I have chosen to interview the clinical nurse consultant from only CCPMD is that the service had the largest patient load at that time, making the CCPMD service an excellent example for study within the Chronic Care Program.

Participants' Experiences in Chronic Care Program

The participants' voices and views of their experiences in CCP are discussed in four parts: (1) collection of patient information, (2) methods of storing patient information, (3) use of patient information for care delivery, and (4) case load distribution and communication among CCP partners.

(1) Collection of patient information.

Participants collect patient information through clinical forms completed during an initial visit and a follow-up assessment. There are a variety of question formats on the forms: dichotomous, multiple choice, rating scale and open-ended. For CCPMD service, the initial assessment form records a patient's medical team, recent state, observations—such as blood pressure—current medication, medical history, social situation—such as support from family—future plans, lifestyle and preventative measures, diet and fluid intake. At the end of the initial assessment form, there is a section for participant 1 to record the assessment summary, identify risk factors,

list next steps and actions to be taken. Normally, participant 1 would see her patient in her office and record this information by typing it into a computer during the assessment meeting. Participant 1 reported that most of her patients are 65 years old and over, and sometimes she needed to perform home visits to see her patient for care assessment and follow up.

The follow-up assessment form contains patient information of observations, such as current weight and self-management, such as coping strategies. At the end of the form, participant 1 records the assessment summary and date of the next review. Both forms have a patient label section which identify the patient's demographic details: patient ID, name, date of birth and gender. Participant 1 thinks the questions on the form are "adequate to paint an accurate picture of patient information that a clinical nurse need". Except for assessment forms, participant 1 does not collect any other patient information for her own references and patient care.

For CC service, participant 2 and 3 reported the use of an initial assessment form for new referrals, and a patient progress e-note during a follow up visit. The initial assessment form consists of two types of questions: Medical and Psychosocial. The patient progress e-note, as its name suggests, is basically a blank field where clinicians can record any patient information during their follow up visit. All forms have a patient label on the top containing the patient's demographic details. Both participants 2 and 3 assessed their patient in a clinic, home visit or using a telephone. Unlike participant 1, care coordinators prefer to print out the electronic forms and avoid using any electronic method during patient visits and assessments. Participants 2 and 3 explained:

> *"We used to have patients complain when we filled in the forms on the computer in front of them during an assessment meeting; they found we were being insensitive, they think we care about the form more than the patient."*

Moreover, both participant 2 and 3 preferred to record everything on paper and have eye to eye interaction with the patient during assessment and follow up visit. They reply heavily on their

clinical notes to keep patient information and provide care based on the notes they recorded during each visit.

(2) Methods of storing patient information.

Once patient information was collected through clinical forms and notes, participant 1 stored them as digital documents and uploaded them to CRIS through the internet. However, the clinical forms sometimes were handwritten if participant 1 visited a patient outside her office, so she had to transcribe written documents into typed ones in order to store the information electronically once she was back in her office. She described this process:

"Ineffective and time wasting." (Participant 1, CCP)

Participant 1 further added:

"I would have preferred a database to store patient information, but this was not possible."

To make up for the non-exist patient database, participant 1 stated that she maintained her own spreadsheet of patients to ensure follow-up. Despite all the trouble participant 1 had go through for storing patient information and maintenance, she reported no mistakes or incidents at work related to her method. Unlike participant 1, both participant 2 and 3 liked to store their patient information the old school way. They printed out the clinical forms and recorded every piece of patient information on paper, and later, they created a paper folder for each patient where the clinical assessment forms, follow-up notes and clinical memos were collected. All the folders were stored in a cabinet onsite and copies of the clinical file were delivered to CRIS by fax. With such work a folder will eventually get heavier and thicker, especially for a long-standing patient, however, according to participant 2 and 3:

"We found this method is effective and we have been using this method to store patient information since the establishment of the service."

They were fully aware of the existence of the electronic forms and online uploading method to CRIS. However, they chose the old school way simply because they felt comfortable with the paper method and had confidence in it. Moreover, other than the paper notes, participant 2 and 3 both mentioned that they knew each patient well enough to memorize all their small details which were not recorded on the clinical forms, such as 'what the swollen leg looks like during the last visit'? In other words, participant 2 and 3 memorized the information of patients who were the 'frequent flyer' of the service instead of recording the patient history on the form.

(3) Use of patient information for care delivery.

In CCP, all the patient information collected through assessment will eventually be turned into a plan of care for each patient. The clinical judgement and assessment are essential methods that clinical nurse consultants and care coordinators use to draft the personized care plan. There is a care plan form for clinicians to use in CCP. The form has a patient label on top with demographic details and the rest of it consists of three 3 parts. The first part requires the clinicians to identify the patient's current and resolved issues, and for each issue, they need to outline the goal, intervention, persons responsible, review data and progress. The second part records the detail of different services provided to the patient, such as transport, gardening, financial or pharmacy, with the provider name and contact detail. The last section records the referrals details correlated to the issue number. Along with the care plan, the clinicians prioritize the needs of the patient, both objective and subjective, in order to make necessary changes. The patient information collected is not only used to produce the care plan, participants state they need to re-read all assessment forms, notes and recent clinic letters to prepare for the follow up session and remind themselves of the patient's history. Participant 1 further added:

> *"It would be quicker and easier to be able to compare changes, perhaps with a graphic, rather than digging through the old assessment forms for a better care delivery."*

Both participant 2 and 3 also agreed:

> *"It will be great if there is a tool can that help us to reach the patient information we need more efficiently."*

The current CRIS system keeps the patient information electronically. However, once the information is uploaded, it is hard to access and extract when needed. According to participant 1:

> *"The system prevents easy extraction of data, and there is no easy way to manipulate the data and find the percentage of diagnosis, for example, gender, or age."*

Whether it is to retrieve data or analyze trends, CRIS does not have easy interface to support more efficient workflow processes and providing links from CRIS that will allow easy access to frequently used references and resources. In participants' view, the inefficient workflow interfered with their care delivery process to a certain extent.

(4) Case load distribution.

There were 4576 patients registered in the CDMCN service, and 294 diagnosed with Parkinson's Disease during August 2013. The case load for participant 1 was overwhelming, as she reported during her interview. There were 170 active patients for her during August 2013 and it the number is constantly increasing over time.

> *"The CCPMD service sits outside of two primary medical specialists – neurology and geriatrics. Neurology wants less community, more complex therapy and inpatient input, while geriatrics would prefer a community-based model with more home visits. The politics required we, the clinical nurses, to maintain the delicate balance between the demands." (Participant 1, CCP)*

Overall, participant 1 thinks the caseload was large due to limited resources and politics played too large a role in protecting the service. Once the clinical nurses assessed their patients need

for help other than the disease itself, they often referred the patients to care coordinator service. There are 3 care coordinators looking after around 100 patients in the service. Each participant (2 and 3) were responsible for around 35 patients at the time of interview. Although the patient number for each care coordinator is less than what participant 1 received, the care depth and intensity provided by the care coordinators for each patient is time consuming. According to participant 2:

> *"The current case load has already reached our working capacity, we simply can't take in any more new patients without compromising the current quality of care."*

(5) Communication among CCP partners

Like all other clinical care settings, most communications between CCP partners were conducted through email and verbally, whether it was about transfer of patient information or defining roles within CCP. If the patient information was not stored electronically, for example, participant 2 and 3 would often bring their paper file with them when communication was needed for patient care with clinicians from different service unit within the hospital. This method of communication is time consuming and ineffective, which will be a huge burden as patient workload continues to increase. For participant 1, most of her patient files were stored electronically. She communicates with CCP partners through email and telephone most of the time. The major concern mentioned by participant 1 was the lack of defined roles among team members.

> *"The continual requirement to defend our roles made interactions frequently a defensive position, for example, I have had to reject requests to check bloods and triage consultant clinics repeatedly over the last 5 years." (Participant 1, CCP)*

Overall, all participants agreed that communication among CCP partners needs to be improved to provide better care for people with chronic conditions, with assigned roles, duties and tasks for planned visits from a multidisciplinary care team.

5.5 Summary of findings

This section presented the findings of the study. These findings are based on analysis for interview transcripts, reviewed documents and observations through fieldwork. Findings were discussed in four sections.

Section one reviewed the role of CCP and its objectives. The program focuses on those chronic disease people who "may need assistance to manage their health and to navigate the ACT health care systems". It aims to: (a) encourage self-management at home or in community settings, including the use of peer support and technology where appropriate; (b) provide education and support to the patient, their carers and family, and assist with accessing appropriate health and community services; and (c) enhance communication among the CCP partners involved in the patient's care, enabling more effective and timely monitoring and management of the patient's condition" (ACT Health 2013).

Section two reviewed the current delivery system in CCP and how a clinical information system facilitates care. CCP employed an interdisciplinary clinical team which consisted of a group of people from relevant clinical disciplines to interact with patients and achieve team-defined favourable patient outcomes. Clinical nurse consultants work with the specialists, GPs, and care coordinators to formulate regular, proactive planned visits which incorporate patient goals to help individuals maintain optimal health. Chronic disease patients with complex conditions

have ensured regular follow-ups by the care team and visits often employ the skills of several team members. Health information systems are developed and used to help care providers better manage their resources. The CDMR was used to record the monthly inclusive list of patients with a given chronic disease, but care providers from CCP have no direct access to the registry. All the clinical forms and files from CCP were uploaded regularly and stored in CRIS, again, the care providers have no direct access to the system. The clinical forms have now been digitized as Word documents and unified with patient labels on top. Word and Excel files are the common method of storing patient information by clinical nurses and care coordinators in CCP.

Data in the third section focused on participants' backgrounds and their role in CCP. The interviewees forming this part of the study are clinical nurse consultant and care coordinators, who are the main care providers in CCP. They are experienced in providing chronic care service and more than three years of working experience in CCP. Only one participant is actively seeking eHealth technologies to help coordinate care and willing to use electronic methods around patients. All clinical nurses and care coordinators have basic office IT skills, though there is a reluctance towards learning new IT skills in care providers in an older age group.

Section four focused on participants' experience in collecting, storing and using patient information; it also reviewed their case load and communication between themselves. Clinical forms are the primary method for collecting patient information. Each service has its own initial assessment form when taking in a new patient, and for the follow up visit records patient information through a care plan and clinical notes. Patient information collected is stored either electronically on a care provider's own desktop, or manually as paper files. Given clinicians have limited access to the patient information stored in CRIS once forms have been uploaded,

they chose to keep a copy of the forms locally, so they can look up the patient information when needed during a care delivery process.

The case load is overwhelming for both clinical nurse consultants and care coordinators in CCP. Unsurprisingly, the capacity for CCP is limited by human resources and politics. Participants have reported the need for a more effective strategy to define roles and distribute tasks among team members. Moreover, participants have also reported the communication methods among the CCP partners which primarily rely on email and verbal (phone call or field visit) are inefficient and time consuming.

5.6 Discussion and recommendation

This chapter reviews, analyzes, and discusses the findings of this study. This chapter also outlines the implications of the findings for CCP and concludes with suggestions for further research.

Changes in the CDM network within the eHealth transition

The use of technologies in CDM changed the network components associated with clinical and practice management processes. The purpose of CDM is to provide better integrated and coordinated care, “planned care with regular follow-up and review”, improve “collaboration

across a multidisciplinary team of care providers" (Georgeff, Digital technologies and chronic disease management 2014), and support for patient self-management. Digital technologies available today have the potential to assist CDM to achieve its purpose. In response to the Australia National eHealth Transition Act, eHealth interventions have been introduced into the CDM network to deliver convenience and confidence, integration of care, improved outcomes, use of evidence, supporting analysis and improvement in care management efficiency. Figure 5.2 illustrates the new network now including both humans and technology. As a result, the following areas have been identified that changed with the support of technology.

1. Care management

   The ongoing care management in CCP needs to assess patients to proactively identify needs, educate patients, and work collaboratively with providers to coordinate services. Currently, the first step in identifying patient needs were done through electronic patient assessment form templates. The development of patient assessment forms from paper to paperless was proposed to reduce risk and cost and improve efficiency. Although many care providers in CCP still rely on paper to capture clinical documentation, including the informed patient consent, many of them also learned and found the benefits of using the electronic method to manage the patient information and identify patient needs. Some of them found its easier to look for patient information if stored electronically, so they could type and search the patient file when needed. eHealth data empowers healthcare providers by providing completely new insights into a patient's health.

   The monthly report generated through CDMR offered clinicians an overall view of their patients' demographics and the care services they have been receiving, allowing each member of the care team to know what the rest of care team is doing.

One of the most serious failings in the management of chronically ill patients is the lack of follow-up and review. The purpose of CCP is to ensure proactive follow-up by the healthcare team. Digital systems can track appointments and progress across the entire care team, compare these with the care plan, and generate an instant snapshot of what has been planned, done, and not done. The purpose is to make sure every action is followed up. Currently, CCP care providers manage this information mainly through Excel spreadsheets which they have to create themselves. They have individual preferences and find gaps in what is available. Meanwhile, accessing and documenting patient education also varies among care providers. They often research the patient–specific education material with the help of the internet. Health sciences librarians frequently provide clinicians with health information and patient education, both of which contribute to improved health care quality and improved patient outcomes.

2. Collaboration and communication

Electronic medical records have been considered as one of the keys was of sharing information across the care team. Currently, CRIS is the primary computer information system used in CCP to support patient care, research, and administrative activities. The overall goal is to configure CRIS so that all clinical information needed to support patient care is available via one system. Nurses and care coordinators upload the clinical documentation to CRIS so it can be shared with other care providers. It includes documentation of patient care plans, vital signs, medication administration, intake and output, and progress notes. They can also request to retrieve laboratory or radiology results if they have the access permission.

CCP clinicians were trained to understand the roles of other care providers, it is their ability to comprehensively assess the patient's clinical, emotional and social situation and draw upon the available resources to create a patient-centric care plan that helps play an important part in collaborative care. The communication among CCP clinicians is critical to collaboration, whether it is verbal, written or electronic. The most often used method was email, which improved personnel competences, the organization of daily operations and administrative tasks. Communication using electronic devices may speed up the management of patient data, improve staff cooperation and make more effective use of working time.

3. Support patient self-management

Patients need effective tools to communicate with their care providers, share information and receive care support and assistance in between visits. Electronic methods that deliver such results are a promising approach, especially to patient self-management that needs effective and sustainable use of electronic tools to engages both the patient and provider to "agree on issues, establish goals, decide on priorities and agree on treatment plans" (Schaefer, et al. 2009). It is difficult for chronic disease patients to keep their self-management over extended periods of time without additional support. Electronic tools are designed to assist patients with "managing their diseases by identifying risk factors, monitoring symptoms, and facilitating communication with the patients' healthcare providers between visits" (Information resources management association 2017). The Chronic Disease Telephone Coaching service is a telephone-based support service provided by ACT Health. The program aims to "help chronic disease patients improve their ability to self-manage their condition which leads to improved quality of life and reduces the incidence of exacerbation and progression of

their disease". Basically, the service provides patient access to 24-hour, 7-days-a-week telephone support operated by registered nurses. Patients get advice on methods to improve aspects of their health, including "weight management, understanding medication and the importance of exercise". Meanwhile, regular support calls from the program's registered nurse provide "appropriate support and information relevant to the patients' health condition". The benefits to patients include increased knowledge of their condition; helping "take control of symptoms by monitoring them and responding appropriately; addressing barriers to making lifestyle changes and living a healthy lifestyle". ACT Health's CCP also provides a Home Telemonitoring Service which takes the support for patient self-management to another level. This service provides monitoring of vital signs of patients by installing a telemonitoring station in their home. The monitor records "patients' temperature, blood pressure, heart rate, heart rhythm, weight, oxygen saturation, blood glucose and respiratory function each day" and data is transferred to clinicians via the internet. The benefits to patients include supporting the referring clinician's current patient health management plan; helping patients to self-manage their chronic disease more effectively and increase patient confidence; helping "stabilize patients' medical condition and reducing the frequency of hospitalization and emergency department presentations" (ACT Health 2013).

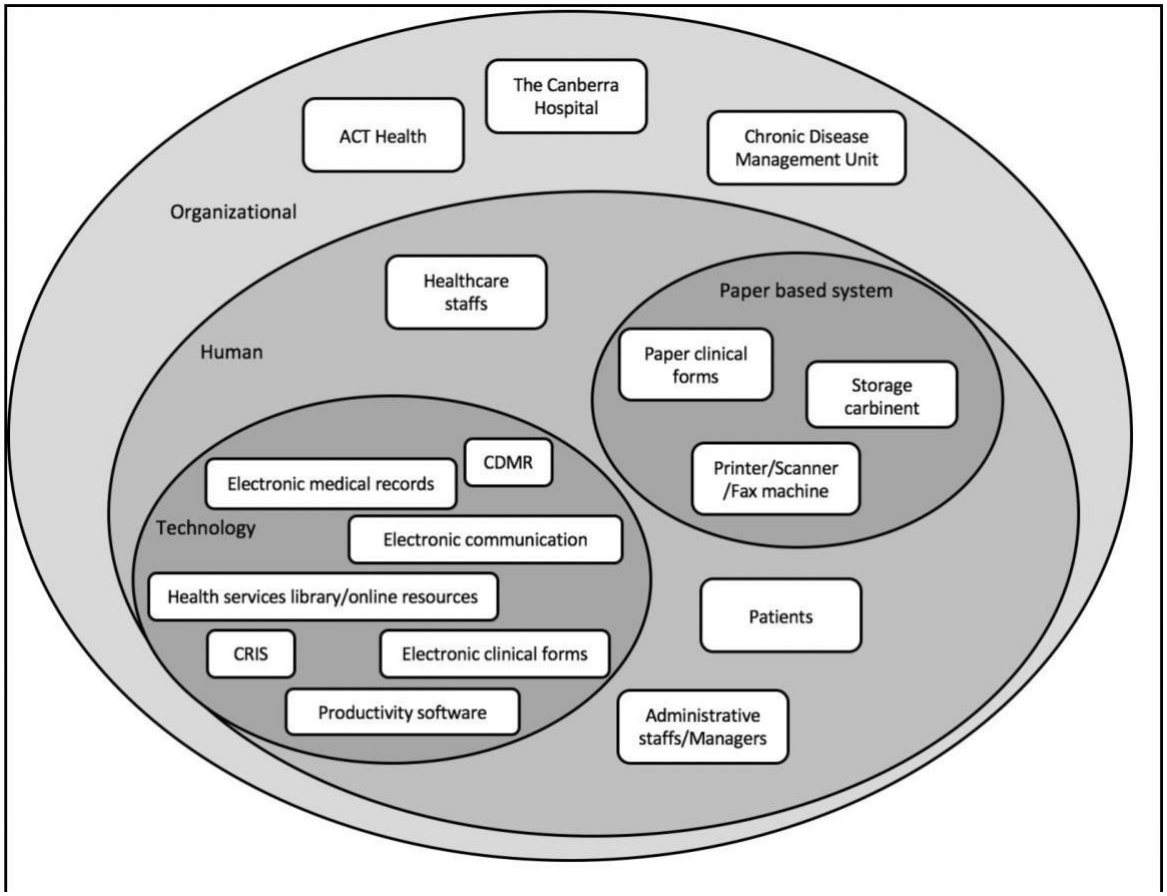


Figure 5.1 A simplified illustration of chronic care management network incorporating different contexts within the Australia E-Health transition

Components in the CCP network and their interactions before and after the implementation of electronic forms

From the case study findings, we identified seven major components in the CCP care management flow. They are (1) Care providers of CCP (e.g. clinical nurses, care coordinators); (2) Managers and policy makers; (3) CCP patients; (4) Partner care providers (e.g. GP, specialist); (5) Paper-based record system (e.g. clinical forms, file cabinets); (6) Clinical Record Information System (CRIS) and (7) Electronic clinical forms. We arranged the interaction between each component in diagrams 5.3 and 5.4 which depict the CCP management flow before and after electronic forms, were added to the established CCP work flow. The intended

electronic clinical form minimizes paper use to improve the care management efficiency, interoperability and enhance communication between clinicians.

The major drawback of having electronic clinical forms in the workflow is the time wasted in information collection, which is one of the worst things that may happen to clinical service providers with their already overwhelming case load. Compare the workflow before and after the introduction of electronic clinical forms. Care providers have to take the extra step of printing the electronic forms before they can upload to CRIS simply because there is no upload function supported between electronic clinical Forms and CRIS. Moreover, the forms are not always assessable by clinicians during home visits, therefore, they have to take extra work hours to manually transfer all the patient information initially recorded on the paper to the computer. The only benefit we see from the figure 5.4 is that communication between care providers has been improved by mostly using email exchanges of patient clinical records instead of field visits. However, the reality is most care providers in CCP still choose to use the old paper system simply because it is less time consuming and more approachable.

Electronic healthcare has remained a main focus in Australia, which has been experimenting with new models of care delivery in an effort to achieve better coordination of services across the continuum of care. The use of an electronic clinical form is the first step towards the proposed fully integrated electronic health record in ACT Health under the Australia National eHealth strategy. We can say that electronic clinical forms implementation in CCP is largely influenced by governance and policy which pushed the innovative initiative in the early stages. Unfortunately, the end users (e.g. care coordinators and clinical nurses) of the electronic clinical forms were not included in strategy planning, which is one of the possible reasons why end users consider the implementation a failure that disrupts their current workflow.

The complexity of relationships between different components in the CCP network lies in the "fluid and multiple nature of reality which means the reality is not predictable and that multiple realities can coexist" (Mol 1999). For example, the electronic clinical form is part of a larger network of eHealth planning but only a small part of the care provider's role in general. The care providers enable the development of electronic medical records by using the electronic clinical forms, but their dissatisfaction with the new implementation is threatening the stability of the existing network. The reality is we need to implement electronic clinical forms to enable other technology innovations; this is in relation to a government-led change initiative. However, the other reality is power relationships have shifted overtime from so called "top-down implementation strategies" led by the government, to expanded input by general users. Moreover, the government's structural change, combined with budge, cut meant that the national eHealth strategy itself has changed over time. As a result, it is possible that the electronic clinical forms don't work because we do not have the right people, the right tools or the right start-up, and we approach it from the wrong angle.

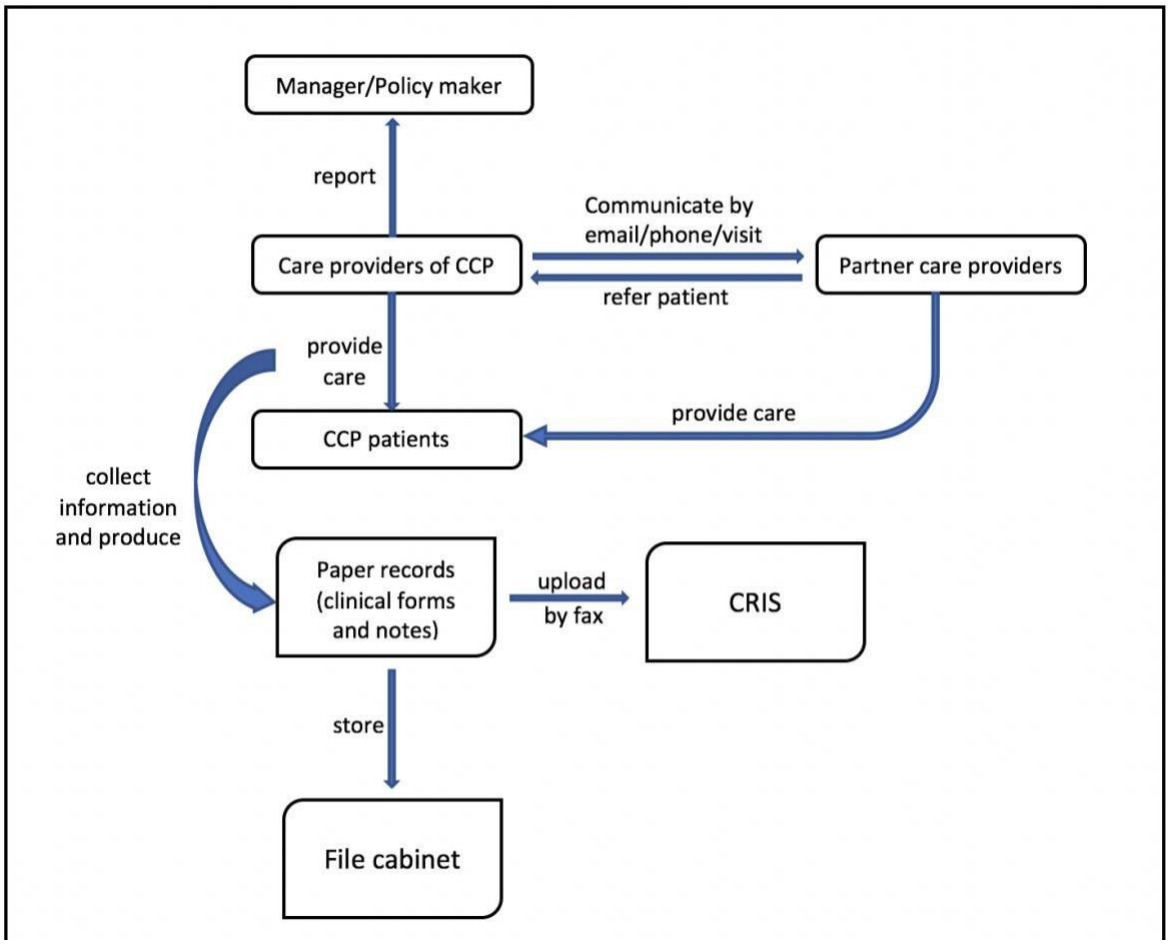


Figure 5.2 A simplified illustration of CCP care management flow before the introduction of electronic forms

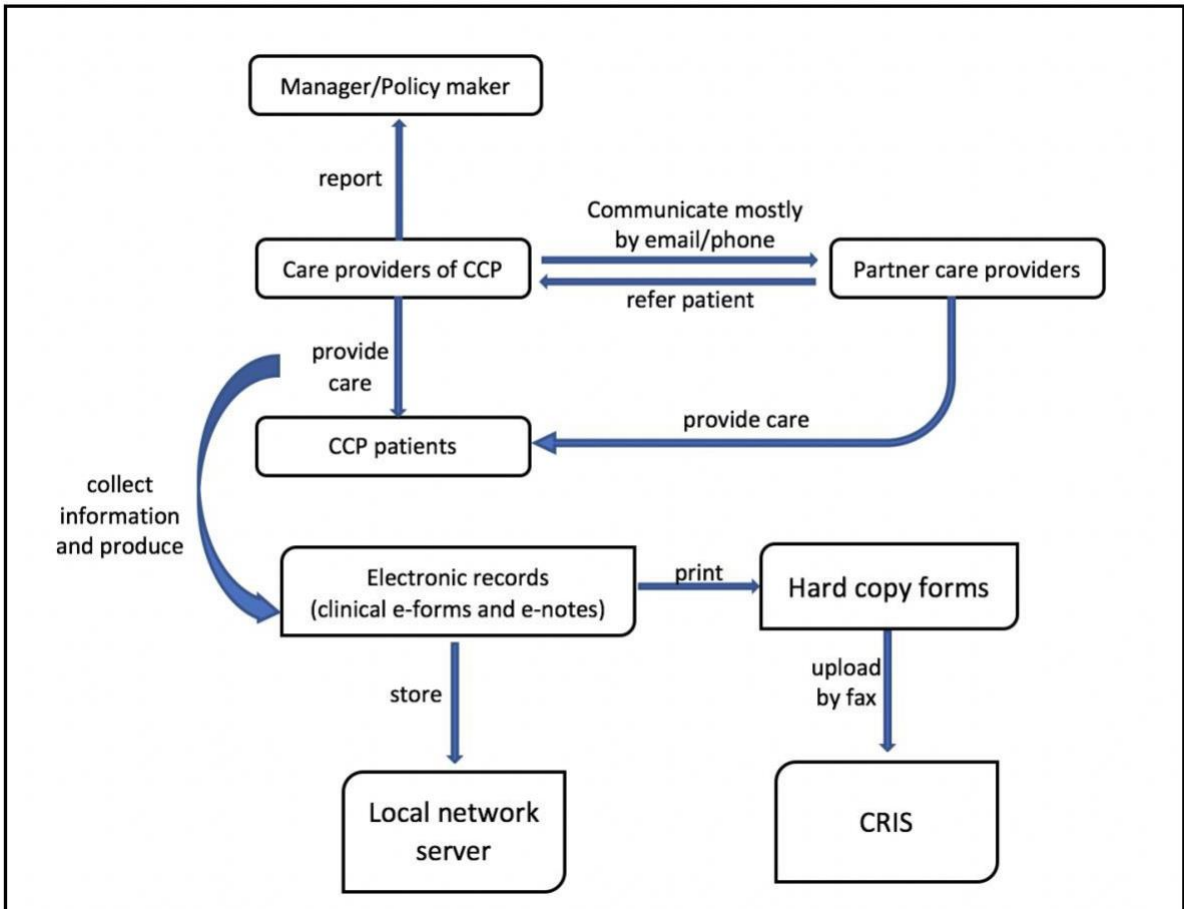


Figure 5.3 A simplified illustration of CCP care management flow after the introduction of electronic forms

Resistance to the new association between old components and eHealth interventions

The evidence from fieldwork observation and interviews suggests that CCP is still in the preliminary stage of eHealth development and there is strong resistance to electronic clinical form use in the CCP service. But a transition from paper to paperless was never the ambition of the digital agenda, which is to provide the essential tools for improving the way care is delivered. Having all the patient data digitized is the first step towards shared electronic health records. The implementation of electronic clinical forms in CCP aims to support clinical workflow by allowing important patient information to be shared between healthcare providers electronically and improve working time efficiency. Yet care providers from CCP still tend to have clinical forms in paper format by printing them out before a patient visit. And even when

some clinicians choose to work with the clinical forms electronically, the patient information they collect is still unready to share between CCP partners. The clinical forms uploaded to CRIS are stored as text-based format, other CCP partners can request a copy of documentation by submitting a "clinical documentation request form" which will be reviewed by members of Clinical Documentation Control Board for approval. This process takes 1-2 weeks, and often this timeline changes depending on the complexity of the request. The lack of a proper solution for sharing information across the care team often limits the collaboration and communication among the team which makes team interactions frequently defensive. Clinical nurses questioned the usefulness of CRIS and often chose to obtain the documents through email request and direct transfer from other care providers holding the original copy of the patient information.

All clinical forms in CCP can now be edited, stored and transferred electronically, but this doesn't make them the electronic forms (eForms) that the service unit needed. The advanced eForms should be based on a database that can be edited by non-technical users.

There are three stages of a paperless maturity model (FORMFAST n.d.): stage 1, print and scan, where pre-printed paper forms and manual scanning are heavily replied on; stage 2, electronic form image, which serves as a vehicle for collecting clinical data as it ensures proper form completion and helps maintain standardization; and stage 3, capture and share data, where the data captured in eForm can be fed back into a data repository to contribute to a more comprehensive electronic health record. CCP is currently equipped with stage 2 capability. However, some care providers still prefer to work with stage 1 where they feel more comfortable with themselves and patients. The underlying reasons for clinicians' resistance to change, is that they feel "*discomfort using the computer and typing when with the patient*". They simply don't see the benefits of changing. All participants in interviews reported overwhelming caseloads. Participant 1 said she has almost triple the case load of other care

coordinators. This could explain one of the reasons why she has more interest in moving eForms development to stage 3 where she can have automatic archival, signature capture and better data control.

Overall, there was a marked disinterest among care providers in CCP, who saw the new system as "*something introduced by management, and something they might engage with when it is all sorted out*" *(Participant 1, CCP)*. For most CCP care providers, the new technology was about "*unreal aspects of care or not about care at all*" *(Participant 2, CCP)*, and detrimental to clinical care. For those care providers who are still satisfied with a paper-based clinical system, it takes effort to demonstrate to them that eliminating scanning is not the only great potential of eForms and that they will actually benefit from a commitment to replace paper-based processes with those the eForm has to offer.

Latour (Latour, Technology is society made durable 1991) has suggested that "if usage of a new technology that aligns with designers' intentions is a 'program', resistant individuals seek to mobilize others into enacting and stabilizing an 'anti-program' (in which the technology may be used differently for different purposes), and this wider program-anti-program dynamic across the network should be the focus of analysis when studying resistance to any technology. The tension between different components must be actively and creatively managed as this gets harder as the network gets bigger". For example, the tensions between those who manage the introduction of the electronic clinical form (e.g. managers and policy makers) and those who need to use it in their everyday work. The resistance to ICTs in CCP service can be summarized from two key issues: the failed efforts made by manager/policy maker/care providers to achieve particular alignments of people and technologies and the poorly inbuilt properties of the ICT system constraining the possibilities open to organization and end users. First, the technology

was introduced and supported by weak justification of the policy. For example, end users were not offered a genuine dialogue during the design stage or implementation of the electronic clinical forms. Second, technology has limitations under conditions of expected use. E.g. eForms can only achieve their full potential they can be accessed remotely—a necessity due to the portable nature of care providers' work. Third, the use of the technology requires the user to compromise to a certain extent, something end users were not comfortable with. E.g. eForms were intrusive to the workflow of the care providers who said they had limited benefit in return. Finally, there are conflicts between social roles and relations when technology is used. E.g. the use of electronic clinical forms requires care providers to adopt roles that not only increase their workload in providing clinical care, but also their efforts in keeping the records digital which were perceived as professionally demeaning. Moreover, completing eForms in front of patients produced relatively minor conflicts in the patient and care providers' relationship which compromised the quality of care. If there is one overarching conclusion to this case study, it is that "when the design and introduction of ICT implementation fails to take account of deeply held professional norms, values and social rules, such technology will receive limited interest and more likely active opposition from professionals and the people who support them in their work" (Greenhalgh, Swinglehurst and Stones 2014).

Recommendations and the future

Acceptance of eHealth interventions in care management is growing rapidly among the overall health care provider community. Despite the slow adoption of electronic methods in care management and collaboration, there has been remarkable success in implementing digital tools and service for supporting patient self-management. Home telemonitoring and telephone coaching services use "digital applications for monitoring patient metrics, and networks for sharing patient experiences and providing support" (Georgeff, Digital technologies and chronic

disease management 2014). These systems improve patient care by sharing information with providers in the comfort of a home setting instead of an institution.

The technologies for "better integrated and coordinated care, collaboration across a multidisciplinary team of care providers, planned care with regular follow-up and review, and support for patient self-management" (Georgeff, Digital technologies and chronic disease management 2014) exist, they just need to be brought together. The question is: how can a busy health care service provider, like CCP, deliver such care to all its chronic disease patients without help from digital healthcare technologies?

The findings of this study point to six recommendations for the development of eHealth interventions in CCP to provide continuing care services within the digital health transition: (1) develop a patient record database to store, share and research, (2) automate documentation, (3) create a more powerful care planning system, and (4) create an effective tracking and reminder system.

Having shared electronic patient records is an obvious solution for sharing information across the care team. Many healthcare organizations today go through the costly and time-consuming process of implementing an Electronic Healthcare Record (EHR) in the hope of becoming "paperless" to reduce associated risks and cost. However, the system must be easy to use and contain the information necessary for effective clinical management. It is a huge step to become a paperless healthcare system but a small health care service center like CCP can benefits from the EHR implementation. However, it might take years before a truly integrated EHR system can be established regionally that is focused not only on getting a medial chart into an electronic format, but also other vial documentation processes not yet addressed. A service center data

repository which feeds on data captured in eForms can be the first step for improvement. While the system of manually printing and scanning has been in place for decades, and has mostly worked, the process still leads to large overhead expenses, lost documents, manual errors and loss of productivity. With data repository combined with eForms, care providers have a better way to capture clinical data and progressive change can be effectively achieved in a variety of ways and with minimal disruption.

The current CCP patient information system prevents easy extraction of data which limits the dataset for research and care improvement purposes. Modern data systems are capable of integrating large amounts of medical information accumulated throughout a patient's life, enabling longitudinal study of disease. It would be useful if the system could bring the most important information readily to hand rather than the whole patient history. Moreover, the system should provide search and filtering tools, so the clinicians can search a patient's record for a query and get all other related information at the same time. Overall, a database in CCP where disease and patient information can be shared so there is no duplication of test orders, and everyone knows what others are doing, would allow improvements in patient care, data collection and overall efficiency.

Chronic care requires information flow before and after each task or task sequence to maintain continuity of care. These tasks are not isolated but intertwined and build on one another to achieve patient goals. Clinical nurses and care coordinators in CCP currently bear a large burden in both managing and implementing the interdisciplinary team's plan for the chronic patient, as well as documenting the care and progress toward goals. Existing digital products and services can help alleviate this burden by automating the

creation and distribution of documentation. For example, eReferral, assuming a comprehensive data repository already exits, allows care providers in CCP to print a report as a letter that provides a strong value proposition for clinicians who are sending, as well as those receiving, electronic referrals. The system should streamline conventional referrals, decreasing the workload for clinical nurses and improving communication with the rest of the care team.

Care plan templates provided in CCP can be used to generate text-based care plans. However, such free-text care plans are not "readable by computers and therefore undercut the potential benefits of digital technologies. More powerful care planning systems use rules to generate structured care plans" (Georgeff, Digital technologies and chronic disease management 2014). Most systems require clinicians to click a thousand buttons to enter structured information (Evans, 2016) which results in resistance from clinicians who continue adding free text notes that cannot be reported on digital technology. As a result, there should be ways to either recognize the free text or create uncomplicated ways to add structured notes.

Proactive follow up by the care team plays a vital role in achieving better outcomes in chronic disease care. Digital systems allow improved multidisciplinary team-approved care, so appointments and progress are tracked and shared across the entire team, and every action is followed up. There is no tracking and reminder system in CCP; care providers can only rely on their memory, paper notes and spreadsheets to track their patient. With the increased use of clinical information systems, the technology infrastructure should be better suited to remind care providers in CCP to offer patients proactive care. A reliable tracking and reminder system should facilitate communication, improve patient safety and quality of care. The reminder system need not be complex but can still be effective and reliable if accessible for ongoing updating and monitoring.

Overall, CCP is in the preliminary stage of eHealth development and the first step is to develop a person-centered database capable of electronic sharing of data within the service. In due course there should be integration of records within and between the primary, community and hospital service with supporting multidisciplinary care planning and shared care for chronic disease patients. If a computerized information system is to meet CCP's full potential, then the processes involved in benefits analysis and realization must be fully established. There is a need for clinical nurses and care coordinators to develop skills in managing information; determining the information they need to collect; ways to analyze data and presenting data in reports. When implementing systems, it is necessary to have users well trained in using the latest technology and provide sustainable support to allow the best use of the information generated. The future development of CCP will be underpinned by a health information system with comprehensive, accurate and timely clinical information that can be readily shared with care providers across teams.

Chapter Six

Case Study 3 – Identify user needs in designing thinking-based IT developments in Obesity Management Service (OMS)

Chapter outline

6.1 Abstract

Developers of digital innovation often start their journey with defining the problem they are trying to solve. The focus of this study is on the design aspect of IT innovation in the Obesity Management Service (OMS). Before we attempt to design software, it is important to understand what it is that the users of the system need it for.

The OMS in ACT Health "supports adults with a high level of obesity to improve their health and wellbeing" (ACT Health 2016). The service team is multidisciplinary and includes doctors, nurses, dietitians, psychologists, physiotherapists and exercise physiologists. Most staff in the service team have expressed a strong demand for a digital storage system that houses patient health information, such as medical history, diagnosies, medications, care plans, and test

results. This system would replace traditional hard copy patient files, which can be crumbersome to store, retrieve, and update.

In their current practice, the first step was obtaining approval for all clinical forms to be transferred to digital format. This is the approach we identified in a previous case study when the Chronic Care Program team decided to transform during its transition to eHealth. From the preceding case study, we learned that any similar service team taking the same approach that the Chronic Care Program did when transitioning to electronic files would likely fail.

Successful IT development is often defined by "the users' point of view rather than by technical perfection" (Lindberg, Meinel and Wagner 2011). In this case study, we took a step back by first looking into the "why" component behind the clinicians' demand for an electronic database in the OMS team. We used design thinking as a method to explore both the problem and solution before any suggested IT development take place. The purpose of this study is to prepare for the future IT innovation in OMS where "professional rationales and expert knowledge" (Lindberg, Meinel and Wagner 2011) may suitably be applied.

6.2 The importance of understanding user needs in healthcare IT development

Information technology has become a necessity in almost all health services to fulfill the needs of business units. In the health care environment, it is of particular importance to understand and agree on customer requirements in order to meet customer business needs before the IT service becomes operational as many applications have life-or-death importance.

We have a complex and dynamic healthcare network. Most problems require considerable time and resources to clarify the requirements for a solution even when the general direction of the problem is clear. A large part of defining and shaping ill-defined problems involves requires us

to “listen to customers’ insights and interpret them to understand what the customer needs in their daily clinical workflows” (Imprivata n.d.). Whether an IT solution is for clinicians, patients, or administrators, it is necessary to “get them to provide deep insights regarding their pain points, empathizing with users can result in stronger collaboration and better feedback” (William, et al. 2007). Moreover, “it is not enough to simply deliver new service based on what customers say they want, but also more on inference and intuition as to what products will appeal to the target customers” (Gardner 2004). Like most of the learning process, customer needs are identified more through the “anticipating – the proactive market orientation” rather than “responsive knowing what the customers want/believe”. Products that move beyond “customers’ expressed needs to their latent needs” (Gardner 2004) are more competitive and sustained.

The complexity of eHealth programs lies in engaging stakeholders as well as developing the technology itself. In the late 2000s the National E-Health Transition Authority (NEHTA) in Australia was “slow to identify the need to engage with clinicians in the development of a user-friendly personally controlled electronic health record (PCEHR) and lost many of its key clinical leads prematurely” (Lawrance 2017). Clinicians are often keen to be involved, but they are busy people with limited time to provide their needs and insights. It can be challenging to engage with busy health professionals, so we might need to be creative in ways to engage with clinicians. For example, eHealth NSW used things like working groups throughout the electronic record for intensive care (eRIC) project to get clinicians on board (Sadauskas 2016).

The digital health industry and healthcare organizations often “consider user needs as an afterthought, a renewed approach is to include user needs and human-centered design on the forefront of digital health transformation” (Mehta 2018). Clinician engagement can influence

the digital health future and lead to big potential benefits for healthcare. Digital health innovation needs to be understood from the organizations/users level on what they really need and want.

6.3 Use design thinking as a problem-solving approach

Different stakeholders, including individuals and organizations using, technology within a healthcare setting, are equally important when finding approaches to solve a complex problem. Digital health innovations need human-centered design, so they interact with the people who truly need these technologies in a meaningful way. To achieve this intention, a design thinking process can "help to create products, services, digital experiences and business models that solve problems" (Katz n.d.).

Design thinking is a "more creative and user-centered approach to problem solving than traditional design methods" (Baeck and Gremett 2011). It is a design methodology which not only just applies to design problems, but also seems to work as a method for solving life's situations. Design thinking is "particularly useful for addressing ill-defined or unknown problems, and the resulting problem solution is regarded as creative, fluid and open and also as the search for an improved future result" (Waloszek 2012). The key to the method lies in understanding the customer's needs to meet their functional and emotional requirements. It is important to consider both behaviour and the underlying reason for it. In traditional IT development, it has "the tendency to take place within an exclusive expert's world" (Lindberg, Meinel and Wagner 2011). However, the importance of a designer's role often gets neglected and replaced by IT engineers who have not been professionally trained in the field. The contribution of design thinking in modern IT development encourages and emphasizes the need

to understand the problem space, and what it is that the users of the system need it for. Only then can anyone attempt to design an IT solution.

Design Thinking process models come in different shapes and stages in today's use, but they are all based upon the same principles featured in Simon's 1969 model. Simon's model consists of "seven major stages, each with component stages and activities, and was largely influential in shaping some of the most widely used Design Thinking process models today" (H. A. Simon 1969). The Institute of Design at Stanford published a model consisting of five stages: "Empathize, Define, Ideate, Prototype and Test" (Institue of Design at Stanford 2010). The steps in the model are "not run through in a linear fashion, they can occur simultaneously and can be repeated" (Institue of Design at Stanford 2010). In the research project Collaborative Creativity of Development Processes in the IT Industry, Lindberg et al argued in their study that design thinking "serves to obtain an exemplary but multi-perspective comprehension in order to deal creatively with the ambiguity of wicked problems" (Lindberg, Meinel and Wagner 2011). Building upon this argument, their study put down three basic characteristics to design thinking (Fig 6.1): "Exploring the problem space, exploring the solution space, and iterative alignment of both spaces".

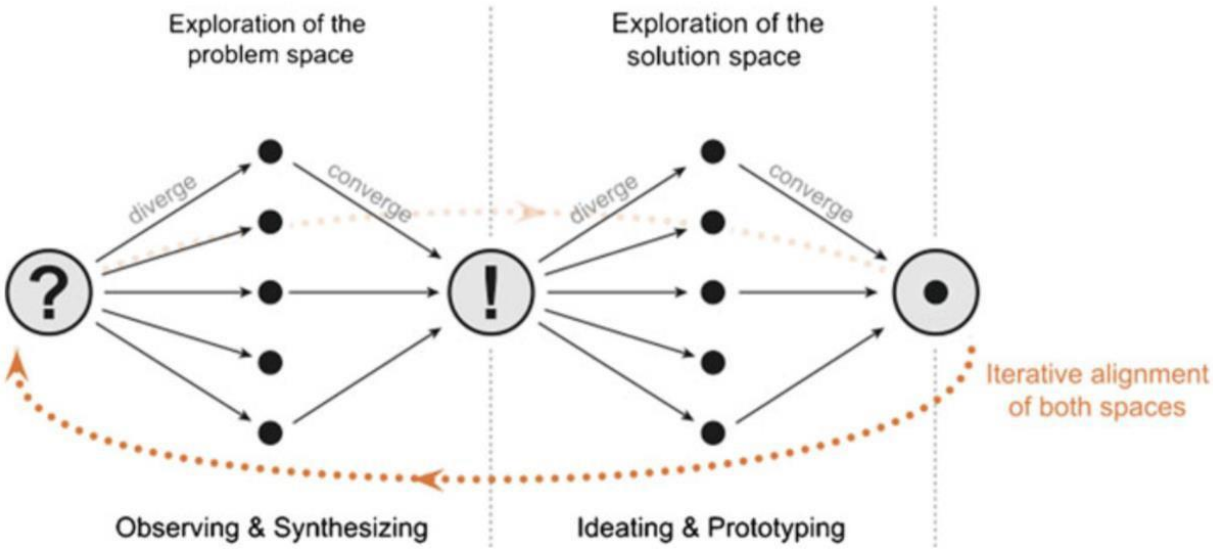


Figure 6.1 The Lindberg et al study of Problem and Solution space in design thinking

This case study only focused on the 'Empathize' and 'Define' steps in the design thinking model because of time and resources limitations. Empathy is the cornerstone of a human centered design, it involves 1. Observe: "view users and their behaviour in the context of their lives"; 2. Engage: "interact with and interview users through both scheduled and short 'intercept' encounters"; 3. Immerse: "experience what (the) user experiences" (Lindberg, Meinel and Wagner 2011). System designers use 'Empathy' as a step to understand and translate the meaning of users' experiences, hoping to uncover the insights that likely lead to innovative solutions. The next step, the 'Define' mode is when "empathy findings are unpacked and synthesized into compelling needs and insights and scope a specific and meaningful challenge" (Kuzniatsou n.d.). The goals of this step are to "develop a deep understanding of the users and the design space and, based on that understanding, to come up with an actionable problem statement" (Lindberg, Meinel and Wagner 2011). Overall, a successful solution depends on the deep understanding of the insights that "we can leverage in the design work to create a successful solution" (Institue of Design at Stanford 2010).

6.4 Introduce the Obesity Management Service in ACT Health

The Australian National Health Survey (2017-18) highlighted the growing problem of obesity in Australia estimating "67% of Australian adults are now overweight or obese, and this figure has increased from 63.4% since 2014-15" (Australian Bureau of Statistics 2022). The abnormal test results for every chronic disease tested in the National Health Measure Survey (NHMS) were strongly associated with the risk of obesity. Obesity often triggers depression as a spin-off effect, lowering the quality of life. The ACT Health Obesity Management Service (OMS)

supports adults with “a high level of obesity to improve their health and wellbeing with focuses on those who are at high risk of developing complications from their obesity or those who already have additional health problems” (ACT Health 2016).

Like other chronic care teams in ACT Health, the service takes the multidisciplinary team (doctors, nurses, dietitians, psychologists, physiotherapists and exercise physiologists) care approach. Initially, patients will be assessed by a nurse or medical practitioner, then followed up by allied health assessments as appropriate. Each patient will be assigned a case manager to develop a personalized obesity management plan consisting of diet, physical activity and wellbeing-related actions. The plan is reviewed regularly by the case manager to make sure it is updated and followed up by associated care providers. Another vital role of OMS is to provide education and physical activity groups for patients and their carers and family. The service focuses on improving patients’ general health status and risk profile rather than just weight loss.

6.5 Understand and define the problem through observation and interview

Ensuring that we are staying true to what business and users need is absolutely key to building better eHealth interventions that enable clinicians to deliver excellent health care to their patients. This study emphasises users’ true feelings by showing empathy for their needs. The research findings reported in this chapter are based primarily on analysis of interview transcripts and are supported by reviewed documents and observations within the Obesity Management Service.

There are five key observations made from the OMS case study:

1. OMS using multidisciplinary team approach in providing professional care.

   Multidisciplinary care provided in OMS involves a range of professionals including

medical, nursing, and allied health professionals (dietitians, psychologists, physiotherapists and exercise physiologists). Multidisciplinary care has been "demonstrated to improve outcomes especially for patients with chronic illness" (McDonald, et al. 2006). The OMS team provides multidisciplinary care with regard to "patient assessment, treatment, support for self-management and follow-up, so patients are receiving aspects of their care from multiple disciplines" (Dugdale, Isaac-Toua and Yaxley 2014). Each team member, regardless of their primary profession, undertakes a multitude of tasks in managing different patients. For example, a dietitian not only

provides professional knowledge in an educational group for all OMS patients who need dietary help, but also case manages assigned patients from initial assessment to follow-up. The elements required for effective multidisciplinary care include “flexibility and cooperative teamwork with a clearly identified coordinator supported by effective communication processes” (Gardner 2004).

2. OMS teams rely heavily on interdisciplinary collaboration and liaison to develop a cohesive care plan.

   Interdisciplinary collaboration, as the words themselves suggest, integrates different discipline viewpoints into a single consultation. An OMS team member from different disciplines, as well as the patient themselves, are “encouraged to question each other and explore alternate avenues to work toward the best outcome for the patient” (ACT Health 2016). The multidisciplinary team approach means the members meet on a set time interval, without the need for the patient to be present, to discuss case findings and plan future directions for the patient’s care. Then the patient’s case manager will “utilize the skills and experience of individuals from different disciplines, together with the patient, to develop a cohesive care plan including short and long-term management goals” (Dugdale, Isaac-Toua and Yaxley 2014). Effective interdisciplinary teamwork consisting of: “positive leadership and management attributes; communication strategies and structures; personal rewards, training and development; appropriate resources and procedures; an appropriate skill mix; supportive team climate; individual characteristics that support interdisciplinary team work; clarity of vision; quality and outcomes of care and respecting and understanding roles” (Nancarrow, et al. 2013).

3. OMS team staff are experiencing a large case load with growing patient numbers.

   On a weekly basis, the OMS provides scheduled medical clinics, education group classes, exercise classes, allied health clinics, case management and care coordination

sessions. The large volume of cases entering the service increases the need for efficient case management. The wait time for an initial medical appointment was "on average seven and a half months in Sep 2015" (Dugdale and Hopkins, Quartely performance report 1 July 2015-30 September 2015 2015).

4. Most OMS care providers are open-minded about eHealth interventions.

   Almost all the OMS care providers have expressed their interest in promoting eHealth interventions for patient care. Especially in demand for the OMS team is an electronic system that clinicians can use to store and view patient information.

   > *"Our goal is eventually to have only electronic patient files and no hard copy" (Participant 1, OMS)*

   Along with the electronic system for managing patient information, care providers have expressed their interest in eHealth interventions for communication among clinical partners, patient recall and information extraction for research purposes.

   > *"I think digital interventions will be helpful, such as an electronic system that is used to enhance communication among clinical partners and easily accessible, so we can all use it to store and view patient information" (Participant 3, OMS)*

   The current electronic interventions used often by the OMS team are Facetime, Google search, smartphone app, email, PowerPoint and Excel spreadsheet. Care providers currently use certain apps and the internet to enable patients' education, monitoring and self-management. For example, a dietitian may use an app called My Fitness Pal to track patients' daily food intake.

5. Paper records remain the dominant method for keeping patient files and providing patient care.

   Within the OMS, care providers keep hard copy files for each patient and each of these files has a section for each health professional, correspondence, medical, pathology etc.

In addition to hard copy files, each patient has an electronic file in the Q drive on the ACT Health system which may or may not have everything that is in the hard copy file. For example, only the hard copy file has the medical assessment form and pathology results. Once the patient is discharged, the hard copy files are sent to Clinical Records Information System (CRIS) for scanning onto the database. CRIS is ACT Health's primary record system and can be accessed by all authorized staff from any site in ACT Health. OMS is in the process of transitioning to electronic instead of hard copy files. The first step is obtaining approval for all clinical forms which is required prior to submitting forms to CRIS for scanning. The goal is eventually to have only electronic patient files and no hard copy. However, this will be a long process and will take time.

The interview participants of this study were comprised of three staff from the OMS. Participant 1 is the manager of the OMS. Her role involves coordinating staff and activities within the OMS. She commenced the role in 2014 and is an accredited practicing dietitian. Participant 1 conducts a dietitian clinic fortnightly and sees approximately six patients each time. Participant 2 is also an accredited practicing dietitian for the OMS. She has been in the role since the service

commenced in early 2014. Participant 2 runs individual and group-based dietary interventions. She also case manages a selection of patients who are currently attending the service. Participant 3 is a clinical psychologist for the OMS. She has been in the role since 2016. As with other participants, she case manages a selection of patients while running individual and group-based mental health interventions for patients who are currently enrolled in the service. Other service members from OMS share similar roles to the three participants, and provide their expert knowledge as doctors, nurses, dietitians, psychologists, physiotherapists and exercise physiologists. A recent study auditing the outcomes of patients within the OMS found the average age of patients to be 48.5+/- 12 years with a larger proportion being female (74%) than male (26%). Patients are mostly from the ACT but may be from surrounding regions in NSW. Patients have a range of educational backgrounds, though most have lower socioeconomic status. The average number of patients case-managed by each care provider is between 30-50 at any one time.

What? How? Why?

This study uses what, how, and why, as a tool to explore a deeper level of observation. The primary role of the care providers in OMS is to case manage a selection of patients while providing their expert knowledge in care coordination.

We first ask the question, "*what are care providers doing in case managing patients*"? The staff workflow usually starts with making an appointment for a patient with referral. During the initial appointment, the staff collect patient information and then, together with the patient, develop a cohesive care plan including short- and long-term management goals through a multidisciplinary team approach. Patients will be recalled for a follow-up review regularly, and clinicians collect patient information, especially any changes since the last review.

Our second question in the study is: "*How are the care providers doing patient case management?*" Patients with referral are randomly assigned to individual care providers in the OMS team based on their current case load. Case managers each keep a list of what their patients are up to, using a manual spreadsheet that is saved electronically. They call patients to make an initial appointment and collect information using an assessment form and take clinical notes. Care providers meet regularly to provide their professional knowledge and develop care plans so that each patient has a hard copy file with a section for each health professional, correspondence, medical issues, pathology, care plan etc. The case manager enters all the material in a spreadsheet when their patients need to have their upcoming medical review. Patients' progress and changes are collected again during reviews using clinical forms and notes which are added to their hard copy file folder. Case managers review each patient's progress and adjust their care plan if needed. Once the patient is discharged, the hard copy files are sent to Clinical Record Information System (CRIS) for scanning on the databases. Last, in order to project meaning into the situation that we have been observing, we make informed guesses regarding motivation and emotions behind care providers case management processes and analysis.

Our third question in the study is: "*Why do care providers case manage patients in this way?*" We observed that care providers are heavily reliant on hard copy patient files and manual spreadsheets to manage and track their patients. One informed guess is that the OMS employ a multidisciplinary team approach and interdisciplinary collaboration in the care management of their obesity patients. As a result, having a record system where each patient's documentation is accessible, updated and comprehensive is essential for care providers to manage their patient and share with team members. The possible reason behind the way the patient record system is set up using hard copy files and manual spreadsheets, is simply because currently there is no better alternatives available to track and record patients in OMS.

Interview for empathy Interviews are necessary when we want to understand OMS care providers' thoughts, emotions and motivations so that we can determine how to innovate for them. We asked "What? How? Why?" and the logical next step was to understand the choices that care providers make and the behaviours that they engage in. We asked unstructured interview questions grouped into two themes. We wanted to: 1. Spot care providers' pain points and the frustration they face when dealing with their routine patient management workflow and 2. Understand deep insights regarding care providers' desire to improve their care process.

All interview participants reported their frustration with the administrative side of patient management.

> *"the administrative side of patient management is a big thing that takes up so much of clinicians' time" (Participant 1, OMS)*

Participant 2 further explained in detail:

> "*currently, most correspondence is faxed to GPs and specialists. This can be quite time consuming due to the necessary steps that need to be taken*".

Participant 3 also shared her story of managing a large case load of patients while also dealing with administrative burdens which consumed her precious time, including typing letters, print, faxing filing etc. The frustration extends to the current patient recall system which was done manually through Excel spreadsheet.

> *"the spreadsheet needs ongoing updates and maintenance to ensure the information is up-to-date. This system is open to errors and requires a significant amount of administration time for the clinician" (Participant 2, OMS)*

Both participant 1 and 3 agree with participant 2's frustration. They have all experienced missed patients as the recall system is not automatic. Participant 1 further added:

"*when patients do not attend appointments or cancel their appointment, we have difficulty keeping track of them*."

The desire for an electronic database or system where all patient documentation can be easily accessible is consistent among all clinicians in OMS. Participant 1 believes that the process of transition to an electronic system needs to have all clinical forms updated to electronic versions as the goal.

"*eventually we must have only electronic patient files and no hard copy*"

She further added:

"*the electronic system should be allowed to be used by both community health and the hospital, be easily accessible, and able to store and view patient information*".

Other participants also believe that an electronic database would ease their administrative burden and facilitate patient recalls. They want regular reports from an electronic system which helps clinicians keep track of their patient flow, such as reports on patients with upcoming referrals about to expire. Their motivation for wanting an electronic database were stated during interviews:

"I believe a database can minimize staff time needed to create and review patient information" (Participant 2, OMS)

"Maybe an electronic database can ensure continuity of patient care between clinicians" (Participant 3, OMS)

"One more benefit of having an electronic database is to allow information to be accessed by other staff when a clinician is sick or on extended leave" (Participant 2, OMS)

"It can certainly minimize the risk of staff error" (Participant 1, OMS)

Define the problem statement

Earlier we built empathy through observation and interview, allowing us to identify what OMS care providers do and how their environment impacts how they complete the patient care management they intend to accomplish. OMS team members are currently still able to complete the whole patient care management process, but the task is considered difficult and inefficient because of the overwhelming administrative side burden. They need some help to ease the burden and believe an electronic database or system is the way to go. Care providers of OMS consider the current paper-based system is time consuming and a waste of their patient care time, meanwhile, they are hoping for the digital intervention to ease their burden on administrative side work and improve the efficiency of their care management (Fig 6.2). In their clinicians' world, they view improving health status and outcomes for morbidly obese people as more fit to their actual role and meaningful than spending time on the administrative work.

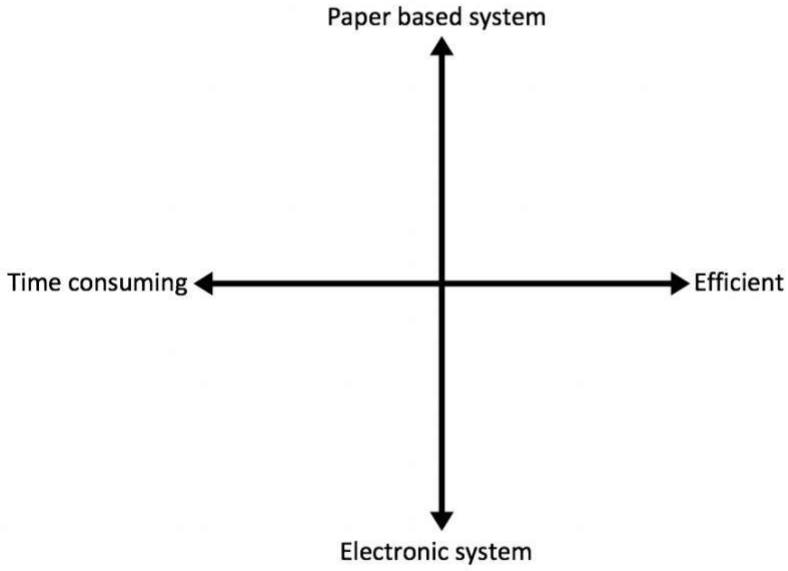


Figure 6.2 The 2x2 matrix to scaffold thinking about care providers and problem space

6.6 Interpret the finding and discussion

We have engaged with users to understand their needs in the Empathise stage, and we have analyzed and synthesized observations in the Define stage. The findings suggested the following insights:

1. Care providers in OMS agree that the current paper-based system is working, but inefficient in managing patients.
2. Care providers in OMS need intervention to relieve their burden of administrative side work.
3. Care providers in OMS believe that an electronic database is the best solution.
4. Care providers in OMS hope the digital intervention can provide a search and sort function of patient for records so they can visualize patient progress better.

The question goes to: "shall we start building the electronic database, given it is what the users wanted and seems like the solution?" We learned from the previous case study where chronic care programs start their journey of eHealth transition towards an electronic database for patient records with implementing electronic clinical forms as the first step. However, the users now complain because their lives have not improved with the digital intervention. Apparently, clinicians from CCP think the implementation of electronic forms disrupts their current clinical workflow and they are more content with the old paper-based system in managing their patients.

We often hear that "the goal of production development isn't necessary to make product". As Jeff Patton (Patton, et al. 2014) states in his book, everything between the idea and the delivery is called output. It is what we build. However, the output isn't the real point although it is necessary. It is the outcome, which comes after the output, that is what we really want. Outcome is difficult to measure because we can't measure it until things do come out. We measure outcome by looking at whether users get better by using the product recommended. Looking at what we learned from the previous case study and the user insights we generated from this case

study, it is possible that users actually don't know what they want. As part of the design process, we gathered user needs by understanding who those users are, what they do now and how things will change for them later with the right product. This is a vital part of the design process which is called "surfacing needs". We cannot simply ask users what they want and go off to create what they have asked for. The job is to identify the needs behind those desires, as—and even before—they exist, and then fill them (Williamson 2013).

We understand the frustrations and reactions of care providers using OMS by observing their use of the existing paper-based system. First of all, the overwhelming case load, which continues growing, requires most of a clinicians' working hours just looking after their assigned patients. So some helpful relief with their administrative side burden would can allow clinicians to focus better on their patients. However, there are many other ways to ease the burden besides digital intervention. For example, hire an experienced administrator to improve clinicians' working efficiency. This could be a temporary solution before a proper digital intervention was developed without unexpected complexities leading to time delays, cost escalations and disruptions in current workflow. Further, clinicians believe that a digital solution, such as an electronic database, can provide extra functions that the currently paper-based system is missing. For example, they would like a search and sort function of the patient record system so they can compare and visualize patient progress much more easily than manually going through all the paperwork. Current developments in IT suggest there would be no problem in providing users with a database system with search and sort function—this is a basic function that a database should contain.

This all leads us to the old dilemma: how do we first get all the patient records digitalized without adding new burdens and disrupting care providers' current workflow? Who will be responsible for keeping the digitalized record complete and correct? A 'human-centered design'

should focus on improving users' engagement and capability with their current workload and demand in mind. In this case, the focus is on minimizing the time and effort required by clinicians to manage patient records. For example, by having system automation to improve usability, or rearranging the system layout so the critical patient information is presented in a meaningful way. This will increase the time clinicians can spend on understanding patients' conditions while reducing time-consuming system navigation. Moreover, if a comprehensive database where all patient records can be accessed easily is the ultimate solution to positive change, another significant change would be collaborating with health technology companies to consider system users and organizational input, rather than focus on purely technical requirements such as determining system needs and specifications.

Chapter Seven

Theme

Chapter outline

7.1 Abstract

7.2 Acceptability of eHealth

7.3 Methods to measure and evaluate the impact of eHealth interventions in healthcare system

7.4 The interoperability of health information systems in the chronic care program

7.5 The standard of "meaningful use" for eHealth enhanced chronic disease management

7.6 Preparing eHealth for chronic disease management

7.1 Abstract

This chapter brings together the findings from the case studies and literature reviews. The findings of qualitative research need synthesizing in order to develop recommendations for practice. We used a thematic synthesis (Thomas and Harden 2008) approach to aggregate findings of three case studies based on framework thematic analysis, together with extracts from major themes in literature to provide a summary of findings of primary studies under thematic headings. We draw on the synthesised findings to present the opportunities, challenges, barriers and innovations in the field of digital health. From these we will to develop recommendations to prepare eHealth for chronic disease management under the ACT Health setting.

Data collected under findings derived from the studies and research questions can be grouped under three themes: (1) the acceptance of eHealth solutions among health professionals; (2) the methods of measuring and evaluating the impact of IT innovations in healthcare services; and (3) their interoperability among healthcare systems. Thematic synthesis is useful when "the evidence is likely to be largely descriptive and will enhance our understanding of why the health stakeholders think, feel and behave as they do" (Ochodo, et al. 2017). We interpreted the findings in line with the emerging themes and present the findings in confidence.

7.2 Acceptability of eHealth

In the healthcare sector both care providers and patients are experiencing the change to increased use of eHealth tools which both groups sometimes find challenging and hard to cope with. For primary care, physicians using office-based computers were invited to support electronic health records and wider healthcare IT systems that aim to provide a more seamless data system (Vandersman, Pinto, Damarell, & Tieman, 2020). This would allow patient records to be shared across all fields of primary, secondary and social care. Outside primary care, most of Australian hospitals have been undergoing a transition to electronic medical records, electronic medication systems, and electronic pathology/imaging system but lacking evidence of benefit for both patients and care providers. The acceptance of eHealth solutions among patients varies depending on whether it is based on self-management, self- education or interventions related to medical care. It is generally accepted that "eHealth development is a participatory process and depends strongly on the involvement of all relevant stakeholders" (Van Gemert-Pijnen, et al. 2011). This chapter describes the current relationship that the majority of health professionals and patients have with eHealth, their acceptability with eHealth interventions and how they are using eHealth now.

Case studies of eHealth by ACT Health have mainly been done from health professionals' perspectives. Two major phenomena have been observed. They can be summarized under the following headings:

1. Care providers are enthusiastic about the potential benefits of eHealth development but most of them are disappointed with the actual outcomes of current eHealth interventions, which eventually lead to low acceptability.
2. Some health professionals are reluctant to take up the health information technology, especially when they are satisfied with the current system.

We want the benefits from eHealth, but we are often disappointed with the outcome

Before the launch of the chronic disease management register (CDMR) in ACT Health, Guda performed a survey primarily focused on "the capacity and readiness of ACT Health to implement a CDMR (Guda, A study to guide the design and implementation of a chronic disease management register in a regional health service 2012)". He found that the clinical information system is "least developed and a real disease register is not in place" (Guda, A study to guide the design and implementation of a chronic disease management register in a regional health service 2012) which is one of the impediments to integrate CCM in the ACT Health jurisdiction. His research findings show that the scope of a CDMR lies within ACT Health public hospital settings with the support of the good policy environment of ACT Health. Clearly, the CDMR was needed to support and improve care coordination. The expected outcome is to extract data from the CDMR which enable data analysis of the performance of service units. The feedback can be used to "reinforce collaborative support to improve the quality of life of the patients" with chronic disease and "help the ACT Health to improve chronic care performance through exploring variations in care management processes" (Guda,

A study to guide the design and implementation of a chronic disease management register in a regional health service 2012).

Clearly, ACT health is enthusiastic about applying information technology to improve access to the information and having a better linkage to a variety of databases. However, from the case studies detailed in the previous chapters, supportive attitudes among users of CDMR for eHealth intervention have been slow to develop. The CDMR case study interview has identified various factors that caused user dissatisfaction, which can be grouped into two categories: (1) CDMR is hard to understand and use and (2) CDMR didn't deliver the results as expected.

The CDMR is designed to serve as "a case management information system for a range of clinical services that participate in the Chronic Disease Management Clinical Network" (ACT Health Chronic Disease 2008). It provides descriptive analyses and various reports about CDMR patients for research and reporting agenda. Clearly, policy holders and project leaders look at CDMR as a clinical information system for "improving and monitoring the quality of health care" (ACT Health Chronic Disease 2008), as well as collecting data to answer existing and emerging research questions. However, the users seem to struggle to understand the purpose of CDMR and question its value. They expect the CDMR to function as a fully capable management system, such as electronic medical records. Their expectations for CDMR even extend to a communication system, where it has store-and-forward function to facilitate the consultation and care management of chronic disease. The expectation differences between vendor/project leader and end users leads to the user disappointment with the CDMR.

The vendor/developer of CDMR explained that the CDMR was implemented as a system with reporting. He recognized that the register need further development to avoid being used as a

merely secondary reporting system. His opinion coincides with the project leader's outlook, which was that he agreed CDMR "needs to be further developed to provide more descriptive analyses and reports of CDMR patients" (ACT Health Chronic Disease 2008), and involve more patient focused information to be analyzed in the care of chronic disease patients. Both CDMR project leader and developer believe that the current CDMR is important to the chronic care system and will play an irreplaceable role in implementing EHR or even clinical data repository in the near future. Unfortunately, many CDMR users weren't aware of the differences between a patient registry and EHR system. They heard there are many benefits to using an information management system for patient data collections that provide better care with the patient centric information. They expect CDMR to be a complete management system, such as EHR, which inevitably leads to disappointment simply because they can't distinguish between the roles of the two systems.

In this case, users were not significantly involved in the design and development of the CDMR, and lacking guides and technical assistance to its use made things worse. Most users do not comprehend the use of CDMR and struggle to understand its value. It is fair to conclude that the development of CDMR has been implemented mainly by policy and development enthusiasts, rather than by health providers and users.

This is a common observation in the field of eHealth development and implementation. Before a new eHealth intervention is implemented, vendors will propose a framework "to identify the strategies that are proposed for addressing the uptake and impact of eHealth technologies" (Sharp, Finkelstein and Galal 1999). Ideally, the development of an eHealth technology should incorporate the multidisciplinary team approach where those who are responsible for developing the system (e.g. system designer, technicians) cooperate with those who will use

the system to deliver patient care and values (e.g. health care providers). However, the target groups for the framework are often "expert driven, such as designers and researchers, as well as policy makers and administrative developers of the information system" (Van Gemert-Pijnen, et al. 2011). They are not the best candidates to assess user satisfaction, acceptance, widespread adoption or implementation of eHealth technology. Moreover, literature on health information system readiness assessment is myriad and fragmented. Especially concerning "technological readiness", "motivational readiness" and "engagement readiness", which all have unreliable measuring tools (Yusif, Hafeez-Baig and Soar 2017) though these are all needed to reduce eHealth intervention implementation failures. A large number of health information system project failures were not due to "flawed technology, but rather due to the lack of systematic considerations of human and other non-technology issues in the design and implementation process" (Zhang and Butler 2007). We take health providers' enthusiasm for using technology to provide better health care for granted despite there being little user engagement in its development, which is one of the reasons why eHealth intervention remains a problem.

Why should we uptake new eHealth intervention if we are satisfied with our current system?

It is generally believed that eHealth is important to the modernization of the healthcare sector. Research has shown that healthcare professionals' beliefs regarding training, technical support, and the need for changes in their health settings are important predictors of their intention to use a new technology for healthcare purppose (Asua, et al. 2012). However, in real-world cases, health care providers who accept the concept that eHealth intervention might be useful for them to provide better care, are often reluctant to change when they are satisfied with their current system.

The evidence from fieldwork observation and interviews suggests that the Chronic Care Program (CCP) is in the preliminary stage of e-health development where it is equipped with electronic form images to collect clinical data, but the data captured cannot be fed back into a data repository to share. Most importantly, many care providers are reluctant to use electronic forms provided for data collection; they are satisfied with the print and scan paper systems.

We have identified many underlying reasons for clinicians' resistance to change in chapter 5, most of which were that users found themselves not benefitting from a commitment to replace paper-based processes with the electronic forms and information system. The low uptake of new technology and willingness to change is particularly noticeable with clinicians who have low IT literacy, though the paper-based system works just fine with their current workload. Health care providers' computer skills, abilities and experience were cited by several studies as "influencing implementation and acceptance of eHealth systems" (Archer, et al. 2011) (Boonstra and Broekhuis 2010) (Goldstein, et al. 2014) (Kilsdonk, et al. 2011) (Lau, et al. 2012) (Lluch 2011). Demographic factors such as "age, education, sex, nationality, and clinical experience may also influence care providers' readiness (to use) e-health systems, but no clear relationships between these characteristics and attitudes could be established" (Goldstein, et al. 2014) (Yarbrough and Smith 2007) (Waneka and Spetz 2010). These non-adopters identified from case studies are significantly more skeptical of the benefits of eHealth even though they claimed interested in new technical interventions. They are all experienced care providers from the counselling-based chronic care management unit and believe that patient relationships would suffer from eHealth use, and that it would diminish patient engagement as well as the delivery, access to and quality of care. Nevertheless, they made a valid point about no need to change when the paper-based system meets their current workload needs. They will likely delay adoption of eHealth-related change until any new

technology is extremely well established and undeniable in its benefits to their profession, unless there are financial incentives or mandatory participation schemes introduced.

Overall, the acceptance of a patient registry, electronic forms and other information systems in the Chronic Disease Management Unit (CDMU) are generally low. The causes for the low acceptability of CDMU from the referenced studies are presented in the following headings:

1. *Lack of user engagement in the planning, development and implementation stage of eHealth systems*.

   User disappointment with the chronic disease register is a prime example of the importance of involving end users in the development and selection of eHealth systems. Key stakeholders in the planning and execution of implementation processes did not communicate the strategy to all potential users—which should be a core communication central to the successful implementation of any new technology. In literature, having multidisciplinary stakeholder engagement can foster a sense of ownership (Saliba, et al. 2012) (Broens, et al. 2007), confidence (Goldstein, et al. 2014), and boost acceptance and enjoyment (Broens, et al. 2007) (Kilsdonk, et al. 2011) towards the eHealth system. However, lacking "coverage in the reviews of the factors that promote or inhibit user engagement and participation" (Mair, et al. 2012) is the weak spot in the literature.

2. *Necessary training, education and technical support were not provided.*

   The Chronic Disease Register is basically an SQL (Structured Query Language) database system, but most staff hired to work with CDMR don't have the background or experience with such a database. A lack of knowledge along with limited training, education and technical support acted as a barrier to CDMR implementation. Generally, access to "appropriate, high-quality, well-funded, and easily available training was reported as a facilitator to implementation, whereas it was reported as a barrier when it

was non-existent or existent but inadequate" (Adaji, Schattner and Jones 2008) (Archer, et al. 2011) (Boonstra and Broekhuis 2010) (Broens, et al. 2007) (Fitzpatrick, et al. 2007) (Gagnon, et al. 2012). However, ongoing technical support to use new systems and education was reported to "increase staff acceptance of eHealth systems" (Archer, et al. 2011) (Gagnon, et al. 2012) (McGinn, et al. 2011).

3. *Some care providers have limited computer skills and, lack abilities and experiences using eHealth intervention.*

   Staff with low IT literacy but who are comfortable with a paper-based system are the most resistant to eHealth interventions. They have a negative impression of eHealth, disagreeing with the potential benefits and emphasizing the barriers. The study "eHealth readiness of Australia's Allied Health Sector" (Australian Department of Health and Ageing 2011) identified almost 17% of its interview participants are firm non-adopters of eHealth applications, which strongly influences the implementation and acceptance of eHealth systems.

4. *Lack of leadership, engagement and management support at each stage of the implementation process.*

   Leadership engagement has been involved in the development stage of every new eHealth intervention. However, along the delivery path of eHealth services, the importance of leadership and management support often gets overlooked. It is necessary to promote a continuous leadership engagement throughout the development and implementation of eHealth technologies to ensure that eHealth interventions are "user informed, fit for context, of high quality, and of demonstrated value" (Boonstra and Broekhuis 2010). Lack of management support can be a barrier to implementation success (Stolee, et al. 2010).

5. *Negative attitude of patients influences health care providers' attitudes.*

Care coordinators from the Chronic Care Program reported constant complaints from their patients when using a computer to fill in eForms during consultation. These negative attitudes were reported in literature to "influence staff attitudes with regard to eHealth acceptance" (Gagnon, et al. 2012) (McGinn, et al. 2011).

6. *New technology interventions disrupt the workflow and delivery of care*

   The use of eForms is an example of a technology that failed to adapt to fit the local context. Due to the inability to access the eForms during home visits, care coordinators and clinical nurses chose to record their patient information manually on a paper form first and later input into digital format after they had access to a computer. The process disrupted their workflow for care management and increase the workload at the same time. When eHealth interventions do not fit well with work practices or clinical workflow, they are less likely to be accepted by users and are often unsuccessful during implementation. Health professionals' perceptions that "eHealth systems disrupt workflows, and the delivery of care, are a barrier to both the implementation and use of these systems" (Fitzpatrick, et al. 2007) (Police, Foster and Wong 2010).

7. *Absence or inadequacy of policy and liability*

   Health care providers are concerned about inadequate policy, professional liability, data integrity, exchange of electronic health information between systems and building interfaces for information databases. The need for "recognized standards for the provision of eHealth systems" was described by many studies (Archer, et al. 2011) (Boonstra and Broekhuis 2010) (Broens, et al. 2007) (Goldstein, et al. 2014) (Jennett, et al. 2004), and a policy's absence or inadequacy may "hamper the implementation of eHealth systems at the organizational and health professional level" (Boonstra and Broekhuis 2010) (Broens, et al. 2007) (Saliba, et al. 2012).

8. *Technical complexity causes users to be unable and unwilling to master the technology that was implemented*

   Technical complexity factors reported by users of CDMR includes: 1. system being difficult to use; 2. lack of extensive software modifications; 3. the inability to supply real-time data access; 4. system being unreliable with slow or unplanned downtime in getting the data. Without sufficient technical assistance and improvement, users are experiencing difficulties in mastering the technologies that were implemented. Different types of technical complexity have been identified in many literature sources which all linked to lower acceptance and adoption by health professionals (Boonstra and Broekhuis 2010) (Goldstein, et al. 2014).

From the case studies and researchers' perspectives, the above-mentioned barriers inhibit the development and deployment of eHealth solutions in CDMU. Having them examined and corrected is important to develop trust and acceptance among health care providers.

7.3 The methods used to measure and evaluate the impact of eHealth interventions in a healthcare system

There has been considerable progress in recent years in the publication of evaluation studies on different eHealth interventions. The evidence base for their effectiveness is still relatively weak. This is due in part to the complexity of healthcare systems and the challenges of conducting rigorous evaluations of eHealth interventions. There is a strong need for solid evidence of the impace which often requires significant investment of time and resources, and decision-makers need to have confidence that these investments will yield positive returns. Impact is understood to "evolve from an interaction between the technology, the person and the context of usage and fluctuates over time and situations" (Van Der Meijden, et al. 2003) (J. Kern 2006). We need

mixed methods using both quantitative and qualitative design to assess

the “added value of eHealth technologies for health care and society” (Van Der Meijden, et al. 2003) (Pagliari 2007) (Kushniruk 2002).

The motivation behind measuring outcomes associated with eHealth applications is to demonstrate the value of each intervention through evidence-based research and evaluation. The literature is filled with studies and conclusions indicating “a lack of rigorous evaluation and research exists by which to clearly demonstrate the value of eHealth interventions” (Scott and Saeed 2008). The number of evaluations has increased in the last few years, however most of available literature referred only to “pilot projects and short-term outcomes with evaluations of low quality” (Blaya, Holt and Fraser 2008). The challenges lie in the “integration of data collection from multiple sources, and too many confounding factors that cannot be controlled and anticipated” (Glasgow 2007). It is not just about value for money, but also about the development of individuals and communities. For example, to determine if a change in data quality or clinical care is due to “an information system requires carefully controlling for potential biases and confounders” (Friedman and Wyatt, Evaluation methods in medical informatics 2005). We need measurement of outcomes from eHealth implementation so policy makers can make important decisions on scarce health care resources allocation to improve the individual, communities and population health.

The elements of an eHealth intervention that can be measured are typically independent of others, and often not common or consistent in the terms used to described processes. Those elements adopted by most studies encompass four categories of measurement: quality, cost, productivity and access. The potential impact of eHealth interventions is often measured in terms of them being clinical, organizational and behavioural. Different eHealth interventions might need different health indicators when measuring their impact. These indicators would

provide “signals, positive and negative, about the changes in health status brought about by eHealth interventions, and how health status changed over time following implementation of the eHealth solutions” (Gemert-Pijnen, et al. 2011). If we choose wisely, the study can help us recognize the differences eHealth technologies make in health care, the rationale behind each health intervention that makes these differences, and why eHealth technologies don’t deliver the expected impact. Delone and McLean have proposed to “subdivide success measures of management information systems into six distinct categories: (1) system quality, (2) information quality, (3) usage, (4) user satisfaction, (5) individual impact, and (6) organizational impact” (DeLone and McLean 1992). Each category has several indicators to assess the information system from “technical aspects of the system itself to effects of large-scale usage”. The eHealth elements that can be measured also depend on the type of health system, which varies from general to specific systems. For example, to examine the efficacy of a Personally controlled electronic health record (PCEHR) in enhancing outcomes, we should study its impact on patient engagement as its indicator for measurement. It is not appropriate to generalize the term and approach when measuring impacts of different eHealth interventions simply because each system has its own unique attributes and functions. In literature, eHealth solutions described in the articles can be placed into nine categories: “(1) Electronic Health Record (EHR), (2) Laboratory Information Management system (LIMS), (3) Pharmacy Information System, (4) Patient Registration or Scheduling System, (5) Monitoring, Evaluation and Patient Tracking System (MEPTS), (6) Clinical Decision Support System (CDSS), (7) Telemedicine, (8) Patient Reminder System, and (9) a Research or Data Collection System”. This section focuses on measuring outcomes associated with patient registry and EHR, and aims to provide an understanding of what elements can be measured and how we might measure their outcomes.

There is some overlap in functionality between EHRs and registries in practice. They are both very important to the health care system, however, their roles are distinct. In many cases where registries are evaluated, they are studied as part of a larger EHR system. EHR is a comprehensive system which can have multiple capabilities consisting of four core functions: “health information and data, results management, order entry and support, and decision support” (Institute of Medicine 2003). Health services are implementing EMRs to fulfill different needs, and a subset of EMR capabilities are offered via single or multiple systems. But while EHRs may “assist in certain functions that a patient registry requires, such as data collection, data cleaning, data storage, and a registry may augment the value of the information collected in an EHR, such as population views and quality reporting, an EHR is still not a registry” (Gliklich, Dreyer and Leavy 2014). When measuring the impact of a registry and EHR, we need to consider their functional differences when deciding what elements need to be measured.

In Australia, the My Health Record System (formally known as the Personally Controlled Electronic Health Record (PCEHR) is the key component of digital health. It aims to “connect different points of care and share health information securely” (ACRRM 2017). My Health Record is a combination of EHR and a personal health record (PHR) where information can be accessed by the owners of that information and their authorized healthcare providers. The My Health record includes two components: “clinical (healthcare-related) information” and “personal (individual entered) information”. Only healthcare providers authorized by their healthcare organization, and providing healthcare to the individual, can access an individual’s My Health Record and modify an individual’s digital health record. It is believed that patients with chronic and complex conditions are likely to derive the greatest benefit from a My Health Record. We introduced discussion of the Chronic Disease Management Register in Chapter 4

and its objectives to identify patients who may benefit from certain chronic disease management services, provide useful feedback reports to clinicians and identify patients for research studies. We chose CDMR and the My Health Record System to represent one type of patient registries and EHRs, and provide an understanding of what elements might be measured for the impact of similar eHealth interventions.

We propose to have the potential impact of CDMR and My Health Record measured in terms of clinical, organizational and behavioural (ref table 7.1). They share similar elements for measurement, but while EHR focusses on direct patient care outcome, a patient registry has processed indicators rather than direct effects on care. Moreover, given the complexity of EHR and that one of EHR objectives is to "share with multiple health providers for collaborative patient care, and improve patient-provider communications" (Goldstein, et al. 2014), we have decided to include both impact on cost and communication/collaboration in EHR measurement.

	CDMR	**My Health Record**
Clinical	Indirect patient care Caregiver engagement	Direct patient care Patient/caregiver engagement
Organizational	System quality Information quality	System quality Information quality Communication/collaboration Cost
Behavioural	User satisfaction and usage	User satisfaction and usage

Table 7.1 Elements to measure the impact of CDMR and My Health Record

Direct/Indirect patient care: The capacity of CDMR to impact patient care will be dependent on a complex set of factors such as organizational structure, human resources, policies, motivation, culture and staff IT literacy. This makes it difficult to quantify and analyze the

impact of the registry in isolation from other factors. For this reason, we have categorized outcomes into measure of indirect patient care. One CDMR impact indicator that can be used is the average time taken to identify patients who may benefit from a chronic disease-related service compare with traditional methods. It is important to have the right patient receive the right follow up care or service at the right time. Providing timeliness of service delivery reflects the quality of patient care. In literature, there are many studies assessing the impact of EHR on patient care and the indicators used are abundant. However, the complexity of EHR provides an additional challenge when assessing its impact. Many studies could provide an insight into possible impacts on patient care, but have had limited scientific precision. We chose three common indicators used to measure the impact of EHR on patient care: time spent during a patient visit, number of repeated examinations and the duration of access to test results.

Patient/Caregiver Engagement: The proposed benefits of My Health Record include patient empowerment, where patients are actively involved, thereby improving clinical outcomes. Also care provider engagement enables continuous health monitoring of the patient. For CDMR, we would like to assess the clinician/care coordinators' engagement in using feedback reports generated from CDMR to evaluate the acceptance of CDMR products. The general indicators used in evaluating the impact of eHealth interventions on patient/provider engagement are the frequency of use and duration of use.

System Quality: System quality is usually assessed by its functionality, performance and security. The most frequently addressed indicators are usability, accessibility and ease of use. The indicators we propose to measure the impact of the My Health Record are the time increased/decreased in documentation and the average record keeping time compared with the

paper method. For CDMR, the indicator used is the change in turnover time when identifying a patient for a certain chronic care service.

Information Quality: Information quality includes system accuracy, completeness, legibility and timeliness. The completeness of a record is important to the generation of useful feedback reports from CDMR, and allows a doctor to have complete understanding of patient health through the My Health Record. The data quality/accuracy indicator is important in improving the value of both eHealth interventions.

Communication/Collaboration: EHR is proposed to improve the communication and collaboration between different care providers by sharing patient records. Moreover, it allows for effective home care and remote monitoring as patients actively engage and communicate with care providers to update their progress and health concerns. The indicators we propose are: the number of phone calls in request tests/examinations results, and number of patient visits affected by provider remote monitoring.

Cost: Only a few studies have quantified "the value of establishing clinical registries in terms of economic impact, hence supporting evidence for costly investment in the registry is minimal" (Hoque, et al. 2016). On the other hand, the impact of EHR on cost can be measured by "timesaving, reduced overtime, savings in personnel or reducing the number of tests ordered" (Meijden, et al. 2003).

User Satisfaction and Usage: "Overall satisfaction, user friendliness, and user attitude" toward the eHealth interventions were user satisfaction attributes. Usage refers to "system usage, information usage or both" (Meijden, et al. 2003). Indicators proposed for My Health Record

are changes in responsibility and total data entry time; while for CDMR, we can assess the number of times that a feedback report was used for care coordination.

To measure the above-mentioned eHealth outcome indicators, both qualitative and quantitative methods need to be used (ref table 7.2). Qualitative measurements will be those where "users, patients or stakeholders gave their opinion regarding a system" (Blaya, Holt and Fraser 2008). Usually, it takes the form of questionnaires, focus groups or interviews. Quantitative measurements are grouped: "Descriptive (uncontrolled) study, historically controlled (before-after) study, case-control (retrospective) study, prospective self-controls (subjects performing same action in both systems), simultaneous nonrandomized controls, simultaneous randomized controls, and externally and internally controlled before-after study" (Friedman and Wyatt 2005) according to the definition by Friedman and Wyatt.

Overall, the impact of eHealth interventions is often doubted because of the inconsistency between the predicted benefits and actual outcomes. There is a strong desire for solid evidence of the impact of eHealth interventions on health care. We recognize the challenges of evaluating the impact of complex eHealth interventions as it "has the potential to impact all aspects of health and health care, hence, the concept of seeking eHealth-related outcome indicators is even more complex" (Gustafson 2004). For any eHealth application, the impact measuring process takes time, effort and money which is a burden globally. The approaches to be considered for measuring eHealth outcomes must reflect the core elements of the system and be measured accurately with minimal intrusion on the current workflow.

	CDMR			My Health Record		
	Element	Indicator	Method to measure	Element	Indicator	Method to measure
Clinical	Indirect patient care	average time to identify patients who may benefit from a chronic disease related service compared with traditional method	Before-after	Direct patient care	time spent with patient visit, number of repeated examinations, and duration of access to test results	Prospective self-controlled study
	Caregiver engagement	frequency of use and duration of use	Before-after	Patient/ Caregiver engagement	frequency of use and duration of use	Before-after
Organizational	System quality	turnover time changed in identifying patient for certain chronic care service	Case-control study	System quality	time increase/decrease in documentation and average record keeping time compared to paper method	Case-control study and Before-after
	Information quality	completeness of record data quality/accuracy	Staff survey and user opinion	Information quality	completeness of record data quality/accuracy	Staff survey and user opinion
				Communication /collaboration	number of phone calls to request tests/examinations results, and number of patient visits affected by provider remote monitoring	Before-after and Case control study
				Cost	timesaving, reduced	Case-control

					overtime, savings in personnel or reducing the number of tests ordered	study and before-after
Behavioural	User satisfaction and usage	number of times that feedback report was used for care coordination	Case-control study	User satisfaction and usage	change in responsibility (documentation habit in patient effecting self-management) and total data entry time	Patient question-aire and before-after

Table 7.2 Suggested methods to measure the impact of CDMR and My Health Record

7.4 The interoperability of health information systems in the chronic care program

The *Healthcare* Information and Management Systems Society (HIMSS) defines the interoperability that it describes as "the ability of health information systems to work together within and across organizational boundaries in order to advance the effective delivery of health care for individuals and communities" (Reis, et al. 2017). It extents to "which systems and devices can exchange data and interpret that shared data" (Pine 2019). When it comes to the healthcare industry, interoperability must include the capability of distant information and data storage systems to exchange and share information from a range of important sources, including health services, clinics, pharmacies and laboratories. The Australian Government Interoperability Framework has three parts: "the Information Interoperability Framework, the Technical Interoperability Framework, and the Business Process Interoperability Framework"

(Information management strategy committee 2006). Most nations and healthcare organizations "engaged with their eHealth strategy to achieve system interoperability" (Hovenga 2008), some incorporate a broad scope and are more effective than others. However, the complexity of system interoperability is still not recognized by most stakeholders and policy makers.

It is generally accepted that "there are different levels or degrees of interoperability and these determine the functionality" (Hovenga 2008). The HIMSS Board established definitions for three levels of health information technology interoperability in 2013 (HIMSS 2013):

> ***"Foundational Interoperability*** - enables one information system to exchange data with another information system. The system receiving this information does not need to have to interpret the data. It will be instantly available for use.
>
> ***Structural Interoperability*** - is an intermediate level which defines the format of data exchange. This has to do with standards that govern the format of messages being sent from one system to another, so that the operational or clinical purpose of the information is evident and passes through without alteration.
>
> ***Semantic Interoperability*** - is the highest level of connection. Two or more different systems or parts of systems can exchange and use information readily."

Walker (Walker, et al. 2005) described a "four level functional taxonomy of interoperability reflecting the amount of human involvement required, the sophistication of IT and the level of required standardization to form the basis: (?)

> ***Non-Electronic Data*** - no use of IT to share information.
>
> ***Machine-transportable Data*** - transmission of non-standardized information via basic IT; information within the document cannot be electronically manipulated.
>
> ***Machine-organizable Data*** - transmission of structured messages containing non-standardized data; requires interfaces that can translate incoming data from the sending

organization's vocabulary to the receiving organization's vocabulary; usually results in imperfect translations because of vocabularies' incompatible levels of detail.

Machine-interpretable Data - transmission of structured messages containing standardized and coded data; idealized state in which all systems exchange information using the same formats and vocabularies."

Elkin and his colleagues (Elkin, et al. 2007) explain "three levels and degrees of interoperability, and each level supports specific application needs described in terms of functionality:

Syntactic Interoperability - deals with interoperable structures. The packets of information transferred from one computer to another anywhere in the world without identifying content, documents, etc.

Semantic Interoperability - deals with the interoperability of a common shared meaning required for the reliable transfer of clinical data because this is where the meaning of data must be retained to enable the transferred data to be processed by the computer and used for decision support systems.

Pragmatic Interoperability - deals with external constraints on the system, taking into account the level of detail needed for common understanding and the complexity or difficulty required to achieve a certain level of interoperability.

Irrespective of what taxonomy or interoperability is adopted, all eHealth interventions need to "establish the functions they need to be able to perform so that the required degree and level of interoperability can be established, enabling the identification of which standard they need to be compliant with" (Hovenga 2008).

A high degree of data fluidity is the foundation for many different eHealth interventions related to chronic disease management, including care coordination, care planning, home monitoring, and the integration of health data into the comprehensive electronic health record. The clinical

information systems with great interoperability can provide “comprehensive information about the patient to those who deliver care, those who manage care, and those who receive care” (Marchilbroda 2008). All health care providers have a shared role in providing person-centered care for chronic disease patients, whether using an interdisciplinary or multidisciplinary approach. The key objective is to provide important clinical information about the patient when and where it is needed in a timely, secure manner. The outcome is supposed to support key elements of the chronic care management. One of the findings from a literature review of chronic care management was “how improvement in care coordination between multiple physicians and other healthcare professionals can positively impact the care received and improve utilization” (Tran 2016). As a result, development and implementation of a chronic care management program using eHealth interventions connects patients and professionals to enhance care delivery in the diversified population of chronic disease patients. The foundation for chronic disease care coordination, care planning, patient activation and remote monitoring is a longitudinal health care record that accurately matches patients with their health data across providers, systems and state.

The main purpose of having interoperability among healthcare systems is to exchange information and services between them. It is only considered as significant if the interactions can take place at least on data, services and processes level with semantic defined in any context (?) (Adenuga, Kewaletswe and Coleman 2015). In chapter 4, we have studied the use of CDMR for chronic disease management program. CDMR aims to provide a longitudinal database for certain chronic disease patients admitted to The Canberra Hospital (TCH) or receiving coordination-related services from the Canberra Hospital and Health Services (CHHS). One recommendation is interfacing registry with her, which will be the primary desktop interface for physicians and other health care providers. In other words, “registries must work through

EHRs in order for interoperability to be feasible" (Gliklich, Dreyer and Leavy 2014). And the registry-specific functionality could be presented as an interface connecting with the EHR at the presentation level on one end and registry database on the other.

Mansoor and Majeed (2010) define five challenges for interoperability with CDMR: (1) interfacing – a boundary at which interaction occurs between two systems or processes, (2) integration – the combining of diverse applications into a relationship for functioning as a joint collaboration of several system components to form a single entity, (3) accessibility – who can access the shared information and at which level a particular user can access medical information through the system, (4) privacy – the access to the information only by authorized users who have permission to use the system, and (5) security – the need for proper authorization and consent to interact with the medical information, more specifically, who is going to access patient data and at which level can access and when can access."

Of these five challenges, having CDMR interfacing and integrating with EHR is important for it to have semantic interoperability where "systems understand the data exchanged at the level of a defined domain concept" (Agency for Healthcare Research and Quality 2005). This means creating standard vocabularies and common data across health care systems to regulate what's collected, the method of collection and what it means. Beyond interfacing and integration, other issues require robust, standardized solutions. Such solutions include permission or authorization, privacy and security management — "how to authenticate users across multiple applications; how they should be maintained and viewable across all the paths through which the data move." The ability of current CDMR to communicate with one EHR requires a strong legal framework to facilitate information sharing to a common standard.

Interoperability is hard to achieve considering that the majority of health information systems are designed and developed by different system providers. The complexity that characterizes healthcare data is the major reason behind the barrier to interoperability. The technical capabilities of transmitting data are no longer the issue, what is hard is be coherent with the data content. A number of different "groups, standards and methodologies are working on the problem of interoperability, such as HL7 with v2 and clinical document architecture (CDA), OpenEHR and Fast Healthcare Interoperability Resources (FHIR)" (K. McDonald 2015). Even when the complexity of data elements results in a standard for a national program like PCEHR, the amount of variability makes them too complex to be used. Interpreting the content is hard partly because clinicians who do the basic words cannot even agree on what they mean. It is a repetitive process where health professionals need to transform the system where IT cannot, but they don't get the support they need to do it.

Recent research studies have proposed a potential solution to achieve levels of interoperability without a holistic and definitive interoperability model. This solution used an incremental approach using the "successive development, testing, and adoption of open, standard building blocks towards an interoperable solution" (Gliklich, Dreyer and Leavy 2014). This approach can at least provide a level of functional interoperability which requires the creation and adoption of effective open-standard building blocks. The functional interoperability is the capability to reliably exchange information without error. A number of cases have demonstrated success in implementing "building-block standards to achieve functional interoperability for registry purposes". In one case, a registry that focused on "effectiveness in pain management was made interoperable with a commercial EHR using RFD communication" (Clinical Research Healthcare Link 2012). Content profiles build the next level, such as clinical research data capture (CRD), and drug safety content (DSC), that allow the "functional interoperability

solution to leverage standardized content as it becomes defined and available within healthcare systems" (Agency for Healthcare Research and Quality 2005). For example, CRD allowing "standard content defined within an EHR to be mapped into the data collection elements for the registry, eliminating duplicate entry for these defined elements" (Gliklich, Dreyer and Leavy 2014). The next level of the building-block approach is to address "the data standards issue, patient privacy protection, appropriate use of digital signature and other related emerging profiles" (Gliklich, Dreyer and Leavy 2014).

While full semantic interoperability remains distant, an open standards building blocks approach to achieve functional interoperability can be adopted in the short term. In the case of CDMR in ACT Health, the first step to achieve functional interoperability is to have a supportive regulatory policy allowing a web service interface for CDMR before integrating it with the existing PCEHR.

7.5 The standard of "meaningful use" for eHealth-enhanced chronic disease management

Since the roll out of the meaningful use program in 2009 which "purposed to encourage doctors and hospitals to adopt and use IT systems and migrate from their old paper records to the new electronic health record systems, no other sector of the U.S. economy of similar size and complexity has undergone such rapid computerization" (Halamka and Tripathi 2017). Hospitals and clinicians are now active users of electronic health record (EHR) systems which attest to the success of this first stage of the meaningful use program. EHR adoption rates have skyrocketed. The HITECH program in the U.S. sought to "first achieve uptake, then integration and interoperability, however, the second stage of the program shows lackluster results"

(Wright, et al. 2013) and was not welcomed in the medical community (Barlas 2010). When the time came to focus on the third stage, which is mainly focused on health information exchange among care providers, it was clear that deficiencies in the current program lost the hearts and minds of clinicians along the way.

Meaningful Use, "a metastasizing web of mandates, regulations, exclusions, incentives and penalties" (Halamka and Tripathi 2017), requires providers show they are using EHR in measurable ways which impose cost on care providers and vendors without contributing sustained benefit. The approach that legislation drive cultural change is destined to fail without involving business and clinical drivers. This deficiency was manifested in the following areas: ***Workflow*** - The top issue concerning the Meaningful Use Program was the workflow. Care providers will choose not to use EHR or develop strong resistance to it if the system fails to accommodate intelligent workflow. Consequently, EHR has not been used efficiently, and definitely not meaningfully. For those physicians who have adopted EHR, their daily practice workflow was disrupted when "Meaningful Use was added to other disconnected regulatory requirements, including the International Classification of Diseases, 10th Revision (ICD-10), the Omnibus Rule of the Health Information Portability and Accountability Act (HIPAA), and new payment models from commercial and government accountable care organization (ACO) programs" (Halamka and Tripathi 2017).

Clinicians have to deal with all these confusing layer of regulation, learning and incorporating new billing codes, keep track of numerous structured data elements required for meaningful use, and convince their patients to use patient portals of a health record system while expected to provide high-quality care at the same time. Meaningful Use failed in the sense that the workflow was untenable when it pushed care providers to focus more on technology than on the patient.

Interoperability – Meaningful Use is not going anywhere if the healthcare industry doesn't address the health data interoperability first. Since the beginning of the Meaningful Use Program, it set unrealistic expectations for interoperability without first building the essential tools, including a directory for provider addresses, a strategy for patient matching, and guidelines for consent and privacy. Governments have a duty to decide who can exchange what for what purpose. It is easy to criticise technical barriers, it's the policy barriers that will become more and more difficult to work with. The importance of interoperability has been acknowledged by the U.S. Department of Health & Human Services (HHS) which released the new proposed rule for the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) describing interoperability as "a key priority for the healthcare industry" (Sherwood 2016). However, in the current systems, users are having trouble sharing results across platforms because little data are easily transferrable between different electronic health record (EHR) systems. Instead, health providers need structured, accurate, complete and real-time information to be shared among team members in an accessible manner.

Innovation – EHR vendors are facing an avalanche of requirements from Meaningful Use. This is an overwhelming burden when innovation is on a deadline and the developed software needs to support a large number of externally controlled mandates. The innovations were supposed to support better care, however, EHR vendors flooded the market and raced to develop and sell their applications leaving solid user experience design considerations in the dust. As a result, developers often produced a capability that meets the requirements of the test, but fails to meet the requirements of the customer. Obviously, more work was needed. Moreover, development resources had to be "diverted to programming of complex certification requirements to meet the technical, functional and workflow requirements of meaningful use, which left little available capacity for innovation" (Halamka and Tripathi 2017).

Patient engagement – Between the different stages of meaningful use and new rule proposals amending the program, the requirements for patient engagement are not always clear. Moreover, there is an overall "immaturity in the market with health IT ill-equipped with the functions required to support the transmission of health information by a patient or the delivery of a secure message from a patient to a third party" (Heath 2016). The incompetency in both policy and technology so challenges health care providers and patients, hat it could have the unintended effect of driving them away from the program. For the providers, whether the patients access their data and what they do with it is beyond the providers' control, so the meaningful use rule of patient engagement could be a real problem in some cases.

There is no doubt that Meaningful Use has driven the adoption of modern health systems and technologies to improve the quality of care and efficiency. Australia could adopt the same approach, but should be mindful of lessons learned from the US scheme. Inevitably, Australia will at some time have its own version of Meaningful Use, but such a program should "stimulate Australian digital health investment" (ACRRM 2017). The Australian College of Rural and Remote Medicine (ACRRM) supports "a transition towards a meaningful use policy with the My Health Record, Australia's national digital health record system, and believes the Australian health sector is even more likely to enhance the return from meaningful use of EHRs because the system is far less complex in contrast to the U.S." (ACRRM 2017). The current uptake of EHR across Australia is nowhere near as fast as in the U.S. but a well-positioned Australian Meaningful Use policy would "deliver benefits for State, Territory and Commonwealth Governments via greater co-ordination of patient care across the public and private acute, community and primary care sectors" (ACRRM 2017). Importantly, it will play a central role in enabling changes in chronic disease management by encouraging the coordination of care

across care settings. We can certainly benefit from government intervention. But the first step is to recalibrate the meaning in ‘meaningful use’ based on the lessons learned.

For complicated and chronic disease patients who need more time and care, the meaningful use of eHealth interventions should help them receive more access to the medical system, not take away their already precious care time. It should also reduce the health care providers’ burden of care coordination, care planning and communication, not disrupt their workflow with overwhelming regulations. The current Meaningful Use Program is focused on adopting and using electronic medical records as a final goal, but imposing the health intervention on the medical community and patient and forcing them to adopt and use the technology without achieving the actual goal of efficiency is destined to fail. To have meaningful use of eHealth interventions in chronic disease management, we need to focus on *Usability, Interoperability, Workflow integration,* and *Patient engagement* to capture customers, developers and multi-stakeholder collaborations.

Usability should not only be defined from the vendor’s experience, but also from the end user’s perspective. The roll out of a new technology has to look like (what?) for a clinician to be able to use it, which will increase buy in (?) from the end user and less resistance to change. For chronic care which has interdisciplinary care model, we need to disregard the one size fits all approach; we need to recognize the differences between care providers and address the unique needs of many different types of medical professionals. EHR is not the only type of IT solution, there are many other IT services that can help medical providers much more.

Interoperability should be led by market action rather than regulation. Systems whichcan communicate with others by recognizing formats, networking structure and codes are likely to

be widely adopted and achieve interoperability. What health services need is a platform that focuses on both managing and exchanging patient data. This platform will have the ability for two or more systems to exchange information and to use the information exchanged. Moreover, health information exchanged to connect provider and patient should be used in a more meaningful way. For example, the data collected from the wearable devices of chronic disease patients could be used by care coordinators to arrange a better care plan.

It is safe to conclude that any widespread adoption and meaningful use of eHealth intervention depends on the successful integration of health information technology into clinical workflow. Without successful workflow integration, health care providers will resist adoption and implementation of health information technology. The pattern of actions clinicians utilize to perform routine tasks and generate results should be recognized by the health information system, so it produces minimal interference with clinical workflow. For example, eForms used in chronic care programs could incorporate an automatic upload function to CRIS, so instead of using print and fax in the clinical nurses' daily routine workflow, they could benefit from the electronic forms and more readily adopt them. Nonetheless, clinicians can undertake various approaches to incorporate clinical workflow into eHealth interventions. Utilizing workflow assessments "in the pre-implementation phase gives clinicians a better understating of the various patterns that create routine workflow in their clinical setting" (Lorenzi, et al. 2009). Additionally, we should recognize that each clinician's workflow pattern might be unique, so the implementation plan should have room for clinicians to modify it. More importantly, ongoing training is needed for clinicians to adopt technologies smoothly, allowing the intervention to be integrated into clinical workflow effortlessly and in a meaningful way.

Patient engagement and chronic disease management are closely connected. eHealth intervention can have meaningful use in patient engagement to detect and prevent their chronic health condition, manage it both with the provider and self-management. The foundation for patient engagement in meaningful use is having data available to all patients and then have providers to monitor and report on patient access. Although it is possible that patients choose not to look at their own data, we still need to acknowledge that theys have the right to do so. To strengthen patient engagement, we should use devices and workflows that are already part of their daily lives, and use a portal that patients feel of is interest to them. For example, portals that can direct important educational material and alert new treatment plans are of great interest to them. Meanwhile, we should simplify the process and provide staff to assist patients with it. Providers can also "drive patient portal adoption by advocating for the technology because patients are far likelier to adopt the portal when their providers suggest doing so" (Ahier 2012).

Overall, meaningful does not depend just on the mass adoption of digital technology, it is mainly depending on the "people involved, their comprehensive engagement, the culture of leadership and enablement, support for, and acceptance of change" (Ahier 2012). Chronic care management should shift the balance of power by connecting patients, and provide new ways of working by connect providers. The challenge of meaningful use is ensuring it actually leads to meaningful benefits.

7.6 Preparing eHealth for chronic disease management

In recent years, the increasing workload in chronic care has led to to a strong focus on promoting self-management in chronic disease patients, and, in addition, require health care professionals to "shift to a role of teacher, partner, and professional supervisor of their patients" (E. P.

Talboom-Kamp, et al. 2016). Patient follow-up has become particularly important in helping patients manage and control their disease. The application of eHealth solutions has been used increasingly in care coordination, care planning and communication to the meet the needs of both patients and health care providers. In the previous section, we identified factors that discourage the uptake of health information technology by care providers in a Chronic Disease Management Unit. The reluctance to eHealth intervention is likely to be modified if barriers are identified and reduced.

The section describes the necessary steps to consider when preparing eHealth for chronic disease management in order to improve its acceptability and sustainability.

Step1: Compatibility planning and knowledge engagement

A strategic plan to ensure compatibility between the eHealth intervention and the organization is "important for success, whereas the lack of a plan was reported as a barrier to eHealth implementation" (Fontaine, et al. 2010) (Jarvis-Selinger, et al. 2008) (Ohinmaa 2006). It is important to have a compatible plan, so the eHealth system fits well with the workflow, t positively influencing workplace efficiency and facilitating use.

A successful chronic disease management model links patients with a range of clinicians and social service providers of different organizations. We need intervention to link service units for care coordination, to simplify the process of outcome-oriented care planning and to improve communication between service units. To incorporate care coordination, care planning and communication with eHealth intervention, it is necessary to include key stakeholders and end users as early as possible in the planning process. The first task is to define who the relevant stakeholders are and who is affected by the problems and solutions. Stakeholders would include

the people responsible for producing the technology, such as designers, technicians, as well as those who "participate to ensure that eHealth technologies fit in with the needs and values, such as end users, health care professionals" (Gemert-Pijnen, et al. 2011). It is important that the opinions of all those involved be considered to ensure a positive effect on future collaboration. For example, to improve the eForm usability in Chronic Care Program, we should consider the fact that clinical nurses do not always consult patients or formulate a care plan in an office with a computer. To avoid increasing their workload, we should consider having eForms that can be accessed remotely during a planning stage. Field observations, interviews and workshops entail "information gathering from the intended users and the environment in which the technology will be implemented" (Gemert-Pijnen, et al. 2011). These value-specific contextual enquiries are necessary when conducting compatibility planning to ensure eHealth solutions fit well with work practices or daily clinical work.

Enabling policy and strategies are part of compatibility planning which is essential to guide "the adaptability of technologies to fit with roles, tasks and workflows" (Ross, et al. 2016). Having supportive legislation and recognized standards should be an important part of a planning process interrelated with organizational working procedures to achieve compatibility. For eHealth solutions to work successfully in new ways, we need an intervention-friendly culture to support its use. For example, CDMR has frequently been identified as not user-friendly by many clinicians. One answer would be to build an interface so users who do not have SQL background can easily extract the output from CDMR. However, ACT Health has strict legislation restricting the sharing of data through interface. How to create an appropriate organizational culture for the use of eHealth solution needs to be discussed in the policy and strategic plan before implementation, so the new roles and responsibilities created by the introduction of an eHealth system are less disruptive to the current workflow.

Well-educated and informed practitioners with positive attitudes and a better understanding of eHealth systems, are the best catalyst to promote compatibility between the eHealth intervention and the organization. Acceptance by health care providers of eHealth solutions will be guaranteed not only "if health professionals accept the benefits they bring to patient care, but also have confidence in using them" (Rosenmoller, Whitehouse and Wilson 2014). Any focus on education, training and support in the planning and implementation of an eHealth system should include the use of technology. For example, many users lack interest in the CDMR and doubt that the registry can improve patient care. If they have better access to knowledge and information, they will have a better understanding of the benefits and realistic expectations for the CDMR. Generally, education was reported to "increase staff acceptance of eHealth systems including education around anticipated benefits and when those benefits could be expected" (Studer 2005).

Step2: Address the complexity of technological adaptability

Digital technologies introduced for health care, such as EHR, telemedicine, telecare and decision support tools disrupt existing networks and eventually will displace their established market and value. The process is inevitable. As eHealth intervention evolves, understanding how to help it work with the old information system, existing national plan or current workflow practice will determine its adaptability.

Many eHealth interventions, such as EHR cannot be used straight out of the box, they must communicate with other existing devices and databases to complete the system. Users are often "reluctant to get rid of the current functional system, which requires the new intervention to be compatible with the existing practice systems" (Boonstra and Broekhuis 2010). Data formats

vary among the different software packages and systems, in large part due to "the lack of consistent data standards within the health care industry" (Boonstra and Broekhuis 2010). These standards must be selected carefully for applicability, durability, consistency and sustainability.

Making the individual eHealth project compatible with a national counterpart requires the technologies to "have technical adjustments made to them to suit the constant modifications of the environment" (Ross, et al. 2016). For example, the South Australian Government claims its work on a patient administration system strongly supports the national PCEHR, but whether the individual system will be compatible with a national intervention would inevitably depend on the final specifications (Swan 2011).

Complexity and usability problems associated with an eHealth intervention results in care providers having to allocate resources and effort if they are to use it meaningfully, which inevitable disrupts the current workload and hence, affects their ability to adopt the technology. Health system vendors should aim to have the system as user-friendly as possible, allowing users to master the new intervention more easily.

Other complex factors such as "software and hardware that were difficult to use" (Gagnon, et al. 2012), the "inability to provide real-time access" (Lu, Xiao and Jacko 2005), and slow system performance (Vreeman, et al. 2006), influence technological adaptability in the current healthcare setting.

Step3: Plan ongoing monitoring, evaluation and support of systems to ensure sustainability

Healthcare is “an open system that needs to be sufficiently adaptive to changes if it is to sustain” (Coiera and Hovenga 2007). Chronic care management has shifted from hospital-based care to community-based care, which creates new processes and infrastructures for health care delivery. Information and communication technologies, such as EHR, telephone coaching and wearable devices enables change if applied appropriately, otherwise, IT can itself create problems. We should plan sustainability analysis at the beginning of eHealth intervention development to identify where the most pressing challenges are to ensure we will have a healthy health system for a long time.

Evaluation and monitoring to influence the use of future eHealth implementations are always promoted as necessary to ensure system sustainability. eHealth technology development is “an iterative, flexible and dynamic process” (Gemert-Pijnen, et al. 2011). Evaluation must be considered right from the start, and the technology developments evaluated continuously without a fixed end. The appropriate level of evaluation depends on the following:

1. User needs

   “The appropriate level of evaluation depends on the needs of the user” (Gustafson 2004). Therefore, it is important for eHealth developers to evaluate users’ needs as the first step in system development. Any new eHealth solution should focus on identifying gaps in the current system and services where users most need and require a new solution.

2. Economic assessment

   Economic evaluation of various healthcare interventions “helps allocate resources in an efficient way and facilitates prioritization” (Slothuus 2000). How eHealth intervention affect the use and costs of healthcare relative to other options need to be closely examined. For example, how does a chronic disease telemonitoring device change the frequency of patient visits to a hospital emergency department compare with visits by a

clinical nurse in-house? “Different methods of economic evaluation have been developed to help guide decisions and inform policymaking” (Slothuus 2000).

3. Acceptability

   Healthcare systems are dependent on “complex human organizational structure” (S. Khoja, et al. 2013), hence the reason for evaluating positive/negative social acceptability to improve its uptake.

4. Technology outcome

   Technologies such as “software, hardware and connectivity infrastructure used to implement and sustain any eHealth solution can be measured in terms of appropriateness, relevance, use, safety, and effectiveness” (S. Khoja, et al. 2013). Technology evaluation by developers is needed to understand usability associated with the adoption and diffusion of digital solutions, and help with the development of an appropriate interface for different users.

5. Policy and legal framework

   Policies are designed to “guide proper implementation of eHealth initiatives, complemented by the legal framework to ensure that malpractices, such as inappropriate access to patient information, breach of privacy, or inadequate quality of care are controlled” (Scott, Chowdhury and Varghese 2002). Evaluation of eHealth policy is required to assist structured and consistent eHealth practice.

6. Health system outcome

   Health outcomes evaluation is using “methodologies to demonstrate program effectiveness and ultimate impact” (Hepworth 1997). eHealth intervention produces changes which can be measured based on disease status, quality of life and health indicators.

Healthcare intervention monitoring and evaluation is a “continuous and reflexive process that leads to matching human, organizational, and technology factors” (Gemert-Pijnen, et al. 2011). Planning healthcare interventions and associated implementation early in developing an intervention can ensure its sustainability.

Having regular system maintenance and strong technical support are important factors ensuring technical sustainability. Detecting issues at an early stage before they become problems is part of strategic planning within complex organizations (Police, Foster and Wong 2010). Health professionals complain about poor service from a vendor, such as poor follow-up and low support for problems associated with eHealth interventions as a barrier to them adopting eHealth solutions. The lack of system maintenance and support can be “more easily solved by larger groups of physicians because they have more and stronger organizational resources, such as management expertise, practical experience, financial resources and support staff, than smaller group” (Miller and Sim 2004).

Ultimately, when preparing eHealth for chronic disease management to improve its acceptability and sustainability, we need to consider steps in terms of clinical, organizational and behavioural.

Chapter Eight

Summary, Limitations and Conclusion

Chapter outline

8.1 Introduction

8.2 IT innovation opportunities for CDM network

8.3 Strengths and limitations of the study

8.4 Areas for further research and practice

8.5 Concluding remarks

8.1 Introduction

Countries worldwide are now committed to the increasing use of Information technology (IT) in healthcare settings (Singleton, Pagliary and Detmer 2009). IT isused to facilitate healthcare teams deliver care more efficiently, and in the area of chronic disease management, IT innovations are helping to assure the delivery of proactive, efficient clinical care and self-management support for people with chronic illness. To maximize the effectiveness of implementation, it is important to highlight the need for these IT interventions to be evaluated and investigated properly (Giuse and Kuhn 2003). The current reality is that the introduction of IT in healthcare does not necessarily translate into improved quality of care; often it has unpredictable outcomes (Mort, Finch and May 2009). We want to develop a good implementation strategy for eHealth interventions and effective evaluation tools after

implementation to ensure meaningful use. However, challenges lie in the multifaceted healthcare environment where reality is often complex and fluid.

The ACT Chronic Disease Strategy framework endorsed the use of a Chronic Disease Management Register and many other IT innovations (e.g. telehealth, PCEHR) to connect service units and integrate CDM elements (ACT Health 2013). The purpose of this research is to get insights into these eHealth tools and evaluate their impact on chronic care management in the regional health service. The findings may shed light on how to develop an effective method of identifying good implementation strategies and evaluating them after implementation to ensuring meaningful use.

The primary investigator conducted research in the ACT Health setting. The research methods utilized qualitative approach and three interlinked case studies to address the research questions. The case studies focus on micro-level qualitative research methods, including observational studies of naturally occurring interactions in health care settings, non-standardized individual interviews with providers of health care and analysis of documentary material produced in health care settings. The research methods together helped an analysis based upon detailed field notes where the process moves backwards and forwards from the data to analytic concepts, refining and synthesizing. The research methods contributed to the harvesting of the findings, and the plan of analysis used open coding and framework approach to interpret results in a practical way.

The organization of the dissertation constructed to reflect the aim of the study and answer the research questions. This final chapter relates the key findings with opportunities to strengthen

chronic disease management in ACT Health and discusses the strengths and limitations of this research. Finally, it recommends new topics for future research.

8.2 IT innovation opportunities for CDM network

Technology has made inroads into chronic disease management in ACT Health through innovation changes in clinical workflow, care delivery methods and patient self-management support. While these technologies have yet to fulfil their potential to contribute to good chronic care practice, it is evident that they provided opportunities to improve patient care management and care efficiency. ACT Health has a fair good environment to assist chronic care, including primary and secondary chronic disease prevention interventions. Under the leadership of the CDM Unit, ACT Health wants the patients to be better informed and more engaged, so they have a greater likelihood of improved outcomes. There are IT innovation opportunities in ACT Health's clinical information system to strengthen chronic care coordination from its current traditional patterns, strengthen collaborative support to enhance the quality of chronic patient care and improve overall chronic care management performance through adaptation in care management processes.

The research findings show that using technologies in CDMU within the Australia eHealth transition changed the network components associated with clinical and practical care management processes. The new network has changed care management, collaboration, communication and patient self-management support. In particular, ACT Health looked at the use of CDMR and new electronic clinical forms in case studies to understand the complex process of change and gained deeper insight into the network of association when new components are added to an existing network.

The service-focused CDMR informs “the service provider about the pool of patients with chronic diseases and assists various service units to coordinate care” (Guda 2012). The study results show that CDMR has not as yet delivered the promised results, which aimed to address the CDM Unit’s problems with the need for seamless patient care. Such care entails access to patient information and allows successful implementation of sustainable chronic disease management initiatives. Contextual barriers are the technology, people, social problems and an organization with an incomplete dataset; poor technical governance; limited human resources; inefficient data sharing processes; incomplete reports with limited value and a lack of communication for improvement. Overall, there are tensions between each factor (technology, people, social and organization) which are supposed to help stabilize the network. As a result, the CDMR failed to fully reflect and respond to local needs and priorities.

In the network of the Chronic Care Program in ACT Health, we explored how individuals interact with technology as well as the existing paper-based system during the development of the eHealth transition. We studied how technology impacts people, environments, and the contexts in which they exist. The CCP is in the preliminary stage of eHealth development and there is strong resistance to electronic clinical form use in the service. The resistance to information and communication technologies (Ts) in CCP services can be summarized from two main issues: the failed efforts made by manager/policy maker/care providers to achieve particular alignments of people and technologies and the incomplete inbuilt properties of an ICT solution that constrained the possibilities open to organizations and end users. Overall, the study results show that the adoption of electronic methods in care management and collaboration in CCP is slow and that most care providers are still satisfied with the paper-based clinical system.

The case studies reveal that ACT Health lacks a unified clinical information system, as a result, most of the service units utilize their own service-specific databases. The inadequate data interoperability limited the competence of service planning, performance monitoring and evaluation of care interventions. A clinical repository embracing hospital, allied health, primary care and other community health services is the ideal information system and probably the first step to a shared electronic health record. It will move ACT Health from point-to-point exchange of clinical information to a centralized model. However, we need to have realistic expectations about the development of a clinical data-linked model of care which is currently diminished due to adherence to the traditional paper-based system and the absence of modern communication portals. We learned from the case studies that it is not necessary to start building an intervention just because the user wants one and it seems like the solution. We want the outcome to be one where, if we build the clinical repository, users will come. We also learned that the vital part of a design process is gathering user needs by understanding who those users are, what they do now, and how things will change for them later with the right product. The real point is to have an outcome where users get better.

When synthesizing the findings, I identified three key issues that interfered with the successful development and implementation of current eHealth solutions in CDMU.

- We need to improve acceptability and sustainability of eHealth interventions
- We don’t have methods to measure the impact of eHealth interventions
- We need to ensure interoperability among healthcare systems to exchange information and services between them.

This is consistent with the findings from the literature review, and possible solutions to resolve these issues have been discussed in chapter seven. Whether it is to improve the current eHealth

interventions or implement future IT innovations, the priority must be to plan for a sustainable IT solution. In the case of CDMU, we need to address the interoperability among independent service specific databases and develop methods to measure and evaluate the impact of IT innovation to ensure its sustainability and meaningful use. While a full semantic interoperability between IT systems remains distant due to challenges with interfacing, integration, accessibility, privacy and security for the current CDM network, we can still adopt incremental approaches in moving forward towards an interoperable solution while achieving functional interoperability between systems in the near term.

We have identified the urgent need to measure and evaluate the impact of eHealth interventions in CDMU so we can compare the postulated benefits and actual outcomes. We propose to use both qualitative and quantitative methods to measure eHealth outcome indicators in terms of clinical, organizational and behavioural outcomes. We understand that outcomes are difficult to measure because we can't measure them until things do "come out". However, whatever approach is considered, it must be simple and minimally intrusive, and it must accurately reflect the fundamental elements of the system being measured. Clinicians and care providers have come to expect that they can manage the transaction of care provision through many IT innovations. They may also tolerate less ease of use if they perceive an eHealth intervention to be productively useful and of high quality. That means a useful and sustainable IT intervention can eventually improve its acceptability among users.

The causes of the low acceptability of current eHealth interventions in CDMU are many, including the lack of user engagement in the planning, development and implementation stages of eHealth systems; the lack of necessary training, education and technical support for users; limited user computer skills, abilities and experiences using eHealth interventions; the lack of

leadership engagement and management support during implementation processes; negative influences from patients, which affect health care providers' attitudes towards eHealth intervention; workflow disruption with new technology; absence of policy and liability and the nature of technical complexity.

We believe it is critical to remove these barriers to improve eHealth intervention acceptance among the health care providers in CDMU. Another key factor that can influence the acceptability of an eHealth intervention is its sustainability. We believe it is important to plan ongoing monitoring, evaluation and support of a system to ensure its sustainability. It is a continuous and reflexive process that leads to matching human, organizational and technological factors. Planning early in the development stage intertwined with implementation are more likely to ensure eHealth sustainability.

The results demonstrate that the introduction of IT innovations in a health care setting is not a "build it and they will come" venture. Transforming healthcare to accommodate digital health is upon us, but first we need to prepare the healthcare landscape to move and transform along with it. IT innovation will certainly help ACT Health to improve chronic care management if it can achieve widespread adoption and improve the lives of its users. Eventually, we want the opportunities, challenges, barriers and innovations unfolding in the field of digital health to lead to meaningful benefits.

8.3 Strengths and Limitations of the study

One of the strengths of the study is the use of a qualitative approach along with three interlinked case studies to conduct an assessment of complex issues and behaviour. The observational studies, key informants' interviews and analysis of documentary material produced in the health

care setting helped me unravel complex phenomena while still providing in-depth information on individual cases. The study demonstrates a holistic focus on IT introduction and implementations in a healthcare setting where the relationship is dynamic. The findings and literature review both identified related themes which established the strengths of the data.

The study lies within ACT Health's CDMU setting and was subject to the broad limitations of case study research. The care for people with chronic conditions in the regional healthcare services has been studied both nationally and internationally. It appears the key findings of this research are applicable to other health system settings. Although the digital health solutions presented in this research are not discrete and immediately replicable interventions for other healthcare settings, they provide a framework and big picture showing how a healthcare organization can transform its general ideas about healthcare reforms and IT introduction. The possibility of generalizing the implementation of similar eHealth solutions, such as CDMR and electronic forms, will vary from organization to organization and from country to country. This depends on the nature and scope of different healthcare organizations, and the extent to which they implement eHealth innovations. Nevertheless, the key findings of this study can be conjectured as a resonably useful guide for people working in other similar health care setting who are considering implementing electronic medical databases, registers or going paperless.

The research provides significant inputs for the design of an eHealth solution for OMS in CDMU. ACT Health can utilize the inputs to relate evidence-based guidelines to clinical practices in preparation for future OMS digital interventions. Meanwhile, professional rationales and expert knowledge may suitably be applied to avoid similar approaches used in CCP when transitioning to electronic files, which are considered as disruptions to care providers' workflow. The research has shown the value of significant inputs by CDMU health staff into

IT innovation development, implementation of quality improvements, and changes in clinicians' capability and engagement.

In addition to investigate research objectives and questions, this study has revealed some vital policy opportunities informing policy decisions related to the use of technology in chronic care. The research findings can be "translated into language that policymakers can understand and act on, and communicate the needs of policymakers to the research community" (Trucano 2015). It is hard to conclude whether the research questions reflect the most important emerging research topics related to ICT use in health services, but it acts much in this list of research questions is applicable today and in fact remains under-studied. For example, one of the research questions studied the impact of technology on people, the environment and the contexts in which they exist. From the perspective of the decision makers who make important and often very costly decisions about technology-enabled approaches, it is vital to explore and understand the underlying reason when a particular impact occurred; under what specific contexts did it take place; and what was the key factors facilitate the success or led to failure.

The main limitation of the study is its small sample size for key informants' interviews. The principal investigator conducted case studies in the ACT Health setting and the ethics application passed through two ethics committees, which include the ACT Health Human Research Ethics Committee, and ANU. Due to the procedures of the ACT Health Ethics Committee at the time of the application, the ethics approval for the study was delayed. In considering the delays, I conducted nine key interviews with staff from ACT Health to meet research progress milestones. While the sample size is small, it covers a decent mix of the most relevant respondents. They include a database manager, project officer, nurse, care coordinator,

dietician, medical registrar and a psychologist. The respondents were from health management, clinical management, information management and primary health care backgrounds.

Another frequently discussed reservation about the qualitative research method used in the study relates to the generalization of its findings. The uniqueness of every research setting and particular characteristics of qualitative methods are seen as major barriers to generalizing findings beyond the particular setting studied (Duffy 1985). This may apply when the research objective is the evaluation of an innovation in a single setting, where there is no intention to replicate the program in other contexts, and the ratio of settings studied to the population to which one wishes to generalize is usually too low to permit statistical extrapolation. The principal investigator has not thoroughly combined the intensive case studies with additional intended examination of a larger volume of cases to uncover whether the observations made in this study hold elsewhere, and this is another limitation of this study. However, the detailed descriptions in this study may allow the reader to make an informed judgement about whether the similarities between the original setting, and those to which the findings are to be applied, are sufficient to give confidence that findings from this setting will hold in the others.

The aim of the research is to get insights into the eHealth tool and evaluate its impact on chronic care management in a regional health service. This study emphasized the role of a clinical information system in the chronic care model, and I have not included patients' perspectives with chronic disease, which is an important part of chronic care management, with highlighted self-management support. I could only briefly discuss and present the eHealth intervention as part of patient self-management support and a patient's interaction with a provider. Due to the time-consuming qualitative data collection process and limited resources available I derived my knowledge from literature review and analysis of documentary material.

Finally, the clinicians' heavy workloads, to some extent, might have affected the results of the correlation between their motivation in learning to use eHealth interventions and their opinions on the performance of these IT innovations. Further, many of them were required to take part in multiple roles at the same time.

8.4 Areas for further research and practice

This study, being of an investigational and guiding nature, raises a number of possibilities for future research, both in terms of IT innovation development in a healthcare setting and concept validation.

One aspect of this study focused on the use of CDMR in its current setting and how the demand for it moves away from the registry field to become more of an electronic medical record tool. This was suggested by its users. The electronic health developments taking place in ACT Health are creating uncertainties as to the role and future of the CDMR given its uniqueness and operation at the interface between the acute and primary care sectors. This underscores the need for the CDMR to review its aims and objectives in conjunction with those involved in electronic health developments in ACT Health. Future formal evaluation should be considered to assess the CDMR strengths and weaknesses in chronic care intervention in relation to meeting its process, impact and outcomes measures. Another aspect to a future evaluation of the CDMR could be to assess its role in improving chronic disease management processes in ACT Health.

This study revealed a high expectation among healthcare providers of a patient-centric medical record with high quality and complete database. Whether the implementation of electronic

clinical forms to replace a paper-based system in CCP or the design of a possible database for a unified patient view will help to ease the administrative side burden for clinicians in OMS and align to the national eHealth strategy, the need for a clinical repository in the near future seems essential.

In this study, we included technology use and development taking place within care providers' boundaries in CDMU. We suggest similar dynamics be explored for innovation across different boundaries, such as patient empowerment with eHealth interventions. This is particularly relevant given technology can change patient self-management to prevent a chronic disease and collaborate with a care provider to improve outcomes. More studies are needed to unfold how technology can "assist those diagnosed with a preventable chronic illness to develop and maintain self-management skills" (Merck 2017).

Finally, as discussed in the limitations of the study, further work is necessary to extend in longitudinal and comparative ways with a number of other larger scale cases to generalize the research findings. Further research can thus "shed light on the dynamics of knowledge circulation" (Nicolini, Powell and Korica 2014), sharing and exchange among the particular group care providers, asking what sort of IT interventions they need, both individually and as a group. Such research could eventually turn the information and data into actionable 'evidence' and the study could be used to evaluate the contributions of other electronic health developments in ACT Health.

8.5 Concluding remarks

The initially stated overarching aim of this research was to gain insights into an eHealth tool and evaluate its impact on chronic care management in a regional health service. While recognizing the limitations of our analysis, we believe we have largely achieved this in our findings in case studies set out in chapter four to six and the synthesis of findings in chapter seven. We have identified the rationales behind the slow adoption of eHealth in its current setting and suggested the necessary steps to prepare for a future IT innovation in a similar health care setting. We have developed methods to assess the impact of one type of patient registry and EHR and provided an understanding of what elements can be measured to assess the impact of similar eHealth interventions. These insights lead to evidence of the impact of eHealth interventions for health care which is sparse and poor in the literature. We have identified the challenges for current patient registry in CDMU to achieve its interoperability and suggested a potential approach towards a functional interoperable solution. This might lead to significant gains in improving workflow and reducing duplication of effort for care providers and patients participating in registries. Following findings from the study and lessons learned, we recalibrated what they mean for Australian digital health investment, especially in chronic care management. The key focus of introducing a fully comprehensive digital solution is on the people involved with their extensive engagement; the setting provided with enablement or restrain; and the change which may or may not lead to meaningful benefits.

In our original proposal we emphasized our desire to have effective implementation of sustainable eHealth solutions in chronic disease management to assist the multidisciplinary care and evidence-based health services. The use of information technology plays an important role in achieving a recommended model of care with clinical outcomes that include “better integrated and coordinated care, collaboration across a multidisciplinary team of care providers, planned care with regular follow-up and review and support for patient self-management”

(Georgeff 2014). This study is a valuable contribution to achieving that aim of creating the meaningful use in eHealth of enhanced chronic care.

ACT Health is committed to "improving chronic care program outcomes within ae a supportive policy environment" (Guda 2012). By moving beyond simply identifying the barriers and enablers, this study provides updated and fundamental insights into the development and implementation of IT solutions incorporating expectations for care providers treating chronic disease using a sustainable chronic care model.

Digital health is a rapidly evolving field with continuous advancements in technology, research, and innovation. New digital initiatives and technologies are constantly emerging, presenting healthcare providers and organizations with a wide array of options and possibilities. However, the speed of research and development often outpaces the pace of implementation and adoption in real-world healthcare settings.

The slow implementation of digital technology into the health system has been observed in this study, and the possible explanations are:

1. The principle of "First, do no harm" is a fundamental ethical guideline in healthcare which many medical professionals uphold as a core part of their practice. Healthcare providers are rightfully cautions about adopting new technologies and digital interventions because they want to ensure that these interventions are safe and effective. Therefore, adopting unproven digital interventions may be seen as a breach of the "do no harm" principle.
2. The health system is often complex and fragmented, with various stakeholders, regulations and existing processes in place.

3. Healthcare professionals and organizations may be resistant to change due to concerns about the impact on the workflows, patient care and privacy. There might be a reluctance to adopt new technologies and processes.
4. Implementing new digital technology in healthcare can require substantial investments in infrastructure, software, training and maintenance. Limited financial resources and competing priorities within healthcare organizations can hinder the adoption and integration of new technologies.
5. The healthcare sector deals with sensitive and confidential patient information, making privacy and security crucial consideration. Ensuring adequate security measures can slow down the implementation process.
6. Healthcare systems often use a variety of disparate EHR systems and other digital tools that may not easily communicate or share data with one another. Achieving interoperability and seamless data exchange between different systems can be complex, impeding the effective implementation of digital technologies.

The intersection of fast-moving technology and slow-moving implementation in my research study arises from the need for careful evaluation, practical considerations, stakeholder collaboration, and addressing complexities within the target systems. Research findings are often influenced by the specific context and conditions in which the study was conducted. Over time, societal, technological, or environmental changes can alter the context, potentially enhance our ability to study and understand complex phenomena. However, the problem of fast-moving technology and slow-moving implementation will continue to exist. Addressing the various barriers, remains a continuous challenge for health care sectors aiming to harness the benefits of rapidly evolving technologies. This research study observed the above listed inherent challenges which is likely to persist and expected to continue.

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Appendix 1

Australia National University

Participant Information Sheet

Study Title – The implementation of E-health enhanced clinical information systems for Chronic Disease Management in a large regional health service

You are being invited to take part in a research study. Before you decide to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please ask the study team any questions you have and request any further information you need.

Why is this study being done?
Yunli Shao is a PhD student at the Australia National University. She is currently being supervised by Paul Dugdale, Director of the Chronic Disease Management Unit. This PhD project aims to study the implementation of e-health enhanced clinical information systems for chronic disease management in a large regional health service. There have been three small-scale projects chosen within the ACT Health for case studies to accomplish the PhD project. The finding will be used to address the following three research aspects:

1. The "meaningful use" of e-health enhance chronic disease management
2. The interoperability of health information systems in chronic care in ACT Health
3. The methods to measure the potential impact of e-Health outcome

What is involved in the study?
The conceptual review was used to bring together the related e-Health concepts and to grasp the using of e-Health tools for chronic disease management. In line with conceptual review and the aim of the study, three case studies were chosen resulting in both a descriptive summary and a thematic analysis.

Case study 1: Chronic Disease Management Register information flow

Case study 2: The development and use of electronic method for the Chronic Care Program

Case study 3: The development of obesity care in local health service

Document review, participate observations, and unstructured interview (by phone or in person) have been used for the data collection. I have worked part time as research assistant within Chronic Disease Management Unit for 1 year, during the period, I have participated in different live projects and kept notes for observation.

To provide rich insight and understanding of the research questions, interviews are needed as one of the survey tools. Key staff from the chronic disease management team will be invited to take part in an interview to add detail to the data collection for the PhD project. The approximate timeframe for each interview should be around an hour and it will be audio recorded. The interview will be held face to face at a convenient time and location for the interviewees, or could be conducted by telephone or by email exchange if they prefer.

Australia National University

Why have I been chosen?
The chosen interviewees are the current staff at the Chronic Disease Management Organisation. They have a sound knowledge about their service unit, and ability to answer my research questions related to the e-health implementation. Their ideal position able to give me valuable first hand information from their own perspective.

Do I have to take part?
Participation in this study is VOLUNTARY. It is completely up to you whether or not you participate. Participants cannot be compelled due to the position they hold within an organisation or team. If you decide not to participate, it will not affect the employment now or in the future.

Are there any risks?
No.

Are there any benefits?
If you agree to take part in this study, there may or may not be direct physical or psychological benefits to you. You participation may help others in the future.

What are the costs?
There will be no cost to you for participating in this study.

Financial disclosure
The project is funded by ANU Medical School through PhD scholarship.

Access to the results of the study
Results will be displayed and analysed in the PhD thesis. A copy of the thesis can be requested upon completion.

Australia National University

What about confidentiality?
The researcher is aware of her responsibility for confidentiality of the data collected. The data used will be de-identified. No identifying details will be provided in any published or presented material. The work will be conducted in accordance with the ACT Information Privacy Act 2014. With holding of the personal information, the researcher must take reasonable steps to protect the information from misuse, interference or lose and from unauthorized access modification or disclosure. The audio recording from interviews will be destroyed once have been transcribed. If necessary, the researcher will protect the security of personal information by destroy the information or to ensure that the information is de-identified.

If you have any questions please contact the research team

Action Officer & Principal researcher who will contact participants, conduct interviews and perform data analysis:

YUNLI SHAO (PhD student of ANU)

U4329734@anu.edu.au

0433 708 377

Project supervised by Assoc Prof Paul Dugdale

Paul.dugdale@act.gov.au

Should you have any problems or queries about the way in which the study is conducted, and do not feel comfortable communicating with the staff conducting this survey, please contact: ACT Health Human Research Ethics Committee (ACTH-HREC), Level 6, Building 10, Canberra Hospital, Telephone: (02) 6174 7968 or ethics@act.gov.au

Appendix 2

Australia National University

Consent Form for Participation in a Research Project.

I, _____ *(name of participant)*

of _____ *(address)*

have been asked to consent to participation in a research project entitled:

The implementation of e-Health enhanced clinical information systems for chronic disease management in a large regional health service

In relation to this study 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 study is to: Assess the impact of current e-health interventions in Chronic Care Management service and analyse the implementations to define meaningful use
3. The results obtained from the study may or may not be of direct benefit to me ☐
4. The study procedure will involve audio recording and list of topics that researcher want the respondent to talk about. Electronic files will be maintained on a secure, password protected network drive and paper files will be maintained in a secure locked cabinet in a suitable work area. The audio recording will be transcribed by paid professionals. The reports of this analysis (not including any identifying information) and records of interviews will be archived in the centre for Health Stewardship within the ANU Medical School, on the university's secure computer systems, and destroyed according to the ACT Health, ANU, UC or other applicable policy. ☐
   - Audio recording ☐
5. 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 the ACT Health Human Research Ethics Committee Secretariat, Canberra Hospital, Yamba Drive, Garran ACT 2605 (ph: 6174 7968) ☐
6. I can refuse to take part in this project or withdraw from it at any time without giving a reason ☐
7. I understand that while the results of the research will be made accessible my involvement and my identity will not be revealed. ☐

After considering all these points, I accept the invitation to participate in this study.

Name: (please print) _____**Date:** _____

Signature (Participant) _____

Investigator: (please print) _____**Date:** _____

Signature (Investigator) _____

PhD project – The implementation of E-Health enhanced Clinical Information Systems for Chronic Disease Management in a large regional health service, 23/02/2017

Appendix 3

ACT Government
Health

ACT Health
Research Ethics and Governance Office
Low Risk Sub-Committee

Miss Yunli Shao
C/- Chronic Disease Management
123 Carruthers St
Curtin ACT 2605

Dear Miss Shao

ETHLR.17.066

The ACT Health Human Research Ethics Committee's Low Risk Sub-Committee received notification of the proposed study:

The Implementation of E-Health Enhanced Clinical Information Systems for Chronic Disease Management in a Large Regional Health Service at its meeting of 22 March 2017.

I am pleased to inform you that, following further correspondence, your application has been approved.

The Sub-Committee agreed that the application is for low risk research and determined that the research meets the requirements of the National Statement on Ethical Conduct in Human Research and is ethically acceptable.

The committee wished to thank you for submitting this application through the streamlined cross-institutional ethics process between ACT Health and the Australian National University HRECs. Please submit your application, with a copy of this letter, for expedited review by the Australian National University HREC.

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 Statement on Ethical Conduct in Human Research 2007 and is certified for single review of multi-centre clinical trials. ACT Health HREC operates in compliance with applicable regulatory requirements and the International Conference on Harmonization Guidelines on Good Clinical Practice.

Yours sincerely

Louise Morauta

Louise Morauta PSM PhD
Chair
ACT Health Human Research Ethics Committee
Low Risk Sub-Committee

19 April 2017

PO Box 11 Woden ACT 2606 | Phone: 6174 7968 or 6174 5659 | E: ethics@act.gov.au

ACT HEALTH HUMAN RESEARCH ETHICS COMMITTEE

Outcome of Consideration of Protocol

Submission No: **ETHLR.17.066** **Date of Approval:** 19 April 2017

Project Title: The Implementation of E-Health Enhanced Clinical Information Systems for Chronic Disease Management in a Large Regional Health Service

Submitted by: Miss Yunli Shao

Your project was considered by the ACT Health Human Research Ethics Committee's Low Risk Sub-Committee and approved for a period of one year from 19 April 2017 to 19 April 2018

NOTE: Projects approved for one year will be automatically marked as 'closed' by the secretariat office on the anniversary of the approval date. This means ethical approval is no longer current and work must not continue on this project. If additional time is required you will need to submit a request for extension of the ethical approval period prior to the anniversary date.

As the project will close automatically you are not required to submit a final report. For the duration of the approval period you will be required to report any amendments and breaches as per the reporting requirements below.

Reporting requirements:

- Amendments to the protocol or project plan
- Changes to project personnel
- Breaches of security of records
- Breaches of compliance with approved consent procedures and documentation
- Breaches of compliance with other approved procedures
- Unexpected adverse effects on participants
- Unforeseen events that might affect continued ethical acceptability of the project.
- All published reports to carry an acknowledgement stating:
  - Approved on 19 April 2017 by the ACT Health Human Research Ethics Committee's Low Risk Sub-Committee.

Louise Morauta PSM PhD
Chair
ACT Health Human Research Ethics Committee
Low Risk Sub-Committee

19 April 2017

PO Box 11 Woden ACT 2606 | Phone: 6174 7968 or 6174 5659 | E: ethics@act.gov.au

Appendix 4

From: aries@anu.edu.au
Subject: Human Ethics Protocol 2014/274 - Approval
Date: 20 July 2017 at 3:07 pm
To: u4329734@anu.edu.au
Cc: human.ethics.officer@anu.edu.au, paul.dugdale@anu.edu.au

THIS IS A SYSTEM-GENERATED E-MAIL. PLEASE DO NOT REPLY. SEE BELOW FOR E-MAIL CONTACT DETAILS.

Dear Dr Yunlin (Lilly) Shao,

Protocol: 2014/274
The implementation of E-health enhanced clinical information systems for Chronic Disease Management in a large regional health service

I am pleased to advise you that your Human Ethics application received approval by the Chair on the 20/07/2017.

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. Please advise the HREC if you receive any complaints about the research work.

5. 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,

Human Ethics Officer
Research Integrity & Compliance
Research Services Division
Level 2, Birch Building 36
Science Road, ANU
The Australian National University
Acton ACT 2601

T: 6125-3427
E: human.ethics.officer@anu.edu.au
W: https://services.anu.edu.au/research-support/ethics-integrity